

## CHALLENGES EXPERIENCED BY PARENTS AND SPECIALISTS IN THE DIAGNOSIS OF YOUNG CHILDREN WITH AUTISM SPECTRUM DISORDER

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### ABSTRACT

*The current study explores the experiences of parents and specialists regarding the diagnostic challenges of young children with autism spectrum disorder. Semi-structured in-depth interviews were conducted with 9 participants, including 4 parents of young children with autism spectrum disorder and 5 specialists who provide diagnostic services for autism spectrum disorder. Eight themes regarding the diagnostic challenges emerged from the shared experiences of the participants. These challenges appeared in diagnostic settings, specialists, diagnostic instruments, overlapping symptoms of autism spectrum disorder and other conditions, heterogeneity of symptoms, time of diagnosis, and results of diagnostic reports. The study recommends the need for increasing the establishment of diagnostic clinics specialized in autism spectrum disorder in the Kingdom of Saudi Arabia, especially in the Tabuk region. Also, the need for training workshops for specialists in administrating the diagnostic instruments.*

*Keywords:* Challenges; Diagnosis; Autism Spectrum Disorder.

### INTRODUCTION

Many decisions related to children with autism spectrum disorder (ASD) depend on diagnostic process (Hamdan, 2019). This process plays an important role in determining problems, accessing appropriate services, helping to understand the difficulties that face children, and finding answers regarding developmental delays. Despite the crucial role that the diagnostic process plays, it is a complex issue due to the fact that ASD is a complex neurodevelopmental disorder impacts a child's ability to communicate. Also, it includes wide variations in symptoms (Hus & Segal, 2021).

A review of the Literature on ASD has documented several challenges that affect the diagnosis of ASD and affect the parent's and specialist's experiences from the beginning diagnosis up to reaching the decision related to child (Saggu, 2015; Russel et al., 2010). Mandell et al. (2007) found that the diagnosis of children with ASD takes more time than other disabilities. Howlin & Moore (1997) noted the challenges experienced by parents in the diagnosis of their children, including the access diagnostic settings, the lack of information about the diagnosis, and the lack of specialists. Bryson et al. (2003) found that inaccurate diagnostic instruments lead to misdiagnosis results (Wiggins et al., 2015).

Moreover, the co-occurring conditions in ASD, such as hyperactivity and attention deficit disorder, intellectual disability, and developmental language disorder may lead to missed or false diagnosis for ASD, for example, Gilles de la Tourette disorder may be misdiagnosed with ASD because it has similar symptoms, such as vocalization (barking) and vocalization (repetition of others) as an involuntary convulsion (Hus & Segal, 2021).

The requirements of diagnostic criteria are one of the other factors that affect the diagnosis of ASD, for example, the first criterion in the diagnostic and statistical manual of mental disorders, fifth edition (DSM-5) requires more than one model from different environments, or the same model cannot be used to meet two criteria (Carpenter, 2021). Also, the lack of qualified specialists who provide diagnostic services for children with ASD is another challenge that may lead to misdiagnosis (Freedman et al., 2012). On the other hand, many clinicians and professionals working in the field of ASD may not be familiar with examination procedures or conditions related to sensitivity and specificity of diagnostic instruments. They may use invalid or insensitive instruments that affect the diagnostic results (Dosreis et al., 2006). Prizant (2012) also found that the lack of training, the type of diagnosis settings, and the presence of parent/caregiver on the assessment day may increase the likelihood of misdiagnosis.

Moreover, accurate and appropriate diagnosis is also obstructed by district policies and practices that determine who is responsible for diagnosing the child. Zwaigenbaum et al. (2013) indicated that non-open communication, poor cooperation, and information sharing among professionals lead to inaccurate diagnostic results (Dwyer, 2020).

Repetitive and restrictive behaviors (RRBs) are also another predictor variable that increases the challenges for specialists in the diagnosis of ASD. For example, Richler et al. (2010) documented that RRBs are considered a major challenge affect the diagnostic process because they are a wide range of compulsive behaviors that may change over time. Also, Lai et al. (2015) noted that females with ASD tend to focus on recurring interests and topics that are similar to their typical peers. Although RRBs are also a key symptom in ASD, they may occur due to the impairment in sensory processing of information in some children. They may occur frequently in some conditions, such as obsessive-compulsive disorder, severe intellectual disability, and others (Hyman et al., 2020). Social pragmatic communication disorder (SPCD) is also the most important challenge in diagnosing ASD. SPCD may not be observed or diagnosed before preschool age even later in children who have language disorders (Brukner-Wertman et al., 2016).

