

EXPLORING PARENTS' EXPERIENCES AND CHALLENGES IN MANAGING AUTISM SPECTRUM DISORDER (ASD) IN CHILDREN: A QUALITATIVE STUDY

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Abstract

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by a multifaceted interplay of genetic, biological, and environmental factors. Despite ongoing research, the etiology of ASD remains not fully understood. A review of existing literature indicates that environmental interactions, including exposure to toxins and air pollutants, may play a significant role in the onset of autism spectrum disorder (ASD). The frequency of ASD has been increasing, globally one in 127 people have autism in 2021, and now It is estimated that worldwide about 1 in 100 children have autism. For Pakistan, research on autism is on early developmental stage and so far, no reliable statistics available on the prevalence of ASD in Pakistan. The current study adopted qualitative approach. To conduct the interview, total of 14 participants (7 parents) was carefully chosen based on predetermined criteria. The age of parents ranges from 32-47 years. All respondents belong to different localities, four parents belong to Rawalpindi and Islamabad, two belong to AJK and one belongs to Gujrat, Pakistan. According to research, difficulty in social interaction, attention challenges, and aggression are the most common problems that children with autism. The state and health departments should create community-based awareness programs that are exclusively focused on genetic health and ensure sensitive genetic counselling for society and involve community influencers, educators, and religious leaders in communication strategies. Sustainable ASD policy requires a whole-family approach that integrates health, social protection, and inclusion strategies.

Keywords:

ASD Challenges, Parents Experience, Qualitative Analysis.

1- Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by a multifaceted interplay of genetic, biological, and environmental factors. The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) characterizes ASD as a neuro-developmental disorder marked by social communication challenges, repetitive behaviors, and restricted interests (5th ed.; DSM-5; APA, 2013). Despite ongoing research, the etiology of ASD remains not fully understood. Individuals with ASD often experience lifelong challenges, including hyperactivity, impulsivity, social skills deficits, communication difficulties, and repetitive behaviors. ASD is influenced by a combination of genetic, environmental, and sociodemographic factors, such as parental age, race, and family history (Emberti et al., 2019; Tordjman et al., 2014). While there is no definitive treatment for ASD, early diagnosis and intervention can potentially mitigate symptoms and improve outcomes. ASD is typically identified by age three, with a higher prevalence among males. Diagnosis relies on a comprehensive assessment of parental descriptions and professional observations of child behavior. Key characteristics of ASD include poor eye contact, social isolation, delayed language development, difficulties with initiating and maintaining conversations and nonverbal interactions with others (American Psychiatric Association, 2013). A nuanced understanding of ASD's complexities is essential for developing effective diagnostic and intervention strategies.

A review of existing literature (Saghazadeh, A., & Rezaei, N. 2017; Chowdhury et al., 2021). indicates that environmental interactions, including exposure to toxins and air pollutants, may play a significant role in the onset of ASD. Particularly during critical periods of neurodevelopment, early exposure to environmental infections has been linked to an increased risk of ASD (Khan et al., 2024). Individuals with ASD frequently exhibit core symptoms that are accompanied by other behavioral challenges such as aggression, depression, and social withdrawal. These co-occurring issues are crucial to address, as they can lead to long-term mental health complications, poor academic outcomes, and strain on family relationships (Modabbernia et al., 2017).

Recent data suggest that approximately 1.9 million children in India are diagnosed with ASD, with a prevalence rate of 1 in 65 among children aged 3 to 9 years (Uke et al., 2024). In the United States, over 5 million individuals are affected, with a prevalence of approximately 1 in 36 children. In Iran, ASD prevalence stands at 0.62%, while Japan reports a notably higher rate of 3.22%. Studies have also noted an increasing trend in ASD diagnoses in Japan from 2009 to 2023 (Rasool et al., 2023; Malik et al., 2023). According to Golden Steps (2025), prevalence rates vary across countries (see Table 1).

