

Breaking the Myths: Understanding the Challenges of Caregivers of Autism in Pakistan – A Systematic ReviewFatima Salman^{1*}, Tehreem Arshad², Aisha Sitwat³**Abstract**

The aim of this systematic review is to critically evaluate selected research articles, examining the nature of the problem, study focus, theoretical and conceptual frameworks, sample size, sampling methods, instruments used, key findings, and limitations. It also explores implications for future research. As part of a PhD project, the researcher reviewed local studies from 2011 to 2024 to identify the main challenges and influencing factors faced by parents of children with autism. This review employed the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) model. Google Scholar, Research Gate, and PubMed were used to find relevant articles. Of 46 articles, 20 met the inclusion criteria. These studies were conducted in major cities of Pakistan, including Karachi, Islamabad, Rawalpindi, Lahore, Peshawar, and Multan. The findings revealed a significant lack of awareness and prevalent cultural myths about autism among stakeholders (e.g., healthcare professionals, general practitioners, psychologists, teachers) in Pakistan, contributing to delays in diagnosis, misdiagnosis, and multiple diagnoses. The study highlighted the need to dispel these myths, as they magnified the challenges faced by parents. It also emphasized the necessity of culturally sensitive interventions and awareness programs. This review primarily focuses on urban populations, with little information on rural populations. Furthermore, most studies collected data from mothers, with few addressing the challenges faced by fathers. Future research should include rural populations, address fathers' concerns, and collect larger sample data.

Keywords: Autism Spectrum Disorder, Awareness, Parents of Children with ASD, Knowledge, Practice, Pakistan, Social Stigma, Systematic Review

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Introduction

Autism Spectrum Disorder (ASD) is a universal neurodevelopmental disorder that affects individuals throughout their lives. Research indicates that early diagnosis

leads to improved developmental and family outcomes (Farooq & Ahmad, 2020). However, despite the significance of early detection, many children in Pakistan are diagnosed after the critical early years or are misdiagnosed with other developmental conditions, such as intellectual disabilities, which can hinder their prognosis and delay appropriate interventions (Akhai et al., 2022). The delay in diagnosis of children with autism spectrum disorder in a third world country like Pakistan is very common, it is due lack of trained mental health professionals, limited special education schools, lack of awareness, usually parents struggle to find the right diagnosis for their children until the age of 7 (Imran & Azeem, 2014; Qureshi et al., 2022). The related studies suggested that in Pakistan teachers, healthcare professionals, general physicians as well as parents lack

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required awareness therefore, thus leading to delays in diagnosis. For this reason, parents go through years and consult with various practitioners only to get to the right diagnosis, and while they are being diagnosed, they often receive the wrong or multiple diagnosis (Khalid et al., 2020).

Misconceptions such as viewing an autistic child as mentally disabled, believing they cannot form relationships, or assuming a lack of awareness not only contribute to stigmatization but also lead to the perception that parents, particularly mothers who often stay at home to care for their children in Pakistan, are incapable of managing their child properly. This stigma results in feelings of social rejection, isolation, stress, anxiety, and depression, adding to the psychological and emotional burdens faced by these mothers (Almansour et al., 2013; Farooq & Ahmed, 2020; Iqbal et al., 2023; Kausar et al., 2019; Rizvi & Batool, 2024). A study including 388 mothers revealed a significant difference in educational level regarding ASD knowledge scores. A significant difference was also found between economic status and ASD knowledge scores. Individuals who had heard of ASD scored significantly higher in ASD knowledge than those who had not heard of it. Similarly, those with acquaintances who have ASD had significantly higher ASD knowledge scores than those without such acquaintances. There was a significant negative correlation between the total ASD score, age, and first gestational age (Parlak et al., 2023).

Stigmatization occurs due to the cultural myths associated with the causes and nature of autism because it is believed that autism stems from bad parenting, parental neglect, mental illnesses or witchcraft works (Asghar et al., 2023; Khalid et al., 2020). These perceptions often culminate in the social exclusion of these families as they are rejected by their societies. Mostly, mothers are reported to be blamed most of the time for their child's condition (Okoye et al., 2023). The psychological impact of

stigma is very devastating, for these parents leading them to develop poor mental health such as anxiety, depression and consequently social isolation. Moreover, the lack of understanding about autism among the stakeholders (e.g., health care professionals, general practitioners, psychologists, teachers, etc.) also results in providing inaccurate information and ineffective treatment options (Ahmed et al., 2024; Furrukh & Anjum, 2020). The lack of knowledge among allied medical personnel within the healthcare system, combined with cultural misconceptions, often leads to delayed diagnoses or misdiagnosis, consequently preventing these children from receiving early interventions that are highly crucial for their development (Imran et al., 2011; Okoye et al., 2023). Early interventions are considered crucial as they significantly contribute to the child's progress toward greater independence and integration into society later on (Kausar et al., 2019; Parlak et al., 2023; Rahbar et al., 2011). However, the persistence of these myths significantly interferes with the ability of families to find appropriate support.

The rationale behind this systematic review is to highlight the challenges that these parents go through due to the lack of awareness about autism and the existing cultural myths and misconceptions about autism in Pakistan by analyzing some of the indigenous work and by identifying the common themes and to look into the demerits of such existing cultural myths. Thus, through a thorough review of local studies, this article highlights how these myths influence diagnosis and intervention (Furrukh & Anjum, 2020). Some researchers have argued that the prevalence of ASD may be higher than previously estimated. According to the Autism Resource Centre (Akhter et al., 2020) in Pakistan, the prevalence of ASD as of 2019, is estimated to be approximately 1 in 100 children, and remains on the same page as global estimations on the prevalence of

autism, which typically range from 1 to 2 percent.

Rationale

Myths and misconceptions about autism significantly affect diagnosis, treatment, and the psychological well-being of parents. These misconceptions contribute to delayed or incorrect diagnoses, social isolation, and inadequate support, forcing parents to struggle in finding accurate information and appropriate help. This highlights the need for exploring local experiences of parents to identify the challenges caused by lack of awareness and cultural myths, which can help improve early diagnosis, interventions, and support systems for families.

