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Lived Experiences of Mothers of Children with Autism Spectrum Disorders in Punjab, Pakistan

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Abstract

The purpose of this study is to investigate the lived experiences of women whose child diagnosed with Autism Spectrum Disorder in Punjab, Pakistan. Semi-structured interviews were used in a qualitative study approach to collect detailed information. Five mothers of children with autism made up the sample; they were chosen using non-probability purposive sampling from rural areas of Punjab. This study aims to comprehend the everyday struggles these moms encounter, the effects of raising a child with ASD on their personal and familial lives, and the coping mechanisms they use to deal with related social and psychological issues. Iterative coding and the creation of Interpretative Phenomenological Analysis (IPA) were used in data analysis to find important patterns in the tales. Results show that, in addition to trying to uphold their domestic responsibilities, moms of children with ASD experience severe social isolation, stigma, and emotional suffering. Despite these obstacles, individuals showed resilience by using community resources, self-care practices, and support systems. The study emphasizes the necessity for specialized support services by highlighting the intricate interactions between mom and ASD children in a culturally particular setting.

Introduction

Autism is a neurodevelopmental disorder and is defined by impairment in restricted and social communication repetitive pattern of interest, activities and behavior [4]. One in 54 children in the US has autism spectrum disorder (ASD), according to the Centers for Disease Control and Prevention's biennial data from the Autism and Developmental Disabilities Monitoring Network (ADDM). This represents a 10% rise over earlier estimates. Moreover, Autistic people perceive the world differently form the non-autistic people and have different lived experiences.

The people who have autism spectrum disorder they are suffering but their mothers experience emotional and financial constrains which have negative impact on their quality of life. They often experience unsatisfied from their lives. Parenting stress is higher in mothers as compared to fathers. Mothers take on the responsibility of managing their child's behavioral and developmental requirements, which requires more time and effort. Higher stress levels among moms were substantially correlated with factors including the severity of the child's autism symptoms [28]. Additionally, because to cultural misconceptions about autism, moms frequently experience mental pain, social isolation, and stigma [7]. These findings are consistent with recent indigenous evidence showing that stigma and myths significantly worsen caregivers' challenges in Pakistan [19]. Families bear significant financial pressures as they pay for therapies and specialized care, which were sometimes expensive and hard to get. Mothers' access to resources and support appears to be influenced by their socioeconomic class and degree of education, which in turn affects their overall quality of life [1]. Despite these difficulties, mothers use coping mechanisms to empower themselves, such as focusing on their children's small accomplishments, seeking out social support, and practicing their religion [7]. In Punjab the mother of Children with Autism Spectrum Disorder deal with the variety of challenging issues such as emotional, financial and social hurdles because of the lot of burden and responsibilities of providing care and the absence of downtime they frequently

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suffer from mental and emotional tiredness [13]. Due to the high expense and difficulty of accessing therapies, medical appointments, and special schooling, financial burden is substantial [8]. The burden is exacerbated by social stigma and rejection from family and community members; as a result of widespread societal attitudes toward autism, many moms experience feelings of loneliness and shame [13,31]. These patterns align with previous Pakistani systematic review findings indicating that myths and misinformation fuel stigma, delayed diagnosis, and psychological distress among caregivers [24]. Particularly in Punjab's rural areas, access to healthcare is hampered by a lack of specialized services, transportation problems, and budgetary limitations [8]. However, while public and societal assistance are still insufficient overall, certain cultural elements, such husband and family support, help these moms become resilient [13,14]. Research highlights the critical need for public awareness campaigns, culturally competent interventions, better healthcare access, and official support networks for these families [11,8,31].