South Korea: 1 in 38 children	Australia: 1 in 70 children	Germany: 1 in 160 children
Finland: 1 in 86 children	Canada: 1 in 66 children	Italy: 1 in 166 children
Japan: 1 in 87 children	UK: 1 in 64 children	Netherlands: 1 in 82 children
Sweden: 1 in 100 children	Belgium: 1 in 134 children	India: 1 in 500 children
Switzerland: 1 in 77 children	China: 1 in 160 children	Spain: 1 in 100 children

Source: Adopted from <https://www.goldenstepsaba.com/resources/what-country-has-the-highest-rate-of-autism>

The frequency of ASD has been increasing, globally 1 in 127 people have autism in 2021, and now projected that worldwide about 1 in 100 children have autism (Zeidan et al., 2022). ASD linked with a combination of genetic susceptibility and further exploration is obligatory to understand the mechanisms through which genetic issues and sociocultural factors contribute to the development of ASD (Rasool et al., 2023; West et al., 2023; Chachar & Mian, 2022). In case of South Asia prevalence of ASD is underreported (Hossain et al., 2017) and around the globe, there is an increase in the number of ASD cases over the past decades (Yang et al., 2023).

For Pakistan, research on autism is on early developmental stage and so far, no reliable statistics available on the prevalence of ASD in Pakistan. According to the Pakistan Autism Society, in 2020 (no data available after 2020), approximately 350,000 to 400,000 children in Pakistan are suffering with ASD. According to 7th population census, approximately 21% experience hearing impairments, 19% have seeing difficulties, 16% face memory issues and 11% experience communication-related issues (PBS-2023), and nearly 24 million people in Pakistan suffering from mental health issues (Shuja A 2025). The disability rate is influenced by weak data collection system, inadequate service delivery and stigma in individuals. The current data regarding disability in Pakistan is both limited and generally unreliable.

Research on autism and support services are at early stage in Pakistan and there are even no reliable statistics on the prevalence of ASD. Different clinical studies highlighted the issues regarding the diagnostic for ASD, like lack of facilities, social stigma, insufficient/inefficient training etc. (Jacobs, 2018). In a country like Pakistan the understanding may be influenced by culture, mostly parents from rural areas admitted their child's disorder as an acceptance of "Allah's will". The word "disability" has different meanings and families with disabled children often hide them, because the handicap is typically interpreted as a sign of retribution (Ravindran, 2012). There are some misinterpretation symptoms like- kid's behavior is socially perceived to be mature but in fact he/she has problem in socialization, -in rural areas late speaking is not a serious issue in majority of the families, -lastly quiet and trouble-free kid can be seen as a nice kid, all these misinterpretations delayed the ASD diagnosis (Bernier et al., 2010). With reference to Pakistan, unprofessional health officials improperly handled the autism which puts a great deal of stress on parents in Pakistan (Hamdani, 2014).

There is a lack of comprehensive research exploring how sociocultural factors shape the diagnosis of children with ASD. Gaining a deeper understanding of these influences is essential—not only to develop culturally sensitive interventions but also to challenge misconceptions and reduce stigma. In some communities, prevailing beliefs that link ASD symptoms to supernatural forces or cultural myths further hinder recognition and proper diagnosis of the condition. The limited access to specialized healthcare and societal views on neurodevelopmental variations exacerbate the difficulties families face in obtaining accurate diagnoses for their children.

There are different studies separately done on mother and father experience with ASD children but not much done to address the viewpoints and difficulties faced by parents. Most of the studies discussed the experience of mothers as mothers are emotionally very close to their children and more likely to fill this role better than father (Meadan et al., 2010). While some other studies claimed that parental joint effort to handle an autistic child can strengthen the emotional relationship of couples (Aylaz, 2012; Fletcher et al., 2012) and on the other hand, inadequate support from spouses can create friction (Luong, 2009). According to Doucet (2009), discussion with couples can be more beneficial as the experiences of both parents may differ.

