

THE ROLE OF PERCEIVED SOCIETAL PRESSURE IN DELAYED HELP-SEEKING AND POST-DIAGNOSIS DENIAL AMONG PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD)

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Abstract

Autism Spectrum Disorder (ASD) was neurodevelopmental disorder which required early diagnosis and early intervention. Nonetheless, the perceived societal pressure, which is common in a collectivist culture such as in Pakistan, also tends to cause delays during help-seeking by parents and exacerbates post-diagnosis denial. The present qualitative research highlighted issues in the lived experiences of parents of children diagnosed with ASD in Lahore, Pakistan, in terms of how familial and social judgment, cultural expectations, and social stigma influenced their behavioral and psychological responses. Semi-structured interviews of N= 18 parents who were recruited in different autism centres and support groups were structured with the help of reflexive thematic analysis. Thematic analysis was inclusive of six phases according to Braun and Clarke. The results indicated four major themes, including: (1) Early Realization and Delay in Help-Seeking, (2) Post-Diagnosis Denial and Emotional Processing, (3) Perceived Societal and Familial Pressure, and (4) Support and Awareness. The research presented a circular tie between social pressure, emotional denial and extensive delays in relating to seek professional assistance. Particularly, the mothers complained about the internalized stigma and shame and the pressure of the cultural norms that caused social isolation and reluctance to receive services. The insights highlighted the necessity of culturally-sensitive awareness-building, parent-focused programs, and a policy change to enhance the autism literacy, early diagnosis tracks in low to middle-income countries (LMICs). The work was also significant because it is one of the few studies that contributed to Pakistani literature supporting the need for more sensitive ways of understanding ASD outside of biased approaches to humanistic and inclusive care models.

Keywords: Autism Spectrum Disorder, delay help seeking, post diagnosis denial, perceived societal pressure, stigma, Pakistani parents, qualitative research, thematic analysis.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a multifaceted neurodevelopmental condition characterized by deficits in social

communication and interaction as well as restricted and repetitive patterns of behaviors (American Psychiatric Association, 2022). The symptoms has been seen able at the early stage of

the child development and requires timely diagnosis and intervention to guarantee better developmental outcomes (Lord et al., 2020). Globally, the prevalence rate of ASD is 0.6%, with variations across regions: 0.4% in Asia and 1.7% in Australia (Qiu et al., 2020). The rates are even lower at 0.31% in South Asia mostly as a result of underreporting and limited access to diagnostic services. Recent meta-analysis of 12 studies in Asia with a total sample of above 2 million demonstrated the pooled prevalence rate to be 0.36% among boys (0.45 %) compared to girls (0.182 %) (Qiu et al., 2020). A growing body of international research has highlighted the importance of cultural stigma and autism awareness in causing delays to seeking help and diagnosis.

In Pakistan, the problem of the ASD prevalence and awareness is still under-explored. It is suggested by local studies that diagnosis is increasing, particularly in urban populations of high-functioning children. To give an example, on the scale of the Autism Spectrum Quotient, it has been revealed that 78% of children in special education institutions in Islamabad and Punjab were diagnosed with High Functioning ASD (Nazir and Noor, 2023). Nevertheless, the cultural stigma, ignorance, and less availability of diagnostic services imply the late detection, especially in urban regions, such as Lahore, whereby this study has been conducted. According to the different precedents exists in the LMICs cultures like Pakistan, the parent's perceived social pressure while asking for help from professional and revealing about the ASD at post diagnosis phase.

It has also stressed the importance of early community-based diagnosis as the main factor leading to a significant improvement in social outcomes in children with ASD (Gabbay-Dizdar et al., 2022). Furthermore, it has been discovered that an overwhelming number of Asian-American parents would wait a substantial period of time to achieve diagnosis because of the stigma they experienced in their cultural communities which sheds some light on why the culturally sensitive care is necessary (De Guzman, 2024). Similar results are found in other parts of the world, such as a recent study in Muslim Arab Americans in Hawaii that identified stigma and religious misinterpretations were significant obstacles to

help seeking (DeMasters, 2023). According to one of the study waitlists and absence of emotional support after the diagnosis caused long delays in Canada (Cook, 2023). A systematic review study revealed a lack of consistency in the pathway of diagnosis that leads to parental stress (Makino et al., 2021). The researchers in Quebec have found out that the barriers to early intervention are fragmented systems and emotional isolation (Courcy and Des Rivières Pigeon, 2020). Evidence provided by Iranian (Ebadi et al., 2021), Portuguese (Martins et al., 2021), and UK (Legg et al., 2022) scholars all agreed on the limited role of stigma, denial, and gaps in systems leads to a delay in help-seeking and interfere with parent coping.

