



Research Article

Investigating Barriers to Healthcare Access for Parents of Children with Autism Spectrum Disorder in South Punjab, Pakistan

Naeem Haider¹, Faisal Amjad¹ & Hira Chaudhry²

¹PhD Scholar, Department of Special Education, Division of Education, University of Education, Township Campus, Lahore – Pakistan

²Department of Psychiatry, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia – Malaysia

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ABSTRACT

This research explores the Barriers to Healthcare Access for Parents of Children with Autism Spectrum Disorder in South Punjab, Pakistan. It investigates factors such as awareness channels, availability of healthcare facilities, and barriers to healthcare access. Utilizing quantitative methods, including structured surveys and statistical analyses, data from 100 participants were analyzed. Findings indicate diverse awareness channels, with disparities in awareness across different aspects of ASD. While healthcare facilities such as general practitioners and speech therapists are somehow available but, specialized services show notable gaps. Transportation problems, financial constraints, and cultural practices emerge as significant barriers to healthcare access. Statistical analyses reveal no significant differences in perceptions based on demographic variables. This study contributes valuable insights into the multifaceted challenges faced by families navigating the healthcare system for their children with ASD in South Punjab, Pakistan. It informs interventions & policy recommendations to ameliorate healthcare access and support services for this vulnerable population..

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INTRODUCTION

The neurodevelopment disorder known as Autism Spectrum Disorder (ASD) is complex. It is typified by difficulties with speech, social contact, and repetitive behaviors. Globally, its prevalence is steadily rising. Its estimates vary across regions (Chiarotti & Venerosi, 2020). In Pakistan, families of children with ASD encounter numerous hurdles in accessing appropriate healthcare services (Furrukh & Anjum, 2020). This article investigates the specific challenges of parents of children. The journey of seeking healthcare for a child with ASD is often fraught with obstacles. It ranges from the limited availability of specialized professionals to the societal stigma surrounding neurodevelopment disorders (Hus & Segal, 2021). Where

*Corresponding author: Faisal Amjad, PhD Scholar, Department of Special Education, Division of Education, University of Education, Township Campus, Lahore – Pakistan
e-mail: amjadfaisal40@gmail.com

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healthcare infrastructure may be sparse and resources limited in South Punjab, Pakistan. These challenges are exacerbated. Despite efforts to improve awareness and support for individuals with ASD, significant gaps remain in understanding and addressing the unique needs of this population (Roche et al., 2021). It is imperative to delve into the experiences and perspectives of parents navigating the healthcare system for their Children with ASD in South Punjab, Pakistan (CASP). By identifying the barriers they encounter from the initial stages of seeking a diagnosis to accessing ongoing interventions and support services, we can gain insights that inform targeted interventions and policy initiatives (Aguirre Velasco, et al., 2020). This article adopts a Quantitative approach. The interviews with parents and surveys of healthcare providers comprehensively explore the challenges faced by families of CASP. We seek not only to highlight the existing barriers but also to propose actionable recommendations for improving healthcare access and support services for CASP. Our goal is to help create a more compassionate and welcoming healthcare environment for CASP by bridging the gap between research and practice.

Research Objectives

- To identify the specific challenges faced by parents of children with ASD in accessing healthcare facilities in South Punjab, Pakistan.
- To evaluate the perceptions of parents and healthcare professionals regarding the diagnostic process and accessibility of healthcare services for children with ASD.
- To assess the impact of socio-demographic factors (such as education level, income, and geographic location) on the accessibility of healthcare facilities for children with ASD.
- To provide evidence-based recommendations for improving healthcare access and diagnostic services for children with ASD in the region.
- Research Questions
- What are the primary challenges faced by parents of children with ASD in accessing healthcare facilities in South Punjab, Pakistan?
- How do parents and healthcare professionals perceive the diagnostic process for children with ASD?
- What are the socio-demographic factors that influence the accessibility of healthcare facilities for children with ASD in South Punjab, Pakistan?
- What interventions and policy recommendations can be made to enhance healthcare access and diagnostic services for children with ASD in the region?

