

PARENTS' KNOWLEDGE, UNDERSTANDING, AND CHALLENGES IN CAREGIVING FOR CHILDREN WITH AUTISM SPECTRUM DISORDER: A QUALITATIVE STUDY

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Abstract

Parents of children with autism spectrum disorder (ASD) face multiple challenges, particularly in low-resource settings, including limited pre-diagnostic awareness, difficulties accessing clinical diagnosis, misconceptions about autism, and reliance on informal peer support. Moreover, inadequate post-diagnostic guidance and limited formal support often constrain parents' capacity to address their children's developmental and educational needs. This qualitative study aims to gain a deeper acquaintance of parents' knowledge and understanding of ASD in children, which are embedded in the context of parents' life stories as careers of children with ASD. The study adopts an Exploratory Qualitative design based on interpretive paradigm. The study population were 65 mothers of autistic children taking admission in Centre of Excellence for Special Children with Autism (COESCA), Peshawar. 15 participants (mothers) were selected through purposive sampling technique. A thematic analysis approach as outlined by Braun and Clarke (2006) is used to analyze the data. The results show considerable awareness of autism in the pre-diagnosis stage, in which several mothers have the impression that autism is only found in foreign countries or related to mental illness. Typically, diagnosis is triggered by parent or child's observation of early developmental warning signs, which include such things as not pointing to what they want, not responding when their name is called, or delayed speech development. Following a diagnosis, parents' attitudes from "illness" to "difference" shift from being one to be cured, to one to be supported. While doctors remain the mainstay of clinical diagnosis, peer parent networks can also serve as a valuable source of practical knowledge and emotional validation. The most impressive discovery is the continued lack of direction following a diagnosis, as most mothers say they are diagnosed with nothing in place to guide them through therapy, resources or what to expect next, leaving them to navigate a stressful and uncertain time alone. The study shows that the parents' understanding of the diagnosis itself, or an attempt to understand it, is not the problem and is the reason for the parents' distress. Distress is not due to parents lack understanding or attempt to understand, but because there is a

lack of systematic post-diagnosis guidance as a systemic serious problem. Therefore, the study recommends to the healthcare provider, education providers and policy makers to develop a coordinated, guided pathway to care to reduce the burden on mothers of children diagnosed with ASD.

INTRODUCTION

ASD is a neurodevelopmental disorder characterized by impairments in social communication and interaction, and by stereotyped, repetitive patterns of behavior and interests (American Psychiatric Association [APA], 2013). There is no precise estimate of the prevalence of developmental disorders globally, though it is estimated to be approximately one in a hundred children, with significant variation across different regions (World Health Organization [WHO], 2023). However, the prevalence of developmental disorders is still poorly documented in LMICs including Pakistan; where there is limited infrastructure for diagnosis, and there is low awareness about developmental disorders among the general population (World Health Organization [WHO], 2023).

Parents' role has been crucial in identification, diagnosis and continued intervention for a child's ASD (Hyman et al., 2020) and their knowledge had a direct impact on the recognition of early signs, the time taken to seek professional help, and the effectiveness of ASD home-based intervention (Zwaigenbaum et al., 2015). However, in South Asian and Pakistani contexts, such perceptions of developmental differences persist due to cultural beliefs, stigma, and lack of access to specialized healthcare (Mohsin et al., 2026; Aftab, Haider, & Shoukat, 2023). Often early signs of ASD are misinterpreted as shyness, stubbornness, or late maturation, which further delays the diagnosis and adds to the burden already suffered by the families of children with ASD (Mohsin et al., 2026; Aftab et al., 2023).

It is not the only case of Pakistan, a similar misconception regarding the environmental causes of atypical development and the absence of a specific neurodevelopmental condition was observed in Heys et al.'s (2017) influential study of parents and professionals in Nepal, where

misconceptions were related to the environmental causes associated with atypical development, such as birth complications or parenting style, rather than a specific neurodevelopmental condition. In Pakistan, Anwar et al. (2018) reported that during their survey, most parents of children living in Karachi were aware of the term 'autism' but not many knew the signs/symptoms and not many knew what to do for specialized care. A phenomenological study by Furrukh and Anjum (2020) on the mothers of autistic children in Karachi took this one step further, revealing that most mothers had never heard the word before their children were diagnosed and had no knowledge of disability in general, even for those families that were able to afford private therapy, again raising questions about the outcomes for the families with fewer resources and even less access to information and support.

