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Silent Struggles: Parental Beliefs and Cultural Barriers to Autism and Developmental Disabilities Understanding in Pakistan

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ABSTRACT

The purpose of this qualitative research was to examine parents' beliefs and cultural perceptions about Autism Spectrum Disorder (ASD) and Developmental Disabilities (DD) in Pakistani families within the sociocultural setting of Gujrat, Punjab. It is evident in Pakistan that perceptions of mental and developmental disabilities are often influenced by cultural, religious, and social beliefs, which are usually explained from a spiritual, supernatural, or biomedical perspective. This research was based on a phenomenological research approach, which aimed to explore parents' experiences of having children with ASD and DD. A purposive sample of 15 parents, both mothers and fathers, was selected from different settings. The research findings revealed parents' perceptions of having children with DD, explained from a religious perspective of divine will, fate, or spiritual interventions, and their lack of awareness about scientific explanations. Other themes that were identified include stigma, which was depicted in "Log Kya Kahenge?"; social isolation; gender roles in caregiving, which showed that the mothers were the ones doing the caregiving, while the fathers were only involved in decision-making; financial issues, which were a barrier in the caregiving process; and the use of medical as well as spiritual forms of treatment. Despite all the challenges that the parents faced, they showed some level of strength through religious coping and having hope for the improvement of their children's conditions. This shows that there is a need for awareness, healthcare services, and the use of biomedical and sociocultural approaches.

Keywords: *Autism Spectrum Disorder, Developmental Disabilities, Cultural Beliefs, Stigma, qualitative research*

INTRODUCTION

In Pakistan, perceptions of mental health are significantly associated with cultural, social, and religious factors that have a profound impact on how mental health problems are understood and addressed. Mental health problems are not defined using technical terms such as "mental illness" but rather using general terms such as "stress" and "physical weakness" due to poor awareness of mental health concepts (Naeem et al., 2012). This results in people being more focused on treating physical problems rather than mental problems.The perceptions of people regarding illness are not monolithic and are mainly associated with various models that they tend to follow when defining illness. These perceptions can include biomedical models, religious models, and spiritual models that can influence people's behaviors when they access health care facilities (Choudhry et al., 2013; Saeed et al., 2000). In accordance with this, individuals possess a unique understanding of illness causation, meaning, and treatment, which may or may not be in line with professional medical views. These understandings are significant in relation to how individuals deal with mental health issues, and this can be a considerable factor in relation to service utilization and therapeutic relationships (Kleinman, 1980; Bhikha et al., 2012).Autism Spectrum Disorder, abbreviated as ASD, is a neurodevelopmental disorder that is marked by challenges in communication and interaction, alongside restricted and repetitive behavior, interests, or activities. This is in line with the classification of developmental disabilities, which encompass conditions that influence cognitive, behavioral, language, and adaptive functioning, and may require long-term support over a person's lifespan.On a global level, developmental disabilities are acknowledged as a significant public health issue with a significant number of children being affected worldwide. In the case of low- and middle-income countries such as Pakistan, the prevalence of ASD and other developmental conditions is less reported owing to the lack of diagnostic facilities and awareness of the condition (Aftab et al., 2024; Roslan & Mohid, 2025).

In Pakistan, autism and other Developmental Disabilities are often Explained through religion and culture lenses, which help how families understand these conditions.Beliefs about disability as a fate, Spiritual influence or community stigma can Encourage when and how families seek professional help .As a result many children are diagnosis late or not at all,delaying access to Productive therapies that could encourage communication, learning and adaptive functioning (Jegatheesan et Al.,2010; Ecker, 2010).Within Pakistan society, disability is not viewed only as an individual issue but a collective family concern that can affect marital prospects , social reputation and family dynamics. Caregiving responsibility especially for children with Challenging needs trend to fa disproportionately on mothers, leading to emotional stress, financial strain and social isolation for caregivers (Mumtaz et al.,2022).Parental perceptions and belief systems play a important role in treatment decisions, therapy engagement and long-term outcomes for affected children. Although international research on Developmental Disabilities and Autism is growing, few Qualitative studies In Pakistan have evaluated how parents construct meaning around ASD and other Developmental Disabilities within their own cultural and religious framework. Most current research focuses on prevalence, caregivers stress or barrier to healthcare access (Aftab et al., 2024; Hussain et al., 2020).To design culturally aligned and efficient support system it is important to understand the lived experiences and belief systems of parents who are raising children with Developmental Disabilities Therefore,this qualitative study aims to explore parental beliefs and cultural perceptions in relation to ASD and other Developmental Disabilities in Pakistani families.By examining these lived experiences within their sociocultural context,the research seeks to generate culturally grounded insights that can inform diagnostic services, Awareness campaigns and family centered intervention strategies that are both impactful and respectful of societal values and realities

