Volume 4, Issue 3, 2026

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

NEGOTIATING SHAME: THE LIVED EXPERIENCES OF PAKISTANI MOTHERS HIDING AUTISM

Dr Mahmood Ahmed Shaikh[1], Bushra Nayaab[*2], Dr. Tehseen Mushtaq[3]

[1]*CEO IUJDI, University Islamabad.*
[*2]*MPhil Scholar Special Education, Division of Education, University of Education, Lahore.*
[3]*Lecturer, Special Education, Division of Education, University of Education, Lahore.*

[1]legser73@hotmail.com, [*2]azeemnayaab@gmail.com, [3]tehseen.mushtaq@ue.edu.pk

DOI: https://doi.org/10.5281/zenodo.19345920

Article History
Received on 28 Feb, 2026
Accepted on 26 March, 2026
Published on 31 March, 2026

Corresponding Author: *
Bushra Nayaab

Abstract

In Pakistan, autism is often constructed through cultural circumstances of family honour (izzat), and this shape how mothers interpret and manage the diagnosis of their child. Despite this, the lived experiences of mothers who often conceal autism remain underexplored. This study explores the experiences of Pakistani mothers who withhold autism diagnosis of their child from social networks. It attempts to examine how shame, stigma, and gendered expectations affect their coping practices. For this purpose, a qualitative phenomenological design was employed. The study employed semi-structured interviews with ten mothers. Recruitment occurred through community networks and autism-related support groups. Data were analysed using thematic analysis informed by Interpretative Phenomenological Analysis (IPA). This enable us to make an in-depth exploration of participants' subjective meaning-making. In this study, five interrelated themes emerged: the pervasive weight of social judgment and shame; strategic practices of disclosure and concealment; the gendered concentration of caregiving responsibilities; reliance on faith and informal support systems; and systemic failures in healthcare, education, and state provision systems. The findings of this study demonstrate that shame is not only internally generated but also socially produced and sustained through everyday interactions. It compels mothers to engage in continuous emotional and informational labour with an aim to protect their family standing. There is a disproportionate burden on mothers, and it will not lesson in the absence of institutional support with practical changes. They have to manage their child and the stigma, often in social isolation. This study concludes that cultural norms, gendered obligations, and structural neglect are shaping lived experiences of Pakistani mothers for their child with autism in Pakistan. Pakistan needs socially responsive initiatives. It must regulate and subsidize therapies of these children. It also requires inclusive educational policies. Such policies that would challenge entrenched stigma and redistribute caregiving responsibility.

I. Introduction

Autism Spectrum Disorder (ASD) is a permanent neurodevelopmental disorder. It shapes communication, social interaction, and engagement with the world of person with ASD. Such persons often have dedicated interests and

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

they tend toward repetitive patterns of behaviour (M. B. Nayaab et al., 2025). These characteristics change how they perceive and respond to their surroundings (Cherewick & Matergia, 2024). The lived experiences of autistic people differ from those of non-autistic people in ways that are both clear and consequential (Lobregt-van Buuren et al., 2021). Children with ASD are facing distinct challenges. Many have co-occurring conditions such as intellectual disability and Attention-Deficit/Hyperactivity Disorder, which affect a large proportion of persons on the spectrum. These conditions, alongside differences in communication, social interaction, and behavioural regulation, place heavy stresses on their daily care (DePape & Lindsay, 2016). They differ from their contemporaries in fundamental ways. Core behaviours, related symptoms, and behavioural difficulties place sustained stress on families and also wear away parental well-being. Differences in communication and social interaction, together with distinct behavioural patterns, create ongoing challenges for them in their daily care. These pressures often take many parents toward prolonged sadness and depression. Over time, such strain has bred self-blame and a negative outlook, rather than a constructive one (Desai et al., 2012).

Research has shown that ASD places substantial difficulties on children and their families equally (Nayaab et al., 2025). These demands have taken a clear toll on parental well-being. Parents carry sustained emotional stress alongside high costs which are tied to treatment and therapy. They closely monitor their child (Parveen et al., 2026). Family relationships come under strain, and daily roles, structure, and routines are often forced to shift. Many parents also report guilt and self-blame following the diagnosis, and this often compounded by the weight of social stigma (DePape & Lindsay, 2016). Furthermore, parenting a child with ASD places greater strain on parents than raising a typically developing child, and mothers bear much of this burden. The needs of child take many forms and generate tension within the household. Common stressors include grief, persistent sadness, and depression. Family outings decline, relationships shift, and social support weakens. Mothers make repeated personal sacrifices. Moreover, the period after diagnosis has proved especially difficult. There is an internal struggle in acceptance of ASD in child for these mothers. They have to face confusion, sadness, guilt, in addition, in some cases, depression as well. A strong sense of loss emerges as expectations for the future of child are forced to change. Socially disapproved behaviour often lead many mothers to retract from public and social life. This withdrawal cuts off support and deepens isolation. Resultantly, it turns sustains and intensifies stress for them over time (Smith et al., 2010).