There is a significant psychological and practical caregiving burden, especially for mothers as primary care takers in South Asian family structure, that exacerbates awareness gaps. An awareness gap is further complicated by a large psychological and practical caregiving burden, particularly for mothers, as primary care takers in South Asian family systems (Formeloza et al., 2025). The burden on parents of children with ASD was also found high, with 78% of Pakistani parents with children with ASD reporting high levels of stress related to core ASD behaviours (Nadeem et al. 2024) and there was evidence of the high burden of mothers in Lahore, Pakistan, closely linked to their expectations about maternal care (Mumtaz et al. 2022). The results confirm with the worldwide evidence: Hosseinpour et al. (2022) in Iran found low awareness by the parents, parenting strain and marital and family relationship issues to be common problems for parents of children with ASD. The hardships of care in South Asia include reduced access to

specialists, financial costs and a lack of trained staff, in addition to the emotional burden. The patterns of delayed help-seeking, negative experiences of healthcare and social withdrawal from extended family following diagnosis, which were documented in Malhi et al. (2022) in their qualitative study of caregivers in North India are pertinent to Pakistan's collectivist social context where visible difference can be a risk factor for stigma and isolation.

Overall, the literature confirms that awareness of ASD and the experience of being a caregiver go hand in hand, but existing studies in Pakistan have predominantly focused on economically stable and urban families, and have not compared these findings with the other awareness gaps and care structures reported across South Asia (Nadeem et al., 2024; Mumtaz et al., 2022; Heys et al., 2017; Malhi et al., 2022). The present study is qualitative in nature to directly fill this gap to understand the knowledge and understanding of parents in Pakistan, and their experience of supporting a child with ASD, to guide clinical practice, community awareness, and policy development.

Theoretical Framework

Vygotsky's sociocultural theory (1978) and Piaget's theory of cognitive development (Piaget & Cook, 1952) are used as the two complementary theories. Key to understanding parental challenges are Vygotsky's work on the Zone of Proximal Development (ZPD) between what a child can do independently and with help, and the More Knowledgeable Other (MKO) who helps him. Given the challenges of communicating, interacting with others, and receiving the support and context they need from the society, children with ASD may not be able to access effective MKOs or participate productively in their ZPD, making it difficult for parents, educators and clinicians to scaffold their growth at home and at school. In Piaget's theory learning is viewed as growth in developmental stages; children are active learners, they build knowledge through experimentation, exploring. However, in children with ASD, the cognitive and developmental differences can impair their problem solving and

how they think, and may result in difficulty with perspective taking and hypothesis testing, which can make it more challenging for parents to support their child's thinking and learning. These frameworks bring to light the focus of the study: Vygotsky's theory provides an explanation for why parents often struggle to provide scaffolding for their children, and Piaget's theory provides an explanation for why parents must cognitively adapt themselves to facilitate their child's learning. Together they offer a lens for examining the factors that influence parents with regards to their knowledge, challenges, and their experience of caregiving at home, school, and community.

Research objective

To explore parents' knowledge and understanding of ASD in children

Research questions

1. How do parents of autistic children understand and perceive Autism Spectrum Disorder (ASD)?
2. What challenges do parents face in supporting their children with ASD, and how do societal and cultural factors shape these experiences?
3. What strategies do parents use to support the development, education, and well-being of their children with ASD?