In the Pakistani context, Farooq and Ahmed (2020) identified the barriers to the timely diagnosis of ASD, namely cultural stigma, the absence of services, and denial. According to the research, caregiver stress adversely effected marital satisfaction in parents (Rizvi and Batool, 2023). It has highlighted that ASD is commonly misjudged as a spiritual punishment, delaying professional support (Mustaqeem et al., 2023). Furthermore, not being socially accepted, financial difficulties, and problematic behavior were the key stressors identified in parents, specifically indicated a high prevalence of the High Functioning Autism Spectrum Disorder within the special education centres, they also revealed a lack of gender-sensitive expectations (Gul et al., 2024; Nazir and Noor, 2023). Thus, the main objective of the current research is to investigate the effects of perceived pressure by society on the psychological and behavioral adaptation of parents with children who are diagnosed with the autism spectrum disorder (ASD) in Pakistan.

Methodology

The present study adopted a qualitative research design based on reflexive thematic analysis in examining lived experiences of the parents of children with autism spectrum disorder (ASD). The study applied a critical realist epistemological approach, which took into account that parental perceptions and behaviors are shaped both by their individual experiences and the larger socio-cultural reality (Naeem et al., 2023). The N=18 participants were recruited by autism centres and parent support networks in

Lahore, Pakistan; semi-structured, in-depth interviews were used to collect the data. Data collection was performed using six-phase framework of the reflexive thematic analysis proposed by Braun and Clarke (2006, 2021), which includes familiarization, generation of initial codes, theme development, review, naming, and presenting the report. Both semantic and latent coding were applied to reveal the surface meanings along with the underlying emotional as well as cultural connotations (Byrne, 2022; Fryer, 2022).

In order to achieve methodological rigor, the reflexive diary was kept, and descriptive and interpretive codes were distinguished. The safety analysis was aided by the thematic maps as well as visual aids (Braun & Clarke, 2022). Purposive sampling was used to recruit 18 participants with the aim of achieving data saturation, so that the stories about help-seeking delays and post-diagnosis denial were particularly rich. Ethical consideration included, among others, informed consent and confidentiality, and voluntary participation and emotional safety of the participants. The research was methodologically coherent so that it would reflect the culturally situated experiences of parenting in the Pakistani context.

Inclusion Criteria

Participants were eligible if they:

- Parents of children who have received a formal diagnosis of Autism Spectrum Disorder (ASD).
- Parents of children aged 2 to 20 years.

- Parents who noticed developmental concerns in their child before diagnosis (relevant to delayed help-seeking).
- Parents who are aware of their child's diagnosis and can reflect on their emotional and Behavioural responses (relevant to post-diagnosis denial)
- Participants who can read and understand Urdu or English, depending on the language of the tools used
- Willingness to participate voluntarily with informed consent.
- Must be a resident of Pakistan.

Exclusion Criteria

Participants were excluded if they:

- Parents of children with multiple neurodevelopment disorders (e.g., ASD with severe intellectual disability or cerebral palsy), as these may confound the help-seeking and acceptance patterns.
- Parents who have not yet received a formal diagnosis for their child (to ensure clarity in assessing post-diagnosis denial).
- Parents with severe psychiatric conditions (e.g., active psychosis or severe depression), as this may affect the reliability of self-report data.
- Parents who do not recall the timeline of noticing symptoms and seeking help (critical for analyzing delayed help-seeking behaviour).
- Parents were unwilling to participate or were unable to complete the questionnaire due to language or literacy barriers.