A family centered approach can be seen as better child outcome, increase in parental satisfaction and reduction in parents' stress level (King et al., 2004) and a father with autistic child may endure higher levels of parenting stress (Moorthy et al., 2023) but there is limited research conducted on parent's experiences attending social events and family get-togethers with their autistic children. According to Osborne, (2008), positive father contribution can foster a stronger sense of family harmony, which can advantage the autistic child like favorable effect on a child's physical, mental, and social-emotional well-being (Flippin, 2011). Generally, there is a lack of awareness and insufficient knowledge about ASD in Pakistan (Anwar et al., 2018; Farrukh & Anjum, 2020; Aftab et al., 2023). Therefore, a deeper understanding of the challenges faced by parents of children with ASD is needed to guide further research, intervention development, and clinical practice in Pakistan. Around the world, ASD phenomenology is well documented but authentic epidemiological data relating to ASD in Pakistan are scarce (Akhter, Ashraf et al., 2018; Ashraf et al., 2022). Social norms alongside an individual's culture intensely shape how a parent understands and reacts towards the child's diagnosis. The current study employs observational and phenomenological methods to explore the lived experiences of parents with children diagnosed ASD. There is a need to understand how cultural myths, religious fatalism, and social stigma specifically delay or prevent the diagnostic process and understand the mechanisms through which genetic susceptibility and sociocultural factors (such as consanguinity) contribute to ASD development in South Asia.

The objective of the study is to explore and understand the socio-cultural factors influencing the diagnosis of children with ASD. Broaden knowledge regarding socio-cultural dynamics and support frameworks required by families living with ASD. Illuminate the real-life experiences, emotional journeys, and resilience of these families while navigating barriers to care and education and understanding the "social reality" of parents through their own perspectives and natural language. The current research may play a critical role in advancing autism research and developing relevant services in Pakistan. Further, this study intends to broaden knowledge on socio-cultural dynamics and the support frameworks required by families with ASD.

2.-Material and Methods

As we know, officially there is no large or even small-scale data available on ASD children. The study is based on qualitative analysis. The qualitative research deals with small samples for a specific purpose, and this is more beneficial to seek comprehensive information, in-depth understanding of people's interpretations, perceptions and lived experiences (Key, 1997; Flick, 2006). Scholars widely agree that the primary aim of qualitative research is to generate in-depth descriptions of social reality using participants' natural language (Neuman, 2006; Creswell, 2003; Denzin & Lincoln, 2003). The research adhered to ethical guidelines. It ensures confidentiality and respect for participants' rights. Participants were informed about the study's purpose, procedures, and their right to withdraw at any point without consequences.

2.1.-Sampling and Data Collection

As compared to quantitative study, qualitative approach uses small sample size, as large sample size will not be suitable to extract the thick and rich information (Onwuegbuzie and Leech 2007; Mark, 2010). According to Marshall (1996), an appropriate sample size for a qualitative study is one that adequately answers the research question. Both convenience and purposive sampling were employed because the researcher intended to get insightful information about the management of ASD children. Convenience and purposive sampling, also known as availability sampling (Creswell, 2003), is a technique that uses to select those participants that

can be easily accessed, and this form of sampling was employed due to affordability, ease of access and efficiency (Doebel & Frank, 2022).

To conduct the interviews, a total of 14 participants, including 7 parents, were carefully selected based on predetermined (convenience and purposive sampling) inclusion criteria. The parents' ages ranged from 32 to 47 years. Participants belonged to different localities: four parents were from Rawalpindi/Islamabad, two from AJK, and one from Gujrat, Pakistan. All parents held at least a bachelor's degree; however, while most mothers were housewives, fathers were comparatively more qualified and proficient in English, Urdu, and Punjabi. The current study was guided by an interpretivist approach (Ryan's 2018) to explore parents lived experiences and perspectives (rather than medical labels) of raising a child with autism as there is no single "right" truth but many valid viewpoints. The interpretivist approach is based on the idea that individuals' perceptions, ideas, thoughts, and meaningful interpretations can be comprehended through research (Boas, 1995).

This study adopts a phenomenological approach, focusing on parents lived experiences and subjective meanings related to the phenomenon under investigation. The interview questions were designed to elicit first-person accounts of participants' experiences, perceptions, and interpretations, thereby aligning with the phenomenological emphasis on how individuals experience and make sense of a phenomenon in their everyday lives. The interviews lasted between 20–30 minutes. Although the researcher took field notes during the interviews, all data were audio-recorded and subsequently transcribed verbatim. The data were analyzed using Braun and Clarke's (2006) six-step thematic analysis approach, involving familiarization with the data, initial coding, theme development, theme review, theme definition and naming, and final analysis. Themes were generated to reflect the core meanings and shared aspects of participants lived experiences, directly addressing the study's purpose during interpretation.