Despite the growing visibility of Autism Spectrum Disorder (ASD), significant gaps in understanding and misconceptions persist, especially in regions like Pakistan, where cultural beliefs and lack of access to proper education about ASD further complicate the issue. Parents of children with autism face numerous difficulties in obtaining a confirmed diagnosis and encounter many hurdles in accessing accurate information or resources due to widespread lack of awareness. The overall knowledge base among stakeholders remains limited and inconsistent. This systematic review aims to fill these gaps by examining the myths and misconceptions surrounding autism in Pakistan, a topic not comprehensively addressed in previous reviews. Although several studies have explored ASD in different cultural contexts, the unique combination of social stigma, religious beliefs, and limited healthcare resources in Pakistan requires focused analysis. Understanding these misconceptions is crucial for shaping effective interventions and policies. By critically assessing the existing literature, this review will provide a more nuanced understanding of the challenges faced by parents and caregivers of children with autism, offering a foundation for future research and interventions that are culturally and contextually appropriate.

Objectives

1. To examine the existing local literature on autism related myths and misconceptions in Pakistan.
2. To systematically review indigenous literature on the awareness and knowledge gaps among relevant stakeholders (e.g., health care professionals, general practitioners, psychologists, teachers)
3. To review how these myths impact early diagnosis, intervention for the child with autism and consequently the well-being of their parents.

Method

A systematic review was conducted by following the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) to explore the challenges and difficulties parents face due to the lack of awareness about autism and the cultural myths that surrounds it in Pakistan. The review aimed to collate, evaluate and synthesize research findings related to the understanding and misconceptions of ASD among health professionals, parents and the implications for parents in Pakistan.

Search Strategy

A comprehensive literature search was conducted to identify relevant indigenous studies published between 2011 and 2024. Databases that were searched included ResearchGate., PubMed, Google Scholar, Medknow and local Pakistani medical and psychological journals. The search terms used included “autism spectrum disorder,” “ASD,” “awareness about autism”, “knowledge about autism”, “myths,” “misconceptions,” “Pakistan,” “parents of children with autism”, “experiences of parents”, “stigma”, “health professionals,” “general physician,” and “cultural beliefs.”

Screening and Selection of Articles

The indigenous studies were finalized for review article after being scrutinized on the basis of the inclusion and exclusion criteria of the study. A formal risk of bias assessment was not conducted for the included studies. This decision was made due to the primary focus of the review on

identifying common themes and challenges faced by parents, rather than evaluating study quality. Out of the 46 articles identified, 26 articles were excluded based on their relevance and focus. While the remaining 20 articles were evaluated and analyzed on the basis of the criteria mentioned below.

Inclusion Criteria

1. Articles that were published in English language.
2. Original research articles.
3. Research conducted from 2011-2024
4. Studies investigating the level of awareness and knowledge about autism spectrum disorder
5. Studies that focus on parents experiencing with having a child with autism.
6. Inclusion of both qualitative and quantitative studies.

Exclusion Criteria

1. Dissertations and theses from HEC portal.
2. Unpublished work was excluded
3. Studies without full-text availability.
4. Research focusing on systematic reviews, opinion pieces, editorials, letter to editor or news articles were also excluded to ensure the reliability and scientific rigor of the findings.
5. Studies unrelated to autism spectrum disorder (ASD) were excluded.
6. Research unrelated to autism awareness or myths and misconceptions (e.g., genetic studies)

Selection Process

The articles related to the experiences of parents of having children with autism and the prevalent myths and misconceptions and its lack of awareness in relevant stakeholders (e.g., health care professionals, general practitioners, psychologists, teachers) in Pakistan were gathered and compiled using a structured search strategy. After data collection, the researcher reviewed the articles and selected them based on the predefined criteria. In the next phase, fully available articles were screened and scrutinized following these criteria.

After a rigorous evaluation, a total sum of $n = 20$ articles were retained for inclusion in the systematic review. While the articles that were excluded were because they did not fulfill the inclusion criteria and did not focus specifically on the experiences of parents of having children with autism or did not address autism-related misconceptions and their effects on diagnosis or treatment approaches were also excluded. Moreover, systematic review articles and dissertations were also excluded.

The final selection included articles published in the English language from 2011 to 2024 included articles from different big cities of Pakistan such as Lahore, Karachi, Islamabad, Rawalpindi, Peshawar etc. An overview of the geographical distribution is given in Figure 1. These articles highlighted the lack of awareness and correct information regarding autism in healthcare professionals, general practitioners, even psychologists and parents as participants.

These selected studies were then analyzed and synthesized to address the research question. After final selection, these articles were thoroughly reviewed, and relevant information was synthesized to derive key themes and findings. The screening and selection process is explained in the flow diagram given in Figure 2. **Main Characteristics of the Studies Included**

All the studies that were included in the review were published online during the period of 2011-2024. There were 12 studies that were selected for inclusion in the systematic review that had used cross-sectional study design, while 6 articles used qualitative research design and the remaining 2 studies used mixed-methods design. The method of data collection mostly was survey forms and in-depth interviews. A wide spectrum of participants from the included research were included, including general practitioners, medical professionals, house officers, pediatricians, psychologists, speech therapists, allied and non-allied specialists, parents and teachers.

In the present systematic review study, out of 20 articles, 17 articles are from the year 2014 onwards while only 3 articles are from 2011-2013. A summary of studies included in the present review article is given in Table 1.

Findings

The systematic review revealed several key challenges faced by parents having children with autism in Pakistan. These challenges primarily stem from widespread myths and misconceptions about autism, delays in diagnosis due to a lack of awareness, and a cultural environment that often stigmatizes

both the disorder and those affected by it. These issues result in significant mental health consequences for parents, particularly mothers, who bear much of the societal blame. Table 1 summarizes the 20 included studies. Most of the studies utilized cross-sectional study design, while few were qualitative researches and fewer included studies employed mixed design. Below themes from studies are described. While Figure 3 illustrate the themes that emerged from the review of studies conducted between 2011 and 2024.

