

Navigating Caregiving Challenges and Societal Barriers: Lived Experiences of Mothers Raising Children with Autism Spectrum Disorder in Peshawar, Pakistan

Uzma Dayan¹, Laila²

Abstract

Raising a child with Autism Spectrum Disorder (ASD) can present significant emotional, social, financial, and practical challenges for parents and families, particularly in low-resource contexts such as Pakistan. These challenges highlight the importance of accessible services, family support, and greater understanding and acceptance within society. This qualitative study explores the challenges experienced by mothers of children with ASD, focusing on their emotional experiences, everyday caregiving responsibilities, family relationships, and interactions with the wider social environment. The study also unfolds parenting practices in responding to societal and cultural barriers. Drawing upon Vygotsky's sociocultural and Piaget's stage theories of cognitive development, 15 mothers were selected purposefully whose children were enrolled in the Centre of Excellence for Special Children with Autism (COESCA), Peshawar. The data were collected through semi structured interviews and analyzed through thematic analysis. The findings revealed that mothers experienced emotional shock and self-blame at diagnosis, communication difficulties, public breakdowns, and financial strain, including job loss. They also encountered social stigma, blame from family and community members, and attributions of autism to spiritual causes. Repeated rejection by mainstream schools further restricted their children's educational opportunities and contributed to families' withdrawal from social life. Although withdrawal offered short-term protection from negative social reactions, it also narrowed children's social experiences. The findings highlight the need for affordable therapeutic services, early psychological support, parent training, and community awareness programs.

Introduction

Article History

Received 22 September 2026

Accepted 14 October 2026

Published 20 October 2026

Corresponding Author*

OPEN ACCESS

Keywords

Autism Spectrum Disorder; mothers; caregiving; stigma; inclusive education; Pakistan.

Introduction

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition characterised by persistent differences in social communication and interaction, alongside restricted and repetitive patterns of behaviour and interests (Lord et al., 2018). Recognition of ASD has increased over time, although reported prevalence estimates vary across populations and surveillance methods. A systematic review estimated the global prevalence of autism at approximately 1 in 100 children (Zeidan et al., 2022), whereas surveillance data from the United States indicated that approximately 1 in 36 children aged eight years had been identified with ASD (Maenner et al., 2023). Given the diverse support needs of individuals with ASD and the lifelong nature of the condition, families often assume substantial responsibility for daily care, advocacy, and navigating educational, therapeutic, and other support services.

¹ Lecturer, Institute of Education and Research, University of Peshawar. uzmadayan@uop.edu.pk

² MPhil scholar, Institute of Education and Research, University of Peshawar lailapst@gmail.com

Raising a child with ASD can place considerable emotional, financial, and practical demands on parents. Previous research has associated caregiving with elevated stress, financial difficulties, disruptions to family routines, and concerns about children's future well-being and independence (Hsiao, 2018; Papadopoulos, 2021). However, these experiences cannot be understood solely in terms of individual caregiving demands. They are also shaped by the social and cultural environments in which families live. Limited public awareness of neurodevelopmental conditions may expose parents to stigma by association, including blame, social avoidance, and negative judgement. Such experiences can intensify parental distress and contribute to social isolation (Papadopoulos, 2021). Understanding parents' experiences therefore requires attention to the interaction between caregiving responsibilities, family relationships, community attitudes, and the availability of social support.

These concerns are particularly important in low- and middle-income countries (LMICs), where autism research has historically been concentrated in high-income settings and access to formal diagnostic, therapeutic, educational, and family-support services may be limited. In Pakistan, the available research has documented several difficulties experienced by parents raising children with ASD. A study conducted in Punjab reported that parents were concerned about their children's futures and highlighted the need for stronger governmental support across social, economic, and educational domains (Ghafoor, 2019). Similarly, a recent survey conducted in Rawalpindi and Islamabad reported parental stress, disruptions to family life, discrimination in family and community settings, and stigma directed towards children following diagnosis (Amin et al., 2024). Collectively, these studies indicate that the experiences of Pakistani families extend beyond the practical demands of caregiving to include social judgement, exclusion, and uncertainty about their children's futures.

Despite these contributions, important gaps remain in the available literature. First, the existing evidence provides limited insight into how parents interpret and make sense of their experiences within their everyday lives and changing family and social circumstances. Although surveys and interview-based studies have identified parental challenges, further qualitative investigation can illuminate the meanings parents attach to these experiences and the ways they navigate them. Second, parental challenges and societal stigma are often discussed as related but distinct concerns. More attention is needed to how parents themselves respond to social and cultural barriers, including whether they avoid particular settings, seek support from family members or religious and spiritual networks, advocate for their children, or adopt other strategies to manage negative social reactions. Examining these responses can help explain how families negotiate the relationship between caregiving, social expectations, and opportunities for their children's participation. Third, research specifically examining mothers' experiences of raising children with ASD in Peshawar and the wider Khyber Pakhtunkhwa (KP) context remains limited. Findings from other regions of Pakistan cannot automatically be assumed to represent the experiences of families in KP, where family structures, gender expectations, community norms, and access to services may shape caregiving in context-specific ways. Locally grounded evidence is therefore important for understanding how mothers experience and respond to the challenges arising within their particular social and institutional environments. Without such evidence, educators, health professionals, and policymakers may have difficulty developing support that is responsive to families' circumstances and needs.