Review of the Literature

Several studies have been conducted, in the recent past to look into the experiences of women who had children with autism spectrum disorder (ASD). Three major ideas emerged from the result extract, the core of life: Attempts at empowerment, progressively growing solitude, and motherhood of two autistic children. According to the results, mothers continue to conduct their lives by prioritizing their children with ASD, which makes them feel more and more alone in social situations. [7]. Mothers find it difficult to go about their everyday lives, worry a lot about the future, believe they don't have the necessary resources for support, and believe that having several children with ASD changes their relationships with their spouses and social networks, which will make them feel more alone. Mothers also create a variety of self-empowerment techniques [7]. The results of the previous study indicate that arrangements were required to make life easier for moms of several children with ASD, and studies including a greater number of participants should be conducted to investigate mothers' experiences [7]. In South Punjab, Pakistan, a study was conducted to identify the obstacles parents of children with autism spectrum disorder have while trying to access healthcare. The results show a variety of awareness channels and differences in awareness of various facets of ASD. However, there were medical facilities like general practitioners and speech therapists. Access to healthcare was significantly hampered by cultural norms, financial limitations, and transportation issues. The complex difficulties families encounter navigating the healthcare system are also reflected in the broader national review documenting systemic barriers and delays in ASD diagnosis [24].

Based on demographic factors, statistical analyses show no discernible variations in perceptions. This study offers important new perspectives on the complex difficulties families in South Punjab, Pakistan, encounter when navigating the healthcare system for their children with ASD. It guides policy suggestions and measures to improve this vulnerable population's access to healthcare and support services [8]. In view of current worries about rising prevalence, additional research was done on variables that can affect prevalence rates, such as recent modifications to the diagnostic criteria. According to research, it is difficult to measure the prevalence of ASD in this population, pinpoint risk factors, or even develop effective intervention strategies because there is a dearth of scholarly, published research from Pakistan (Imran & Azeem, 2014).

Investigating and understanding the day-to-day experiences of moms raising children with autism spectrum disorder (ASD) is the goal of one phenomenological study. Pre-diagnosis Concerns, Reaction after Diagnosis, Parenting Challenges, and Positive Aspects of Pakistani Culture are the four key topics highlighted in the findings. Pre-Diagnosis Maternal Recognition, Behavioral Observations, and Knowledge Gaps are the three separate subthemes that md5ake up the Pre-Diagnosis Concerns theme. This theme provides important insights into early identification and intervention techniques by examining the relationship between maternal intuition, observed behaviors of children with ASD, and the gaps in knowledge regarding the diagnosis process.

The subthemes of Delay in Diagnosis, Reaction to Diagnosis, and Seeking Management Assistance are included in the second topic, "Reaction towards Diagnosis." This feature clarifies the proactive, emotional, and temporal aspects of the diagnostic process by explaining the responses and activities of parents of children with ASD following a diagnosis. Mothers' sacrifices and struggles, financial strain, treatment options, social stigma, family rejection, and positive aspects of Pakistani culture are all included in the third theme, "Challenges of Parenting." The variety of challenges faced by parents of children with ASD are described in this theme. Support from family members and support from spouses are subthemes of the fourth topic, "Positive Aspect of Pakistani Culture" [13]. to investigate the effectiveness of good habits in everyday life in order to comprehend the pressures faced by moms. The goal of the research was to use everyday lifestyle behaviors to enhance the lives of mothers of children with ASD. The approach significantly reduced the mother's perceived stress, according to the results. After changing their regular routines, mothers of children with ASD reported feeling less stressed. These findings also resonate with local research showing high caregiver strain and the need to consider both negative and positive dimensions of caregiving [24].

One Research on stress management for caregivers of children with ASD in Pakistan refers to a mix of official and informal treatments. Peer support groups and family-based coping

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strategies supplement psychological educational programs, caregiver training, and organized therapy. While local service delivery may be fragmented, these approaches demonstrate potential to reduce caregiver strain and increase coping efficacy when customized to cultural and resource situations [15]. Children with ASD in Pakistan have scholastic and social obstacles, including inclusion in mainstream settings, access to appropriate therapies, and inconsistent assistance within schools. Qualitative descriptions emphasize daily lived experiences—communication hurdles, reduced involvement in activities, and the emotional impact on families. These observations demand for child-centered therapies and school-based supports that accommodate various needs while honoring cultural contexts [5]. A research conducted on challenges faced by parents of children. Punjab-based qualitative studies capture themes such as financial pressure, limited service availability, lack of awareness, transportation constraints, and reliance on extended family for help. Parents report navigating complex systems for diagnosis and treatment, fighting for resources, and overcoming societal stigma. The Punjab-focused approach shows regional differences and the need for tailored policy and programmatic measures to increase access and cost of care [6]. A research done on obstacles experienced by parents of children. Themes including financial strain, a lack of understanding, restricted service availability, transportation limitations, and dependence on extended family for assistance are captured in qualitative studies based in Punjab. Parents describe overcoming social stigma, battling for resources, and navigating complicated systems for diagnosis and treatment. According to Mushtaq et al. [22], the Punjab-focused approach highlights regional variations and the necessity of customized policy and programmatic initiatives to improve access and lower healthcare costs.