On the other hand, gender differences are one of the factors that may affect the diagnosis of children with ASD. Many parents and specialists may not understand with characteristics of ASD in women and girls (Dwyer, 2020). For example, females who have the condition called "The female phenotype of autism" may intentionally or unconsciously develop a range of strategies including hiding, compensating, mimicking, or adapting to certain situations (Hus & Segal, 2021). Females with ASD may exhibit more efficient communication skills than males, while they may display internal problems, such as anxiety, depressive symptoms, loss of identity, self-harm, or suicidal thoughts which can lead to misdiagnosis (Rynkiewicz & Łucka, 2018).

On the other hand, practices and methods related to collecting data about children are an additional obstacle in the diagnosis of ASD. There are many methods are used to collect data about symptoms, such as parental reports, notes, and interviews with parent, but some parents may fail to recognize the child's abnormal behaviors, while others may believe these behaviors as pathological appropriate developmentally behaviors. Also, parents may have biases toward identifying their children's behaviors and they may have limited knowledge about their children's early development (Mesh, 2009).

Furthermore, many societies that provide diagnosis in multidisciplinary settings often have long waiting lists that may delay children to receive the diagnosis and delay the early interventions that they need (Boyd et al., 2010). The area type also may play a key predictor that affects the diagnosis (Bogdashina, 2005). For example, children who live in rural areas may be diagnosed later than children who live in larger cities (Frenette et al., 2013). Moreover, the child's performance on the assessment day, such as the test location, the person accompanying the child, and the child's reactions to the evaluator, etc. also may affect the diagnostic results (Mesh, 2009).

Finally, cultural and social factors may influence the interpretation of the symptoms of ASD. For example, a minority of parents may believe that language and social skills deficits are temporary symptoms. They also may don't know how they can identify the important symptoms of ASD, such as poor communication, lack of imitation, and lack of appropriate social behavior (Ennis-Cole et al., 2013). An American study found that African American and Hispanic children had received diagnosis at late times (Hyman et al., 2010). An American study also found that higher education is associated with early diagnosis in children with ASD (Accordino et al., 2017). In contrast, a Danish study found that lower education is associated with early diagnosis in children with ASD (Larsson, 2005).

The current study aims to investigate the challenges experienced by parents and specialists in the diagnosis of ASD in KSA by using the parent's and specialists' reports. This kind of study provides the necessary solutions that improve the quality of diagnostic services and reduce the problems that parents and specialists experience in the diagnosis of ASD. It came to fill the gap in previous literature related to challenges of diagnosis in children with ASD in Arab environments, especially in KSA and Tabuk region. The study statement was identified by asking the question: What are the challenges experienced by parents and specialists in the diagnosis of ASD KSA?

## **METHODS**

### **PARTICIPANTS**

Nine participants from parents of young children with ASD and specialists were recruited in this study to share their experiences about the challenges they experience in the diagnosis of ASD. The parents (2 males and 2 females) are registering as beneficiaries in the autism society in Tabuk region during the year 2021-2022. The specialists (4 males and females) are working as psychologists, pediatrician, and Psychiatrist in the psychiatric clinic of king Fahd Bin Sultan hospital and king Salman armed forces hospital in Tabuk in KSA. The parents have been

contacted in coordination with the autism society, while the specialists have been contacted in coordination with their workplaces.

**Table 1.**

Demographic characteristics of parents and their children

No.	Parent Gender	Educational level	Child's age	The presence of disorders/disabilities associated with the child	Severity of ASD	living location
1	Male	Bachelor's	4 years	Yes	moderate	City
2	Male	Bachelor's	6 years	Yes	moderate	City
3	Female	Bachelor's	5 years	No	Mild	village
4	Female	Secondary	8 years	No	moderate	village

**Table 2.**

Demographic characteristics of specialists

No.	Occupation	Gender	Level of experience in diagnosis
5	Psychiatrist	Male	23 years
6	Psychologist	Male	9 years
7	Psychologist	Female	16 years
8	Psychologist	Male	15 years
9	pediatrician	Male	25 years

## **INSTRUMENT**

Semi-structured in-depth interviews with parents and specialists were used to examine the challenges experienced by them in the diagnosis of ASD. The author developed an interview guide of two parts, the first asked the participants about their demographic information. Parents particularly were asked for additional information about their children. The second part included open-ended questions about the parent's and specialist's experiences in the diagnosis of ASD. The interviews with parents were conducted at the Autism Society in Tabuk city, while the interviews with specialists were conducted in their workplaces. All the interviews with the participants were conducted by the author individually, they lasted between 50-120 minutes.