Addressing these gaps requires a qualitative approach that foregrounds mothers' accounts of caregiving, the meanings they attach to their experiences, and their encounters with social and cultural responses to autism. Accordingly, the present study explores the experiences of mothers raising children with ASD in Peshawar, Pakistan. It examines the challenges and

barriers they encounter and how they respond to societal and cultural barriers affecting their children. By focusing on mothers' accounts in an under-researched regional context, the study aims to contribute a more contextually grounded understanding of the relationship between caregiving demands, social attitudes, and barriers to educational and social participation. The findings may also inform the development of culturally responsive, family-centred support services and policies. To address these aims, the study was guided by the following research objectives and questions.

Research objectives

- To explore the challenges and barriers mothers encounter while raising children with autism spectrum disorder in Peshawar, Pakistan.
- To examine how mothers respond to societal and cultural barriers affecting their children with autism spectrum disorder.

Research Questions

1. What challenges and barriers do mothers raising children with autism spectrum disorder experience in Peshawar, Pakistan?
2. How do mothers respond to the societal and cultural barriers affecting their children with autism spectrum disorder?

Theoretical Framework

This study is guided by Bronfenbrenner's Ecological Systems Theory (1979), complemented by Goffman's theory of stigma (1963) and Link and Phelan's (2001) conceptualization of stigma. Together, these perspectives provide a framework for understanding how mothers' experiences of raising children with ASD are shaped by caregiving demands, social relationships, cultural expectations, and institutional conditions.

Bronfenbrenner's ecological perspective explains how individual and family experiences are influenced by interconnected environmental systems, including immediate relationships (microsystem), connections between settings such as home and school (mesosystem), external institutional conditions (ecosystem), broader cultural and socioeconomic contexts (macro system), and changes over time (chronosystem). This framework helps examine how family relationships, community responses, educational access, service availability, financial circumstances, and cultural understandings of autism shape mothers' caregiving experiences (Bronfenbrenner, 1979).

To understand social judgement and discrimination, Goffman's (1963) theory of stigma and Link and Phelan's (2001) conceptualization offer complementary insights. Stigma involves the negative social meanings attached to perceived differences and processes of labelling, stereotyping, separation, status loss, and discrimination, shaped by power relations. These perspectives help interpret mothers' accounts of blame, social avoidance, negative public reactions, and barriers to school admission, including stigma experienced by mothers through their association with their children.

Together, these perspectives provide an analytical framework in which ecological theory situates mothers' experiences within their social and institutional contexts, while stigma

theory explains how negative attitudes may contribute to exclusion and restricted participation. The framework also allows for variation in mothers' experiences and responses, without assuming that all families encounter or respond to stigma in the same way.

Methodology

Research Approach and Design

This study employed a qualitative exploratory design to investigate the experiences, perceptions, and challenges of mothers raising children with autism spectrum disorder (ASD) in Peshawar, Pakistan. A qualitative approach was appropriate for examining the meanings mothers attached to their caregiving experiences and understanding how they navigated the social and cultural circumstances affecting their children. Qualitative inquiry facilitates an in-depth exploration of complex social phenomena through participants' accounts, perspectives, and interpretations (Creswell & Creswell, 2022; Strauss & Corbin, 1998). An exploratory design was suitable for developing a contextual understanding of the challenges mothers encountered and their responses to these challenges without testing hypotheses or establishing causal relationships (Saunders et al., 2012).

Research Setting and Population

The study was conducted at COESCA, an institute for children with special educational needs in Peshawar, Pakistan. The institute provides services to children with diverse disabilities, including visual, hearing, physical, and intellectual disabilities, as well as autism. According to information provided by the institute's management, 65 children were enrolled at the centre. The study focused on mothers of children diagnosed with ASD who were enrolled at the institute.

Sample and Sampling Technique

Purposive sampling was used to select 15 mothers of children diagnosed with ASD and enrolled at COESCA. The participants were selected because their direct experiences of raising children with ASD were relevant to the study's objectives. Purposive sampling is appropriate in qualitative research when participants are deliberately recruited for their ability to provide information-rich accounts of the phenomenon under investigation (Creswell & Poth, 2018). This approach enabled the researcher to explore mothers' caregiving experiences, the challenges they encountered, and their responses to societal and cultural barriers. The sample was intended to provide an in-depth, context-specific understanding of these experiences rather than statistical representation of all mothers raising children with ASD.

Data Collection Tool and Procedure

Data were collected through semi-structured, in-depth interviews with 15 mothers of children diagnosed with autism spectrum disorder (ASD) enrolled at COESCA in Peshawar, Pakistan. This approach enabled the researcher to explore mothers' experiences, perceptions, and understandings of ASD while allowing flexibility to probe issues emerging during the interviews (Creswell & Poth, 2018; Fontana & Frey, 2000). The semi-structured format provided a consistent focus on the research objectives while allowing participants to describe their experiences in their own terms.

