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CrossRef DOI Number: [10.67244/jar.bwo-researches.v6i3.a640](https://doi.org/10.67244/jar.bwo-researches.v6i3.a640)

Link to the Paper: <https://jar.bwo-researches.com/index.php/jarh/article/view/640>

Edition Link: [Journal of Academic Research for Humanities JARH, 6\(3\), Jul-Sep 2026](#)

HJRS Link: [Journal of Academic Research for Humanities JARH \(HEC-Recognised for 2026-2027\)](#)

YouTube Link for the Paper Video Overview: <https://youtube.com/shorts/d1VD8Z1ITIs>

Understanding Delayed Autism Diagnosis in Pakistan: A Qualitative Study of Caregiver Experiences

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Paper Information

Citation of the paper:

(JARH)Shafique, M., Bukhari, F. K., (2026). Understanding Delayed Autism Diagnosis in Pakistan: A Qualitative Study of Caregiver Experiences. In *Journal of Academic Research for Humanities*, 6(3), 185–195.

Subject Areas for JARH:

- 1 Autism Diagnosis
- 2 Caregiver Experiences
- 3 Social Sciences & Humanities

Timeline of the Paper at JARH:

Received on: 22-09-2026.
Reviews Completed on: 28-09-2026.
Accepted on: 02-10-2026.
Online on: 03-10-2026.

License:



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Recognised for BWO-R:



HEC Journal
Recognition System

Jointly Published by BWO Research INTL:



CrossRef DOI Image of the paper:



Abstract

QR Code for the Paper:



Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder for which early diagnosis is critical to long-term developmental outcomes. Yet children in Pakistan frequently receive a formal diagnosis well beyond the developmental window in which intervention is most effective. This qualitative study examined the factors contributing to delayed diagnosis of ASD in Pakistan, drawing on the lived experiences of eight caregivers (parents and grandparents) recruited using purposive sampling. Data were gathered using in-depth, semi-structured interviews and analyzed using Reflexive Thematic Analysis (Braun & Clarke, 2006, 2019)—a framework with Bronfenbrenner's Ecological Systems Theory and the Health Belief Model as guides. The analysis revealed seven themes, which included: Family dynamics and denial, Healthcare System Inadequacies, Help Seeking Difficulties, Limited Resources and Accessibility, Maternal wellbeing, Parent knowledge and Awareness, and Sociocultural influences. Diagnostic delay in Pakistan was identified as a combination of family, institutional, and cultural barriers, not one particular factor, and health-care experiences that were supposed to reassure the parents sometimes actively delayed the recognition of developmental concerns. These findings suggest that addressing diagnostic delay in Pakistan requires attention to family dynamics, healthcare provider communication, and sociocultural stigma, with implications for clinical screening protocols and public health messaging.

Keywords: Autism Spectrum Disorder, Neurodevelopmental Disorder, Delayed Diagnosis, Early Identification, Qualitative Research

Introduction

Autism Spectrum Disorder (ASD) involves persistent difficulties in social communication and interaction, with restricted and repetitive behaviours and interests (Hirota & King, 2023). Timely diagnosis and structured intervention are associated with more favourable developmental outcomes (Asta & Persico, 2022). Diagnostic delay may occur between initial caregiver concerns, first professional contact, assessment, and formal diagnosis. This study focuses specifically on the age at which formal ASD diagnosis is received. Untreated developmental difficulties may persist and intensify into adolescence and adulthood (Lord et al., 2020).

Global autism prevalence has increased partly due to improved awareness, diagnosis, and broader diagnostic definitions, with higher estimates in regions with effective surveillance (Carter et al., 2024). In Pakistan, limited population-level screening may contribute to underestimation of the actual burden (Hossain et al., 2017). This creates a situation in which only a small proportion of children with a diagnosis of autism become visible in the health system, either clinically or in research records, leaving the rest of children with a diagnosis of autism invisible and under-recognized by the health system (Khudiakova et al., 2026; Tegtmejer & Säljö, 2024).