Disability in Pakistan is not understood solely on a biomedical model; rather, it is deeply embedded in the culture and belief systems of the people. Developmental disabilities are understood to be a test from Allah, divine will (taqdeer), a spiritual trial, fate, and past deeds. At the same time, a biomedical model of understanding developmental disabilities has also been noted to exist in Pakistan, particularly in cities (Hussain et al., 2020).It has been researched that belief systems play a significant role in understanding developmental disabilities and seeking appropriate interventions. Hussain et al. (2020) researched and found that in many rural areas of Pakistan, developmental disabilities are understood to be a source of shame and social burden. This is further understood to be related to stigma and social exclusion. This impacts not only the inclusion of the child in school but also influences the willingness of the parent to seek early diagnosis and intervention for their child.The cultural context has been understood to provide the backdrop to understanding the perceptions of parents regarding Autism Spectrum Disorder (ASD) and developmental disabilities.In a study conducted by Mushtaq et al. (2024) to investigate the influence of parental beliefs on intervention strategies for children with hearing, visual, intellectual, and physical disabilities in Pakistan, the researchers used a qualitative study and included 40 parents, with 10 parents from each of the four disability categories. The findings of the study revealed that cultural, religious, and societal beliefs are major influences on parents' perceptions of disability and their choice of intervention strategies. Parents used a combination of medical treatment, prayer, and visiting faith healers, and using herbal medicine. The study established that parental belief systems are not secondary influences but are the primary influences in the development of intervention strategies. In a conceptual study conducted by

Ravindran and Myers (2011) to investigate the influence of culture in understanding autism and other development disabilities, the researchers established that parental belief about causation of disability, whether spiritual, fate, or biological, influences treatment strategies.Religious meaning-making can serve as a coping tool and a guiding model for inclusion.

Jegatheesan et al. (2010), who conducted a 17-month ethnographic research on the experiences of South Asian

Muslim immigrant parents of children with ASD, found that the parents saw their child as a blessing from Allah. Instead of dwelling on the child's deficits, the parents focused on the child's strengths and spiritual purpose.This approach to ASD defies the deficit model and underscores the importance of religious meaning-making. Another research conducted by Ecker (2010), which explored the experiences of parents of children with ASD from Pakistan, Bangladesh, South Korea, China, and Ultraorthodox Jewish communities in Israel, found that despite the presence of ASD symptoms, the meaning given to the experience was different. This implies that, apart from being exclusionary factors, religion and culture can serve as psychological resources for parents.Although belief systems are essential for meaning-making, they also have the potential for delaying diagnosis. In a study conducted by Aftab et al. (2024) based on a literature review, the research focused on the sociocultural barriers to the diagnosis of ASD among the people of South Punjab, Pakistan. In the study, the authors identified sociocultural stigmatization, lack of awareness, and cultural competence of the health workers as the major factors that influence the delayed diagnosis of ASD.On the other hand, Barrio et al. (2018) conducted multiple literature reviews based on the culturally and linguistically diverse families of the USA and India regarding the influence of cultural beliefs, stigmatization, linguistic diversity, and minority group membership on the understanding of the causes of ASD. In the study, the causes of ASD were described by the families of the patients, ranging from a divine gift or karma, environmental factors, and genetic factors.This study, based on the research conducted by different authors, has indicated that the disparity in the diagnosis of ASD among different people cannot be attributed to the lack of facilities alone, but also the sociocultural frameworks of understanding the disorder.The psychological effects of cultural perceptions are also evident in the mental health of parents. In a crosssectional study of 84 Pakistani mothers of children with ASD ranging from 3 to 16 years of age, conducted by Mumtaz et al. (2022), the researchers used the Parental Stress Scale and Zarit Burden Interview to measure parental stress and caregiver burden. In this study, more than half of the mothers were identified to have a moderate to severe caregiver burden. Positive correlations were identified between parental stress and caregiver burden, which were related to the severity of autism, medication, and child's age. These findings indicate that in addition to the challenges posed by the disability, the psychological burden of parents is compounded by societal perceptions and lack of support. Disability is stigmatized in society, and this stigmatization is more pronounced in the case of mothers, who are the primary caregivers in a family.