Interviews were conducted in Pashto, the local lingua franca, and Urdu, Pakistan's national language, to facilitate communication and enable participants to express their experiences in familiar languages. Before each interview, the purpose of the study was explained to the participant. Confidentiality and anonymity were assured to protect participants' identities and the information they shared. Formal permission to conduct the study was obtained from the institute's management in advance.

Data Analysis

The interview data were analysed thematically, following the six-phase approach outlined by Braun and Clarke (2006). First, the interview data were transcribed, translated from Pashto and Urdu into English, and read repeatedly to develop familiarity with the content. Second, initial codes were generated to identify meaningful features of the data relevant to the research questions. Third, related codes were grouped to develop preliminary themes. Fourth, the themes were reviewed and refined in relation to the coded data and the overall dataset. Fifth, the themes were defined and named to clarify their central meanings and analytical relevance. Finally, the themes were interpreted and presented in a structured account addressing the study's objectives and research questions.

The analysis focused on patterns across mothers' accounts of caregiving challenges and their responses to societal and cultural barriers affecting their children. The resulting themes provided the basis for presenting and interpreting the study's findings.

Ethical Consideration

Formal permission to conduct the study was obtained from the management of COESCA, Peshawar, before data collection. The purpose of the study was explained to each participant before the interview, and informed consent was obtained individually from all participating mothers. Participants were assured of the confidentiality of the information they provided and the anonymity of their identities. These measures were undertaken to protect participants' privacy and support their informed participation in the study.

Findings

A total of 15 mothers of children diagnosed with autism spectrum disorder (ASD) were interviewed. The thematic analysis generated eight themes addressing the mothers' caregiving challenges and their experiences of societal and cultural barriers. These themes concerned emotional responses to diagnosis, communication difficulties and public meltdowns, financial and employment pressures, family relationships, public stigma, blame and spiritual explanations, exclusion from mainstream schooling, and social withdrawal and its consequences for children's confidence. Together, the findings illustrate how the challenges associated with raising a child with ASD extended beyond caregiving demands to include financial constraints, social judgement, and barriers to educational and social participation.

Theme 1: Emotional Shock at Diagnosis and Maternal Self-Blame

Receiving an ASD diagnosis was described as an emotionally distressing experience, characterized by shock, disbelief, and sadness. Mothers' accounts suggested that the diagnosis could be difficult to comprehend initially, with some describing intense emotional and

physical reactions. These responses indicate that receiving a diagnosis was not simply an informational event but a significant emotional experience for mothers.

One mother described her immediate reaction:

“As soon as the doctor told me that my son was autistic, ‘my ear stopped working’ was what it was. I thought, ‘I feel like I heard wrong,’” (M-12).

This account conveys the mother’s sense of disbelief and difficulty processing the diagnosis. Her description of her ear “stopping” suggests the intensity of the moment and the difficulty of accepting unexpected information about her child.

Alongside shock and sadness, some mothers questioned whether their own actions had contributed to their child’s condition. These feelings of self-blame sometimes emerged before other people explicitly held them responsible, suggesting that mothers also internalized uncertainty and social expectations surrounding caregiving.

One participant reflected:

“I said, ‘Is this my fault?’ That due to my negligence my child was autistic.” (M-9)

This account illustrates how uncertainty surrounding the diagnosis could become entangled with maternal responsibility and guilt. The mother’s concern about personal negligence reflects a tendency to interpret the child’s condition through the lens of her own parenting practices. Such accounts also provide context for understanding the later findings concerning social blame, in which mothers were held responsible for their children’s developmental differences.

Theme 2: Communication Difficulties and Public Meltdowns as Daily Challenges

Mothers identified communication difficulties as a persistent challenge in everyday caregiving. When children had limited or no spoken language, mothers often had to interpret their needs through facial expressions, body language, and other behavioural cues. This placed additional demands on mothers, who described the ongoing effort required to understand and respond to their children. One mother explained:

“My child has no way of telling me what he wants, and I have to do all the talking for him all day, trying to determine from his facial expression and body language what he wants.” (M-5)

The account highlights the continuous interpretive work involved in caregiving when a child has limited verbal communication. The mother’s description of having to “do all the talking” conveys both her responsibility for anticipating her child’s needs and the difficulty of understanding those needs without direct verbal communication.

Mothers also described public meltdowns in environments involving loud sounds, crowds, and other forms of sensory stimulation. Weddings, markets, and shopping trips could become particularly challenging when children experienced distress in busy or noisy settings. These incidents were made more difficult by the attention and comments of people nearby.

The same participant recounted:

“Too loud music, too many people, my kid had a meltdown, covered his ears, cried and talked about the people looking at him and commenting.” (M-5)

This account illustrates the interaction between a child’s distress in a stimulating environment and the social reactions surrounding the incident. The child’s response to noise and crowds became a public experience, exposing both the child and the mother to the attention of others. Thus, the challenges mothers encountered involved not only responding to their children’s communication and sensory needs but also managing the social consequences of these experiences.