Hypotheses

- H1: There are significant challenges faced by parents of children with ASD in accessing healthcare facilities in South Punjab, Pakistan.
- H2: Perceptions of the diagnostic process for children with ASD differ significantly between parents and healthcare professionals.
- H3: Socio-demographic factors, such as education level, income, and geographic location, significantly influence the accessibility of healthcare facilities for children with ASD.
- H4: Implementing evidence-based interventions and policy changes can improve healthcare access and diagnostic services for children with ASD in South Punjab, Pakistan.

LITERATURE REVIEW

ASD is classified as a neurodevelopmental disorder that is typified by deficiencies in social interaction and communication. In addition, limited, recurring interests, activities, or behavioral patterns (Shah, et al., 2014). The prevalence of ASD has been rising worldwide. Between one in 54 and one in 160 children are thought to be affected (Chiarotti, & Venerosi, 2020). It is dependent upon research populations and diagnostic criteria. It is imperative that people with ASD have access to healthcare services in order to obtain prompt diagnosis, intervention, and support. Nonetheless, a number of studies have brought attention to the difficulties parents of ASD children encounter while trying to get their kids to the doctor. In Low and Middle Income Nations (LMICs) like Pakistan, it is especially prevalent (Pervin et al., 2022).

A study conducted in Pakistan found that parents of children with ASD encountered various barriers in accessing healthcare services. It includes limited availability of specialized professionals, long waiting times, and financial constraints (Farooq & Ahmed, 2020). Similarly, a qualitative study revealed that parents in Pakistan faced stigma and discrimination when seeking healthcare for their children with ASD. And further exacerbating their difficulties in accessing services (Imran et al., 2011). The geographical factors and disparities in healthcare infrastructure contribute to the challenges in accessibility in the rural areas. A study focused on rural communities in LMICs including Pakistan identified a lack of awareness, limited access to specialized services, and transportation barriers as significant obstacles to accessing healthcare for children with developmental disorders (Hamdani et al., 2022). ASD presents significant challenges not only for affected individuals but also for their families, healthcare systems, and communities (Antezana et al., 2017).

While the prevalence of ASD continues to rise globally, particularly in LMICs. The barriers to accessing healthcare services for individuals with ASD remain pervasive and multifaceted (Bauer, et al., 2022). In addition to the challenges highlighted in the existing literature, several other factors contribute to the complexities of accessing healthcare for individuals with ASD. It is particularly in resource-constrained settings like South Punjab, Pakistan. One such factor is the intersectionality of socioeconomic status and healthcare disparities. Studies have shown that families from lower socio-economic backgrounds often face greater challenges in accessing specialized healthcare services for their children with ASD due to financial constraints (Raouafi et al., 2018). Also due to limited transportation options (Dababnah, & Bulson, 2015) and competing demands on their resources (Henry, 2013).

Furthermore, the experiences of people with ASD and their families are greatly influenced by cultural views and beliefs regarding neurodevelopmental diseases (Aftab, et al., 2024). In many cultures, there may be stigma and misconceptions surrounding ASD. It leads to social isolation and reluctance to seek formal medical care (Aftab, et al., 2023). Addressing cultural barriers to healthcare access requires not only increasing awareness and understanding of ASD within communities but also ensuring that healthcare providers are culturally competent and sensitive to the needs of diverse populations (Dillenburger, et al., 2013; Young, & Guo, 2020). Moreover, the lack of trained professionals and specialized services for diagnosing and treating ASD in rural and underserved areas exacerbates the challenges faced by families in accessing appropriate care for their children (Malik-Soni, et al., 2022). Telehealth interventions and task-sharing models have shown promise in bridging this gap by providing remote consultations (Chia, & Turner, 2022). Training local healthcare workers and increasing community awareness about ASD have also shown promise in bridging this gap (Siller et al., 2013).