Theoretical Framework

Social Role theory best fit in with my research topic according to Alice H. Eagly's Social Role Theory (1987), gender disparities in behavior are mostly caused by the various social roles that men and women have historically been allocated. This hypothesis holds that different gender roles and stereotypes developed as a result of the division of work based on physical disparities (men are typically stronger and women are more involved in caring). Through socialization and cultural reinforcement, these gender roles which are socially created behaviors expected of men and women influence attitudes and actions throughout time. According to the notion, sex-differentiated actions in society are shaped by these roles and stereotypes rather than just intrinsic biological differences. It also implies that gender preconceptions and related behavioral disparities may lessen as gender roles become less rigid.

Rationale

Mothers of children with autism spectrum disorder (ASD) face complex challenges, including psychological, physical, social, and emotional constrains, which are largely under-researched in the Pakistani context. This was the motivation behind the study of the lived experiences of mothers with ASD in Punjab, Pakistan. In Punjab and throughout Pakistan, there is a dearth of specialized autism treatment programs, so it is critical to comprehend mothers' experiences in order to enhance support networks. Mothers' challenges are exacerbated by the social shame, financial hardship, and familial rejection that come with raising autistic children; these factors must be recorded for culturally appropriate treatments. Strong family and spousal support networks are examples of Pakistani cultural features that contribute significantly to these moms' resilience, necessitating investigation for the creation of effective policies and services. Comprehending the lived experiences of mothers will add in customizing support services, raising awareness, and informing policies meant to enhance the welfare of Punjabi families impacted by autism. Although Pakistan has substantial literature on autism, much of it focuses on clinical aspects or parental stress rather than mothers' first-hand lived experiences, particularly in Punjab. Existing studies rarely explore cultural, social, and healthcare realities in rural areas, where support and awareness are significantly lower. Therefore, region-specific research is needed to capture deep, nuanced, and rural–urban differences that current literature does not adequately address.

Research design

Phenomenological research design (PRD) was used to explore the lived experience of waitresses.

Sample

The research sample was Mothers of children with autism of age range from 20 to 35 years. The sample size was 5.

Sampling

Study participants was recruited by non-probability sampling. Purposive sampling technique was used to select the participants. There were five individuals in the sample for this study, all were women. They were in the 20 to 35 age brackets. Regarding their socioeconomic background, the sample remained homogeneous (all belonged to the middle socioeconomic class).

Inclusion Criteria

This study included mothers of children with autism who could read and write. Must have experience with their-own child. Age range from 20 to 35 years. Only mothers were included for this study, only from rural areas. Participants must have the cognitive ability to understand and respond to the questions. Participants must express willingness to engage in the study procedure.

Ethical Considerations

APA code of ethics was followed during the entire process of research. Participants must be fully informed about the study objective, procedure and potential risks. Inform consent was taken before the interview. Anonymity and confidentiality were ensured. They were be given right of withdrawn from research at any moment. Deception was avoided unless absolute necessary, and participants, were fully debriefed afterwards to explain any deception used during study. No physical and psychological haram was given. They will be given right to withdraw.

Measures

Data was collected through semi-structured interviews Semi-structured in-depth interviews was carried out (with mothers of children with autism) as an important method of qualitative research, ensuring a fine balance between consistency in the interviewing framework and flexibility in eliciting individual experiences among participants. Such flexibility within semi-structured interviewing allows for the emergence of comprehensive insight into the thoughts, feelings, and views of participants, which otherwise may not emerge through a strictly structured interview. It was argued that it is one of the most effective ways of eliciting in-depth information.