Methodology

Nature and Research Design

The study used a qualitative research approach, exploratory design, to gain a clearer and deeper understanding of parents' experiences, perceptions and challenges in caring for their child diagnosed with Autism Spectrum Disorder (ASD). Qualitative research is well suited for various social and experiential phenomena that are complex and cannot be fully explained through quantitative methods, and are best understood through the detailed accounts, feelings, perceptions and interpretations of participants in their natural setting (Creswell & Creswell, 2022; Strauss & Corbin, 1998). An exploratory design is suitable when the phenomenon needs to be studied in detail to gain more insight into the phenomenon, its extent, and the experiences within the phenomenon, although it is not used to test

hypothesis or to establish causality (Saunders et al., 2012).

A qualitative exploratory design was felt to be appropriate for the present study as it focuses on the issues faced by parents of children with ASD and their knowledge and understanding of the condition. It allowed the researchers to gain a depth and complexity of the lived experiences of the participants and to understand how they experienced and reacted to the challenges of caring for their children.

Population of the Study

The study population comprised of the children of the COESCA, Peshawar. This institute offers services to visually impaired children, hearing impaired, physically challenged, intellectually challenged, ASD challenged and to children with various disabilities. The administration of the institute reported that they have total population of 65 children and the children whose mothers joined for studying are those who were diagnosed with ASD in the centre.

Sample and Sampling Technique

The selected area was COESCA, Peshawar and 'purposive sampling technique' was used for the selection of 15 mothers of children with ASD. The sampling method in this study was purposive sampling in which the subjects were deliberately selected from the population based on the research objectives, which relates to the qualitative research method (Creswell, 2014). This method was found to be appropriate in the current study because it enabled the researcher to obtain insight from information-rich participants (mothers with personal experience of raising their children with an ASD) that could provide the depth and detail necessary to consider the research objectives in meaningful ways.

Data Collection Tool

Data were collected through semi-structured in-depth interviews which allowed the researcher to gain an overall picture of the participants' subjective experiences and their perspectives (Creswell, 2003; Fontana & Frey, 2000). This

approach provides a holistic and rich knowledge of the respondents' thoughts, knowledge, beliefs, and values (Tuckman, 1972). The semi-structured interview format was selected because it enabled the researcher to focus directly on the problems and experiences of parents of children with autism and allowed for flexibility in exploring new lines of enquiry in the interview as it went (Cohen, Manion & Morrison, 2007).

Data Analysis

Thematic analysis was used, following the six phases outlined by Braun and Clarke (2006). The data obtained in the interviews were transcribed and translated, and then read multiple times to get familiar with the data. Codes were systematically generated from the beginning, and the related codes were clustered to form possible themes. Each theme was then reviewed, refined and defined as it related to the study goals. Lastly, the themes identified were interpreted and shared with the participants to make sense of their experiences and to meet the goals of the research.

Findings

The main findings of this study have been discussed under (5) themes: Pre-diagnosis awareness, Referral-Dependent Diagnosis, from Illness to Wiring, Clinical Diagnosis, Peer Wisdom, and Diagnosed not guided.

Parents' Knowledge & Understanding of Autism

Pre-diagnosis awareness

Prior to the diagnosis of autism, all participants were not very knowledgeable about autism. Some had never had a meaningful experience with the word and some have had only inappropriate experiences.

"Whenever I met any autistic kid for the first time I thought 'Oh, no, the kid can't talk at all, the kid can't learn anything.'" R 8

Another Respondent relied

"I heard the word autism, and I didn't know anything, I thought, it was pagan or mental illness". R 11

In a similar manner, other Respondents shared their opinions as follows:

“This is a matter that only happens abroad.” R10

Referral-Dependent Diagnosis

These early warning signs were most commonly noticed by a parent, usually a mother, or the child's pediatrician (Interviews 1-13). These observations were then followed by a formal assessment and diagnosis from a specialist, like a developmental pediatrician, child psychologist or child neurologist.

From Illness to Wiring

In nearly every transcript, parents noted a change in thinking, from the first thought that something was wrong (or that it could be ‘fixed’) and accepting autism as a difference that they would need to support for life.

“This is not an illness to cure this is how she is. Now my goal is not to make her normal, but to help her to be the best version of herself.” R8

How to help him improve:

“His brain just works differently, and it will improve with therapy.” R 5, 6

Clinical Diagnosis, Peer Wisdom

Consistently, doctors and therapists were found to be the most important and trusted sources of clinical advice. However, parents also repeatedly pointed to the importance of WhatsApp and Facebook parent groups, and friendships with other mothers of autistic children both for dealing with everyday problems and the practical tips, understanding and emotional support that these groups offered.