As ASD occurrence has increased worldwide, therefore, families have had to carry mounting physical, psychological, and financial burdens which are tied to long-term brought up of their child. Acharya and Sharma (2021) found that those mothers who are raising children with autism are encountering persistent and multidimensional difficulties in their social life. Continuous supervision is causing in many mothers the unending physical exhaustion. Emotional strain has taken clear forms in them: denial, distress, and constant worry. Social pressure has remained severe; mothers have to face blame, isolation, and neglect from relatives and the wider community, often in direct response to their child's atypical behaviour. Moreover, financial strain is also equally difficult for them. High treatment costs and ongoing therapy expenses are also pushing many families to the edge. In response, mothers resort to

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

various coping practices: respite care, problem-focused efforts, religious reliance, and other adaptive schemes intertwined into daily life.

Mothers' experiences differ as per their national and social contexts (Rezq et al., 2025). In the United Kingdom, it was reported that many describe autism as difficult to interpret and manage. They report self-injury in children, harm to others, and damage within the home. These conditions have produced more stress and further placed mothers into isolation from their social life (Gorlin et al., 2016). Research also shows that in Australia mothers of children with ASD show poorer health and lower well-being in comparison with other mothers of children with other disabilities (Safe et al., 2012). In Canada, in a research work, mothers have also shared deep personal emotional issuances which they face in their daily life with an autistic child. Evidence from South Korea indicates that mothers have to struggle to accept the condition imposed for their children which result in discouragement and emotional worries (Kang et al., 2016). Mothers have to deal with instability in their lives due to ASD child and non-balance in various life stages even though they strive for equilibrium for themselves besides for their families (Rafii et al., 2024).

Al-Showaily et al., (2025) explains in their study that mothers are facing high levels of needs due to difficulties caused by behavioural problems of their child, the need for special care, and the core issue of community acceptance. Their lives are filled with various emotional imbalances and stress (Zandi et al., 2025). Yet, research on this subject regarding real life experience of mothers who look after their children with ASD in low-income and non-Western contexts still remains insufficient specially with regards to the Pakistan. This absence has made grounded real life knowledge about how culture shapes maternal experience in such situations. The present study attempts to cover this directly. It examines the lived experiences and emotional accounts of Pakistani mothers who have autistic children but do not disclose the condition publicly. It identifies the cultural, social, and familial pressures relating to concealment of autism and their responses. It attempts to examine how shame, stigma, and social expectations bear on maternal identity, family relationships, and psychological health. Finally, it analyses the coping practices and support systems these mothers rely on as they manage daily life.

II. Research Methodology and Question(s)

This study primarily used a qualitative phenomenological approach with an aim to explore the real-life living experiences of Pakistani mothers with autistic children; who decided not to disclose the diagnosis in public. This approach give precedence to depth over breadth. It allows close engagement with how participants interpret and feel their own experiences, rather than to measure outcomes in a large sample. Ten participants participate in this study. They are from the age 25 to 55 years. The study used purposive sampling, through which deliberate and informed selection was made rather than random assignment. Participants came from Pakistani community. They were reached through online forums and autism-related support groups. This strategy ensured that all participants had direct and relevant experience of the phenomenon under this study. Each participant had at least one autistic child, either formally diagnosed by a medical professional or suspected on the basis of observed developmental differences, which they are looking after.

Data came from semi-structured and in-depth interviews which were conducted through Google Forms. Approximately 15 to 20 minutes were

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

required for participants to answer. This format provided a consistent platform to participants with freedom to explain their experiences in their own words. For this purpose, a structured questionnaire was shared with participants through Google Forms. This served as the basis for each interview and allowed for systematic data collection in all ten cases. This study followed the framework of Interpretative Phenomenological Analysis (IPA). IPA suits this kind of research because it looks into the personal and subjective dimensions of experience. It also allowed the researcher to move between the participant's own explanation and a comprehensive interpretive conception of what that account reveals (MacLeod, 2019).