These were the questions which were used during the interview

1. Could you explain your immediate thoughts and emotions upon learning that your child has been diagnosed with ASD?
2. When raising a child with ASD, what are the primary emotional obstacles you encounter?
3. What effects has your child's illness had on your family and community relationships?
4. Has the diagnosis of ASD caused you or your child to face stigma or social judgment? Describe, please.
5. What kinds of support governmental, societal, and familial do you currently receive, and what do you think is lacking?
6. What effects has having a child with ASD had on your everyday wellbeing and mental health?
7. Could you describe the practical or financial obstacles to getting your kid the care and treatment they need?
8. How do you deal with the stress and challenges of raising a child with ASD?
9. How much do you know about ASD, and what obstacles have you encountered while trying to teach others about it?
10. How do you envision your child's growth and social acceptance in the future?

Procedure

After gaining Permission from the authorities for data collection before approaching the sample and conducting research. Protocol question translated into Urdu for better understanding of the participants. Inform consent was taken from participants and debrief term about the purpose of research. Data was collected through interview method.

During interview researcher guided participants through a series of questions design to explore various aspects of research. Data was recorded in audio tape after data collection data was transcribed (verbatim into written text, preserving and nuances of participant's responses). The data collected was coded inductively and themes were developed. Data was in voice recorded form then we transcribe it, and then analyzed afterword's themes were drawn according to the IPA (Interpretative Phenomenological analysis)

Analysis

It is a qualitative research approach known as interpretative phenomenological analysis, which seeks to explore how individuals make sense of their personal and social experiences. It is especially useful when the focus is on understanding the lived experiences of people and how they make sense of these experiences within their unique contexts. IPA is grounded in phenomenology, which means that the approach is designed to understand phenomena through individuals' subjective experiences, and hermeneutics, which means the interpretation of what these experiences truly mean [32]. Moreover, some important steps play a useful role in IPA. First, through in-depth, semi structured interviews are elicited rich, detailed accounts of participants' experiences. Transcripts of the interviews are then produced verbatim. Detailed analysis is done on these transcripts by the researcher. This would begin by first reading the transcript to make one familiar with the data, which is then followed by a more systematic examination where emergent themes can be identified. These themes go on to be organized into superordinate themes that reflect broader patterns across the accounts of participants. In this, one engages in a double hermeneutic process at every stage of analysis. It is iterative, often requiring several readings and refinements to bring out deep insight from the data [32]. In particular, IPA proves most useful when the research is intended to examine complex, emotive, or under-researched phenomena that provide insight into how people construe and make sense of their experiences. The in-depth nature of IPA makes it a potent tool for understanding participants' subjective realities and the way these shape behaviors and attitudes [32].

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Table 1.1

Demographic Information of participants (N=5)

Age	Marital Status	No of Children	Monthly income	Family system	Education	Employment Status	Experience with Autistic Child	Accommodation
20	Married	3	70000	Nuclear family system	F.A	Part- time	2years	Rented
24	Married	5	30000	Nuclear family system	Matric	Part-time	3 years	Rented
30	Married	2	25000	Nuclear family system	Matric	Part- time	9 years	Own house
34	Married	4	150000	Nuclear family system	F.A	Part-time	3 years	Own house
27	Married	4	250000	Nuclear family system	Matric	Part-time	1Year	Own house

Table 2

The transcribed interviews of every participant yielded the following superordinate themes, which are related to the lived experiences of the participants.

Superordinate Theme	Master Theme	Emergent Theme
Emotional Challenges	Mental Health Impact	Anxiety and stress related to child's behavior. Feeling of loneliness and isolation. Emotional Exhaustion and Depression.
	Emotional Resilience	Faith and hope as a coping mechanism. Strengthened emotionally with time.
Social Impact	Social Perception and stigma	Experiences of being misunderstood and judged by society. Fear of reactions from the community and extended family.
	Family Dynamics	Absence of assistance from a spouse or other family members. Relationship changes and an increase in family conflict.
Financial Issues	Economic Burden	Exorbitant therapy and treatment expenses. Effects on income and employment.
	Resource Constrains	Limited local access to specialized services. Accessing healthcare facilities is difficult.
Coping Strategies	Seeking Support	Dependence on community organizations and religious convictions. Using governmental or non-governmental services.
	Personal Adaptation	Creating regular schedules based on the requirements of the child. Learning via networks of support and experience
Awareness and Education	Knowledge Gaps	Insufficient knowledge and comprehension of ASD in the community

		Difficulties in teaching neighbors and family.
	Need for information	Desire for additional child care instruction and direction.