Theme 3: Financial Strain and Disruption of Maternal Employment

The costs associated with caring for children with ASD emerged as a substantial source of pressure for some families. Mothers referred to transportation expenses, therapy, and the costs of special education, describing these as continuing financial demands on household resources. These expenses could require families to adjust other spending and make difficult decisions about educational and therapeutic services.

One mother described the financial burden:

“Rickshaw and fuel costs 12,000 to 15,000 PKR monthly and we can't afford a normal school, the fees at the special school are high.” (M-11)

This account demonstrates how transportation and educational costs could combine to create financial pressure. The reference to monthly transport expenses provides a concrete example of the recurring costs associated with accessing services. The mother’s statement that the family could not afford a mainstream school, while special-school fees were also high, points to the financial constraints affecting educational choices.

Financial pressures were also linked to changes in mothers’ employment. Some mothers reported leaving paid employment or changing their work arrangements to accommodate childcare and therapy schedules. These changes affected their routines and the roles they occupied within and beyond the household.

One participant explained:

“I am now working full-time as a parent and so I can no longer attend therapy sessions - ‘my job went, my son is my priority now.’” (M-10)

The description of working “full-time as a parent” conveys the intensity of caregiving responsibilities and the extent to which they could reshape a mother’s daily life. The statement that her son had become her priority also reflects the personal decisions mothers made in response to competing employment and caregiving demands. Her account illustrates how caring for a child with ASD could involve not only additional expenditure but also the loss of paid work and changes in maternal identity.

Theme 4: Strain on Family Relationships and Subsequent Adaptation

Mothers’ accounts indicated that raising a child with ASD could affect family relationships, particularly when family members disagreed about responsibility or how to respond to the

child's needs. Blame and tensions within the extended family could add to the emotional pressures experienced by mothers. However, the accounts also suggested that some families gradually developed more cooperative ways of managing caregiving responsibilities.

One mother described a change in how responsibilities were understood within her marriage:

“When we started our marriage together, we took the blame on ourselves for each other, but after 3 years it was a team.” (M-9)

Although the wording of this quotation is somewhat unclear, the mother appears to contrast an earlier period of mutual blame with a later sense of teamwork. Her account suggests that family responses were not necessarily fixed and that relationships could change over time as family members adjusted to their circumstances.

This experience provides a counterpoint to the accounts of blame and conflict elsewhere in the findings. It indicates that, alongside the difficulties associated with caregiving, some families developed more cooperative approaches. However, this quotation alone does not establish that such adaptation occurred across all participating families.

Theme 5: Public Stigma, Staring, and Social Avoidance

Public stigma emerged as an important feature of mothers' experiences. Mothers described being watched, hearing negative comments, and observing other parents distancing their children from children with ASD. These responses contributed to the perception that their children were viewed negatively or regarded as unsuitable companions.

One mother recounted:

“Other mothers take their kids away from him, they make him look bad. They think that something is wrong with him, that he is dangerous.” (M-11)

The participant interpreted the behaviour of other mothers as a sign that her child was perceived as different or potentially dangerous. Her account illustrates how social distancing could be experienced as rejection, reinforcing the stigma associated with the child's condition. Such reactions could also affect mothers by making ordinary social interactions more difficult and emotionally demanding.

The significance of these experiences extends beyond individual incidents of staring or avoidance. They reveal how public perceptions of autism could shape the social environments in which mothers and their children participated. When other people responded with fear, judgement, or avoidance, families faced additional barriers to social inclusion alongside the practical demands of caregiving.

Theme 6: Maternal Blame and Spiritual Explanations of Autism

Mothers reported encountering explanations of autism that attributed the child's condition to maternal behaviour, including mobile-phone use during pregnancy, inadequate discipline, or excessive indulgence. These accounts placed responsibility on mothers and suggested that the child's developmental differences resulted from their actions or parenting practices.

One mother recalled being asked:

“Tumny pregnancy mein zyada mobile use kiya hoga [you might have used mobile more during pregnancy]?” (M-11)

The question illustrates how assumptions about maternal behaviour could become explanations for a child’s autism. Rather than treating the diagnosis as a developmental condition requiring understanding and support, such comments could encourage guilt and place mothers under scrutiny. This theme connects with the self-blame described earlier, showing how mothers’ personal concerns could be reinforced by judgements from others.

Some mothers also reported that members of their communities interpreted autism through spiritual or supernatural explanations. Six participants (M-5, M-6, M-8, M-9, M-10, and M-11) described encountering beliefs involving nazar (the evil eye), jinn (supernatural beings), or the idea that a child’s condition represented a test or punishment from God. Some reported that elders recommended spiritual interventions rather than clinical services.