Moreover, this study used thematic analysis for identification of recurring patterns, themes, and implications in the dataset. Manual line-by-line coding was applied to each interview transcript. This kept the analysis justified in the data and reduced the pre-existing assumptions. This step reinforced the credibility and validity of the findings as well. Further, this study observed ethical protocols at every stage. Informed consent was obtained from all participants before their involvement. Confidentiality and anonymity were protected through the use of pseudonyms in place of real their names throughout data collection, analysis, and its presentation in this work.

This paper attempts to answer the following research questions:

I. What are the real-life living experiences and emotional perception of Pakistani mothers in their social life about the autism in their child from the public angle?

II. What role do cultural beliefs about this disability, shame, and family honour have in mothers' lives about coping with these issues?

III. How do mothers perceive shame with related to autism? What are the main sources of this shame: family, community, or religious beliefs?

IV. What strategies do mothers use in order to conceal ASD from their real social-life?

V. What are the social and psychological effects of this secrecy?

III. Findings

Thematic analysis of the ten interviews generated five major themes. These themes cover the main patterns regarding participants' views about raising autistic children in Lahore. The themes are: (1) the weight of social judgment and shame; (2) disclosure, concealment, and the management of information; (3) the gendered burden of sole caregiving; (4) faith and informal support as coping resources; and (5) structural and institutional failures. Each theme is developed below with reference to direct participant accounts. Pseudonyms have been used throughout to protect participant anonymity.

Theme 1: The Weight of Social Judgment and Shame

Social judgment was the most persistent source of distress across the dataset. The majority of participants described public spaces as hostile rather than neutral. The community's gaze, not the child's diagnosis itself, was what many mothers identified as the primary source of their shame. For Ayesha (26), the two pressures were inseparable:

"I can't go anywhere because I can't handle him and people start judging him and gave me advice also makes me feel ashamed."

Ayesha did not simply find outings difficult to manage logistically. She found them unbearable because the social response to her son's behaviour compounded her already-present exhaustion. The shame she described was not private guilt but

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

public exposure, produced by the reactions of others.

Amna (31) framed this dynamic with care. She separated her own understanding of her child from the meaning the community imposed on him:

"I sometimes feel embarrassed because of my child's unusual or silent behaviour in public. These feelings mostly come from the reactions of people in the community and sometimes family members, who may not understand autism. At times we feel excluded, and society tends to keep its distance, which can be very painful."

Amna's account makes clear that exclusion was not incidental. The community actively withdrew. The pain she described was the pain of having that withdrawal treated as a natural and acceptable response. Samira (age not given) named the community as the direct source of shame. Hina (32) located it within the family. Li et al., (2025) also highlight this aspect in their study. These distinctions matter. Shame, in this dataset, did not arrive from a single direction. It came from families, from relatives, from neighbours, and from strangers. Its sources were multiple, and they strengthened one another.

Nadia (32) described shame as coming from every direction:

"From everywhere... nobody wants to accept this reality."

This account is brief but precise. The refusal to accept the child's condition was experienced as a form of rejection directed at the mother. The diagnosis became, in social life, a verdict on her.

Theme 2: Disclosure, Concealment, and the Management of Information

The decision of whether and how to disclose the diagnosis emerged as one of the most carefully managed aspects of participants' daily lives (Almog et al., 2023). Patterns of disclosure varied in mothers as show in various studies (Eaton et al., 2017; Hays & Butauski, 2018; Khudiakova et al., 2024), but the underlying concerns were consistent. Mothers who had disclosed fully still had to manage how others received that information. Those who had not disclosed fully described the effort this cost them.

Nadia (32) had disclosed the diagnosis but consistently reframed it in conversation:

"I told them it's developmental delay."

This substitution was not casual. The term 'developmental delay' carries less social stigma in Pakistani contexts than autism. Using it allowed Nadia to be truthful without triggering the full force of the community's judgment. The disclosure was real, but the label was strategically softened.

Rukhsana (42) drew a clear boundary between people she knew and strangers:

"Yes I told everyone I know... but no strangers, because some even don't know about autism."

Her reasoning was practical. Disclosure to strangers carried no benefit and real risk. Awareness of autism in the wider community was low. She had learned to calibrate disclosure according to the likely response.

Ayesha (26) described a different situation. Most of her relatives did not know. She managed this through avoidance rather than active concealment:

"Some close relatives know but mostly my relatives don't know about him. They stare at him and pass judgement."