While progress has been made in raising awareness about ASD and improving access to healthcare services globally, significant disparities persist, particularly in LMICs like Pakistan. Addressing these disparities requires a multifaceted approach that encompasses policy changes, community engagement, and investment in healthcare infrastructure and workforce development. By addressing the socio-cultural, economic, and geographical barriers to healthcare access, we can ensure that individuals with ASD receive the timely diagnosis, intervention, and support they need to thrive. While there is a growing body of literature on the Barriers to Healthcare Access for Parents of Children with ASD in accessing healthcare services globally, there is a paucity of research specifically focusing on South Punjab, Pakistan. Given the unique cultural, socio-economic, and geographical context of the region, it is essential to investigate the specific barriers encountered by parents in this area. Understanding the Barriers to Healthcare Access for Parents of Children with ASD in accessing healthcare facilities in South Punjab, Pakistan, it is crucial for informing targeted interventions and policies. It aimed at improving healthcare access and quality for this vulnerable population. By addressing these barriers, healthcare systems can better support individuals with ASD and their families. It will promote their overall well-being and quality of life.

Theoretical Framework

The theoretical framework for this study is based on the Health Belief Model (Rosenstock, et al. 1988) and the Social Ecological Model (Bronfenbrenner, 1979). The Social Ecological Model (SEM) and the Health Belief Model (HBM) offers comprehensive lenses for understanding ASD diagnosis in South

Punjab, Pakistan. The SEM emphasizes environmental systems' interaction from micro to macro systems shaping individual development (Bronfenbrenner, 1979). In the ASD diagnosis context, it explores how individual traits, family beliefs, and healthcare accessibility converge. The macro system includes cultural views on neurodevelopmental disorders that influence community perceptions. Complementing SEM, the HBM highlights cognitive processes in health behaviors (Rosenstock et al., 1988). It emphasizes perceived susceptibility, severity, benefits, and barriers in decision-making. Applied to ASD diagnosis it explores parents' perceptions of their child's susceptibility to ASD. It also explores the condition's severity and barriers to seeking diagnosis. This study aims to examine ASD diagnosis in South Punjab, by integrating SEM and HBM. By exploring individual, family, community, and societal factors within SEM and understanding parents' decision-making through HBM, the study seeks to unravel the complexities of ASD diagnosis in the region.

METHODOLOGY

In order to better understand the obstacles parents of children with autism spectrum disorder in South Punjab, Pakistan face while trying to access healthcare, this study used a quantitative method. Through the use of structured surveys that centered on diagnostic experiences, numerical data was collected. The target group comprised medical experts as well as parents of children with ASD. To ensure participation from both urban and rural areas, a stratified random sampling technique was used. This resulted in a sample size of 100 participants, who were split equally between parents and healthcare professionals. The chosen participants were given structured surveys using standardized questionnaires. In addition to topics intended to evaluate diagnostic experiences and perceptions on ASD, the survey asked questions about demographics. Standard deviations, means, frequencies, and percentages were among the descriptive statistics utilized to summarize the major variables and demographic data. The study utilized inferential statistical methods, such as ANOVA and T-tests, to investigate the correlation between demographic characteristics and the diagnosis of ASD. The Statistical Package for the Social Sciences (SPSS) was used for data entry and analysis.

Ethical Considerations & Limitations

The confidentiality and privacy of the participants were protected throughout the research procedure by strictly following to ethical rules. Participants were fully informed about the goal of the study, its methods, and their opportunity to withdraw at any moment without obligation. Confidentiality was maintained throughout. Parents of children with autism spectrum disorder in South Punjab, Pakistan face barriers to healthcare access. The quantitative research technique provided important numerical insights into these issues. This method, however, was unable to fully capture the breadth and context of the socio-cultural elements affecting healthcare access. The study recognized the limited generalizability of the results within the studied group as well as potential biases present in self-reported survey data. Notwithstanding these drawbacks, the goal of the quantitative approach was to offer a solid knowledge of the obstacles. The results provided important information to support evidence-based treatments and policy suggestions meant to enhance the diagnostic environment for kids with ASD in the area.

Descriptive Statistical Frequency Tables

Table 01

Perceptions of Parents & Healthcare Professionals on Ways of Awareness about ASD in South Punjab, Pakistan.