Interviews are the central resource through which contemporary social science engages with issues which concern it (Silverman, 2004). The interview manifests in the production of accounts regarding experiences, emotions, identities, knowledge and opinions (Silverman, 2007). Face to face discussions allow people to convey to others a situation from their own perspective and in their own words. In-depth interviews enable researchers to get holistic understanding of the interviewee's point of view or situation (Berry, 1999). Through this method participant can express their views and experiences, and researchers can probe and ask follow questions to solicit in-depth information from respondents. The interviews were conducted in Urdu as well as in local language Punjabi and were translated and transcribed into English. The utmost purpose of this exploratory study is to understand the social reality of parents through thematic analysis approach.

2.2.-Participants Description

For the current analysis, a total of 14 participants were chosen, representing a wide range of parents with children who have been diagnosed with autism spectrum disorder (ASD). Participant description is as below

Box-1 Participants Description
Family-A belongs to Islamabad, non-consanguineous marriage with no family history of ASD. The family has two children, an older 10-year-old autistic boy and a 2-year-old girl reported as normal developmental progression. Boy was diagnosed with ASD at the age of 36 months by a pediatrician and has poor eye contact, aggressive and repetitive behavior, sensory issues and no intellectual disability.

Family-B-belongs to Rawalpindi, with three children, the affected child a boy (08 year) with two sisters (10 and 05 years), both are age-appropriate. From generations there is no history of consanguineous marriages. The child was diagnosed with ASD at the age of 48 months by a pediatrician. So far parents are not involved in any kind of therapy, but homeopathies treatment is ongoing. The affected individual has poor eye contact, always trying for running, nonverbal communication (just shouting), social isolation and severe aggression. The positive thing is since last 04 months he has been responding/repeating the listing words but not speaking by self.

Family-C belongs to Gujrat, Pakistan. From last two generations parents have consanguineous marriage history The family has two children, one affected boy with age of 06 years and one daughter (04-years) has no sign of developmental delay. The affected child has clinical manifestations including bone marrow issue¹ (bone marrow is unable to produce enough healthy blood cells and this causes reduction in red blood cells and low platelets), poor eye contact, poor communication, severe intellectual disability, severe aggression, repetitive behavior with developmental delay. The boy was vocal at the age 58-months and parents enrolled him in school at one class but according to his teacher “he is very weak with intellectual and developmental disability, and he will be in same class for next year”. Boy was diagnosed with ASD at the age of 3.5 years by a pediatrician.

Family-D from AJK, Pakistan, non-consanguineous marriage with no family history of ASD. The family has two children, an older 6-year-old autistic boy and a 9-year-old girl reported as normal. Parents were not involved in any kind of medications/ therapies. The boy was vocal at age 62-months and now school going but others issue like socialization, aggression, repetitive behavior are there.

Family-E-from AJK and had consanguineous marriages in last two generations with clear but unrecorded history of ASD². The family has one son (4-years) and one daughter (8-years-old) meeting all expected milestones of her age. The boys were diagnosed with ASD at the age of 32 months, reported ASD features along with poor eye contact, aggressive behavior, sever digestive issues, repetitive behavior, sensory issues and intellectual disability.

Family-F- has only one son (07 years), from Islamabad, according to parents he spoke once only three words at the age 26 months and after that no communication. The affected child was diagnosed with ASD at the age of 36 months by a pediatrician. Child has diverse clinical manifestation including severe aggression, poor eye contact, nonverbal, social isolation and intellectual disability. The positive thing is with the help of his grandmother the child is toilet trained and aggression is slowing down day by day. The parents have had a consanguineous marriage for the last two generations.

Family-G- has only one daughter (10 years), from AJK, according to parents she is vocal and very good at academics (she vocal at the age of 5-years). Due to limited awareness (social stigma), so far parents have not been involved in any kind of medications/ therapies. The affected individual has the issue of social isolation, aggression and poor eye contact. The parents have no consanguineous marriage history.