The decision not to disclose had reduced the number of judgements she had to absorb directly. But it had not ended the problem. The stares still came. The judgement was visible even without the diagnosis being named. Concealment, in her case, offered partial protection rather than relief.

Tahreem (39) chose a different strategy. When faced with questions about her child's behaviour, she simply kept quiet. Silence, in her account, was the least costly option. It required no performance, no explanation, and no negotiation. It was not

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

passivity but a deliberate form of social management.

Theme 3: The Gendered Burden of Sole Caregiving

In all the dataset, the burden of caregiving had fallen almost entirely on mothers. Fathers were largely absent from participants' accounts, and where they did appear, the picture was rarely supportive. This distribution of responsibility was not described by participants as unusual. It was treated as expected, which made it harder rather than easier to challenge.

Ayesha (26) spoke most directly about the inequity in this arrangement:

"Always mother's have to sacrifice. Always mother's have to feel the guilt of child condition. Why, when she thinks about his child only and fades off herself, then husband and society complained and shows husband other option for peace. If I want peace where can I go? Should I also leave my husband and my special need child like always husband did?"

This account is one of the most significant in the dataset. Ayesha did not simply describe exhaustion. She described a situation in which the same society that ignored the father's departure held the mother responsible for maintaining family stability. The question she asked, where can I go for peace? had no answer available to her. The option that had been available to her husband was not available to her.

Hina (32) described a version of the same pattern. Others around her expected her to manage everything, not just the child's care but all household functions, at the same level as mothers who had no child with additional needs:

"No one really cares about a mother's condition as everyone expects that she should always be ready to manage everything, not only her child but she should manage all things like others who don't have a child with special needs."

The comparison she drew was pointed. She was not asking for recognition of an extraordinary effort. She was asking for a basic acknowledgement that her circumstances differed. That acknowledgement was not forthcoming.

Sana (33) offered a contrasting account in terms of outcome but not structure. She had strong support from her sister. The support she described, however, was informal and family-based. No institutional support underpinned it. Had the sister not been present and willing, the situation would have looked different. The presence of support in her case highlighted by contrast how exposed participants without it had become.

Theme 4: Faith and Informal Support as Coping Resources

Prayer was the most consistently named coping resource across the dataset. Eight of ten participants mentioned it directly. Several named it as their primary source of strength. This was not incidental. In the context of scarce professional support, high costs, and social judgment, faith offered something that other resources could not: it was always available, it imposed no shame, and it provided a framework of meaning that did not require the community's approval.

Amna (31) described prayer as a source of both emotional strength and practical orientation:

"I pray to Allah for patience and guidance, which gives me emotional strength. I also talk with other parents who have children on the autism spectrum. Sharing experiences with them brings me comfort and reassurance."

For Amna, faith and peer connection worked together. Both reduced isolation, though in different ways. Prayer gave her a private resource. Contact with other parents gave her a social one.

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Together they formed a coping system that operated entirely outside formal support structures.

Nadia (32) was blunter about the limits of human assistance:

"No comments... because no one can help except Allah SWT."

This was not fatalism. It was a direct assessment of what was and was not available to her. She had tried to find help elsewhere and had found it absent. Faith was what remained.

Sana (33) described talking to her sister as her main source of support. The trusted relationship, rather than the formal support structure, was what held. This pattern appeared across several accounts. Where support existed, it was personal and informal. Where it did not, participants had little to draw on.

Theme 5: Structural and Institutional Failures

Participants did not only describe personal struggle. They described a context in which the structures that should have supported them were either absent or extractive. Therapy was expensive. Schools were unprepared. Government provision was negligible. The combination had forced many families into a position in which the cost of care was borne entirely by the mother.

Amna (31) named the financial dimension with precision:

"Therapy and support services for children with ASD were more accessible and not treated as a business. Many times, medical professionals, therapists, or clinics charge very high fees, especially because of children's behaviours, which makes it financially difficult for families to provide the care their children need. I hope the government could offer more affordable facilities and support so that families are not seen as weak or taken advantage of."

The language she used: 'treated as a business,' 'taken advantage of', indicated that the problem was not simply high cost but exploitation. Families had no leverage and no alternatives. The people providing services knew this.

Rukhsana (42) wanted educational inclusion. She named the model she had in mind:

"Got admission in a normal school with trained staff... they will perform normally although society and our education system may fix them so in a normal school like Europe."

Her comparison to European educational models suggested an awareness of what was possible elsewhere. The gap between those standards and what was available in Lahore was experienced not as unfortunate variation but as a failure with a known remedy.