## **DATA ANALYSIS**

The Qualitative Data Analysis Software Package - 9th Edition (QSR NVivo-V) was administered to analyze data. The participants' data were collected and revised. The responses were encoded as pre-defined themes using the free nodes method. Finally, all the results of study were discussed.

## **METHODOLOGY**

Qualitative analysis method was used to explore the perspectives and experiences of parents and specialists regarding the challenges of diagnosis of ASD.

## **RESULTS**

Analyzes of the interviews with parents and specialists indicated eight types of challenges experienced by them in the diagnosis of young children with ASD. The challenges were classified into themes and sub-themes as follows:

### **Settings of diagnosis**

Most analyzes of the parents and specialists showed that the challenges related to the settings of diagnosis are the most challenges of the diagnosis of ASD. They included the lack of specialized clinics in the diagnosis of ASD and the distance of clinics from the region. One mother (participant 4) reports that, "There is no center or clinic specialized in diagnosing ASD in the area. I moved to Riyadh city to find a specialized center". Another parent (participant 3) adds, "The region faces a big lack of diagnostic centers. There is one only clinic in the city; therefore, we are forced to look for other specialized centers in the large cities in KSA". One of the specialists (participant 7) says, "From my own experience as a psychologist in diagnosing cases of ASD, I found the region suffers from the lack of clinics specialized in diagnosing ASD".

### **Specialists of diagnosis**

The Lack of specialists is one of the challenges indicated by most of the parents. They stated that there is a lack of specialists in this field of ASD. Also, they indicated that many of the specialists don't have qualifications in ASD and they have different views of point about diagnostic decisions of ASD. Participant 1 says, "I visited a pediatrician in the area to diagnose my son, but he hadn't not qualifications in the diagnosis of ASD. Unfortunately, I didn't find a person specialized in diagnosing my son except for a special education specialist". Participant 3 tells, "I looked for a specialist to diagnose my son, I visited many specialists, I found only one psychologist who had experience in the diagnosis. After that, I had moved to the large cities to look for other specialists". Participant 2 also says, "Unfortunately, Tabuk region is one of the most regions in KSA that suffer from the lack of specialists in the field of ASD whether the diagnosis or the intervention".

### **Instruments of diagnosis**

Most of the specialists (n = 4) expressed that there are some challenges related to the diagnostic instruments, including the big lack of standardized diagnostic instruments for ASD in KSA, the lack of many instruments in the diagnostic clinics, and there are no available modified instruments for the diagnosis of ASD. Participant 8 says that "One of the biggest problems I face in diagnosing ASD is the lack of modified versions of diagnostic instruments". Participant 5 adds, "Unfortunately, there is an obvious lack of diagnostic instruments, I personally use one only instrument to diagnose the cases, but this is not certain enough to accurately judge". On the other hand, participant 9 reports, "We urgently need accurate instruments in the diagnosis of ASD, such as the autism diagnostic interview (ADI), and the autism

diagnostic Observation Schedule (ADOS), etc. These instruments are considered gold standards in diagnosing ASD, but unfortunately, they aren't available in KSA. Participant 7 also confirms, "We suffer from the lack of the diagnostic instruments in KSA. Undoubtedly one instrument is not absolutely enough to diagnose ASD. We need several standardized and valid instruments in KSA". Participant 6 adds that, "One of the important issues in the diagnosis is the conditions related to the diagnostic instruments, such as the sensitivity and specificity. Many of the diagnostic instruments used with ASD in KSA are not subjected to measuring the degree of sensitivity and specificity".

### **Overlapping symptoms of ASD and other conditions**

More than half of the participants from specialists (n = 3) stated that some conditions overlap with ASD and may lead to false diagnostic results. For example, one of the specialists (participant 6) reports, "I worked with many cases that I supposed that they had ASD, but after they had diagnosed for several times in the clinic, I had recognized that they had had other conditions, such as anxiety, communication disorder, intellectual disability, and others". A specialist (participant 8) states that, "It is possible that symptoms of mild ASD occur in children who have anxiety, depression, and others conditions". Another specialist (participant 9) tells that, "The diagnosis of ASD is a complex procedure because some symptoms don't necessarily indicate to ASD, but they may indicate to other different symptoms. We must use differential diagnosis to examine the diagnostic accuracy using valid instruments". Participant 7 says that, "Many disorders are similar to ASD, this may mask symptoms of ASD and may lead to missed diagnostic results". Participant 5 adds that, "Symptoms of ASD, such as social deficits and restricted interests are more likely to appear in young children, socially deprived or sensory deprived children, for example, the children who have visual or hearing impairments".