Figure 1

Geographical Distribution of Studies on Parental Experiences and Awareness of Autism in Pakistan

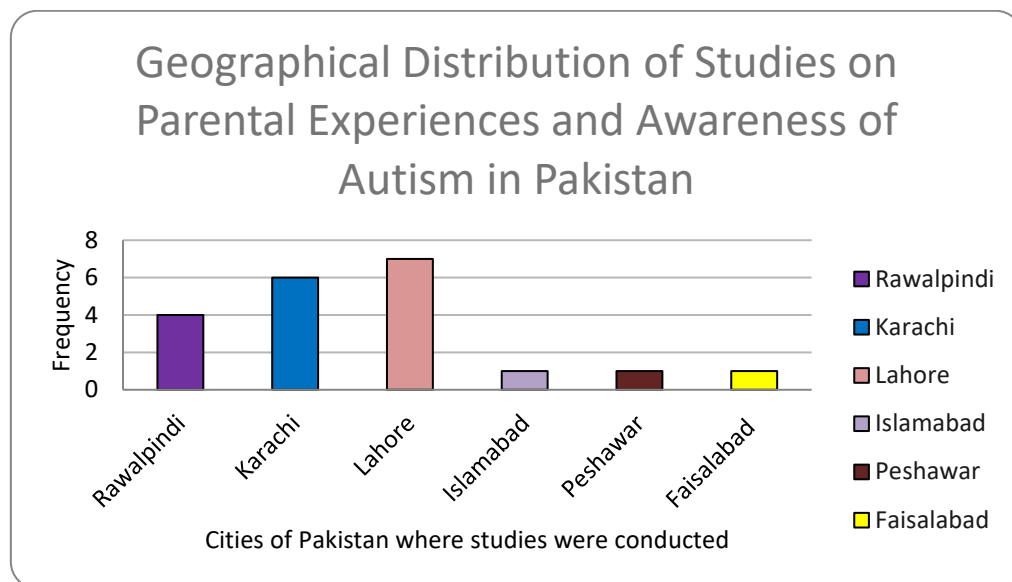


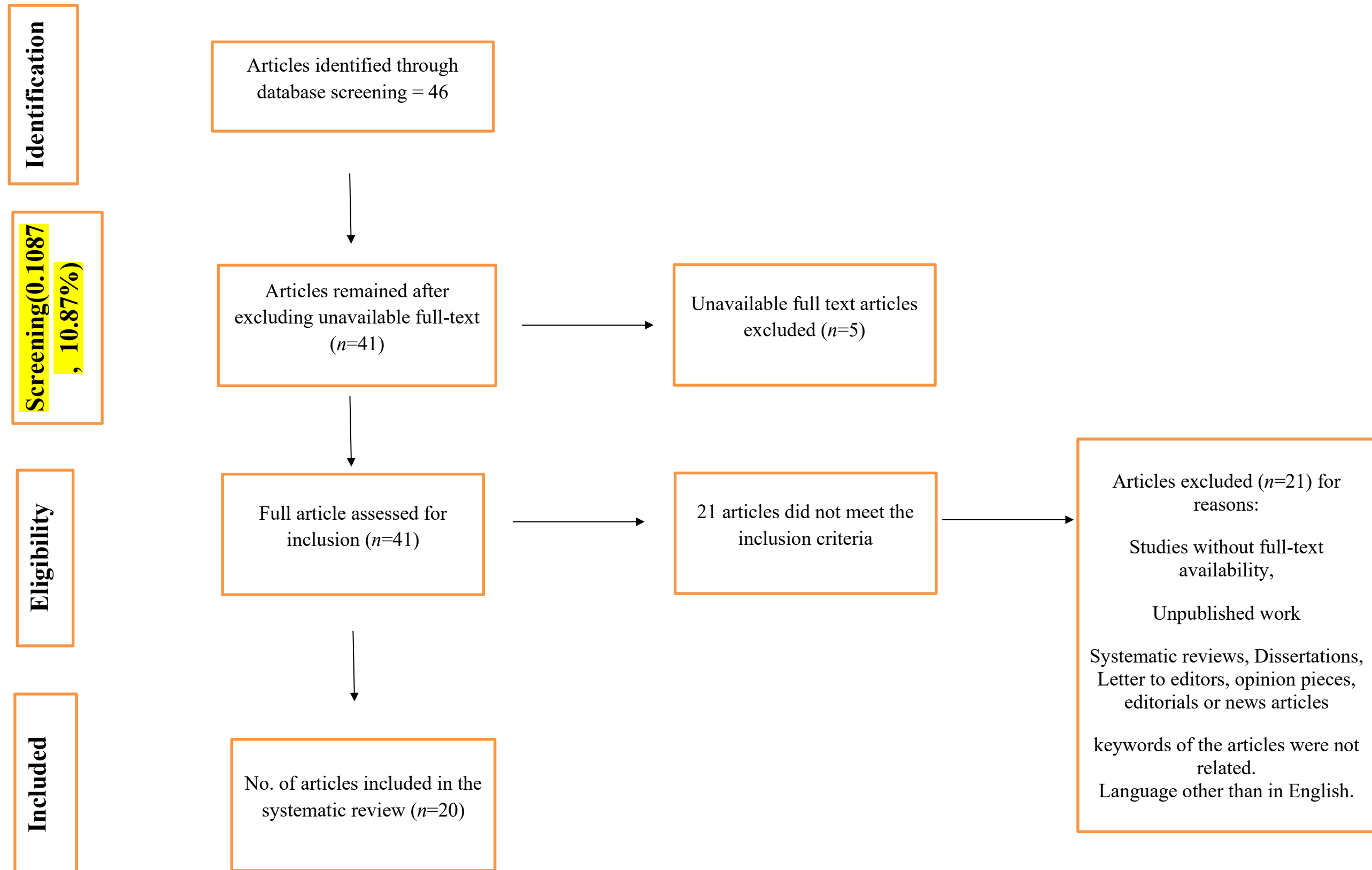
Figure 2. PRISMA Flow Diagram for Paper Selection Process Used in the Current Review

Table 1
Characteristics of the Studies included in Systematic Review (N=20)