Ayesha (26) connected the financial burden directly to the absence of community and government support. She described needing community and financial support in the same breath. The two were not separate problems. Without financial relief, community support alone was insufficient. Without community support, financial pressure became socially isolating as well as economically damaging.

IV. Analysis

The five themes developed above do not sit alongside one another as parallel concerns. They interact, and their interaction produces a specific and compounding form of harm. This section traces the structural logic that connects them.

Shame, in this dataset, was not a feeling that mothers held privately. It was produced in public, through the responses of others to the child's behaviour and, by extension, to the mother's perceived failure of control. The community did not observe and remain neutral. It judged, withdrew, and attributed. The mother was held accountable not only for her child's condition but for the disruption his visibility caused in public space. This dynamic placed mothers in an

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

impossible position. To manage it required them either to absorb the judgement, withdraw from public life, or invest significant effort in controlling what information reached whom.

Disclosure became a form of risk management rather than a personal choice. The evidence here does not support a simple divide between mothers who disclosed and mothers who hid. Rather, it shows that disclosure was always partial, strategic, and costly. Nadia's use of "developmental delay" rather than autism was not dishonesty. It was a survival strategy developed in response to a social environment that could not be trusted to receive the diagnosis without weaponising it. Rukhsana's boundary between known contacts and strangers was the same kind of strategy, applied differently. Even mothers who described full disclosure had managed how that disclosure was framed and to whom it was initially given.

The gendered structure of care underpinned all of this. Mothers bore the caregiving burden, the social burden, and the shame; whereas fathers faced neither the same expectation nor the same consequences for withdrawal. Ayesha's account made this asymmetry visible with unusual clarity. The option of leaving, which her husband had exercised, was not available to her. This was not only because of her attachment to her child but because the social and moral structures of her community did not permit it. Mothers who stayed and struggled were blamed for struggling. Fathers who left were not held to equivalent account. The system that produced this outcome was not described by participants as unjust in an abstract sense. It was described as simply real, a condition they had to work within rather than against.

Faith filled the gap that institutions had left open. This is not a finding about religiosity as a personality trait. It is a structural observation. Where professional support was unavailable or unaffordable, and where community support was judgmental rather than supporting, there prayer was used as a resource that was accessible, non-judgmental, and meaningful. It did not resolve the material conditions. But it gave mothers a way to continue functioning within them. The near-universality of this coping strategy across the dataset was itself a comment on the absence of alternatives.

The institutional failures described by participants were not background context. They were active forces shaping daily life. High therapy costs, the absence of inclusive school system, and the lack of government support resultantly made the care responsibility for the family alone: and within the family, it is on the mother. The judgment of community added into this that the withdrawal of the mother from public life also reduced the social contact that might otherwise would have provided informal support. The isolation was complete: institutional rejection further reinforced social exclusion, which in turn reinforced the confinement of the mother to the home and the intensify the sole lookafter of the child. Collectively, these influences produced a specific perceptions for the maternal subjective life. The mothers in this study did not describe themselves primarily as those navigating private emotional challenges. They described themselves as people caught within a social, cultural, and economic system that had assigned them a role it refused to support. The shame they carried was real. But it was not self-generated. It was imposed, and the structures that imposed it remained largely intact.

V. Discussion

The findings of this study extend and complicate existing research on maternal caregiving and autism in several important directions. Most existing literature on mothers of autistic children

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

has been produced in high-income, Western contexts. The pressures documented there: emotional exhaustion, social isolation, financial strain, and marital stress, are also present in this dataset too. But the specific configuration of those pressures in Lahore differs from what the comparative literature describes, and those differences are analytically significant.

The role of *izzat*, family honour, in shaping disclosure decisions has no direct equivalent in Western literature on autism concealment. Nadia's framing of her child's diagnosis as *'developmental delay'* was not a response to generic social stigma. It was a response to a specific cultural economy in which the family's social standing, marital prospects of siblings, and community membership could all be affected by the presence of a visibly different child. The management of information was therefore not simply personal. It was a form of collective risk management, conducted on behalf of the extended family, by the mother. The burden of this management fell to her precisely because she was positioned as the one whose vigilance was responsible for containing the potential damage.

This finding aligns with Goffman's (2009) framework of stigma management, in which persons who bear a 'spoiled identity' develop strategies to control the information others hold about them. What this study adds is a view of how that management operates within a cultural system structured by *izzat*. The stigma in this context was not only individual. It was relational and familial. The management of mother about the disclosure was an act of care for in the interest of family, not only for herself or for her child. This made the burden double and invisible: she was doing work on behalf for those others family members which have no appreciation or reward for her.