¹ According to doctor this may be because of consanguineous marriage

² Due to unawareness and non-availability of proper identification, families have no idea about ASD. The detailed family history will be discussed in discussion section

3.-Qualitative Analysis

This research delves into the multifaceted challenges faced by parents having children with autism, exploring the cultural, economic, and social barriers that may hinder timely diagnosis. The research seeks to illuminate the real-life experiences of families raising ASD children, understanding their emotional journeys, and resilience in navigating these obstacles. The thematic analysis is as below:

3.1 Reaction upon diagnosis

Every respondent mentioned feeling distressed upon learning the diagnosis, as they were unfamiliar with autism and felt overwhelmed by what they learned. No one can help their son unless he/she understands the diagnosis. *"I was shocked... Allah Ge please let it not be. It's not like you hear about a terminal disease it'd go away with therapies. Therapy would be done and it's just for 2 to 3 years but ...now I know it's lifelong"*. One mother described that she initially experienced domestic difficulties related to conflicts with her in-laws, as she is living in a joint family system. *"Initial reaction doesn't sink in; ...denial phase was there. I think, ...I guess it didn't sink in, let's give it time, so if you want me to put a word to it, then it is denial; I think ...upsetting as well when you realize"*. All parents expressed apprehension regarding their child's future, particularly concerning their potential for independent living, and emphasized the limited opportunities available for their child's development and integration

3.2 Lack of awareness

Out of 14, ten respondents had no idea about autism before the diagnosis of their own child. All the respondents are critical with available awareness system, lack of proper diagnosis, lack of therapies, *"two of the fathers used internet to look for therapists, while two mothers admitted that private therapies are very expensive"* and private institutions focus more on earning. *"There are very few who knows what autism is, ...what can you expect from common people living in rural areas...where social stigma is very strong"*. From the perspective of lived experiences, parents in the study sample—particularly who are well educated and residing in Islamabad—reveal a profound perceptual void in their understanding of autism. This experiential unawareness, even among such informed individuals, underscores the scarcity of knowledgeable voices on the matter. If this perceptual gap persists in urban, educated circles, one must question the feasibility of broader societal recognition permeating the general populace, especially in the remote and resource-constrained rural landscapes of Pakistan.

3.3 Goals and Effectiveness of Early Intervention

The foremost goal for the parents was to improve their child's communication, particularly transitioning from non-verbal to verbal communication. majority parents observed positive changes through early intervention strategies, with improvements in speech and eye contact. Parents highlighted the significance of early intervention, active parental engagement, and creating a stimulating and interactive home environment as essential for managing ASD. Evidence-based interventions focus on improving quality of life for autistic individuals through early identification and tailored therapeutic strategies. These approaches seek to strengthen communication abilities, enhance social engagement, and promote greater independence in everyday adaptive functioning. According to one male respondent, *"there is lack of reliable data on the prevalence of individuals with disabilities"*. On the same token another male respondent- *"NADRA-2025, our big data registration authority has the data of disable persons (724761- included visual, hearing, mental*

and physical) but invisible disability i.e. Autism spectrum disorder (ASD), not include, in which a child seems to be slow learner for the rest of his/her life”.

Inclusive schools are staffed with trained educators and therapists, foster supportive learning environments and promote social integration. In addition, active engagement of local communities in awareness-raising and support initiatives helps reduce stigma surrounding autism and encourages acceptance and inclusion. Despite existing challenges, several organizations continue to enhance awareness, deliver training programs, and provide support to families of individuals with autism.

Addressing the multifaceted challenges associated with autism necessitates a multifaceted approach that encompasses various sectors and stakeholders. First and foremost, with the help of social and print media, raise the public awareness about autism. Schools, colleges, mosques, madrassas and community centers can play a significant role in educating people about autism, its signs, and the importance of early intervention, health sector needs to be equipped with proper training and knowledge. There is need to expand diagnostic services, particularly in underserved areas, is essential to ensuring early diagnosis and intervention (Jawaid et al., 2020).