Recent Pakistani Literature

Recent Pakistani studies report barriers to timely ASD diagnosis, including professional shortages, stigma, low awareness, inconsistent screening, and geographic isolation, particularly in rural areas (Khaliq et al., 2025; Munawar & Abbas, 2025; Riaz & Zaka, 2026; Salman et al., 2024; Yasir et al., 2025).

Research Gap

Despite increasing ASD prevalence in Pakistan, diagnostic delay remains understudied. Existing research has focused mainly on parental stress and diagnostic difficulties, while inconsistent definitions and limited inclusion of grandparents restrict understanding of how delays are experienced within families (Akram et al., 2025; Rashid et al., 2025; Riaz & Zaka, 2026).

The study addresses these gaps by examining factors contributing to delayed diagnosis, using age three as a study-specific threshold. Including parents and grandparents captures the multigenerational diagnostic experience, while Reflexive Thematic Analysis explores structural, cultural, and interpersonal factors beyond quantitative measures.

Purpose of the Study

Prolonged diagnostic processes may involve emotional fatigue, repeated consultations, travel, and limited continuity of care, reducing opportunities for timely intervention. This study examines the underlying factors contributing to delayed ASD diagnosis through the firsthand experiences of parents and grandparents in Pakistan.

Research Objectives

To explore caregivers' experiences of delayed ASD diagnosis in Pakistan; identify family, healthcare, accessibility, psychological, knowledge-related, and sociocultural factors associated with delay; and interpret these experiences through Bronfenbrenner's Ecological Systems Theory and the Health Belief Model.

Research Question

The following research question will guide this study: How do Pakistani caregivers describe the family, healthcare, accessibility, psychological, knowledge-related, and sociocultural factors that shape the pathway from recognition of developmental concerns to formal ASD diagnosis?

Theoretical Framework

Two complementary theories guided the study: Bronfenbrenner's Ecological Systems Theory (1979, 1994) and the Health Belief Model. Ecological Systems Theory explains diagnostic pathways through interacting family, healthcare, educational, structural, and sociocultural systems, while the chronosystem emphasizes the role of timing in development and diagnosis. The Health Belief Model (Rosenstock, 1966; Becker, 1974) explains caregivers' interpretations and help-seeking behaviours through perceived susceptibility,

severity, benefits, barriers, cues to action, and self-efficacy. Together, these frameworks provided an interpretive lens for understanding the findings rather than assigning barriers to specific ecological levels.

Methods

Research Design

A qualitative exploratory design examined factors associated with delayed ASD diagnosis through parents' and grandparents' lived experiences in Pakistan, focusing on contextual meanings rather than frequency or statistical associations.

Participants and Sampling

Participants were purposively recruited from hospitals, autism centres, and special education schools in Bahawalpur and Lahore (August 2025–March 2026). Eligible Urdu-speaking caregivers had firsthand experience of their child's ASD diagnostic process; caregivers of children under three were excluded. After six interviews, two additional interviews deepened emerging patterns (Guest et al., 2006; Saunders et al., 2018), resulting in eight parents and grandparents. Coding and theme development remained iterative, consistent with Reflexive Thematic Analysis.

Participant Characteristics

Table 1 presents the demographic and contextual characteristics of the eight participants, including their relationship to the child, years of formal education, the child's gender, and the primary language used during the interview.

Table 1

Demographic Characteristics of Study Participants

Participant	Relation to Child	Education (Caregiver)	Child's Age	Child's Gender	Language Mode
P1	Mother	16 years	7 years	Female	Urdu
P2	Father	16 years	13 years	Male	Urdu
P3	Mother	14 years	9 years	Female	Urdu
P4	Grandmother	5 years	4 years	Male	Urdu
P5	Mother	12 years	5 years	Female	Urdu

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P6	Mother	14 years	8 years	Male	Urdu
P7	Grandfather	10 years	6 years	Female	Urdu
P8	Mother	18 years	4 years	Male	Urdu

Note. Education is reported in total years of formal schooling completed. Participant identifiers (P1–P8) are used throughout the article to preserve confidentiality.