Discussion

The current study focuses on the diverse experiences of women in Punjab, Pakistan, who are raising children with autism spectrum disorder (ASD). Participants reports of emotional difficulties such worry, tension, loneliness, and depression are consistent with earlier studies showing the significant psychological load these caregivers endure [27,3]. Mothers often feel emotional weariness and mental health repercussions that require culturally appropriate mental health therapies, which is consistent with these findings [16,17].

It's interesting to note that mothers showed emotional resilience based on hope and faith, which is consistent with other qualitative research highlighting spirituality as an essential coping mechanism for caregivers in comparable cultural contexts [24,2,23]. In addition to reducing stress, this resilience helps moms gradually adjust to the difficulties of providing care [9].

Mothers are greatly impacted by social stigma and unfavorable community opinions, which promote social isolation and a fear of being judged. Maternal wellbeing is significantly hampered by these cultural attitudes concerning ASD in Pakistani communities, which have been previously documented [24,21,18]. Due to a lack of support from spouses and other family members, families frequently experience poor interpersonal connections, which exacerbates difficulties for these women [11].

A recurring topic in autism caregiving research from low-resource settings is the financial burden brought on by expensive therapies and lower household income, which restricts access to essential services and increases caregiver distress [17]. Furthermore, Punjab's poor healthcare system and scarcity of specialized ASD services make it more difficult to get prompt intervention [24,27].

Participants' use of religious convictions, community groups, and intermittent government assistance as coping techniques is consistent with earlier findings that these tactics lessen caregiver stress in Pakistani settings [1,23]. Common adaptive strategies that maintain family functioning in the face of hardship include creating regulated daily routines and learning from peer support networks [24,9].

Lastly, societal knowledge and awareness gaps on autism impede acceptance and informed caring, highlighting the urgent need for comprehensive education initiatives aimed at families and communities [24,20,18]. In order to empower caregivers and enhance child outcomes, mothers' reported desire for more information supports earlier demands for increased training and resource distribution [21]. There is a need of women empowerment and need to rise voice for them because women being a mother is considered submissive, subjugated and inferior in the context of Pakistani culture and men are considered more assertive and confident [12,29,30]

Conclusion

The lived experiences of women in Punjab, Pakistan, whose children have been diagnosed with autism spectrum disorder depict a complex journey filled with fortitude, emotional difficulties, social stigma, and financial burdens. With the help of their faith and the support of their communities, these mothers were able to deal with difficult situations and change throughout time. In order to effectively help these families, this study emphasizes the critical need for culturally responsive treatments, improved healthcare access, and more public awareness. As we get a deeper grasp of their complex reality, it is evident that empowering mothers through resources, education, and inclusive social policies is crucial to enhancing their own and their children's wellness. The stories told shed light on difficulties as well as opportunities for a more sympathetic and encouraging future.

Limitations

The results of this study's exclusive emphasis on a particular region of Punjab limit their applicability to other areas. Wider application is limited by the qualitative methodology and small sample size. Social desirability bias may also affect participants' self-reported experiences. Lastly, a lack of access to rural populations could ignore the particular difficulties those areas experience.

Suggestions

For a thorough understanding, future studies should encompass a variety of rural and urban communities throughout Pakistan. Using mixed approaches and expanding the sample size could improve the robustness of the data. There is an immediate need for awareness campaigns to lessen stigma and educate communities about ASD. Last but not least, governmental initiatives ought to concentrate on enhancing the healthcare system and offering impacted families easily available support services.

Conflict of Interest: NIL

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Declarations:

Authors' Contribution:

- a-b-cConceptualization, data collection, interpretation, drafting of the manuscript
- d-e-fData collection and intellectual revisions
- The authors agree to take responsibility for every facet of the work, making sure that any concerns about its integrity or veracity are thoroughly examined and addressed

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