One participant explained:

“Some believe that autism comes from ‘nazar’ or ‘jinn ka saya’ [the shadow of jinn] and some elders have told me to visit a peer [spiritual healer] or to do ‘dam’ [spiritual blowing/recitation].” (M-10)

This account demonstrates how cultural and religious interpretations could shape the advice mothers received following diagnosis. The recommendation to consult a spiritual healer reflects the presence of explanatory frameworks that differ from clinical understandings of autism. The findings do not establish that all families held these beliefs or rejected clinical care. Rather, they show that some mothers encountered spiritual explanations and recommendations that formed part of their wider social experiences of raising a child with ASD.

Theme 7: Repeated Exclusion from Mainstream Schooling

Access to mainstream education was another challenge reported by mothers. Several described approaching mainstream schools but being refused admission because the schools reportedly lacked trained staff, appropriate facilities, or the capacity to accommodate their children’s needs. Some mothers reported approaching multiple schools before concluding that mainstream education was inaccessible to their children.

One mother explained:

“Well, I took my son to 5 schools and they all told me that there are no facilities for special kids.” (M-11)

The mother’s account of approaching five schools illustrates the difficulties some families encountered when seeking educational placement. The explanation that schools lacked facilities points to perceived institutional constraints, particularly the availability of resources and provision for children with additional learning needs.

Repeated rejection could leave mothers with limited educational choices, especially when special-school fees and transportation costs were already placing pressure on household finances. The findings therefore suggest an intersection between educational exclusion and

economic disadvantage: barriers to mainstream admission could increase families' dependence on specialist provision, while the cost of accessing that provision could create further difficulties.

These accounts represent mothers' reports of school admission experiences rather than independent assessments of the schools' capacities. Nevertheless, they reveal how repeated refusals were experienced by families seeking educational opportunities for their children.

Theme 8: Social Withdrawal and Perceived Erosion of Children's Confidence

Mothers described withdrawing from social events because they anticipated negative reactions to their children. Their accounts generally indicated self-imposed withdrawal rather than formal exclusion from every gathering. The possibility of encountering staring, comments, or uncomfortable interactions influenced decisions about whether to attend social occasions.

One participant expressed this concern:

"Not being excluded, but I don't want to go to social events because I don't want to have to deal with the reactions of people around me to my child." (M-1, M-12)

This account distinguishes direct exclusion from withdrawal motivated by the expectation of social judgement. The mothers' decisions not to attend events can be understood as attempts to avoid potentially distressing encounters. Such withdrawal may offer short-term protection from negative reactions, but it can also reduce opportunities for children and families to participate in wider social life.

Some mothers also described comments from relatives that discouraged visits or implied that their children's presence might disrupt household gatherings.

One mother recalled:

"Uncle told me, 'Ghar mein bahut bachay hain, shor ho jayega, agli dafa aana' [There are a lot of kids in the house, it will be noisy, come next time]." (M-11)

The relative's response suggests that concerns about noise and disruption could become grounds for postponing or discouraging family visits. Even when expressed as a temporary arrangement, such comments could communicate that the child's presence was unwelcome. Experiences of this kind may help explain why some mothers chose to avoid social gatherings rather than risk further uncomfortable encounters. Mothers also perceived changes in their children's behaviour and confidence in social settings. They described children becoming less socially expressive or appearing increasingly aware of how others viewed them.

One participant reflected:

"He would wave to people and now he doesn't, I think he feels like, 'I am different and that's bad.'" (M-11)

The mother interpreted her child's reduced social gesture as a possible response to feeling different from others. Although the quotation cannot establish the child's internal feelings directly, it reveals the mother's concern that negative social experiences might affect the

child's confidence and willingness to engage with others. Her interpretation highlights the potential emotional consequences of stigma as perceived by caregivers.

Taken together, these accounts suggest that social withdrawal could operate as a protective response to anticipated or experienced judgement while also narrowing opportunities for social participation. Mothers' concerns extended beyond immediate incidents of stigma to the possibility that repeated negative interactions could influence their children's social engagement. Across the eight themes, mothers reported interconnected emotional, practical, financial, educational, and social challenges in raising children with ASD. These included shock and self-blame following diagnosis, communication and sensory difficulties, financial pressures, changing family relationships, and public stigma.

Overall, the findings show that mothers' challenges arose not only from their children's support needs but also from social stigma, limited educational opportunities, and inadequate acceptance within families and communities

Discussion

This study explored the experiences of 15 mothers raising children with autism spectrum disorder (ASD) in Peshawar, Pakistan, with particular attention to the challenges they encountered and their responses to societal and cultural barriers. The findings indicate that mothers' experiences were shaped by the interaction of caregiving demands, financial pressures, family relationships, community attitudes, and institutional barriers to educational and social participation. Bronfenbrenner's Ecological Systems Theory (1979) provides a useful framework for interpreting how these influences operate across interconnected social environments, while Goffman's theory of stigma (1963) and the conceptualization developed by Link and Phelan (2001) help explain how negative social judgements may contribute to exclusion. Together, these perspectives highlight that the challenges reported by mothers were not attributable solely to their children's support needs but were also connected to the social and institutional conditions in which caregiving took place.