Conceptual and Operational Definitions

Disorder of the Autism Spectrum (Conceptual Definition). Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by persistent difficulties in social communication and interaction, alongside restricted and repetitive behaviours, interests, or activities (American Psychiatric Association, 2022). Symptoms emerge early in development but may become apparent when social demands exceed a child's abilities and must cause significant functional impairment (Bertelli et al., 2022; Maich et al., 2020).

Delayed Diagnosis (Operational Definition). Definitions of "delayed diagnosis" vary across autism research, with Russell et al. (2025) reporting substantial variation in age thresholds across 420 studies. Accordingly, this study classified diagnosis at or before age three as timely and after age three as delayed. This study-specific threshold reflects early childhood and opportunities for intervention but does not imply that later diagnosis is clinically inappropriate or determines developmental outcomes (Ozonoff et al., 2018; Rogers, 2000; Russell et al., 2025).

Data Collection

Data were collected over eight months through in-depth, semi-structured interviews using an open-ended guide exploring diagnostic experiences, healthcare access, and sociocultural influences. Questions avoided predetermined themes, while theoretical frameworks informed interpretation. Interviews lasted 30–60 minutes, were conducted in person or virtually, audio-recorded with consent, and supplemented by field notes.

Data Analysis

Data were analysed using Braun and Clarke's (2006, 2019) Reflexive Thematic Analysis.

Interviews were transcribed verbatim and coded in NVivo 15. Transcripts were repeatedly reviewed for familiarisation, followed by systematic coding, theme development and refinement. Themes were labelled and integrated into the analytical narrative using participant quotations.

Ethical Considerations

The study purpose, procedures, risks, and participant rights were explained, and written informed consent was obtained. Participants were assigned numerical identifiers (e.g., P1, P2) to ensure confidentiality. Given the emotionally sensitive nature of the topic, all participants were offered professional psychoeducational counselling after the interview. No monetary or material incentives were provided.

Trustworthiness

Trustworthiness was established using Lincoln and Guba's (1985) criteria of credibility, transferability, dependability, and confirmability. Credibility was enhanced through prolonged engagement, observations during interviews, triangulation of interview data and field notes, and member checking of initial interpretations.

Triangulation

Interview transcripts and contemporaneous field notes were considered together during interpretation to provide contextual information alongside participants' verbal accounts.

Member Checking

For member checking, participants were provided with a summary of the preliminary interpretation of their accounts and were invited to clarify, confirm, or amend the interpretation where necessary. Any clarifications provided were considered during subsequent analysis.

Transferability

Transferability was supported through detailed description of the participant characteristics, research context, and accounts, allowing readers to judge the relevance of the findings to other comparable settings.

Results

Annexure (A)

Family Dynamics and Denial

Several participants spoke about a time when

developmental concerns were not identified or noticed within the family system, and possibly made worse by multiple demands for care. The mother said she didn't notice anything was wrong: "No, I did not see any signs. I did not know that he was like this" (P4). In others, attention was spread between several children, which meant that other things happened that didn't lead to earlier concern: "Secondly, my other children get disturbed, because of that, something also happened that my attention got stuck" (P2). There was also an apparent delay in recognition where the parent or family had not encountered autism before, for example, "We are cousins. But there is no such thing in our family before. That is why we got to know about it a little late" (P3). These delays were worsened by disagreement between parents, with one mother mentioning that her husband wasn't concerned: "When I told my husband, he said that everything is fine" (P3), and another participant noting that only one parent had noticed the need for evaluation: "His father did not feel it at all. His mother told me to get him checked" (P4).

Healthcare System Inadequacies

Participants often reported experiences with health care providers that delayed rather than rushed diagnosis, often by reassurance that turned out to be premature. Several recalled being told their child's development was within the normal range: "I got a check-up done by a doctor. Both private and government. When I went to the government, they said that she is fine. She will be fine according to her age" (P3). Another participant said, "One told me he will definitely speak, but he will speak late. And because of this, we got delayed" (P5).

