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RECEIVING A DIAGNOSIS OF AUTISM SPECTRUM DISORDER (ASD) IN PAKISTAN

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Abstract

For children diagnosed with Autism Spectrum Disorder (ASD), early intervention can have a positive impact on their cognitive, social, and linguistic development outcomes if they are diagnosed at an early age (Fujiwara et al. 2011). Getting a diagnosis of ASD in a country with limited resources, such as Pakistan, can be difficult and time-consuming for families of children with the disorder. This is because of the lack of trained mental health professionals and a lack of general knowledge about autism spectrum disorders (Elsabbagh et al. 2012; Malhotra and Vikas, 2005; Sharan, 2008; Samadi, 2011; Tareen et al. 2008; WHO, 2005). This study is a subset of a wider investigation of the most effective means of knowledge transfer for Pakistani parents of children with ASD. Data was collected using a questionnaire, interviews, and a focus group. Results indicated that child's mean age at diagnosis was 4 years and 4 months (SD = 1.9), with a range of 6 months to 10 years. According to the study's findings, parents had numerous difficulties in obtaining an ASD diagnosis for their child. For up to seven years in some circumstances, parents were unable to receive a diagnosis that matched their child's symptoms.

Keywords: *Autism spectrum disorder, diagnosis, disability.*

Introduction

Autism Spectrum Disorder (ASD) involves deficits in socialization and communication to varied degrees (American Psychiatric Association (APA), 2020; Centers for Disease Control and Prevention (CDC), 2020; National Autistic Society (NAS), 2020; US National Institute of Mental Health, 2018; World Health Organization (WHO), 2019). Individuals with ASD are also known for their inflexible routines and their inability to imagine , their stereotypical pursuits and sensory sensitivities (Autism Society, 2021; CDC, 2020, Prior and Roberts, 2012). Estimated prevalence of autism is between 1 in 100 (NAS, UK, 2021) and 1 in 59 (Autism Speaks, US, 2021). Research has shown a lack of studies on risk factors of autism in many developing countries (Action for Autism (AFA), India, 2008; Autismi-jaAspergerliittory, Bangladesh, 2013). These countries include Bangladesh, India, Iran, the United Arab Emirates (UAE), and many others. According to some reports, Pakistan has "the world's highest rates of mental retardation," even though there are no official statistics on the incidence of ASD in the country (Tareen et al. 2008). Since the sooner a child is diagnosed with an ASD, early intervention has been shown to improve outcomes for those with neurodevelopmental disorders such as ASD (Fujiwara et al. 2011). According to research, beginning early intervention for children with ASD in the age range of two to three years can significantly reduce their symptoms (Eikeseth et al. 2009). It has a beneficial effect on a child's future functioning as well (Rickards et al. 2009). Ability of children to communicate, socialize and behave gets better when they receive early intervention services (Chaabane et al. 2009; Fazil, et al., 2021; Rocha et al. 2007). Research has also shown that if you don't intervene early and properly, you're setting yourself up for a lifetime of troubles (Wilkins and Matson, 2009). Adding to the strain on the family is the fact that these issues necessitate a significant investment of time and money (Wang et al. 2012). A timely ASD diagnosis is, thus, of paramount importance (Shields, 2001; Wachtel and Carter, 2008).

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Even in affluent countries, considerable time gaps between parental concern about their child's issues or developmental delay and the child's diagnosis have been observed (Fujiwara et al. 2011; Sivberg, 2003; Wiggins et al. 2006). More worrisome is the state of affairs in the emerging world. Research shows that in many poor nations, even among experts who are knowledgeable about ASD, there is a lack of thorough understanding of symptoms of the disorder (AFA, 2008). For children with mental health issues in Pakistan, there is a scarcity of published research or government records on the process of acquiring an ASD diagnosis (Imran et al. 2009; Tareen et al. 2008). More than 300 psychiatrists have been licenced in Pakistan since the country's independence, but only ten of them are trained in child psychiatry and there are no in-patient children's psychiatric clinics (Syed et al. 2006). "Child and Adolescent Psychiatrists are somewhat scarce outside of industrialised nations and there are very few who are fully trained in underdeveloped countries," according to WHO (2005, p.21).

Many developing countries tend to have limited assessment and diagnostic facilities for developmental disorders (Elsabbagh et al., 2012). Many children suspected of having ASD are not diagnosed. For the majority of young people in underdeveloped nations, mental health problems are either undiagnosed or badly treated (Sharan, 2008). According to Samadi, autism is still a relatively new concept in the Iranian scientific community (2011). Most children with ASD go undiagnosed or are misdiagnosed, according to Malhotra and Vikas (2005). This is because the general public and even healthcare professionals lack knowledge about ASD. This study intended to explore parents' experiences of receiving a diagnosis of ASD for their child in Pakistan.

Objective of the study

Followings were the objectives of the study.