One important finding concerned the emotional impact of diagnosis and the self-blame experienced by some mothers. Participants described shock, disbelief, and questions about whether their own actions had caused their child's condition. These experiences are consistent with research identifying emotional distress, uncertainty about children's futures, and parental stress among families raising children with ASD (Hsiao, 2018; Papadopoulos, 2021). An ecological perspective helps situate these reactions within the mothers' wider circumstances, including family expectations, community beliefs, and the availability of reliable information and professional support. Maternal self-blame may also be reinforced when autism is attributed to mothers' behaviour during pregnancy or other perceived parental shortcomings. In this respect, the findings suggest that emotional responses to diagnosis cannot be understood independently of the social explanations and expectations surrounding motherhood. They also highlight the importance of providing parents with clear information and emotional support at and following diagnosis.

Communication difficulties and sensory distress constituted another significant aspect of mothers' daily experiences. One mother explained that she had to interpret her child's facial expressions and body language to understand his needs, while another described her child becoming distressed in crowded or noisy environments. These accounts illustrate the continuous attention and adaptation required when mothers are trying to respond to communication needs and sensory distress. From an ecological perspective, these challenges

emerge through the interaction between children's individual needs and the characteristics of the environments in which they participate. A crowded social gathering, for example, may become particularly difficult when sensory needs are not recognised and others respond to distress with judgement rather than understanding. This interpretation complements previous research on parental stress in families raising children with ASD (Hsiao, 2018; Papadopoulos, 2021) by highlighting how caregiving demands can be intensified by environments that provide limited accommodation or support.

The findings further indicate that mothers' experiences were shaped by family and community responses to autism. Some participants described maternal blame, negative social reactions, and spiritual explanations involving nazar, jinn, or divine testing and punishment. These accounts reveal how understandings of autism may be shaped by culturally situated beliefs and the information available within families and communities. An ecological framework directs attention to the relationship between immediate family interactions and broader cultural expectations, while stigma theory helps interpret how negative assumptions may attach to both children and their mothers. Goffman's (1963) concept of stigma is particularly relevant to the social distancing and negative judgements described by participants. Link and Phelan's (2001) account further highlights how labelling and stereotyping may be associated with separation and discriminatory treatment.

These findings are consistent with literature showing that stigma can extend to parents through their association with children with ASD (Mitter et al., 2019) and with Pakistani research reporting stigma and discrimination within family and community settings (Amin et al., 2024; Ghafoor, 2019). There are also parallels with research on Somali families in the United Kingdom, which examined cultural and religious understandings of autism (Hussein et al., 2019). Such comparisons suggest that families' experiences may be shaped by the interaction between local cultural understandings and wider social attitudes. However, the present findings do not establish that these beliefs are shared by all families in Peshawar or that religious beliefs necessarily prevent the use of professional services. Rather, some mothers reported encountering explanations or advice that they experienced as blaming or unhelpful. Culturally responsive support therefore requires respectful engagement with families' beliefs alongside access to accurate information and appropriate services.

Educational exclusion illustrates how barriers at the institutional level can interact with pressures within family life. One mother reported taking her son to five schools, all of which indicated that they lacked facilities for children with special educational needs. Although the study did not independently assess these schools, the mother's account demonstrates the difficulty she experienced in securing mainstream educational access for her child. From an ecological perspective, the relationship between home and school is particularly important because educational settings form part of the environments in which children may develop relationships and participate in learning. When admission is refused, families may have to seek alternative provision, potentially increasing their financial and caregiving responsibilities. The reported school refusals can also be understood through a stigma lens where decisions reflect negative assumptions or exclusionary practices; however, the present data do not establish the motivations behind individual schools' decisions. The findings nevertheless highlight the importance of examining educational access as both a family concern and an institutional issue.

Financial pressures and disruption to maternal employment further demonstrate the interconnected nature of mothers' experiences. Participants described substantial transportation expenses, the high cost of specialist schooling, and difficulties maintaining employment alongside caregiving responsibilities. One mother explained that she could no longer attend therapy sessions because her employment had been affected by her caregiving role. These accounts are consistent with research associating the care of children with ASD

with financial strain, parental stress, and disruption to family routines (Hsiao, 2018; Amin et al., 2024). Bronfenbrenner's ecological perspective helps locate these pressures within the wider conditions affecting families, including employment opportunities, service availability, and the costs of obtaining support. The findings suggest that mothers' capacity to meet their children's needs was shaped not only by their willingness or knowledge but also by the material resources available to them. Support programmes that overlook these constraints may therefore fail to address important aspects of families' lived experiences.

Social withdrawal emerged as a response to the negative reactions that some mothers experienced or anticipated in public and family settings. Participants described avoiding social gatherings because they did not want to face staring, judgement, or exclusion directed towards their children. One mother recounted being discouraged from visiting relatives because her child might create noise, while another expressed concern that her child had stopped waving to people. These accounts suggest that withdrawal could offer mothers a way of avoiding distressing encounters, although it also risked narrowing opportunities for family and community participation. Stigma theory helps interpret avoidance as a possible response to anticipated or experienced negative social judgement rather than simply a personal preference for isolation. The ecological perspective further highlights that children's opportunities for participation are shaped by the availability of accepting and accommodating social environments. Nevertheless, the reported change in one child's behaviour represents the mother's interpretation and does not establish the child's internal feelings or the cause of that change.