Overall, the synthesis of the literature from the local and international studies reveals the following commonalities Cultural and religious beliefs impact the interpretation of disability,Beliefs about causation impact treatment options and intervention strategies,The impact of stigma and social judgment on seeking help is significant,The cultural competence level of the healthcare systems is a challenge,The level of psychological stress is significant among mothers,The cross-cultural studies clearly indicate that the symptoms of ASD are universal however, the interpretation is cultural-specific. While the above studies contribute valuable insights into the phenomenon under consideration, the overwhelming majority of the studies focus on a specific dimension: beliefs, stigma, stress, diagnosis, etc., without integrating the dimensions into a comprehensive framework. Furthermore, the studies predominantly employ conceptual or review research designs with a paucity of qualitative studies on the experiences of parents from the Pakistani community.

The rationale for conducting the present study is embedded in the need to address the gap between cultural perceptions and clinical practices in Pakistan. Past studies have shown that parental beliefs do impact intervention decisions and stress levels; however, not much comprehensive qualitative research has been conducted on the phenomenon of how parental beliefs impact the overall decision-making processes in the context of Pakistan. This study is relevant because:Cultural beliefs may impact the diagnosis and treatment processes,Religious beliefs may impact coping strategies and inclusion practices,Stigma may impact help-seeking behaviors,Burden on the caregiver may be increased by cultural perceptions and Past studies on the phenomenon have not been comprehensive or integrative.This study is also relevant because it is conducted with the aim of exploring the phenomenon of parental beliefs through a structured qualitative approach.

Research Questions

What are the parental beliefs, cultural perceptions, and lived experiences of families raising children with Autism Spectrum Disorder and developmental disabilities in the sociocultural context of Gujrat, Pakistan?

METHOD

A qualitative research design is being followed in this study, which is based on the concept of active involvement of the researcher in the social world of the participants. Such a research design is helpful in filling the gap between clinical definitions and realities of life. A phenomenological research design is being followed in this study to explore the realities of life faced by parents in Gujrat in raising children with Autism Spectrum Disorder (ASD) and other developmental disabilities. Such a research design is helpful in exploring the depths of human emotions and putting aside all academic assumptions.

Setting

The research was carried out in the District of Gujrat, Punjab. The participants were recruited through Government Special Education Schools and Community Centers. This ensured that there was a strong connection to families who are already utilizing the public system and are seeking support and services through special education.

Participants

The participants of this research are residing in Gujrat, classified according to their educational background and their involvement in their child’s therapeutic journey. Purposive sampling was employed to recruit participants who could give detailed and rich data regarding their experiences. The data collection was continued until data saturation was achieved, which means there was no new data emerging from the participants’ interviews.

The participants of this research are twenty (N=15), and they are categorized into:8 participants are parents of children suffering from Autism Spectrum Disorder (ASD). 7 participants are parents of children suffering from Developmental Disabilities (DD).The participants are equally distributed between fathers and mothers, with ages between 30-60 years. The participants are diverse and have represented both urban and rural areas of Gujrat District.

Procedures

Semi-structured interviews were employed as an instrument of data collection. The idea behind conducting semi-structured interviews is to have a "collaborative and open-ended conversation." This allowed parents to “speak freely" about issues related to "religious interpretation," "family pressures," and "societal stigmatization."Semi-structured interviews were informed by a series of open-ended questions related to:

The local construct of disability (physical "tension" and spiritual trials),The role of extended families and "Log Kya Kahenge" (societal judgments) and Coping strategies, which ranged from medical interventions to spiritual healing.Interviews ranged between 45 to 50 minutes and were conducted at a "convenient" time and place for parents. To ensure that participants expressed their "true feelings" without any "language barriers," interviews were conducted in Urdu and Punjabi. All interviews were audio-recorded, and word-for-word transcription was completed by the researcher to maintain "original meaning and tone" of participants' responses.

Analysis of Data

The researcher used Thematic Analysis to interpret the findings. This involved a systematic process of identifying patterns across the different stories told by the parents.The analysis followed a step-by-step approach:

Familiarization: Transcripts were read multiple times to get a "feel" for the common struggles and beliefs prevalent in Gujrat.Coding: Key phrases and words (like "Allah ki marzi," "Nazar," or "Social burden") were labeled as initial codes. Thematic Development:These codes were grouped into sub-themes and eventually into major themes that represented the core findings of the study.Final Review: The themes were checked back against the original interviews to ensure they accurately represented the parents' voices.