Some were given explanations that recalibrated clear indicators of development: "He(doctor) said that her brain is still small, and as she grows, she will get better. When she turned 3 years, he said that it would still take time, and she might start speaking much later" (P7). There was also a lack of consistency and contradiction in professionals' assessments, which reduced parents' confidence in seeking

timely assessments, as one participant reported being told that “I told him that these reports do not match. We will not go to her next time” (P1). Another statement: “They still do not believe me. My in-laws and my husband do not believe me either. I took them to the hospital. The reports were fine there too” (P3). These findings also correspond with [Smith et al. \(2024\)](#), who examined the experiences of South Asian parents, including Pakistani parents, during the autism diagnostic pathway and identified difficulties related to limited knowledge, waiting periods, the quality of clinical encounters, and the emotional consequences of the assessment process.

This also meant that families sometimes sought treatment from more than one provider without finding a resolution: “Sometimes we got treatment from one doctor, and sometimes from another” (P5), or that if they had been guided appropriately by the doctors, they wouldn't be delayed at all: “If they were guided properly by the doctors, then they should not be late” (P5). Another participant reported receiving ambiguous information about diagnosis and future outcomes: “They told me at the age of 2 that we are not sure. But there is some information that this child is autistic. But it is possible that in the next 3 years, he will be able to speak” (P6). Additionally, one participant highlighted a lack of proper professional engagement: “No, I did not take him to a professional. They told me that if the child can speak, then you should talk to him, in such a way that he gives you an answer” (P6). These findings align with [O'Neill and O'Donnell \(2024\)](#), who highlighted how uncertainty, communication difficulties, and professional information shape caregivers' understanding of developmental concerns and navigation of the autism assessment pathway.

Help Seeking Difficulties

In addition to specific clinical situations, participants reported that they often had problems dealing with the health care system as a whole, such as knowing whom to ask for guidance. The confusion was witnessed firsthand

by one parent: “The issue that is going on is that we are not getting a proper person with whom we can get satisfactory medical guidance” (P1) and “It was difficult. Actually, what happened, we were not able to understand what to do and what not to do. This was the main reason” (P1). [Wilson et al. \(2023\)](#), in a UK qualitative meta-synthesis, identified barriers to autism assessment, feelings of being misunderstood, and limited professional understanding during the diagnostic pathway.

Some participants reported inconsistent advice from different professionals, complicating decision-making. One participant shared: “When we got her checked, he said that her brain is still small, and as he grows, she will get better. When she turned 3 years old, he said that it would still take time, and she might start speaking much later. Then we got her checked privately, and that doctor gave her homoeopathic medicine” (P7). Such uncertainty and confusion sometimes continued after the first session, and parents were unsure how to proceed: “I did not know what to do and what not to do” (P7). [Fisher et al. \(2025\)](#) found that caregivers' experiences of the autism diagnostic process were shaped by information, provider interactions, waiting times, and referrals.

Limited Resource and Accessibility

Structural barriers included financial limitations and limited availability of services that are specialized in the community. Others cited cost as an issue: “And there was also an issue of money” (P5), while another emphasized this barrier by stating, “Of course, there is a financial factor” (P5).

The present findings align with [Stahmer et al. \(2019\)](#), who identified family, community, and systemic barriers to timely ASD diagnosis, including limited information, provider shortages, logistical difficulties, and complex services, and emphasized improved family-provider communication and accessible service information. There were no services at all in the area: “There was no such thing. There was no Availability here” (P6). One of the participants remarked that it had improved over time but

pointed to the scantiness of services in the past: "There was no school. Now we have one school there. In fact, one private setup of a psychologist. She actually guided us" (P2). Findings on limited resources and service access were consistent with [Battanta et al. \(2024\)](#), who reported difficulties within diagnostic and support systems, financial challenges, and a need for greater post-diagnostic follow-up and support.