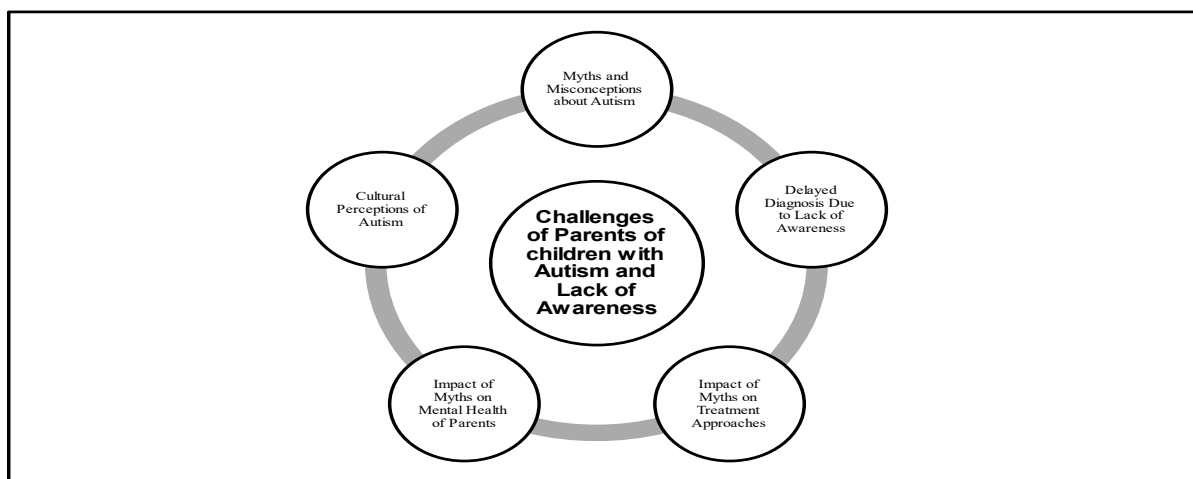
| S# | 1st Author | Year | Country | Sample | Type of Study | Data Collection Method | Findings |
|----|--------------------------|------|-----------------------|---|-------------------------------------|---|--|
| 1 | (Ayub et al., 2017) | 2017 | Pakistan (Karachi) | 73 primary school teachers | Cross-sectional survey | Self-administered questionnaire | The study found that teachers had gaps in awareness and knowledge about autism. Approximately 71.2% of teachers had some knowledge of autism, with only 44.2% understanding it as a neurological/mental disorder. Significant misconceptions were identified, such as believing autistic children do not form social attachments, even with parents. |
| 2 | (Akhter et al., 2020) | 2020 | Pakistan (Rawalpindi) | 300 participants (150 Medical and 150 Allied-Medical practitioners) | Cross-sectional survey | Knowledge about Childhood Autism among Health Workers (KCAHW) Questionnaire | Allied-Medical practitioners scored significantly higher on knowledge about autism compared to medical practitioners. The total mean KCAHW score was 15.20 for Allied-Medical practitioners and 8.84 for medical practitioners. There were significant gaps in knowledge among medical practitioners, highlighting a need for improved training and awareness. |
| 3 | (Arif et al., 2013) | 2013 | Pakistan (Karachi) | 170 teachers (85 from private schools and 85 from public schools) | Cross-sectional survey | Self-administered questionnaires | 55% of the teachers only knew about autism, mostly from media. But only 9% had some formal training and knew about autism. Finally, 62% believed autism to be treatable and 57% indicated that training is necessary for teaching children with autism. There is a need for formal training to help in early diagnosis and support. |
| 4 | (Anwar et al., 2018) | 2018 | Pakistan (Karachi) | 339 parents | Cross-sectional survey | Validated questionnaire | 75% of participants had heard of autism, but knowledge scores were low. 95.6% were willing to seek treatment for their children if diagnosed with autism. The study indicated a lack of awareness and knowledge about autism, especially concerning signs, symptoms, and treatment centers in Karachi. |
| 5 | (Haider & Shehzad, 2015) | 2015 | Pakistan (Lahore) | 300 participants (100 parents, 100 professionals, 100 doctors) | Cross-sectional study | Questionnaire-based survey | Significant knowledge gaps about autism management in all groups, especially among doctors. |
| 6 | (Aftab et al., 2023) | 2023 | Pakistan (Karachi) | 76 caregivers | Cross-sectional study | Caregiver Strain Questionnaire (CGSQ) and demographic questionnaire | 47.4% of caregivers reported moderate strain, and 11.8% reported severe strain. Female caregivers were more likely to report subjective strain than male caregivers. Highlights the need for better support systems to help caregivers manage their responsibilities. |
| 7 | (Noor et al., 2021) | 2021 | Pakistan (Lahore) | 105 medical professionals | Correlational study | Self-administered questionnaire | Medical students had significant knowledge of autism, while house officers and medical officers showed a lack of awareness. Most professionals were aware of genetic and environmental risk factors but were unclear about the early signs of autism. |
| 8 | (Khalil et al., 2024) | 2024 | Pakistan (Lahore) | 15 fathers | Qualitative, phenomenological study | Semi-structured interviews | The fathers had little awareness of autism when their children were first diagnosed. Most of them struggled with acceptance and had limited initial knowledge about autism spectrum disorder (ASD). |
| 9 | (Rahbar et al., 2011) | 2011 | Pakistan (Karachi) | 348 General practitioners (GPs) | Cross-sectional survey | Questionnaire-based survey | General practitioners displayed inadequate knowledge about autism. Significant gaps in understanding autism symptoms, causes and treatment. This lack of awareness negatively impacted early diagnosis and intervention efforts. |