The universal reliance on prayer as a coping strategy also connects this study with already available research on religion and resilience in contexts of Muslims. In a recent study, Daulay et al., (2025) have documented this protective role of religion in mothers of children with ASD. This study finds a similar pattern, but the protective function of faith here cannot be fully understood without reference to what it was compensating for. Faith did not exist alongside professional support. It existed instead of it. Its prevalence was a measure not only of religious commitment but of institutional absence.

The accounts of financial strain and the absence of affordable therapy align with the broader literature on autism services in low-income countries (Nayaab et al., 2025). This study adds the experiential dimension of this field. Mothers were not simply aware of the gap in the abstract. They had encountered it directly, often after having already invested emotionally in the possibility of formal support. Amna's description of services being *'treated as a business'* indicated that the encounter with inaccessible or exploitative provision was itself a source of harm, not only a practical barrier.

The gender dynamics documented in this study are consistent with findings from other countries on the feminisation of care labour (Nematollahi et al., 2025). What distinguishes this study is the specificity of how that dynamic operated in the context of autism concealment. The mother's sole responsibility for managing the child's public presentation, controlling disclosure, absorbing community judgment, and sustaining household function in the absence of institutional support created a compounded and largely invisible labour burden. The expectation that she manage all of this without complaint, and at the same level of function as mothers without additional care demands, was the most damaging element of the social structure participants described.

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Ayesha's account of her husband's departure and her own inability to exercise the same option offers a stark illustration of what Hochschild & Machung, (2012) termed the *"second shift"* but in a far more extreme form. For Ayesha, the double standard was not one of household labour distribution within a maintained marriage. It was one of social permission. The community that condemned her for struggling had not condemned her husband for leaving. The inequity was absolute, and it had material consequences for her daily life.

Sana (33) presented a partial counter-case. She had not experienced the same isolation as other participants. The support she received from her sister was genuine and had sustained her. But her account also reinforced the broader argument. The support she had was informal and kin-based. Its presence was contingent on a particular family configuration. It could not be relied upon as a structural resource, and it was not available to the other participants. The difference between Sana's experience and Ayesha's was not one of individual characteristics. It was one of available social resources. The structural conditions that had failed Ayesha had also determined what was available to Sana.

The findings show a clear gap in the policy of Pakistan and social provision. To place autism as a source of family shame, rather than as a developmental condition which requires support, is being augmented through cultural norms, family expectations, and the absence of any institutional supportive counter-narrative. Schools could not accommodate autistic children. The therapeutic services are too much expensive that families could not bear. Government support is insufficient. The mothers in this study showed that they are managing the burden with considerable skill and resilience. The study's main argument is that they should not have had to it alone.

VI. Conclusion

This study was conducted with an aim to examine the real-life lived experiences of Pakistani mothers who raise autistic children in the social context. The purpose was to cover shame about the autism within the family settings in Pakistan. It has found five interconnected themes: the production of shame through social judgment, the strategic management of disclosure, the gendered distribution of care and its consequences, the reliance on faith and informal support in the absence of institutional provision, and the structural failures of therapeutic, educational, and government systems. Collectively, these themes present a coherent picture of a specific and principally undocumented form of maternal experience and their perceptions.

The findings of this study are that the shame these mothers are carried was not a psychological response with regards to particular person and her difficulty. Study show that it was produced and then sustained due to a social system: the system which assigned them duty to act as a sole responsible person for a condition they did not cause in their child. The system also shown to have removed support of what and when they needed it most. The system also judged them for the consequences if they opt to withdraw. The management of autism in these mothers' lives was, at its core, a form of social labour: the labour to control the information, absorb the judgments passed by society, maintain family honour, and sustain the child with due care without the resources that would make that care more manageable and meaningful.

The study has several limitations that also need to be acknowledged. The sample was taken from a

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

single city, and participants joined through digital means, which made other mothers excluded. The interview format, conducted through Google Forms, also limited the deepness of some responses and it may have discouraged them to elaborate on sensitive topics. The sample size of ten, though appropriate for basic IPA-guided qualitative study, yet does not cover the broader maternal population. Future research should use in-person methods, and may join participants from a wider geographic and socioeconomic context.