Taken together, the findings suggest a connected pattern in which caregiving demands interact with social attitudes, financial constraints, and institutional barriers. Communication and sensory-related needs required sustained maternal attention; negative social responses and school-access difficulties restricted opportunities for participation; and withdrawal sometimes became a way of managing anticipated or experienced judgement. These processes may reinforce one another, although the study's design does not establish a causal sequence. The combined theoretical framework helps interpret this pattern by locating mothers' experiences within interconnected environmental systems and examining how stigma may operate across family, community, and institutional settings. It also draws attention to the possibility that support and exclusion can coexist: some family members or community figures may provide assistance, while others may reinforce blame or misunderstanding.

The study's contribution lies in bringing ecological and stigma perspectives together to interpret mothers' accounts in an under-researched regional context. The ecological framework helps demonstrate how caregiving experiences are connected to family relationships, educational access, service availability, and broader cultural expectations. Stigma theory offers a more specific explanation of the negative labelling, social distancing, and exclusion reported by some participants. In combination, these perspectives suggest that efforts to support families need to address not only individual caregiving needs but also the environments in which children and mothers seek acceptance, education, and services. This is a contextually grounded interpretation of the present findings rather than a claim that the study establishes a new theory.

Several practical implications follow. First, accessible parent-support programmes could provide information about autism, strategies for responding to communication and sensory needs, and opportunities for emotional support. Such programmes need to recognise mothers' existing knowledge of their children and account for the financial and practical constraints they face. Second, schools require appropriate resources, trained personnel, and inclusive practices to improve educational access for children with ASD. Third, community awareness initiatives could address misconceptions, maternal blame, and negative social attitudes. Where appropriate, collaboration with trusted community and religious leaders may support

respectful discussion of autism while avoiding the stigmatisation of families or the dismissal of their beliefs. Finally, accessible and affordable therapeutic, educational, and family-support services are important for reducing the practical and financial pressures described by mothers. These measures require coordinated attention to families, educational institutions, service providers, and wider community environments.

The findings should be interpreted in light of several limitations. The study involved 15 mothers recruited from one institute in Peshawar, and its findings are therefore context-specific rather than statistically generalisable to all families raising children with ASD in Pakistan. Participants' accounts of community attitudes and school refusals were not independently verified through interviews with community members or school personnel. The study also relied on mothers' perspectives and did not directly examine the experiences of children, fathers, extended family members, teachers, or religious leaders. Finally, the ecological and stigma perspectives were used as interpretive frameworks; the study did not independently test these theories or establish causal relationships between social stigma, withdrawal, and children's participation. Future research could include multiple family and community perspectives to explore how support and exclusion are negotiated across settings. Longitudinal qualitative research could also examine how mothers' experiences, coping responses, and support needs change over time.

Conclusion

This study explored the experiences of 15 mothers raising children with autism spectrum disorder (ASD) in Peshawar, Pakistan. The findings revealed interconnected emotional, practical, financial, educational, and social challenges. Mothers described emotional shock and self-blame following diagnosis, daily communication and sensory-related challenges, financial pressures, changes in family relationships, public stigma, mother-blaming, spiritual explanations of autism, and repeated difficulties obtaining admission to mainstream schools. Some mothers responded to negative social reactions by withdrawing from social events, a strategy that could offer short-term protection while restricting opportunities for their children's social participation.

Bronfenbrenner's Ecological Systems Theory provides a useful perspective for understanding how these experiences were shaped by interactions among family relationships, community attitudes, educational institutions, and wider cultural and socioeconomic conditions. Goffman's theory of stigma and Link and Phelan's conceptualisation of stigma further illuminate how negative social judgements may contribute to blame, exclusion, and restricted participation. Together, these perspectives highlight that the challenges reported by mothers were not attributable solely to their children's support needs but were also associated with the social and institutional environments surrounding them.

The study contributes context-specific qualitative evidence from an under-researched setting in Pakistan. Although the findings cannot be generalised to all families raising children with ASD, they highlight the importance of accessible support services, inclusive educational opportunities, and informed and non-judgemental community responses. Improving these conditions may help reduce the additional burdens associated with stigma and exclusion and support the participation and well-being of children and their families.

Implications

The findings have implications for health and therapy providers, educational institutions, families, and community organisations.

Early support for mothers and families: Emotional support and clear information about ASD at the point of diagnosis may help families navigate initial uncertainty and reduce self-blame.

Parent support and training: Accessible training in communication strategies, responding to sensory needs, and supporting learning at home may strengthen mothers' and other caregivers' confidence in everyday interactions with their children.

Inclusive educational provision: The reported difficulties securing mainstream school admission point to the importance of trained teachers, appropriate learning support, reasonable adjustments, and clear admission procedures for children with ASD.