| | | | | | | | |
|----|-------------------------|------|---------------------------------|---|------------------------------------|---|---|
| 10 | (Imran et al., 2011) | 2011 | Pakistan (Lahore) | 247 healthcare professionals (154 physicians and 93 non-physicians) | Cross-sectional survey | Questionnaire-based survey | The study found that overall knowledge of autism was low among Pakistani healthcare professionals, with many misconceptions regarding autism's developmental, cognitive, and emotional features. Physicians were less familiar with DSM-IV criteria compared to non-physicians like psychologists and speech therapists. There were significant misunderstandings among professionals, such as the incorrect belief that autism is primarily an emotional disorder or that it can be outgrown with proper treatment. |
| 11 | (Farooq & Ahmed, 2020) | 2020 | Pakistan (Islamabad) | 8 mothers of children diagnosed with ASD | Phenomenological qualitative study | In-depth interviews | The study findings highlight several barriers to obtaining an ASD diagnosis, including parents' lack of knowledge and misconceptions, healthcare system issues such as unclear care pathways, dissatisfaction with medical professionals, and delays due to structural barriers. Additionally, family factors like stigma, denial, and financial constraints were identified as significant challenges. |
| 12 | (Qureshi et al., 2022) | 2022 | Pakistan (Lahore) | 122 parents of children with ASD (97 mothers, 21 fathers, 4 grandparents) | Descriptive qualitative study | Questionnaire, interviews, and focus group | A lack of knowledge among healthcare professionals, leading to confusion and incorrect diagnoses, was cited as a major issue. Parents reported difficulties in accessing healthcare and multiple consultations with various specialists before a diagnosis was confirmed. Many children were misdiagnosed as having mental retardation or hyperactivity. |
| 13 | (Mushtaq et al., 2024) | 2024 | Pakistan (Rawalpindi) | 10 mothers | Phenomenological qualitative study | Semi-structured interviews | Mothers reported significant emotional and physical stress, lack of awareness about autism, delays in diagnosis, and financial strain. |
| 14 | (Rizvi & Batool., 2024) | 2024 | Pakistan (Lahore) | 28 parents (15 mothers, 13 fathers) | Qualitative study | Semi-structured interviews | High levels of stress were associated with lack of guidance, social stigma, financial burdens, and marital conflicts, with parents reporting significant strain on their relationships due to parenting responsibilities. |
| 15 | (Qadir et al., 2023) | 2023 | Pakistan (Peshawar) | 262 healthcare professionals (doctors, dentists, psychologists, nurses, occupational and physical therapists, speech therapist) | Cross-sectional study | Knowledge of Childhood Autism among Healthcare Workers (KCAHW) questionnaire | The findings highlight significant knowledge gaps, especially in language development and behaviors related to autism. Speech therapists had the highest knowledge scores (mean 13.16), while psychologists scored the lowest (mean 7.20). |
| 16 | (Faiz et al., 2021) | 2021 | Pakistan (Lahore) | 15 school teachers and 15 parents of children with ASD | Qualitative study | Semi-structured interviews with open-ended questions | The study found that parents lacked knowledge about autism and did not regularly attend their child's Individualized Education Plan (IEP) meetings. Teachers reported several challenges, including lack of resources, inadequate training, and difficulties in curriculum adaptation to meet the educational needs of students with ASD |
| 17 | (Minhas et al, 2015) | 2015 | Pakistan (Rawalpindi) and India | Pakistani parents (N = 15) Rawalpindi, Narrative review of existing studies from India from 2003-2013 (N=5 studies) | Qualitative study | In-depth interviews of Pakistani parents Narrative review of existing studies from India | The study highlights the social stigma faced by families, with many turning to spiritual and traditional healers due to a lack of access to professional healthcare services. Community stigma further isolates families, as children with autism are often labeled derogatorily. Misinformation in educational settings adds to the difficulties parents face, with autism being misunderstood as a form of mental retardation. The findings revealed high stress levels indicating that the sole responsibility for caring for the child is often with mothers. Lack of understanding of the condition on the part of |

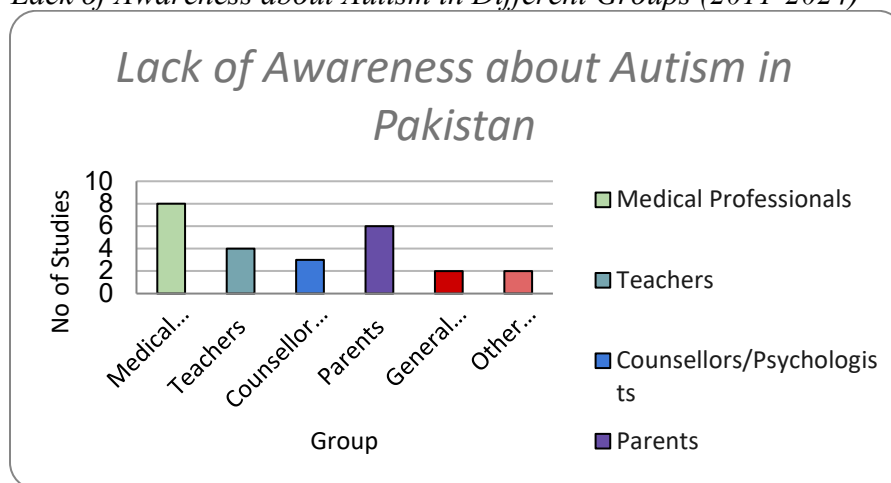
| | | | | | | |
|----|------------------------|------|-----------------------|---|--|--|
| | | | | | | family members and health-care providers causes delay in identification and treatment. Currently, children with autism and their families experience a great deal of stigma and discrimination because of it. |
| | | | | Descriptive cross-sectional study | Screening of patients using the Adult Autism Spectrum Quotient (AQ) and ADHD Self-Report Scale-V1.1 (ASRS-V1.1), followed by clinical interviews conducted by consultant psychiatrists to confirm diagnoses. | The study found that 8.6% of the screened patients were diagnosed with ASD and 11% with ADHD after clinical interviews. The study highlighted that male gender, low education, illicit substance use, and poor response to treatment were significantly associated with the presence of ASD and ADHD among adult psychiatric patients. The authors concluded that there is a high prevalence of undiagnosed ASD and ADHD in the adult psychiatric population of Pakistan, emphasizing the need for better screening and early diagnosis. |
| 18 | (Khan et al., 2019) | 2019 | Pakistan (Rawalpindi) | 1,889 adult psychiatric patients | | |
| | | | | Comparative cross-sectional study | Self-report measures, including Burden Assessment Scale and Depression Anxiety Stress Scale (DASS-21) | The results showed no significant differences in levels of caregiver burden and psychological distress between the two groups. Both groups experienced high levels of emotional, physical, and financial strain, exacerbated by social and cultural factors. |
| 19 | (Hayat & Yousaf, 2023) | 2023 | Pakistan (Karachi) | N=100 (50 mothers of children with thalassemia, 50 mothers of children with autism) | | |
| | | | | Cross-sectional study | Self-Reported Questionnaire (SRQ-20), Autism Parenting Stress Index (APSI), WHOQOL-BREF | The findings revealed that parents experienced reduced psychological well-being and strained social relationships. Mothers reported higher levels of mental distress than fathers, with significantly poorer psychological health. |
| 20 | (Nadeem et al., 2024) | 2024 | Pakistan (Faisalabad) | 103 parents of children with ASD | | |