1. To identify the challenges faced by parents of children with ASD in receiving a diagnosis for their child.
2. To identify the time lag between first parental concern and the diagnosis of their child with ASD

Research Methodology

This study is a subset of a wider investigation of the most effective means of knowledge transfer for Pakistani parents of children with ASD. In order to acquire a better grasp of the issue, descriptive research method was used. Tools used to collect data for this study included a questionnaire, an interview, and a focus group. All these three tools were designed for parents of children with ASD. Pakistani parents of children with ASD were the population of the study. Due to the lack of publicly accessible databases of parents of children with ASD in Pakistan, convenience sampling was used to find possible participants (Cohen, 2007; Fink, 1995; Gravetter and Forzano, 2011; Wood and Kerr, 2011). Potential participants were identified with the help of medical and educational experts (from schools of children with ASD or hospitals and therapy units). Majority of parents who participated in this survey were from Lahore, Karachi, Islamabad, and Multan. The questionnaire was completed by 122 parents of children with ASD. There were 97 mothers, 21 fathers, and four grandparents that participated in this survey. 34% participants were from Karachi, 48% from Lahore, while rest were from other major cities of Punjab. Mean age of their ASD child was 7 years and 4 months that ranged from 3 to 11 years with a standard deviation of 2.03. 70% of the ASD children were boys. 122 parents who completed the survey were invited to participate in interview or focus group. The study was able to interview 41 parents and one grandparent. There were 30 mothers, eleven fathers, and one grandfather among the responders. Six parents also volunteered to participate in a focus group. Of the six respondents, five were mothers and one was a father.

Analysis of data

In order to describe the data from the questionnaire, descriptive statistics were used. Thematic analysis was used to examine the information collected from the focus groups and interviews with parents in the study population. Verbatim transcriptions of the Urdu-language interviews were used for both individual and group interviews. Following that, two researchers were given access to the transcripts in order to check their apparent accuracy by comparing them to the audiotape recordings. It was then translated into English by two bilingual speakers from the corrected transcripts (whose first language was Urdu). A few people chose to answer questions in both Urdu and English, but the vast majority of respondents opted for Urdu. To identify discrepancies, the transcripts' translated and original versions were compared. The researchers and translators worked together to come up with a final document that everyone could agree on. Once this data was collected, it was subjected to a thematic analysis.

Results

Questionnaire data

Mean age of the child at the time of diagnosis was 52 months with a standard deviation of 23 months; and it ranged from six months to ten years old. Most parents (44 percent) first sought help for their kid's issues while their child was between the ages of 0 and 1 years old. Ninety-nine percent of the respondents stated that they had to see a doctor an excessive number of times before their child was diagnosed with ASD, which made it difficult to count or recall. Developmental delays were the primary factor in parents deciding to seek a diagnosis for their kid (93%). Another primary reasons they sought a diagnosis for their child was the observation by another person (26%). Sixty-six percent of parents said they were able to follow up with the doctor who initially diagnosed their kid to ask more questions. However, 85 percent of the respondents stated that parents had difficulty obtaining a diagnosis for their child with ASD.

Interview and focus group data

A total of seven themes emerged from the narratives of parents who had their children diagnosed.

i. Numerous consultations

A majority of the parents who answered this question in both individual interviews and focus group discussions claimed to have seen multiple specialists and visited several hospitals to address their child's challenges. Paediatricians, psychiatrists, and neurologists were among the experts consulted. If the child expert had recommended it, they may have consulted with other health care providers. As a result, parents said that if they learned of a reputable medical facility, whether public or private, they would immediately take their children there. In most cases (35), the kid's disability was not discovered for several years, despite the fact that the kid had numerous consultations with a variety of specialists.

ii. Multiple diagnosis

In one-on-one and focus group interviews, thirty eight parents revealed that different professionals had provided them with varying diagnoses or opinions regarding their children. The diagnosis supplied by one professional did not match the diagnostic given by another, according to nine interview participants and three focus group participants.

iii. Incorrect diagnosis

Twenty one respondents claimed that their child had been misdiagnosed. Prior to diagnosis of ASD, the child was incorrectly labelled as MR, slow learner or hyperactive by neurologist, psychologist, paediatrician, or another medical expert.

iv. Limited understanding of ASD among specialists in the field

As mentioned previously, fifteen of the parents indicated that their child's symptoms were not improved by the prescription prescribed by the doctors, in addition to the various or inaccurate diagnoses made by the experts involved. Parents also said that as their children grew, their behaviour became worse (kept on changing) as a result of their refusal to take the medication. Medications for hyperactivity, mental illness, cognitive problems, and vitamin syrup were prescribed to three children, while two parents were unable to identify the sort of drug prescribed to their child.