“Other parents gave me hope, doctor gave the diagnosis.” R 11

So talking to other mothers,

“I learned more than from any book.” R 8

Diagnosed, Not Guided

One of the most robust elements identified in Objective 1. Most parents (Interviews 8, 9, 10, 11, 13, and less frequently 2-4) said they had been diagnosed, but not provided with any details about the treatments to be considered, in order, or any

recommendations about who to seek out for advice. They were left on their own to find all these out in a period of stress.

“They didn't explain what autism was or what therapy she would need to get, but just told the diagnosis, and went for therapy, a lost and very frightening situation for about a year”. R 8

Another viewed that

“Had there been someone to guide us at that time our 6 months would have been saved.” R 9

Another replied that

“Parents need a plan, a road map go here for speech, go here for OT, and this is what you can do at home. Without that we spent 3 months crying and Googling.” R 10

Discussion

The aim of this study was to gain insight into the knowledge and understanding of mothers of children with ASD in Peshawar, and to situate this knowledge within their lived experience as mothers in a low-resource, culturally different context, with requirements for identification, diagnosis and continuing management. The results suggest a consistent story line that starts with minimal pre-diagnosis awareness, is strongly influenced by cultural framing and misinterpretation of early signs, evolves through a diagnostic pathway facilitated by parental and clinical observation, and culminates in a gradual transformation of the conception of autism from a treatable disease to a lifelong difference that needs continuous intervention. This changing conception was complemented by mothers' accounts of a diagnostic and post-diagnostic journey in which doctors continued to be the key players in making official diagnoses, and peer parent networks became another powerful, although less formal, source of practical advice and emotional validation. Most importantly, the data indicated that there was a systemic deficit not when the diagnosis happened but immediately following it, when mothers were left without any systematic plan for therapy, education or next steps. The findings collectively reflect and expand upon the existing literature on parental awareness of ASD in low resource contexts in South Asia and

other parts of the world, and provide a more complex picture of how gaps in awareness interact to create overall gaps in the postdiagnostic support, which in turn influences the overall parental experience. The low level of pre-diagnosis awareness, with the term autism often being mistakenly associated with "mental illness" and the belief that autism "only occurs in foreign countries," aligns with the results of studies conducted in Nepal, where no pre-diagnosis awareness was seen, with associations of the term with mental illness and the belief that autism "only occurs in foreign countries" also reflected in the Karachi study (Heys et al., 2017; Anwar et al., 2018). The observation trajectory of the pediatrician or family member is also consistent with the trajectory reported by Zwaigenbaum et al. (2015) which is the caregiver focused trajectory as reported by the mothers in Pakistani studies (Mumtaz, Fatima, & Saqulain, 2022; Nadeem et al., 2024). The transition from treatment to acceptance of autism as a difference for a lifetime shows that the parents' understanding of autism did not stand still at the time of diagnosis, but changed over the years. This is consistent with existing literature, which found that physicians' sources of information were used for clinical diagnoses, while peer network was another source that helped physicians to gain practical and emotional knowledge, and which was also found by Sarwar et al. (2022) that social support is also very important for buffering the parental stress of a mother of child with ASD. Malhi et al (2022) and Rao et al (2024) highlight delayed help-seeking and parent-mediated intervention as the strongest themes identified, respectively, which is in line with the findings of this study. Parents were not denied a diagnosis very often, but a plan was always denied, further increasing distress during a challenging time (Hosseinpour et al., 2022). In general, this corroborates the general literature that document a lack of pre-diagnosis awareness and refines it by adding another dimension that there is a lack of post-diagnosis guidance in its form and nature.