Ethical Consideration

Each parent gave their consent before participating. The researcher ensured that no parent felt pressured to open up on painful memories or family issues. To ensure the social reputation and privacy of the families, the names were replaced with pseudonyms. The information gathered was kept safe, and the trust of the participants was maintained

RESULT

The results of the study suggest that the beliefs and cultural perceptions of parents about Autism Spectrum Disorder (ASD) and developmental disabilities (DD) in Pakistani culture are the result of a complex interplay of cultural and religious factors. Parents tend to understand the condition from a biomedical perspective and a cultural-religious perspective, perceiving it as a test from Allah, an act of taqdeer or divine will, or a spiritual test. Moreover, the belief that it is a result of Nazar or evil eye is also quite common, along with a lack of awareness about the scientific explanations for the condition, such as genetic and neurological factors. Misconceptions about the causes of the condition, such as bad parenting, too much screen time, vaccines, and developmental delays, are also quite common. One of the key findings has been the impact of societal stigma, especially the concept of “Log Kya Kahenge,” which results in fear of judgment. Disability has also been found to be seen as not only affecting the individual but also the family. Disability has been found to impact the social lives of families, with many avoiding social gatherings, social events, and even religious spaces due to fear of being judged and criticized. Another key finding has been the gender roles, with women being the primary caregivers, providing emotional support to their disabled family members. Men have been found to have authority in decision-making regarding finances and treatment, but this has also been found to result in emotional stress for women, despite their minimal role in decision-making. The study further reveals that families make use of a combination of medical, traditional, and spiritual forms of treatment and care for their patients. Some families make use of faith healers, prayer, and spiritual treatment, among others, in addition to or instead of medical and therapeutic treatment. Financial issues, lack of knowledge, and cultural influences all play a role in shaping help-seeking behaviors, which in turn delays early diagnosis and treatment of patients. Furthermore, the lack of institutional and governmental support makes families feel helpless and uncertain about their future.

Thematic Analysis Table

Main Theme	Sub-Themes	Initial Codes	Explanation / Interpretation
Cultural and Religious Interpretations of Disability	Spiritual causation	Nazar, black magic, “Allah ki marzi”, taqdeer, Jannati child	Parents commonly interpret autism and developmental disabilities through spiritual and religious lenses. Instead of clinical understanding, disability is seen as fate, divine will, or supernatural influence. This reflects strong culturalreligious meaning-making within Pakistani society.
	Religious coping	Taweez, prayer, faith healer (Peer), belief in divine reward	Not only is religion used to understand disability, it is also used to cope with it. Families are actively engaged in religious activities to find healing for their disabled members. This may cause a delay in seeking medical care for the disabled members.
Misconceptions and Lack of Awareness	Mislabeling of disorder	“Screen disorder”, “weak brain”, “phase”, “bad parenting”	There is a significant lack of accurate knowledge about ASD and ADHD. Families and communities often use incorrect labels, leading to misunderstanding and improper guidance.
	Confusion about causes	Vaccination, genetics, diet during pregnancy	There are different, conflicting explanations among families, indicating poor mental health literacy.
Stigma and Social Pressure	Social judgment	“Log kya kahenge”, societal gaze, shame, family reputation	Stigma It is the most important factor, as families feel stigmatized by the rest of society, resulting in feelings of shame and isolation.Disability is seen as a social burden, rather than something that is developmentally related.
	Impact on family honor	Negative perception of daughters, marriage prospects, reputation	Especially in the case of daughters, disability is linked with reduced marriage prospects and family status, increasing emotional burden on parents.

Family Dynamics and DecisionMaking Power	Patriarchal decision control	Father makes final decisions, financial control, treatment authority	Fathers hold decision-making power regarding treatment and education. Mothers, despite being primary caregivers, have limited authority. This reflects patriarchal family structures.
	Role of extended family	In-law influence, pressure from elders	Extended family members influence beliefs and decisions, sometimes reinforcing misconceptions and limiting evidence-based interventions.
Parental Emotional Experience	Emotional distress	Heavy heart, helplessness, anxiety about future	Parents experience deep emotional stress, confusion, and fear about their child's future, especially regarding independence and care after their death.
	Denial phase	"She will talk next month", rejection of diagnosis	Initial denial is common, where parents avoid accepting the diagnosis due to fear and social pressure, delaying intervention.
Social Isolation and Daily Life Challenges	Restricted mobility	Avoiding markets, social gatherings, travel difficulties	Families restrict their social life due to fear of judgment and behavioral challenges of the child, leading to isolation.
	Negative public reaction	Staring, judgmental behavior, lack of empathy	Public misunderstanding and lack of awareness cause discomfort and discrimination, further isolating families.
Access to Services and Support	Lack of institutional support	No government support, no community help	Families report absence of structured support systems such as government services or community-based programs, increasing burden.
	Limited access to therapy	Financial constraints, lack of nearby services	Access to specialized education and therapy is limited, especially due to financial issues and availability in rural areas.
Caregiver Burden and Role Strain	Primary caregiver stress	Mothers managing daily care, emotional exhaustion	Mothers bear the majority of caregiving responsibilities, leading to high stress, fatigue, and emotional overload.
	Financial burden	Treatment cost, therapy expenses	Financial limitations restrict access to proper treatment and interventions, affecting overall child development outcomes.