3.4 Family and Societal acceptance

As compared to Western society, level of tolerance in our society is very low. The public in developed countries has more awareness and more accessibility as compared to Pakistan. According to one mother, *“my in-laws and family members blamed that...I consumed too much sugar during her? pregnancy...so you have those problems”*. One of my neighbors said to me, *“Look at your life—you must have made mistakes. Your parents are unhappy with you, and Allah has punished you in this way.”*

At the outset, all participants expressed uncertainty about the appropriate course of action, perceiving the future as unclear. Over time, they engaged with the diagnostic and therapeutic processes incrementally, adapting at each stage. For many mothers, avoidance and the deliberate disregard of social reactions and judgments were identified as primary coping strategies. *“Someone said ‘wazifa se gunnah chordein ...’ (leave your sins) so I was like... are you telling me that you know I should leave my sins!”*. Most mothers acknowledged that their husbands provided both financial and emotional support; however, the emotional support was primarily directed toward the mothers rather than the children. All mothers emphasized that their husbands had less passion and could not deal with their child’s emotional needs. This may be attributed to the fact that most mothers were housewives and, as a result, spent significantly more time with their children. Parents felt that their other children had been ignored. *“Two mothers had issues between her two children, as the daughter felt neglected”*, and these features can expressively contribute to a child's daily functioning and social interactions.

According to the participants, other parents should develop greater tolerance and patience toward children with autism and strive to understand the experiences of their caregivers rather than offering judgmental comments or criticism. They also emphasized the importance of educating the broader community about autism and related disorders to foster an inclusive, respectful, and neurodiversity-affirming society. *“Don’t turn your back; single out, judge or bully ASD kids and their parents. Reach out into the world of autism and interact with ASD kids on their terms in a way that they understand. Create environments (at schools, hotels, parks, malls) that are autism friendly”*. The awareness should be built in at the very smallest level, that should cover not only autism but also physical impairment and weakness.

3.5 Challenges in ASD Management

Financial constraints were a primary concern for most parents, with therapies being perceived as costly. Additionally, many parents felt that there was a lack of awareness about autism, both among families and healthcare providers. A significant portion expressed dissatisfaction with available resources, they stimulated others to seek timely intervention and pay close attention to their children. A major challenge identified by parents, lack of awareness about autism, among parents, among public and healthcare providers. Parents expressed frustration over the financial burden posed by therapies, particularly in a region with limited resources.

"I remember...I met a doctor, and he asked, 'have you ever thought to kill yourself because of your family/child?' ...I was like ...are you crazy? but now I feel that there is a societal fear of raising these kids and unable to manage them, attempt suicide as well". ASD is associated with numerous challenges that impact on the lives of individuals and their families. According to one respondent ... *"prime challenge is lack of understanding about ASD among the general public, including teachers, healthcare professionals, and community members"*. There is a shortage of trained professionals, including behavior, speech therapists, and special education teachers (Asif, Sultana, & Manzoor, 2017). In addition to this the cost of autism interventions can be a significant burden for a large segment of the population.

3.6 Socialization, empathy and communication skills

Social skills play a vital role in helping children engage and communicate successfully with others, whereas empathy represents a more intricate ability that requires recognizing and relating to people's feelings through elements like spoken words and facial cues. Kids on the autism spectrum (ASD) commonly experience challenges with emotional reactions, which can hinder their ability to start and sustain social connections (Khalid et al., 2020). *"Sometimes we feel extremely exhausted... constantly fear about their future and where we want to head in future. With growing age, we can image that life will be harder, but we cannot afford to be hopeless...hope is only friend we have...in developing countries like Pakistan, future is a big question mark"*. These social deficits can lead to loneliness, anxiety, and destructive feelings (Rabia et al., 2022). A child's cognitive level plays a key role in understanding their outlook with autism. It is important to give parents up-to-date knowledge and practical tools so they can support their child's learning at home and help apply what the child learns in different settings.

3.7 Health Services and Prevalence of Autism

All respondents expressed concerns about Pakistan's healthcare system, stating that it suffers from lack of professional staff and funding. They noted that public hospitals mainly serve low-income patients, while private hospitals are more accessible to those from higher socioeconomic backgrounds. The distrust in Pakistan's public healthcare system is widespread and deeply rooted, affecting how families — especially those dealing with conditions like (ASD) — approach diagnosis, care, and support. Many Pakistanis view public facilities as unreliable, under-resourced, and sometimes even exploitative, leading them to delay seeking help, turn to private options (when affordable), or rely on informal/unqualified practitioners. This gap helps perpetuate under-diagnosis or under-treatment of neurodevelopmental disorders like ASD. According to Economic Survey (2024-25), our spending on health is less than 1% of GDP while WHO recommended minimum 06%. Diagnostic and intervention capacity is very limited; there are fewer than 100