Table 1

Factors influencing the computation of sample size in this study

Sr.No	Factors	Criteria for the current study	Sample size
1.	Aim and scope of the study	The study focused on understanding subjective experiences of parents of children with ASD regarding societal pressure and denial, thus required in-depth narratives.	Small
2.	Types of data collection methods	One-on-one semi-structured interviews were conducted to explore deeply personal and contextual experiences.	Large
3.	Multiple methods in data collection	Only qualitative methods (interviews) were employed without triangulation.	Small
4.	Nature of the study	This was a phenomenological study focusing on lived parental experiences post-child diagnosis.	Small

5.	Study design	The design required gathering rich, in-depth data from a homogenous group of parents.	Small
6.	Heterogeneity of the population	Participants shared similar socio-cultural backgrounds, parental roles, and experiences.	Small
7.	Availability of the participants	Recruiting parents was challenging due to their caregiving responsibilities and emotional exhaustion	Small
8.	Number of selection criteria	Participants were selected based on two main criteria: being a parent of a formally diagnosed ASD child and experiencing help-seeking delay or denial.	Small
9.	Extent to which nesting of criteria was needed	No complex nesting was needed as inclusion criteria were clearly defined and focused.	Not relevant
10.	Group of special interest	All participants were of equal research interest; no distinct subgroup required additional focus.	Not relevant
11.	Multiple samples with one study	The study focused on a single, specific population (parents of ASD children in Pakistan).	Small
12.	Participants as content experts	Participants were not academic experts but were experiential experts (lived experience of parenting an ASD child).	Small
13.	Transparency of the population	Participants were willing to share their emotional and personal experiences openly.	Small
14.	Quality of data	Data obtained was rich and detailed, reflecting authentic parental voices, enhancing trustworthiness	Small
15.	Shadowed data	Some participants referred to others' experiences, expanding understanding beyond their own.	Medium
16.	Researcher experience	The researcher was trained in qualitative methods but conducting interviews of this sensitive nature was a new experience.	Small

Adapted from: (Ritchie & Lewis 2003; Mason 2010; Charmaz 2006; Glaser & Strauss 1967; Jette et al. 2003; Lee et al. 2002; Kasim & Algahuri 2015; Morse 2000

Results

Thematic analysis has been conducted to identify the themes. There are four identified central themes with the experiences of the

parents going through the Autism Spectrum Disorder (ASD) in their children as they were emotional, social, and cultural processes has been identified.

Table 2

Summary of Themes and Subthemes

Main Themes	Subthemes
1. Initial Realization and Help-Seeking Delay	1.1 Initial Behavioural Observations
	1.2 Delay Between First Concern and Clinical Help
	1.3 Barriers to Seeking Help (Financial, Social, emotional)

Main Themes	Subthemes
2. Post-Diagnosis Denial and Emotional Processing	2.1 Denial and Disbelief 2.2 Emotional Confusion or Grief 2.3 Diagnosis Concealment 2.4 Self-Blame or Guilt 2.5 Emotional Coping
3. Perceived Societal Pressure	3.1 Fear of Judgment or Blame 3.2 Pressure to Normalize the Child 3.3 Extended Family Reaction 3.4 Social Stigma in public settings 3.5 Support vs. Criticism from social circles 3.6 Cultural and Religious Influences
4. Support and Awareness	4.1 Need for Awareness 4.2 Role of Media and Social Platforms 4.3 Advice for New Parents 4.4 Parenting Support Resources

Theme 1: Early Realization and Delay in Help-Seeking

Parents reported the early symptoms, which included poor eye contact, unresponsiveness, and speech delays, however, the help seeking was postponed because of the social suggestions, the financial reasons, and the emotional reluctance (Leach et al., 2025).

“She used to jump excessively didn’t respond to her name no eye contact lost behavior. She would often play alone and never interacted with other children.” (P1)

“She wasn’t speaking, didn’t respond to her name, and would often flap her hands. I thought she was just a late talker at first.” (P2)

“For the first two years, I didn’t realize anything. When his cousin, just 20 days older, followed commands easily and my son didn’t, I first noticed a difference.” (P12)

Theme 2: Post-Diagnosis Denial and Emotional Processing

Parents described diverse emotional responses following diagnosis including denial, grief, confusion, and even the coping process. The diagnosis was not accepted by many people, particularly in case where the child did not have obvious symptoms (Hughes, 2024).