Figure 3

PRISMA checklist was used for extracting themes from the review of studies conducted between 2011 and 2024

**Figure 4**

Frequency of Lack of Awareness about Autism in Different Groups (2011-2024)



Note: Data compiled from studies conducted between 2011 and 2024 on autism awareness in Pakistan.

Figure 4 illustrates the level of awareness among various groups regarding autism. Medical professionals were most frequently identified as lacking knowledge about autism ($n=8$ studies, 40%), followed by parents who displayed significant gaps in understanding ($n=6$ studies, 30%). Teachers were also shown to have limited awareness ($n=4$ studies, 20%), while counselors and

psychologists were less frequently mentioned ($n=3$ studies, 15%). The general public and other stakeholders, such as allied medical and non-medical allied, were least aware, with only a small number of studies highlighting these groups ($n=2$ studies each, 10%). These findings emphasize the need for targeted educational efforts across these key groups to address the widespread lack of awareness.

Theme 1: Myths and Misconceptions about Autism

Autism Spectrum Disorder (ASD) is widespread in Pakistan, but significant delays in diagnosis and treatment are often caused by prevalent myths and misconceptions. Many people believe autism is caused by poor parenting, evil spirits, or vaccines, which leads to a lack of proper understanding and delays in seeking appropriate care. A study involving seven semi-structured interviews with mothers raising children with autism identified themes such as denial of red flags, emotional paradox, cognitive processing, and family dynamics. These findings highlighted the mothers' limited awareness of autism's signs and the importance of health professionals working closely with families to reduce confusion and stress (Akhai et al., 2020).

A different study conducted at the Autism Resource Centre Islamabad explored the barriers to early ASD diagnosis through in-depth interviews with eight mothers. The three main barriers identified were parental misconceptions, issues within the healthcare system, and family-related factors, such as stigma and financial challenges. Recommendations included educational outreach, efforts to reduce the stigma around ASD, and improvements in diagnostic processes to speed up identification (Farooq & Ahmed, 2020). Many indigenous beliefs mistakenly attribute autism to neglect or emotional problems, which only adds to the stigma (Furrukh & Anjum, 2020; Kausar et al., 2019).

A survey of 73 teachers (mean age 34 years, 66% female) also highlighted significant gaps in awareness. Although 52 teachers (71.2%) acknowledged some knowledge of autism, only 23 (44.2%) understood it as a neurological/mental disorder. A majority (73.1%) believed special education was an effective intervention. The only factor significantly affecting teachers' knowledge

was attending behavioral classes (Ayub et al., 2017).

Additionally, an indigenous Parental Perceived Stress Scale was developed and validated through interviews with 502 parents of children with ASD. The scale proved reliable and valid, with important clinical implications for counseling and support services (Kausar et al., 2019). These myths and misconceptions surrounding autism continue to hinder early diagnosis and intervention, contributing to social isolation and stigma.

Theme 2: Delayed Diagnosis Due to Lack of Awareness

From the articles embodied in this review, a number of challenges were identified and one of the major challenges that these parents experience is getting a delayed diagnosis, mis-diagnosis and/or multiple diagnosis due to repeated and unsatisfactory consultations with different professionals. These sufferings are mostly due to lack of awareness among the stakeholders which, in turn, becomes a major impediment to early identification and intervention of child with autism in Pakistan (Rahbar et al., 2011). In addition, some of the studies in the present review also revealed that healthcare professionals in Pakistan were found to have a poor understanding of the disorder and would delay referrals based on mistaken beliefs such as linking ASD to delayed speech, while psychiatrists tend to focus on behavioral features, aggravating the delay in diagnosing the disorder for children (Akhter et al., 2020; Rahbar et al., 2010). Findings from the systematic review also suggest that the stigma surrounding mental health in Pakistan also contributes to significant delays. Many people perceive autism as either a mental illness or a spiritual problem, which results in families avoiding seeking professional help out of fear of social judgment (Mushtaq et al., 2024; Rizvi & Batool, 2024).

Theme 3: Impact of Myths on Treatment Approaches

Some of the studies revealed that the knowledge about autism among such parents and healthcare providers in Pakistan is limited and impacted by the cultural myths – which is yet another barrier for these parents. Parents may attribute their child's condition to spiritual causes, leading them to seek help from traditional healers or spiritual leaders, instead of seeking evidence-based treatments (Rizvi & Batool, 2024). Findings of the studies included in the review also suggested that mothers are usually under more pressure to explore these alternative treatments, which in turn heightens their emotional and psychological burden. Misunderstandings among healthcare professionals, such as the belief that autism is primarily an emotional disorder or can be treated through dietary modifications, further complicate the situation (Arif, 2019). These myths also contribute to a situation where some parents will opt for medication instead of behavior therapies, hoping for a cure through medication. Such focus on the sham treatments merely prolongs the delay in implementing necessary interventions that are vital for the child's progress (Rizvi & Batool, 2024; Qureshi et al., 2022). Families may only seek proper competent mental health professionals when the child's condition does not respond to treatments, often after significant time has been lost.

Theme 4: Impact of Myths on Mental Health of Parents

Research on the experiences of parents raising children with autism in Pakistan reveals significant challenges to their psychological well-being, particularly due to misconceptions and cultural myths about autism. In many cases, autism is wrongly attributed to supernatural causes or parental failure. A study by Ahmed et al. (2024) and Imran et al. (2011) involving 247 participants (154 physicians and 93 non-physicians)

found that non-physicians were more likely to correctly identify the features of autism than medical professionals. Despite this, significant misunderstandings about autism persisted in both groups, highlighting a widespread lack of awareness and understanding.