trained consultants in Pakistan capable of diagnosing autism accurately (The Dawn-2025). The weaknesses of the health services linked with limited capacity; uneven access creates a barrier for early detection and treatment of ASD. To understand the behavioral and emotional difficulties in children there is need for increasing attention and resources to address the mental health needs of children in Pakistan (Noor et al., 2021). Healthcare experts often lack sufficient knowledge and awareness of ASD, resulting in outdated perceptions and delays in providing prompt interventions (Fellowes, 2020). Pakistan, with a population of over 247.5 million in 2023 and a vibrant cultural diversity, has historically neglected issues of child mental health and learning impairments. To date, robust and reliable epidemiological data on autism spectrum disorders is scarce.

4.-Discussion

The results of this study align with previous research particularly regarding the prevalence of behavioral challenges such as aggression and attention problems. The most common behavioral issues identified in this study, attention problems and aggression, reflect similar patterns found by (Kanne and Mazurek, 2011). The connection between gastrointestinal symptoms, such as headaches or stomachaches, without clear medical causes, highlighted aggression as a prevalent issue among children with ASD (Ferguson, 2019). Common characteristics of autism are limited interest, language deficiency, repetitive motor movements and social interaction issues. For a human being, socialization skills played very effective role but for ASD individuals' bad social skills can hinder growth, isolation, loneliness with poor academic performance and on time intervention may help in development of social skills. There are different intervention methods like relationship development and cognitive training, but none address the social skills directly (Rowland, 2020).

As mentioned in participant description Family-E has the history of autism. One thing which is very interesting and alarming, out of our sample one father is autistic, and according to him "he always suffered with issues like short temperament (aggression) and lack of social capital. As he gets to know about his child, he understands that he is also an autistic guy. According to him, his father was very strict with children. He described himself as an average student and mentioned that he's particularly bad at calculus".

While discussing his situation, "he said, *according to my mother, I began speaking at around six years of age and tended to play by myself as a young child. ...he pointed out that childhood or school friendships are typically very long-lasting, yet I never developed any lasting friendships. Over the years, I've held jobs in different departments and interacted with colleagues, but.... I've never had real friends*". Initially he thought, everyone has issues with him, but after passing time he realizes that "*I have personality disorder issue*" everyone cannot be wrong and this realization was very painful (when you know the problem without solution). "*I ever took long to understand the people saying, even not understand the jokes of my siblings, most of the time cannot understand others point of view, as I have small canvas. I always love to follow the usual routine and become anxious if it changes, not happy with gathering, during official discussion most of the time on back foot, feel comfortable alone, cannot face the people and most of the time catch the negative things. Cannot accept any change easily as I am spontaneous, overall, one can easily said that I have confusing personality*". Although it is terrible but one can easily predict the future of ASD children. According to him "*his aunty, sister and a cousin- all have ASD symptoms but has no idea and realization about this disorder*".

According to one mother “*to handle with an autistic child is not an easy job, daily routine is full of depression and anxiety as your child requires full attention. We got to know he is autistic at age of 3 years and there is no medicine for that disorder, before that we have no idea about autism³. We started his therapies (behavior/speech) into a State-owned center for five months, but it could not help (most of the therapists are trainee-most of trainees were short tempered, we have not seen any trained specialist who deal or monitor the child progress). After that we visited one private center, fee was PKR-80,000 per month, and one-hour daily session (not manageable for us). Meanwhile I secured a permanent teaching job but resigned due to my child. Since last four months, he is in a school of inclusive education. We cannot leave him alone even for a while as he has very little sitting span and has behavior issues. Our socialization is limited - to visiting someone's house you feel awkward when your child is not listening and most of the time you engage with your child- they don't tolerate. I feel relaxed and at ease whenever I visit my mother's home because my sisters always look after my kid (not the case with my in-laws). My kid is happy with mobile phone, I always tried to reduce his screen time, but if we have some guests then mobile phone is the only solution as we are a nuclear family (the issues are different with joint family, but consequences are same)*”. From the analysis, none of the parents had idea about ASD before the diagnosis. The prevalence of ASD is a hidden and serious disability, there must be awareness workshops at larger level, and there is dire need to involve all BHUs (basic health units) in this awareness campaign. With the help of these workshops all parents, especially mothers, can adopt early intervention approaches for the betterment of their children.