Despite these limitations, this study has successfully makes several concrete contributions in the already existing research on the topic. It provides the first qualitative viewpoint about autism concealment prevalent in Pakistani mothers. It also demonstrates that the perception about *izzat* operates in a specific and distinct manner to shape disclosure decisions, which is distinguishable from the generic stigma which dominate the Western culture. It also covers the structural function of religion which helps mothers to cope with the emotional burden. And this study also highlights the viewpoint on the mother's experience through the lens of gendered-based societal norms and obligations.

There are few basic practical implications which are required to deal with this problem (Mehrabi & Amiri, 2025). Awareness campaigns about autism in Pakistani communities are required to be initiated with serious efforts (Zhu et al., 2026) while covering the role of *izzat* in families as well. It is high-time to stop treating ASD as a stigma. Therapeutic services or required therapies must be regulated and subsidized on governmental level. Schools should develop and resource inclusive models (Nayaab et al., 2025), which should be an obligation upon them imposed by the government. Social workers and community health practitioners are required to train more (Woods, 2026) with an aim to equip them to understand the intersection of disability and disorder with disease in cultural context. Above all, the expectation that mothers should bear the full cost of care: social, financial, physical, and psychological, without institutional support is required to be challenged at every level, be it of policy or community.

Though these mothers have found ways to manage (Zhou & Ning, 2025), yet the question the study leaves open is that whether the society around them will find ways to help?

VII. REFERENCES

Acharya, S., & Sharma, K. (2021). Lived Experiences of Mothers Raising Children with Autism in Chitwan District, Nepal. *Autism Research and Treatment*, *2021*, 1–12. https://doi.org/10.1155/2021/6614490

Almog, N., Kassel, O., Levy, N., & Gabai, T. (2023). Mapping the Dilemmas Parents Face with Disclosing Autism Diagnosis to their Child. *Journal of Autism and Developmental Disorders*, *53*(10), 4060–4075. https://doi.org/10.1007/s10803-022-05711-y

Al-Showaily, J. S., Saiwan, M. J., & Dawood, M. A. (2025). Mothers of Autistic Children Insisting Needs. *Medical Forum Monthly*, *36*(11). http://medicalforummonthly.com/index.php/mfm/article/view/5487

Cherewick, M., & Matergia, M. (2024). Neurodiversity in Practice: A Conceptual Model of Autistic Strengths and Potential Mechanisms of Change to Support Positive Mental Health and Wellbeing in Autistic Children and Adolescents. *Advances in Neurodevelopmental Disorders*, *8*(3), 408–422. https://doi.org/10.1007/s41252-023-00348-z

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Daulay, N., Daulay, H., & Rohman, F. (2025). Religious Coping of Muslim Mothers of Children with Autism Spectrum Disorder in Indonesia. *Journal of Disability & Religion*, *29*(1), 33–50. https://doi.org/10.1080/23312521.2024.2372021

DePape, A.-M., & Lindsay, S. (2016). Lived Experiences From the Perspective of Individuals With Autism Spectrum Disorder: A Qualitative Meta-Synthesis. *Focus on Autism and Other Developmental Disabilities*, *31*(1), 60–71. https://doi.org/10.1177/1088357615587504

Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*, *49*(3–4), 613–637. https://doi.org/10.1177/1363461512447139

Eaton, K., Ohan, J. L., Stritzke, W. G. K., Courtauld, H. M., & Corrigan, P. W. (2017). Mothers' Decisions to Disclose or Conceal Their Child's Mental Health Disorder. *Qualitative Health Research*, *27*(11), 1628–1639. https://doi.org/10.1177/1049732317697096

Goffman, E. (2009). *Stigma: Notes on the management of spoiled identity*. Simon and schuster. https://books.google.com/books?hl=en&lr=&id=zuMFXuTMAqAC&oi=fnd&pg=PA1&dq=Goffman%27s+(1963)+framework+of+stigma+management&ots=Rb1oFp4CKd&sig=FjMV6ITujxsyw-x6p2rzA3ezm48

Gorlin, J. B., McAlpine, C. P., Garwick, A., & Wieling, E. (2016). Severe childhood autism: The family lived experience. *Journal of Pediatric Nursing*, *31*(6), 580–597.

Hays, A., & Butauski, M. (2018). Privacy, Disability, and Family: Exploring the Privacy Management Behaviors of Parents with a Child with Autism. *Western Journal of Communication*, *82*(3), 376–391. https://doi.org/10.1080/10570314.2017.1398834

Hochschild, A., & Machung, A. (2012). *The Second Shift: Working Families and the Revolution at Home*. Penguin Publishing Group.