In your area, parents of children with ASD are Aware of Autism in which of the following ways?	Yes	No
Workshops	19	81
Websites	21	79
Books	29	71
Regular Degrees	15	85
Certificate Courses	15	85
Parents Groups	29	71
Through Social Organizations	36	64
TV, Radio, and Other Social Media	40	60
Social Programs	24	76

Table 01 illustrates the perceptions of parents and healthcare professionals regarding various channels

through which parents of CASP. Acquire awareness about ASD. Among the surveyed methods, TV, Radio, and Other Social Media were the most commonly cited sources of awareness. With 40% of respondents acknowledging their effectiveness. Social Organizations and Social Programs were also reported as significant channels. With 36% and 24% of respondents respectively citing their impact. Conversely, Workshops, Websites, and Certificate Courses were among the least cited methods. With only 19%, 21%, and 15% of respondents respectively reporting them as sources of awareness. Books and parent groups were relatively more acknowledged. With 29% of respondents each recognizing their role in raising awareness about ASD. These findings emphasize the importance of utilizing diverse channels to effectively reach and support parents of CASP.

Table 02

Perceptions of Parents & Healthcare Professionals on Aspects of Awareness about ASD in South Punjab, Pakistan.

What do you think Parents of children with ASD in your area are aware of which of the following aspects related to autism?	Yes	No
Diagnosis of Autism	26	74
Social Aspects	50	50
Sensory Differences	34	66
Sexual Needs	28	72
Basic Personal Needs	50	50
Attitudes	40	60
Their Health-Related	50	50
Economic Aspects	15	85
Their Marital Life	24	76
Related to Their Sports	15	85

Table 02 presents the perceptions of parents and healthcare professionals regarding different aspects of awareness about Autism Spectrum Disorder (ASD) among parents of CASP. Social Aspects and Basic Personal Needs emerge as the most widely acknowledged areas of awareness. With 50% of respondents affirming parents' understanding. Attitudes and Health-Related aspects also show notable awareness levels. With 40% and 50% of respondents respectively acknowledging parents' knowledge. However, Economic Aspects Related to Their Sports are identified as areas with lower levels of awareness. Only 15% of respondents cited parents' awareness in these domains. The findings underscore the need for targeted interventions and educational initiatives to enhance awareness across a broad spectrum of aspects related to ASD in South Punjab, Pakistan. Ultimately it aims to better support individuals with ASD and their families in the region.

Table 03

Perceptions of Parents & Healthcare Professionals on Facilities Available For Children with ASD in South Punjab.

Which of the following facilities are available for children with autism in medical facilities in your area?	Yes	No
Special Experienced Team for ASD	27	73
Special experienced nursing staff for ASD	27	73
Psychologist	35	65
Gastroenterologist	43	57
Audiologist	45	55
Speech and Language Pathologists	55	45
GP (General Practitioner)	77	23
Developmental Psychologist.	28	72
Least Restrictive Environment (LRE)	15	85
Neurologist	25	75
Physical Therapist	48	52
Diet nutritionist	15	85
First Aid Unit	50	50
Urologist	26	74
Orthopedic	48	52
Ophthalmologist	38	62
Computer and IT facilities	26	74

Table 03 presents perceptions of parents and healthcare professionals regarding the availability of medical facilities for CASP. General Practitioners (GPs) are reported as the most widely available resource.

With 77% of respondents affirming their presence. Speech and Language Pathologists at 55%. Audiologists (45%), Physical Therapists (48%), and First Aid Units (50%) are also commonly available. It indicates comprehensive support for sensory, motor, and emergency care needs. However, specialized resources such as the Least Restrictive Environment (LRE) (15%), Diet Nutritionists (15%), and Urologists (26%) show lower availability. It highlights potential gaps in addressing environmental adaptations, dietary needs, and urological concerns. These findings underscore the importance of ensuring access to a comprehensive range of services to provide holistic care for ASD children in medical settings in South Punjab, Pakistan.

Table 04

Perceptions of Parents & Healthcare Professionals on Reasons for Not Sending Children with ASD to Healthcare Facilities in South Punjab, Pakistan.