Maternal Wellbeing

Several participants linked maternal psychological and physical health difficulties with delayed recognition. One mother reported depression during pregnancy related to work and family stress, followed by alopecia universalis and another depressive episode. "The psychological issue was related to me. If we look at the history. The history was like this. When I was pregnant. The pregnancy was going on. I was very much under stress. I was in a depression phase. Because of my job. And because of my family issues" (P1). The same participant further described severe mental health consequences, stating, "I developed alopecia universalis, a condition in which all body hair falls out. As a result, I went into another episode of depression" (P1). Other mothers' self-blame was linked to their emotions: "Even though I was in a lot of depression, I felt that my child is like this only because of me" (P6). Some went beyond the immediate caregiving mother, as one grandmother participant observed: "Other than this, his mother diagnosed diabetes because of these two children" (P4). Participants' emotional difficulties were consistent with [Hughes et al. \(2024\)](#), who found emotional strain, social isolation, communication demands, and changes in parental identity following an autism diagnosis.

Parental Knowledge and Awareness

Limited autism awareness was reported across educational levels, with some mothers, including university graduates, unfamiliar with the condition: "There was no acceptance and awareness" (P1). She also stated that "The problem was there. But we did not have the awareness of autism" (P1). Misinterpretation of

symptoms as unrelated developmental issues was common: "We thought that it was a matter of his speech. We got him treated for his hearing. His hearing was fine. We got him treated for two years. After 10 years, we found that he had autism" (P2). One participant showed hope rather than understanding, as she said, "I thought he would be able to speak. But it was too late" (P4).

One participant described concealing her child's actual age, stating: "He is actually nine years old, but I reported him as young, so that he can speak" (P6). By analyzing this statement, it is very clear that she still does not have enough knowledge about autism. Another participant said that "I do not have awareness. I thought he would be fine like other kids" (P6). Others realized their child had some problems years after their child was born: "I came to know after 4-5 years that she has some issues" (P3). Some families had compounded this lack of education due to lack of formal schooling: "I did not study enough. My husband did not study. My family was not well educated. That's why there was an issue. No one noticed" (P3). And one participant said that "His elder brother also spoke a little late. But then I noticed that his elder brother spoke a little late, but his understanding was complete. He is not able to understand these things" (P8). This statement projects the comparison and limited knowledge that led to the delayed diagnosis, as they were confident they had enough knowledge but faced consequences later.

Sociocultural Influences

Early signs were interpreted through cultural beliefs and concerns about stigma. Some parents were reluctant to accept the diagnosis due to fear of social judgment. "I don't want anyone to tell me that my child is abnormal" (P6). Others referred to the cultural norm of developmental delay by comparing it to typical variation: "There was a cultural norm. There was a myth. That a certain child was like this. He got better. At a certain age, every child behaves like this. As he grew up, he got better. We were also waiting" (P1).

Fisher et al. (2023) identified stigma, family perspectives, limited knowledge, communication difficulties, and “wait and see” approaches as factors that may complicate or delay ASD diagnosis among minority caregivers. The participant explained that “Everyone told me that he would speak late. He is also very weak. He will speak late” (P5). Within families too, denial was present, with one participant talking about her own initial reluctance to accept her child's situation: “I myself was not accepting that my child is autistic” (P6) and another talking about a wider psychological resistance: “The mind is not accepting that, no, this cannot happen with me. Or my child cannot be like this” (P8). Social Stigma and Bullying also falls under this group of codes. Highlighted the societal attitudes towards children with Autism Spectrum Disorder. One of our participants explained their experience, stating that “Society does not identify a normal child with special needs” (P1).

A “wait-and-see” approach was also reported, sometimes based on older siblings’ developmental patterns: “I thought he would be able to speak. But it was too late” (P4). Another said, “My elder daughter was also 5 years old when she started speaking. So, seeing this, I stopped for a while” (P5). And “Because my first son also started speaking a little late...So, this was the main factor in our mind that he is not able to speak” (P8).

Discussion

The findings align with Matos et al. (2022), who reported an average gap of over two years between initial concerns and ASD diagnosis, consistent with participants’ experiences of concerns arising before formal diagnosis. Alam (2024) emphasized parental involvement, while the present study found that disagreement, denial, divided attention, and limited emotional support shaped how concerns were addressed. The importance of accessible and appropriate special-education services is also relevant to the Pakistani context. Iqbal et al. (2024) examined Quranic education for visually impaired students in special-education schools and highlighted issues related to educational provision for

International “Journal of Academic Research for Humanities (JARH) 6(3)” students with disabilities. Although their study focused on visual impairment rather than autism, it provides a broader local context for understanding disability-related educational services.