Kang, G.-Y., Choi, C.-S., & Ju, S.-J. (2016). Parenting experience of mothers with children with autism spectrum disorder: An analysis of the mothers' diaries. *Indian Journal of Science and Technology*, *9*(20), 1–7.

Khudiakova, V., Le Forestier, J. M., & Chasteen, A. L. (2024). To mask or not to mask: The role of concealment behavior, stigma experience, and community connectedness in autistic people's mental health. *Neurodiversity*, *2*, 27546330241255121. https://doi.org/10.1177/27546330241255121

Li, J.-L., Washington-Nortey, M., Kifle, T. H., Cotier, F., & Hoekstra, R. A. (2025). The Role of Extended Family Members in the Lives of Autistic Individuals and Their Parents: A Systematic Review and Meta-Synthesis. *Clinical Child and Family Psychology Review*, *28*(2), 507–539. https://doi.org/10.1007/s10567-025-00525-7

Lobregt-van Buuren, E., Hoekert, M., & Sizoo, B. (2021). Autism, adverse events, and trauma. *Exon Publications*, 33–42.

MacLeod, A. (2019). Interpretative phenomenological analysis (IPA) as a tool for participatory research within critical autism studies: A systematic review. *Research in Autism Spectrum Disorders*, *64*, 49–62.

Frontier in Medical & Health Research

ISSN: (e) 3007-1607 (p) 3007-1593

Mehrabi, M., & Amiri, A. (2025). Phenomenology of Mothers' Lived Experiences of Raising Children with Autism and Study of the Legal Status of Social Protections for Mothers of Certain Children. *International Journal of Education and Cognitive Sciences*, *6*(1), 178–187.

Nayaab, B., Manzoor, D. A., & Sabah, N. U. (2025). Challenges Faced by Parents in Educational Inclusion of Children with Autism Spectrum Disorder. *Journal of Social Signs Review*, *3*(12), 99–117.

Nayaab, M. B., Tahir, K., & Fatima, A. (2025). Practices of Assessment of Behavioural Outcomes in Children with ASD in Lahore. *Annual Methodological Archive Research Review*, *3*(12), 5–37.

Nematollahi, M., Rigi, Z. E., Bagherian, B., & Fard, S. B. (2025). A journey from suffering to appreciation: Mother living with autistic child– a hermeneutic phenomenological study. *BMC Women's Health*, *25*(1), 517. https://doi.org/10.1186/s12905-025-04047-w

Parveen, D. Z., Nayaab*, B., & Mushtaq, D. T. (2026). Parental Views on Effectiveness of Early Behavioral Therapies on Social Skills of Children with Autism. *Dialogue Social Science Review (DSSR)*, *4*(1), 9–27.

Rafii, F., Seyedfatemi, N., & Asgarabad, H. E. (2024). The life of mothers of children with Autism: A grounded theory study. *Revista Latinoamericana de Hipertension*, *19*(4), 154–162.

Rezq, K. A., Albalawi, H. M. H., & Alharbi, H. F. (2025). Exploring social support and quality of life among mothers of children with autism spectrum disorders: A cross-sectional study. *Healthcare*, *13*(2), 95. https://www.mdpi.com/2227-9032/13/2/95

Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual & Developmental Disability*, *37*(4), 294–302. https://doi.org/10.3109/13668250.2012.736614

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily Experiences Among Mothers of Adolescents and Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *40*(2), 167–178. https://doi.org/10.1007/s10803-009-0844-y

Woods, S. E. O. (2026). Why We Need More Autistic Health Care Professionals and How to Support Them. *Autism in Adulthood*, *8*(1), 5–13. https://doi.org/10.1089/aut.2023.0099

Zandi, S., Jenabi, E., Bashirian, S., Mohammadi, R., Karbin, F., & Khazaei, S. (2025). The Experience of Parents When they Find Out that their Child has Autism: A Phenomenological Study. *Current Psychiatry Research and Reviews*, *21*(2), 162–171. https://doi.org/10.2174/0126660822301547240415060803

Zhou, J., & Ning, Y. (2025). Exploring motherhood dilemmas and coping strategies among mothers of children with autism: A qualitative study in mainland China. *Frontiers in Psychiatry*, *16*, 1569928.

Zhu, H., Yan, H. K., Ye, J., Li, Y., Xiao, L., Yu, Z., Wang, X., & Li, X. (2026). The pathway of early detection, diagnosis, and intervention for autistic children: A multi-center mixed method study. *Pediatric Research*, 1–13.