As a Pakistani, it is very easy to judge other children labeled as “bad and out of control” as parents are unable to control the behavior of their children. At large, there is low level of empathy in our society, but parents love and support their child. One family thought “*this is Allah's will; they are providing feed and clothe and no need to spend money and time on therapeutic activities*”. On the other way, rest of the parents admitted Allah's will but working hard with their child in developing her skills.

Children with ASD benefit from a range of therapies that can support their communication, social skills, behavior, and daily functioning. Behavioral therapies, such as Applied Behavior Analysis (ABA), focus on improving positive behaviors through structured learning and reinforcement (Lovaas, 1987). Speech and language therapy helps children develop verbal and non-verbal communication skills (ASHA, 2020). Occupational therapy supports daily living skills and sensory integration (Case-Smith et al., 2015). Social skills training helps children learn appropriate social interaction and peer engagement (Gates et al., 2017) and sensory integration therapy addresses sensory sensitivities common in ASD (Schaaf et al., 2014). Furthermore, there is no rigorous and reliable data on prevalence of ASD, and up-to-date data can significantly contribute to understanding the issue. First and foremost, with the help of social and print media, raise the public awareness about autism. Schools, colleges, mosques, madrassas and community centers can play a substantial role in educating people about the autism, and the consequence of early intervention.

5.-Conclusion, Policy Implications and Limitations

This study underscores the importance of early identification and intervention in managing the behavioral challenges associated with autism. The findings suggest that social attraction, attention problems and

³ She recalled her experience from the time we were in the United States, where two children—a brother and a sister—were placed under the custody of the social protection department following their parents' separation. Both children were diagnosed with autism spectrum disorder. The brother was minimally verbal, whereas the sister had no speech at that time. Apart from this difference in verbal ability, the remaining symptoms were similar in both children.

aggression are the most prevalent issues faced by autistic children. State and health department should ensure sensitive genetic counseling for society, develop community-based awareness campaigns that focus purely on genetic health. Engage religious leaders, educators, and community influencers in communication strategies. Sustainable ASD policy requires a whole-family approach that integrates health, social protection, and inclusion strategies. The limited recognition and evidence on autism spectrum disorder directly challenges progress toward SDG 3 (Good Health and Well-Being), SDG 4 (Inclusive and Quality Education), and SDG 10 (Reduced Inequalities), underscoring the urgent need for context-specific research. Here are some policy implications for future research

- There is a need to move toward a family centered model that integrates healthcare with social protection and inclusion strategies to reduce parental stress.
- Policies should mandate awareness campaigns through Basic Health Units (BHUs) and involve religious leaders, educators, and community influencers to challenge cultural myths and fatalism.
- State-led sensitive genetic counselling and programs focused purely on genetic health to educate the public on inherited risks.
- Educational reforms, development of inclusive schooling with trained specialists.
- National authorities like NADRA and the Pakistan Census should explicitly record ASD data rather than grouping it under general disability categories to facilitate better resource allocation.
- To improve health facilities, increase the health budget from 1% to 6% of GDP

There are number of limitations like one limitation is relatively small sample (14 interviews), which may not capture the diversity of parental experiences. We cannot generalize the analysis even on those families who don't have the resources for early interventions. In Pakistan, majority of the families are not ready to accept the prevalence of ASD, mainly due to the taboos associated with mental health. The study is limited to parents' experience, not including other family members. Additionally, the study focused on children under the age of 11, limiting its generalizability to older children with ASD. Nevertheless, this research can serve as a starting point for probing the circumstances of children with ASD in their community, including their acceptance and integration into routine activities, while also fostering greater awareness, as recommended by most parents. Future studies could expand the scope to include older children and explore the long-term impacts of early interventions. Finally, non-availability of large data in Pakistan is also a limitation of the study. With the help of reliable and concrete data, future research will address these issues by employing more representative sample from population.

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