Conclusion

The results reveal that before their child was diagnosed with autism, these mothers had little knowledge about the disorder and held many misconceptions about it, some of which involved thinking that it was a mental illness, others that it was a disorder found elsewhere in the world. Patients were generally identified by the parents or pediatricians when they observed early signs and symptoms of developmental delay, usually delayed speech or failure to maintain eye contact or respond to their own name, and confirmed by a specialist. As time went on, parents' perceptions of autism as a disease with a cure gave way to an understanding of it as a life-long difference that needs support. It was a real emotional and cognitive adaptation process as parents came to understand that autism is a difference rather than an illness for which there is a cure. Doctors were the first and most reliable source of clinical diagnoses, but other mothers of kids with autism, or peer groups, also proved to be a strong source of practical information and emotional validation, often filling in gaps in the formal healthcare system. This study was notable for the fact that the parents most frequently encountered the diagnosis itself, but not the information they subsequently needed: No provision was made for the parents to get any structured information about the next steps, therapy options, or available resources; they had to work out a plan of action for themselves during one of the most stressful times of their lives. Combined, these findings indicate that increasing awareness about autism in Pakistan is not possible by targeting only pre-diagnosis. It is likely that providing healthcare providers with a clear, actionable plan for what to do after diagnosis and formally acknowledging and supporting peer parent networks as a trusted source of knowledge more likely will help to alleviate parent distress and get them on a path to timely intervention than raising awareness about early signs and symptoms. This study provides context-specific evidence from Pakistan which has been largely absent from literature and begins to create a framework for the future work in assessing the feasibility of creating structured post

diagnostic support systems in local health and educational institutions.

Recommendations

The following recommendations are made based on the results of this study, especially the significant differences in post-diagnosis guidance and the persisting pre-diagnosis misconceptions about autism, for healthcare professionals, educational facilities, families, and policy makers. The recommendations are intended to take the key insights from the study and make them actionable to minimize parental distress, ensure timely intervention and improve the systems that serve the families of children with ASD.

1. Develop a standardized post-diagnosis guidance protocol healthcare providers and diagnostic centers should have a clear, written plan that they give the parent at the time of diagnosis, describing therapies that are recommended (speech, occupational, behavioral), and the sequence in which they are recommended to be pursued, and where they can be found in the local area. This directly encompasses the most significant gap that was identified from this study.

2. Formally integrate peer parent networks into support services because mothers said other parents were as or more knowledgeable than clinicians for their real-life experience and knowledge, institutions like COESCA could develop more formalized peer mentorship programs where new parents can connect with another parent with experience to help mitigate the isolation and confusion of the initial months following the diagnosis.

3. Train frontline healthcare workers and pediatricians to deliver diagnosis with basic psycho education Many parents were diagnosed with little to no explanation of what autism is; pediatricians and general physicians should be trained to communicate a diagnosis in an informative, compassionate and actionable way, rather than simply a clinical label.

4. Launch community-level autism awareness campaigns specific outreach to the community via community health workers, schools, and local media could help destigmatize early detection and

discourage delays in accessing autism treatment due to pre-diagnosis misconceptions seen in this study (associating autism with mental illness or autism's foreign-only prevalence).

5.

Future Research Recommendations

1. Expand the sample beyond a single institution and city It is recommended that future research be carried out involving parents from various special education centers in both urban and rural areas of Pakistan to determine if the post-diagnosis guidance gap and awareness trends identified here are also found in more diverse socio-economic and geographic settings.

2. Include fathers and extended family caregivers. Due to the focus on mothers in this study, further research is needed to examine the knowledge and role of fathers and grandparents; the family dynamic and shared caregiving responsibilities may impact knowledge and coping differently.

3. Conduct longitudinal research tracking parental understanding over time. A longitudinal study would be useful to look at the change in parental knowledge and coping over time, from pre-diagnosis to several years after the diagnosis to get an in-depth look at the shift from "illness to different wiring" found in this study.

4. Evaluate the effectiveness of a structured post-diagnosis roadmap intervention. Future studies could test the impact of such a formal guidance protocol or peer mentorship program implemented at the time of diagnosis in a center setting, on parental stress, time to therapy, and family health and wellbeing, with the aim of building upon this study's main finding.

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