A recent study by Nadeem et al. (2024) further illuminates the mental health struggles of parents raising children with autism, finding that they experience high levels of stress, especially related to core autism behaviors and associated comorbidities. The SRQ-20 scores indicated moderate mental distress among many parents, with signs of probable mental disorders. In particular, mothers reported poorer psychological health and greater mental distress than fathers. Additionally, parents of younger children with autism spectrum disorder (ASD) demonstrated better social relationships and environmental health, suggesting that age and developmental stage may influence the level of stress and support available to parents.

The cultural stigma surrounding autism in Pakistan contributes significantly to the mental health challenges faced by these parents, leading to higher rates of anxiety, depression, and social isolation. The lack of knowledge among healthcare professionals and society at large exacerbates this issue, as many parents find it difficult to access proper diagnoses and services like Applied Behavior Analysis (ABA) therapy. Farooq and Ahmed (2020) and Ashraf et al. (2022) note that, among primary school teachers, 53.3% reported noticing learning difficulties in children with ASD, highlighting a lack of formal recognition of the condition. Additionally, 53% of participants in a survey on autism diagnosis and services were female, with a median age of 33, suggesting that challenges are particularly pronounced for mothers.

The limited availability of resources and professional guidance leads to a sense of isolation for parents, worsening their psychological health. Akhai et al. (2022), Kausar (2019), and Nadeem et al. (2018) underscore how the combination of misconceptions about autism, coupled with a dearth of mental health literacy, makes parents more vulnerable to poor mental health outcomes. The mental health challenges faced by parents of children with autism are thus not only a result of the child's condition but are also heavily influenced by societal misconceptions, stigma, and inadequate professional support, which limit parents' ability to seek help or understand their child's needs

Theme 5: Educational Challenges Due to Misunderstanding of ASD

Some other studies included in the review also emphasized that the misunderstandings about autism also affects the educational system which also contribute significantly to the challenges these parents undergo. Due to a misconception that children with ASD are defiant or undisciplined, teachers may mistake ASD behaviors as defiance, misbehavior or disobedience (Rizvi & Batool, 2024). Arif et al. (2013) also stated in his study with primary school teachers that teachers displayed poor knowledge about the facts of autism. Moreover, many teachers in Pakistan lack awareness and training on how to accommodate autistic children in the classroom (Ahmed et al., 2024). This leads to inappropriate teaching strategies and many autistic children are excluded from mainstream education (Faiz et al., 2021).

Theme 6: Cultural Perceptions of Autism Spectrum Disorder

It has been observed in multiple studies in this review article that cultural context plays a vital role in understanding these deficiencies in knowledge of autism, which forms the foundation of incorrect information and lack of awareness and guidance available

about autism. In many cases, autism is viewed as a form of mental illnesses or the result of supernatural forces, such as evil spirits or divine punishment (Furrukh & Anjum, 2020) rather than recognized as a neurological condition (Arif, 2019; Mushtaq et al., 2024). It is also reported in the included studies that mothers are considered the reason and are blamed for their child's condition, resulting in feelings of shame and guilt (Furrukh & Anjum, 2020; Kausar et al., 2019; Rauf et al., 2016; Rizvi & Batool, 2024). Moreover, studies have also shown as to how many families in our culture turn to alternative healers or local practitioners, such as amil babas, homeopaths or general physicians, before consulting trained mental health professionals. This delay in seeking professional medical help is often driven by cultural beliefs, as well as financial constraints that make psychiatric care inaccessible for many families (Akhai et al., 2022; Aziz & Khan, 2021).

Discussion

The purpose of this systematic review was to find out the difficulties and challenges that parents of children with autism have to suffer through in order to get to a correct diagnosis and start early intervention. The research questions of the review article were addressed which were based on the review of 20 full-text articles, which revealed the following major findings: (a) cultural misconceptions such as blaming autism on poor parenting, mental illness or spiritual causes delay diagnosis and appropriate intervention; (b) societal pressure and lack of accurate knowledge often lead families to seek alternative, unproven therapies rather than evidence-based treatments; (c) mothers of children with ASD face significant social stigma, resulting in emotional distress, isolation, and poor mental health outcomes; and (d) a lack of training among healthcare professionals and teachers exacerbates these challenges by contributing to delayed

diagnosis, misdiagnosis, and ineffective interventions (Arif, 2019; Farooq & Ahmad, 2020; Kausar et al., 2019).

The findings from this systematic review reveal pervasive difficulties faced by parents of having children with autism spectrum disorder (ASD) in Pakistan. The challenges largely originate from cultural misconceptions, a lack of awareness among both parents and healthcare professionals and societal stigma. The myths surrounding autism, such as it being caused by poor parenting or supernatural forces, deeply influence how families approach diagnosis and treatment. Many parents, driven by these myths, turn to alternative remedies, delaying essential medical interventions and consequently, the child's development. The misconception that autism can be cured through spiritual healers or traditional methods not only perpetuates misinformation but often result in misinformed prevention and treatment approaches, which can worsen the condition (Mushtaq et al., 2024). For instance, the belief that vaccines cause autism has contributed to vaccine hesitancy, which undermines public health efforts (Asghar et al., 2023; Nadeem et al., 2019).

The research findings indicate that parent may also fail to recognize early signs of ASD due to cultural misconceptions and poor knowledge, resulting in delayed diagnosis and treatment (Anwar et al., 2018; Furrukh & Anjum, 2020). The cultural fear of being stigmatized for having a child with autism results in furthering the delay, making it difficult for families to access early interventions that are critical for improving outcomes. The combination of lack of awareness, insufficient professional knowledge, and mental health stigma continues to hinder timely diagnosis and treatment of ASD in Pakistan (Aziz & Khan, 2021).