Sociocultural influences were consistent with stigma-related barriers reported by Riaz and Zaka (2026) and Imran et al. (2011). Participants’ avoidance of labeling, resistance to acceptance, and “wait and see” approach reflected concerns about social judgment, suggesting that awareness campaigns should also address stigma to promote timely action. The role of social and community support is also relevant when considering the broader rehabilitation needs of families. Alam (2023) discussed rehabilitation through a model emphasizing peer support, social inclusion, and restoration of personhood. Although the proposed model addressed immigrants and refugees rather than families of autistic children, its emphasis on social support and inclusion provides a broader perspective for understanding the importance of supportive environments. Lastly, maternal wellbeing emerged as a recurring theme, highlighting the influence of caregivers’ psychological and physical wellbeing on diagnostic delays, a factor less explored in Pakistan’s autism care context.

Conclusion

This study explored factors contributing to delayed ASD diagnosis in Pakistan through interviews with parents and grandparents. Seven interrelated themes showed that diagnostic delay is not a single event but results from complex family, healthcare, sociocultural, and caregiver-related factors. By examining these factors within an ecological and cognitive-behavioural perspective, the study provides a contextual understanding of diagnostic delay and an evidence base for policies aimed at improving early ASD identification in Pakistan.

Limitations

Several limitations should be considered. Rural and remote areas were underrepresented, limiting transferability. The predominantly female sample, with only two male caregivers, limited male perspectives. Retrospective

accounts may have been affected by memory limitations. Families without a formal diagnosis were excluded, preventing insight into unidentified or unreported cases. Finally, perspectives of other individuals involved in the child's developmental journey were not included; future research should address these gaps.

Future research recommendations

Future research should include rural and underserved areas, as well as more fathers and male caregivers, to broaden representation. Longitudinal studies could reduce limitations associated with retrospective recall by tracking families from initial concerns to diagnosis. Including healthcare providers and educators could also provide a more comprehensive understanding of diagnostic barriers from both family and professional perspectives.

Innovation/Cutting Edge Research

The key innovation of this study is that it looks at delayed Autism Spectrum Disorder (ASD) diagnosis in Pakistan as a complex, interconnected process rather than simply a problem of limited parental awareness. By drawing on the lived experiences of both parents and grandparents, the study highlights how family relationships, caregiver understanding, healthcare experiences, access to services, maternal wellbeing, and sociocultural beliefs can interact to influence when a child receives a diagnosis. The inclusion of grandparents is particularly important in the Pakistani context, where extended family members can play a significant role in childcare and health-related decisions. The study also brings together Bronfenbrenner's Ecological Systems Theory and the Health Belief Model to explain how wider social and healthcare environments interact with caregivers' perceptions and help-seeking decisions. A particularly important insight is that delays may occur even when families reach healthcare services, because inconsistent professional advice or premature reassurance can discourage further assessment. The study also shows how stigma, cultural expectations, comparison with other children, and a "wait-and-

see" approach can shape caregivers' responses to early developmental concerns. By bringing these experiences together, the research offers a more realistic, family-centered, and culturally sensitive understanding of ASD diagnostic delay in Pakistan and provides a foundation for improving early screening, referral practices, professional guidance, and public awareness strategies.

Research Location

The study was conducted in Pakistan, within healthcare and educational settings relevant to the diagnosis and support of children with autism spectrum disorder (ASD). Participants were recruited from hospitals, autism centres, and special education schools across several cities, providing access to caregivers with direct experience of delayed ASD diagnosis. The study included eight caregivers—five mothers, one father, one grandmother, and one grandfather—who had firsthand knowledge of their child's diagnostic journey. Interviews were conducted in Urdu, either face-to-face or virtually, according to participants' availability and preference. This setting enabled the study to capture caregivers' experiences within the broader Pakistani healthcare, family, and sociocultural context.

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Annexure (A)

Figure 1

Thematic Map of Factors Contributing to Delayed Diagnosis of Autism Spectrum Disorder