What do you think are the reasons that parents do not send their children with ASD to Healthcare facilities?	Yes	No
Climate Severity	26	74
Distance From Healthcare Institutions	74	26
Fees, medicine, And Other Expenses	74	26
Transport Problems And Non-Availability of Transportation	82	18
Absence of Doctors	62	38
Good Treatment by Hakims	76	24
They go to the "Murshid and Fakirs"	78	22
Lack Of Time	40	60
Social Barriers	62	38
Fear Of Sexual Abuse	74	26
Staff Attitude & Behavior	40	60
Poverty And Unemployment	68	32
Disappointment And Hopelessness	68	32

Table 04 illustrates the perceptions of parents and healthcare professionals regarding the reasons why parents do not send their CASP to healthcare institutions. Transport problems and the non-availability of self-transportation emerge as the most prevalent reasons. 82% of respondents affirmed their significance. Distance from healthcare institutions and financial constraints were the same. Each was cited by 74% of respondents. Additionally, good treatment by Hakims (76%) and visits to "Murshid and Fakirs" (78%) indicate the influence of cultural and alternative healing practices. Other notable reasons were also reported. These include social barriers (62%) and fear of sexual abuse (74%). Staff attitude and behavior (40%), poverty and unemployment (68%), and disappointment and hopelessness (68%). These findings underscore the multifaceted challenges faced by parents of ASD children in accessing healthcare services in South Punjab, Pakistan.. It emphasizes the need for comprehensive interventions addressing logistical, financial, cultural, and psychosocial barriers. So that healthcare access and utilization can be improved for this vulnerable population.

Inferential Statistical Frequency Tables

Table 05

Comparison of Means based on Relationship (Independent Sample t-test)

Relationship	N	M	S.D	t	Df	Sig.
Parents	50	19.9400	9.23262	-1.314	98	.192
Healthcare professionals	50	22.4000	9.48898			

* $p > .05$ Level of Significance

Table 05 presents a comparison of means between parents and healthcare professionals based on their relationship with CASP. The mean score for healthcare professionals ($M = 22.4000$, $SD = 9.48898$) is higher than that of parents ($M = 19.9400$, $SD = 9.23262$). It indicates a numerical difference in perceptions between the two groups. However, with a t-value of -1.314 and 98 degrees of freedom, the non-significant p-value ($p > .05$) suggests that this difference is not statistically significant at the specified level of significance. These findings imply that while there may be variations in perceptions between parents and healthcare professionals regarding ASD-related issues in South Punjab, Pakistan. However, these

differences are not statistically significant. Further exploration of potential factors influencing these perceptions is warranted to gain a deeper understanding of the dynamics between these two groups.

Table 06

Comparison of Means based on Gender of Parents (Independent Sample t-test)

Gender	N	M	S.D	T	Df	Sig.
Female	13	20.2308	10.63919	-1.458	48	.897
Male	37	19.8378	8.84595			

* $p > .05$ Level of Significance

Table 06 compares the means of ASD-related perceptions between female and male parents of children with ASD using an independent sample t-test. The mean score for female parents ($M = 20.2308$, $SD = 10.63919$) is slightly higher than that of male parents ($M = 19.8378$, $SD = 8.84595$). It indicates a marginal difference in perceptions between the two gender groups. However, with a t-value of -1.458 , 48 degrees of freedom and the non-significant p-value ($p > .05$) suggest that this difference is not statistically significant at the specified level of significance. These findings imply that while there may be a slight numerical discrepancy in ASD-related perceptions between female and male parents. However, this difference is not statistically significant.

Table 07

Comparison of Mean Based on Education of parents (One Way ANOVA)

Description	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	151.498	3	50.499	.577	.633
Within Groups	4025.322	46	87.507		
Total	4176.820	49			

* $P > .05$ Level of Significance

Table 07 presents the results of a one-way analysis of variance (ANOVA) comparing ASD-related perceptions among parents based on their education levels. The analysis shows that perceptions do not significantly differ across different education levels. As is evidenced by an F-value of $.577$ with 3 and 46 degrees of freedom and a p-value exceeding the specified level of significance ($p > .05$). These findings suggest that parents' education levels do not significantly influence their perceptions of ASD-related issues in South Punjab, Pakistan. The relatively small variation between groups compared to within groups further supports this conclusion. Further exploration may be needed to identify other potential factors contributing to variations in perceptions among parents of children with ASD.