Community awareness and stigma reduction: Awareness initiatives involving families, schools, healthcare providers, and religious and community leaders may challenge mother-blaming and misconceptions about autism while respecting families' cultural and religious beliefs.

Financial and service accessibility: The reported costs of therapy, transport, and specialist education highlight the need to consider affordability and geographical access when planning services for children with ASD and their families.

These implications arise from the experiences reported by the participating mothers and require further evaluation in different settings.

Recommendations for Practice and Policy

Improve access to affordable services and psychological support. Relevant health and education authorities and service providers may explore affordable therapy, financial assistance for families facing substantial costs, and timely psychological support following diagnosis.

Develop accessible parent-training programmes. Clinicians and special educators may provide practical guidance on communication, sensory needs, and home-based learning. Where possible, training and support may be extended to fathers and other family members involved in caregiving.

Strengthen inclusive school admission and support. Education authorities and school management may review barriers to admission, provide teacher training on ASD, and make appropriate learning support and resources available. Children's support needs can be assessed individually rather than treating an ASD diagnosis alone as a reason for exclusion.

Promote culturally responsive community awareness. Awareness activities may address misconceptions that autism results from maternal behaviour, the evil eye (nazar), or jinn. Collaboration with trusted community and religious leaders may help communicate accurate information about autism while ensuring that families are not blamed or discouraged from seeking appropriate clinical and educational support.

Support family and peer networks. Community organisations and relevant service providers may consider facilitating parent-support groups where families can share experiences, access reliable information, and explore ways to maintain social participation for themselves and their children.

These recommendations are suggested directions for practice and policy rather than interventions whose effectiveness has been established by this study.

Limitations

The findings must be interpreted in light of several limitations. The study involved 15 mothers recruited from one institute in Peshawar; therefore, the experiences described may not represent the diversity of families raising children with ASD in other settings. Accounts of stigma, community beliefs, and school exclusion reflect the mothers' reported experiences and were not independently verified through interviews with community members or schools. Children's perspectives and the experiences of fathers, extended family members, and service providers were not directly examined. The findings are therefore context-specific and exploratory. The theoretical frameworks provide interpretive lenses for understanding the

accounts rather than evidence that particular social processes or interventions have been causally established.

Statement of AI use

ChatGPT has been used for grammar and proofreading purposes.

References

- Amin, B., Mahmood, Q. K., & Akram, M. B. (2024). Socio-psychological challenges faced by the parents of children with autism spectrum disorder: A cross-sectional study in Rawalpindi and Islamabad. *Journal of Development and Social Sciences*, 5(4), 642–649.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Cohen, L., Manion, L., & Morrison, K. (2007). *Research methods in education* (6th ed.). Routledge.
- Creswell, J. W., & Creswell, J. D. (2022). *Research design: Qualitative, quantitative, and mixed methods approaches* (6th ed.). SAGE Publications.
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). SAGE Publications.
- Fontana, A., & Frey, J. H. (2000). The interview: From structured questions to negotiated text. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 645–672). SAGE Publications.
- Ghafoor, B. (2019). Problems faced by the parents of autistic children: A qualitative study in Punjab, Pakistan. *Rawal Medical Journal*, 44(3), 505–508.
- Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Social Sciences*, 7(8), Article 133.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Prentice-Hall.
- Hsiao, Y.-J. (2018). Autism spectrum disorders: Family demographics, parental stress, and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, 15(1), 70–79.
- Hussein, A. M., Pellicano, E., & Crane, L. (2019). Understanding and awareness of autism among Somali parents living in the United Kingdom. *Autism*, 23(6), 1408–1418. <https://doi.org/10.1177/1362361318813996>
- Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 27, 363–385. <https://doi.org/10.1146/annurev.soc.27.1.363>

- Lord, C., Elsabbagh, M., Baird, G., & Veenstra-Vanderweele, J. (2018). Autism spectrum disorder. *The Lancet*, 392(10146), 508–520. [https://doi.org/10.1016/S0140-6736\(18\)31129-2](https://doi.org/10.1016/S0140-6736(18)31129-2)
- Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArthur, D., Pas, E. T., Salinas, A., Vehorn, A., Williams, S., Esler, A., Grzybowski, A., Hall-Lande, J., ... Shaw, K. A. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years: Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020. *MMWR Surveillance Summaries*, 72(2), 1–14. <https://doi.org/10.15585/mmwr.ss7202a1>
- Mitter, N., Ali, A., & Scior, K. (2019). Stigma experienced by families of individuals with intellectual disabilities and autism: A systematic review. *Research in Developmental Disabilities*, 89, 10–21. <https://doi.org/10.1016/j.ridd.2019.03.001>
- Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain Sciences*, 11(3), Article 309. <https://doi.org/10.3390/brainsci11030309>
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). SAGE Publications.
- Tuckman, B. W. (1972). *Conducting educational research*. Harcourt Brace Jovanovich.
- Zeidan, J., Fombonne, E., Scior, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, 15(5), 778–790. <https://doi.org/10.1002/aur.2696>