“Denial.Total denial. I just couldn’t accept it.” (P1)

“First comes denial. You ask yourself why me?” (P2)

“When I found out it was autism, I went into complete denial my son is active, cooperative,

and happy when guests arrive he didn’t seem like that.” (P6)

“I cried for 2–3 nights nothing made sense.” (P1)

“I used to cry a lot I told Allah to veil them from my eyes.” (P2)

Theme 3: Perceived Societal and Familial Pressure

The diagnosis was concealed and parents engaged in self-blame due to societal stigma, judgment and cultural misconception. Pressure from extended family members further aggravated the emotional distress (Efe et al., 2024)

“My own mother blamed me my in-laws said our prayers didn’t reach you.” (P3)

“People say ‘she’s possessed’ or ‘they must have done something wrong.’” (P2)

“Some people said, ‘The mother doesn’t talk much; that’s why the child is quiet.’” (P12)

“People say he should stay away from their kids no one wants to talk to him or feed him.” (P5)

Theme 4: Support and Awareness

The parents emphasized the importance of early awareness, access to therapy, and education among the people. Some recognized the value of awareness campaigns and the networks of peers they guide and support their emotional issues (Tadros, 2022).

“People don’t even know what autism is.” (P1)

“If your child doesn’t respond to name or becomes hyper, act early.” (P3)

“We didn’t start therapy early due to lack of awareness.” (P4)

“I kept seeing autism-related posts but never clicked on them Only when I read one seriously did I realize everything matched my son.” (P12) Thematic analysis revealed that responses of parents to ASD diagnosis of their child were greatly affected due to cultural and societal conformity. Among all participants, behavioral precursors were identified but often ignored due to emotional reluctance and misleading social reassurance. Denial and emotional turmoil were very typical after diagnosis even though most parents fluctuated between confusion, guilt, and evasion. The pressure of the expectations of this society and family members added up to the burden psychologically resulting in blame, shame, and isolation. The last theme, however, also indicated that there was an emerging hope that the parents wanted some awareness, support, and early intervention, which left hopes that autism could be looked at differently with the necessary knowledge and education that the community could do towards this change.

Discussion

The reason behind delays in help-seeking was more likely linked to social stigma, denial and lack of awareness especially in collectivist societies such as Pakistan where extended family and opinion by the society play a pivotal role. These results coincide with previous research worldwide that underlines the role of the cultural narratives and social norms that slow the process of diagnosis and treatment (Makino et al., 2021; Gabby et al., 2022).

The post-diagnosis rejection was emotional and socially enforced because parents tended to be pushed to be silent or conceal the disease. This is consistent with Gul et al. (2024) who discovered that Pakistani families in most cases end up spiritualizing the fact or blaming it on the parents. Furthermore, many participants internalized societal reactions to disabilities that included exclusion, gossip, and blame since this trend is common in other LMICs (De Guzman, 2024). In addition, many participants were affected by a lack of public awareness and proper intervention services in early years promoting psychological burden and delay. Nevertheless, in spite of these issues, some parents were also resilient: they found online information or support networks. Nonetheless, socio-cultural obstacles and systemic discrepancies are still

evident, and critical changes in the system of awareness, diagnosis, and supports should be made soon (Nazir & Noor, 2023).

Finally, this research determines that the acceptance and the time of ASD diagnosis among Pakistani parents are highly affected by societal expectations and cultural stigma. Parents were burdened with cultural stigma, fear of judgment, and emotions overwhelming them. The interplay between delayed help-seeking and denial after the diagnosis draws attention to an overall more fundamental requirement of culturally integrated paradigms of autism care. The study promotes awareness, empathy, and policy-level change to secure an early diagnosis and promote a high quality of life of children with ASD and their parents through providing parents with a voice. Nevertheless, the study has limitations in that its non-random sample of the urban environment is limited to a small group and it favors mostly maternal views thus leading to limited generalizability. In spite of these limitations, the results have provided good insights into the socio-cultural forces influencing the treatment of autism in the lower-middle-income countries. They highlight the necessity of culturally competent awareness raising activities, early detection schemes, and humanistic-based support systems that deal with emotional denial, and stigma within family systems. This research should appeal to educators, mental health professionals, and policymakers to work together on establishing inclusive frameworks that strengthen families and enhance better outcomes of autism.

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