Table 08

Comparison of Mean based on Occupation of the Parents (One Way ANOVA)

Description	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	421.160	3	140.387	1.719	.176
Within Groups	3755.660	46	81.645		
Total	4176.820	49			

* $P > .05$ Level of Significance

Table 08 presents the outcomes of a one-way analysis of variance (ANOVA) investigating ASD-related perceptions among parents categorized by their occupations. The analysis reveals no statistically significant difference in perceptions across various occupational groups. As indicated by an F-value of 1.719 with 3 and 46 degrees of freedom and a p-value exceeding the specified level of significance ($p > .05$). These results suggest that parents' occupations do not significantly impact their perceptions of ASD-related issues in South Punjab, Pakistan.. With the variation between groups not substantially greater than within groups and the lack of statistically significant differences. Further exploration may be required to identify these factors and their contributions to ASD-related perceptions among parents.

Discussion

The findings of this study are consistent with previous research. The Research on the Barriers to Healthcare Access for Parents of Children with Autism Spectrum Disorder, particularly in LMICs like Pakistan. Previous studies, such as those conducted by Farooq and Ahmed (2020) and Imran et al. (2011), have highlighted similar barriers. The barriers include the limited availability of specialized profession-

als, long waiting times, and financial constraints. These challenges align with the findings of the current study, emphasizing the ongoing struggles that parents face in navigating the healthcare system for their children with ASD. Furthermore, the disparities in awareness across different aspects of ASD identified in this study echo findings from previous research. For instance, Imran et al. (2011) found that parents in Pakistan faced stigma and discrimination when seeking healthcare for their children with ASD. Which may contribute to the lack of awareness about certain aspects of the disorder.

Hamdani et al. (2022) highlighted the lack of awareness and limited access to specialized services in rural communities in LMICs. This parallels the findings of the current study regarding disparities in healthcare access in South Punjab, Pakistan. The availability of various healthcare facilities for CASP, as reported in this study, aligns with findings from previous research on the general landscape of healthcare services in the region. While general practitioners and basic healthcare services may be more accessible. Specialized services such as speech and language pathology and developmental psychology may be limited, as noted by Pervin et al., (2022). Moreover, the multifaceted challenges faced by parents reported such as transportation problems, financial constraints, and social barriers. They have been documented in previous studies on healthcare access for children with ASD. These challenges intersect with broader issues related to healthcare infrastructure, socioeconomic disparities, and cultural beliefs, as highlighted by Shah et al. (2014) and Rosenstock et al. (1988). Overall, the findings of this study contribute to the existing body of literature on ASD healthcare access in LMICs like Pakistan. By building upon previous research and providing context-specific insights into the challenges faced by parents in South Punjab, Pakistan, this study adds valuable knowledge. The knowledge to inform targeted interventions and policy initiatives aimed at improving healthcare access and support services for children with ASD and their families in the region.

CONCLUSION

In conclusion, this study provides valuable insights into Barriers to Healthcare Access for Parents of Children with Autism Spectrum Disorder in South Punjab, Pakistan. Through an exploration of awareness channels, availability of facilities, and barriers to healthcare access, the study highlights the multifaceted nature of the obstacles encountered by families navigating the healthcare system for their children with ASD. While significant strides have been made in improving awareness and service availability. Notable gaps remain, particularly in specialized services and addressing socio-cultural barriers. The findings underscore the importance of targeted interventions to enhance awareness. The findings underscore improving service provision and addressing barriers to healthcare access for individuals with ASD and their families in South Punjab, Pakistan. By addressing these challenges, healthcare systems can better support the needs of this vulnerable population and promote their overall well-being and quality of life.

Competing Interests

The authors has declared that no competing interests exist.

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