Hope, Coping, and Future Orientation	Positive coping strategies	Hope, belief in improvement, seeking proper treatment	Despite challenges, parents maintain hope and seek improvement through proper treatment and awareness, showing resilience.
	Need for guidance	Desire for experts, structured guidance	Parents express a strong need for professional guidance and structured
			support systems to improve outcomes for their children.

DISCUSSION

The findings of this study also revealed that the concept of disability in Pakistani society does not exist merely as a biological construct; rather, it is deeply rooted in cultural, religious, and social constructs. Therefore, the presence of biological factors with cultural and religious factors implies that there is a dual belief system that tries to understand their child's disability both biologically and spiritually. Moreover, the prevalence of cultural factors often leads to misconceptions about the cause of disability; therefore, interventions are delayed. This also reflects a discrepancy between awareness and understanding that may have implications for the developmental prognosis of children with ASD and DD. The presence of stigma in the form of "Log Kya Kahenge" has been found to play a crucial role in influencing family behavior; this has also been found to be a major barrier for social inclusion and access to healthcare services. This also confirms the literature that has emphasized the role of social stigma in the limitation of seeking help. The family disability issue being more of a family issue rather than an individual issue also increases the social pressure on the family, especially in terms of social reputation and marriage.It has also been emphasized by the research that the patriarchal family structure plays an important role, where the father plays the most important role in terms of decision-making, whereas the mother plays the most important role in terms of caregiving, which has also been seen to increase the psychological burden on the mother, as the mother is already under a great deal of stress due to the caregiving role. This is a reflection of the existing societal norms, thus emphasizing the need for a more inclusive family setup in terms of caregiving and decision-making Another factor that is quite relevant is the aspect of traditional and spiritual medicine with or without medical interventions. This may be beneficial in that it gives the family emotional solace and is in line with the cultural and religious values of the family. However, this may also mean that there is a delay in the provision of appropriate interventions, which could be a consequence of the financial constraints and lack of awareness, thus not being beneficial for the family. The lack of institutional and governmental support is a major factor that needs attention, and the family is forced to cope with the situation on their own.However, despite all the challenges that the family is going through, the study also shows some aspects of resilience and coping mechanisms, especially for the parents, through religious faith, hope, and acceptance. These are coping mechanisms that help the parents cope with emotional stress. However, it also shows the need to strike a balance between cultural and religious values, on one hand, and the need to raise awareness and implement evidence-based interventions, on the other hand. In conclusion,It is worth saying that the study shows the need to raise awareness, ensure access to health care, and develop support systems to address the various challenges faced by parents of children living with ASD and other developmental disabilities.

CONCLUSION

This study has tried to explore the beliefs of parents, culture, and experiences of parents of children suffering from Autism Spectrum Disorders and other developmental disabilities. The findings of this study revealed that the issue of disability is greatly affected by culture, religion, and society as a whole. The parents of this study believe the issue of autism as a spiritual belief or fate, but they have a partial understanding of the biomedical model of autism. The parents showed resilience and coping skills in adversity.

Implications

The implications of the findings are that a need exists to be sensitive to cultural variations in awareness programs, early diagnosis, and mental health interventions, including beliefs held by the parents. Family-centered interventions, counseling, caregiver support, and education can be effective in reducing burden and promoting well-being. It is necessary to address both medical and sociocultural needs to offer effective interventions for children with developmental disabilities.

Limitations and Recommendations

The limitation of this study was that it was carried out on a small and regional sample, and the method was subjective, which could lead to bias. Future studies should be carried out on a large and diverse sample, and the method should be a mix and longitudinal one to observe the dynamics of the condition. Culturally sensitive interventions should be developed to enhance early diagnosis and treatment outcomes

Conflict of Interest

No conflict of interest was reported.

Data Availability

Data are confidential due to participant privacy. Anonymized data can be shared upon reasonable request.

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