According to one parent, each doctor's judgement of their child was different, and each doctor recommended a different drug or test for the child. According to him, doctors recommended that his son undergo "rays" therapy in the hospital, but that did not help his condition either. One mother reported a similar case who sought the advice of a number of doctors for her daughter who was experiencing developmental delays and difficulties communicating. She reported that a child specialist informed her that after some therapy, her daughter will be able to talk because he would free her tongue. However, after the therapy, she went utterly deafeningly silent.

v. Parents' confusion induced by lack of relevant information

All parents in focus group and 33 in interviews claimed that no doctor or therapist had ever clarified why their child's behaviour was unique. According to eight more parents, they had to cope with confused resulting from doctor's differing viewpoints about their child's disability.

vi. Late diagnosis

The majority of parents (35) in individual interviews and all six parents in focus group interviews said that their child was diagnosed with ASD only after numerous visits to experts over a period of several years. "It took ten years to recognise that he is autistic," one mother reported. 'From the time he was a few months old, I'd known he was unique, but I had no idea what kind of impairment he had... and physicians couldn't figure it out'.

vii. Pathway to diagnosis

The diagnostic process for ASD was reported to be inefficient by all respondents. The vast majority of those surveyed (36 in interviews and 6 in focus group) agreed that it was a laborious and time-consuming process.

Discussion

Due to a lack of reliable data on mental health issues affecting children and adolescents in Pakistan (WHO, 2005), it was difficult to reflect on findings in relation to previous studies on the topic of children's care in Pakistan. The study's findings revealed that the average diagnostic age for the children was slightly over 4 years ranging up to 10 years. Several investigations conducted in wealthy countries yielded similar results (e.g. the UK, the US). It was found that the diagnosis was made at an average age of between 5 and 6 years old (Howlin, et al. 1999). A child's average age at diagnosis was little over 4 years old, according to Keenan et al. (2009) in Northern Ireland, the average age of diagnosis was 4.5 years, but in the Republic of Ireland, it was 3.2 years. Researchers observed that in the US, diagnosis age was a little over 5 years old (Wiggins et al, 2006). The results of the study's interviews and focus groups confirmed those from the questionnaire, which showed that parents had a difficult time acquiring a diagnosis for their ASD child. Parents had sought the advice of numerous professionals and had visited numerous hospitals for diagnosis. But correct diagnosis took up to seven years in certain settings.

Findings of this study show that professionals sometimes misidentified children with ASD. Misdiagnosis of mental retardation, slow learner, hyperactivity, and cerebral palsy were all part of this pattern of carelessness. A lot of the time, parents stated that professionals didn't give their children any labels at all, instead telling them that their children were just slow learners. One professional's diagnosis differed from another's, according to the parents. Many underdeveloped nations, including Bangladesh, India, and Iran, have reported limited identification, evaluation, and diagnosis, even misdiagnosis (Samadi, 2011; Sharan, 2008). An even smaller percentage of children in underdeveloped countries receive a diagnosis matching their symptoms and the therapy that is appropriate for them ('Autismi-jaAspergerliittory' in Bangladesh in 2013; Malhotra and Vikas in 2005; Sharan in 2008).

Due to parents' lack of knowledge about ASD and cultural beliefs, a delay in consultation with specialists was documented in previous studies. 'The child would be OK when he or she grows up,' the Indian parents thought (Kishore and Basu, 2011, p.162). This may be due to parents' lack of knowledge about the disease (Qureshi, et al., 2015). Qureshi et al. (2015, p.383) reported, 'there is limited provision for parents to gain information or training for supporting their child with ASD in Pakistan'. In addition to limited sources of knowledge for parents, professionals in some circumstances as found in this study told parents that their child will be fine once he or she was an adult. It may be due to a lack of knowledge about the illness among some professionals. The results are supported by Action for Autism, India, (2008) which indicates that underdeveloped countries have also been found to have a lack of understanding about ASD among key experts. There is a shortage of qualified specialists in these areas, according to reports (WHO, 2005). Additionally, there is a lack of understanding about ASD among key specialists, which might lead to misdiagnosis in some circumstances (Malhotra and Vikas, 2005; Sharan, 2008).

There is a long, difficult and chaotic process in Pakistan to acquire an ASD diagnosis. Even in the UK, the diagnostic procedure is lengthy, upsetting, ambiguous, and difficult for families to comprehend (Keenan et al., 2009). Developing countries, on the other hand, face an even more dire position. In impoverished nations, there is no screening or referral mechanism that can identify all children with ASD (Action for Autism, India, 2008). In these countries, the procedure of acquiring a diagnosis isn't as simple or straightforward as it is in other countries (Malhotra and Vikas, 2005). Developing countries have also been reported to have a lack of specialised diagnostic centres (Ethirajan, 2011). Additionally, in some circumstances, a single professional diagnosis is common. Diagnoses are typically made by a team of health and education specialists in developed countries. Because of a dearth of health professionals and qualified workers in developing nations, such a facility is limited (AFA, 2008; Malhotra and Vikas, 2005).

Conclusions

According to the findings of this study, the diagnostic procedure for autism in Pakistan is inefficient, time consuming, difficult and unclear.

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