Research has shown that the impact of these cultural misconceptions is particularly

damaging for mothers, who are often the primary caregivers and are subjected to intense scrutiny from their families and communities. Mothers report feelings of guilt, inadequacy and failure as a result of the stigma surrounding ASD, which leads to increased levels of stress and poor mental health (Khalil et al., 2024; Rizvi & Batool, 2024). Moreover, it has been reported that the lack of awareness among healthcare professionals further isolates these mothers (Batool & Khurshid, 2015; Noor et al., 2021). Many medical professionals, including psychiatrists, misinterpret ASD as a mental illness or behavioral issue rather than recognizing it as a neurodevelopmental disorder. This reliance on alternative therapies delays crucial interventions, causing a loss of valuable time during which early treatments could significantly improve the child's development (Asghar et al., 2023). Additionally, the cultural context plays a significant role in shaping these knowledge gaps. Since Pakistani culture is heavily influenced by magical and superstitious beliefs, superstitious explanations are often more easily accepted than medical or physiological ones (Aziz & Khan, 2021). These deeply rooted cultural myths and superstitious beliefs contribute to the stigma surrounding autism and prevent families from seeking proper medical care. This cultural influence may often intensify the stigma and shapes how communities treat children with autism, often marginalizing both the child and the caregiver (Rizvi & Batool, 2024) and end up isolating both the child and the family (Akhai et al., 2022). The lack of formal knowledge about autism among these traditional healers and general practitioners contributes to the continuation of ineffective treatments, further delaying proper interventions (Rizvi & Batool, 2024). Because of how autism is understood and dealt by parents and health care professionals due to their lack of awareness, this may lead

to more sinister problem than the condition of child itself. Some of these fears and worries may be realistic; a lot of them, however, may not even have to do with the actual condition of the child, but with our own fear of the unknown due to the misconceptions about autism (Georganda, 1990). As research suggests that lack of awareness and stigma related to a child's health condition is linked with psychological health of the parents (Masulani-Mwale et al., 2018) so this ongoing cycle of stress, blame, and ineffective care significantly impacts both the children and their families, delaying the benefits of early intervention and worsening the long-term outcomes for children with autism.

Literature related to the educational opportunities for children with ASD are also reported to be affected by these misconceptions. These misperceptions have an impact on disciplinary strategies and decreases support for integrating ASD kids into regular mainstream schools. (Arif et al., 2013; Faiz et al., 2021; Thakur et al., 2020). Teachers, often unprepared to handle children with autism, may exclude them from mainstream classrooms, further isolating the child and placing the burden of advocacy on mothers, who may lack the knowledge and resources to navigate the educational system. For parents, advocating for their child in such a hostile and stigmatizing environment becomes an additional source of stress, as they are already marginalized due to the stigma associated with ASD (Khalil et al., 2024; Nadeem et al., 2022; Thakur et al., 2020). This exclusion from education not only limits the child's developmental opportunities but also exacerbates the emotional and psychological toll on mothers, who already face significant stress from societal stigma (Khalil et al., 2024; Rizvi & Batool, 2024).

These findings align with the findings of Huggett et al. (2018) study which highlighted

the need to develop or adapt and implement culture-based stigma reduction intervention for mental health problems that these parents suffer from. Moreover, to foster positive change, it is essential to enhance family and community support systems of these parents. Establishing parent support groups, providing access to the correct information and access to the available resources and creating peer networks can help alleviate the emotional burden on parents, particularly mothers, who are often isolated due to stigma (Bashir et al., 2024; Khalid et al., 2020; Rizvi & Batool, 2024). This would not only improve their mental health but also ensure better care for their children.

Strengths and Limitations

This systematic review is the first to comprehensively examine local research on the challenges faced by parents of children with autism in Pakistan, particularly due to cultural myths, misconceptions, and a lack of awareness about autism. It highlights several factors contributing to the stigma, delayed diagnosis, misdiagnosis, and missed early intervention opportunities. The review sheds light on the unique challenges faced by mothers, including poor mental health, social isolation, and emotional distress. Furthermore, it serves as the foundation for the researcher's PhD work, which will involve developing a stigma protection therapy tailored to address the identified challenges. However, the study has limitations. Most of the included studies were conducted in urban areas, which limits the generalizability of the findings to rural communities where access to healthcare and education may be even more constrained. Additionally, the underrepresentation of fathers in the included studies limits the comprehensiveness of the findings. A formal risk of bias assessment was not conducted, which could impact the reliability of the conclusions. Future research should address this gap by incorporating a bias evaluation,

focusing on fathers' mental health, and including larger and more diverse samples, especially from underrepresented areas, to enhance the understanding of autism across different contexts.

Implications

Bearing in mind the evidence provided in this review for the lack of awareness among the masses and stakeholders about autism and the resulting challenges and mental turmoil that the parents have to suffer from emphasized the need for addressing the cultural misconceptions surrounding ASD which in turn is crucial for reducing stigma and encouraging early diagnosis and intervention. The review also highlighted the importance of training healthcare providers, educators and the broader community to recognize the signs of autism and understand its complexities. Empowering these mothers with accurate information and access to resources would not only improve their mental health but also ensure better care for their children.

Conclusion

In conclusion, the systematic review reveals that the major challenges that parents have to face while getting a diagnosis; opting a correct line of treatment and early intervention are majorly due to widespread cultural myths and misconceptions about autism, coupled with a lack of awareness among the stakeholders in Pakistan. This consequently led to further difficulties for parents, particularly mothers, who experience stigma, social isolation and mental health difficulties. Given the cultural misconceptions surrounding ASD (e.g., beliefs about causes such as poor parenting or divine punishment), interventions and awareness programs must be culturally sensitive.

Contribution of Authors

Fatima Salman: Conceptualization, Investigation, Methodology, Data Curation, Formal Analysis, Writing – Original Draft

Tehreem Arshad: Methodology, Writing - Reviewing & Editing, Supervision

Aisha Sitwat: Conceptualization, Methodology, Writing - Reviewing & Editing, Supervision

Conflict of Interest

There is no conflict of interest declared by the authors.

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Data Availability Statement

The datasets of the current study are not available publicly due to ethical reasons but are available from the corresponding author [F.S.] upon the reasonable request.

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