### **Heterogeneity in symptoms of ASD**

More than one-third of the participants from parents and specialists reported that the heterogeneity in symptoms of ASD is the most challenging related to the diagnosis. The participants indicated that symptoms of ASD greatly vary across the affected children and differ between both genders. One of the parents (participant 3) states, "I often observe variations in the symptoms of ASD between males and females. Symptoms in male children tend to be more severe than female children. This means that the diagnosis of ASD is more difficult in females than males because the symptoms in females are difficult to be observed". Another parent tells, "I sometimes feel that my daughter doesn't suffer from the symptoms of ASD, I observe her interacts with me and with my family members, but she sometimes doesn't do that. She sometimes performs stereotyped behaviors, but other times she stops that; therefore, it's difficult for me to determine the accurate symptoms".

### **Time of diagnosis**

The participants' responses varied regarding time of diagnosis. A group of them reported that time of diagnosis takes a long time while another group said that it takes a short time. For example, one of the participants from specialists (participant 5) expresses that, "The diagnosis of ASD usually takes a long time to identify accurate judgment. It also usually requires several interviews with parent identify severity of

symptoms. Indeed, this matter leads to a great challenge for us as specialists, particularly as a result of the lack of appropriate facilities, cooperation, and participation by parents". Another participant from the specialists (participant 8) states that, "The diagnosis of children with ASD is not easy, it requires long time for accurate judgment. Some cases take more than two weeks, while others take some months to collect information and data about child's behaviors from different environments". One parent (participant 2) adds, "During my visit to a clinic in my district, a psychiatrist observed my daughter, he told me that my daughter suffers from ASD. I hadn't believed that, so I had looked for another clinic outside of the district. After several visits that lasted for more than six months, I had realized that my daughter actually suffers from ASD. Indeed, the looking for diagnostic clinics took a lot of time". Another participant from the parents (participant 1) says that, "The accurate diagnosis requires long time. When I moved among several clinics and centers, I had recognized that the qualified specialist in diagnosing ASD is the special education teacher".

### **Results of diagnostic report**

The parent's responses showed that there are a number of challenges related to the results of diagnostic report. These challenges have been classified into sub-themes, including the difficulty with understanding the results of report, the lack of information, the unreliability of reports, and the interventions are not explained in reports". Participant 3 states, "When I received my daughter's diagnostic report, I had found ambiguity with understanding its results. I didn't understand the numbers that indicate to the degree of severity of ASD, or type of disorder. Unfortunately, there is a lack of information provided by clinics and specialists to understand my daughter's problem. Also, a lot of information was difficult to understand". Participant 4 says, "I received more than one diagnostic report for my son, I had observed that all reports hadn't agreed on the type of services and interventions that my son needs". Participant 1 adds, "When I received the diagnostic report for my son, I hadn't received the opportunity to discuss the report orally. On the other hand, the report didn't show the recommendations for the services that my son needs. When I reviewed the report, I had found missed information about my son's condition. Also, the report didn't clarify the possible causes or the accurate degree of ASD, and it didn't define the current and future interventions that my son needs". Participant 2 states, "When I took my daughter to many specialists, I had found different results in the diagnostic reports, for example, I remember that a psychiatrist told me that my daughter suffers from infantile schizophrenia, while another told me that she suffers from autistic traits. Eventually, my only concern was to looking for a special education institute to help my daughter on communication".

### **DISCUSSION**

The current study explored the experiences of parents and specialists regarding the diagnostic challenges of ASD. The results showed a number of challenges that have been classified into themes and sub-themes. The challenges related to settings of diagnosis were the most challenges reported by the participants. These kinds of challenges have been classified into two sub-themes, including the lack of specialized diagnostic clinics and the distance of clinics from the region. Saggu, (2015) found the lacking of diagnostic clinics for ASD constitutes is one of the big challenges which usually begin before diagnostic process, especially when thinking about the existence

of problem in child. Saggu indicated that these challenges began when looking for diagnostic clinics up to reaching diagnostic decisions about child. Also, Howlin & Moore (1997) reported that the accessing diagnostic clinics is one of the challenges experiencing diagnostic process. On the other hand, the overlapping among some specializations may increase the difficulty of accessing the specialized settings of diagnosis.

Furthermore, the results of parents' responses in the current study showed that there are diagnostic challenges related to specialists. The lack of specialists in the field of ASD is one of the most challenges. Also, many specialists don't have qualifications in ASD and they have different views of point about diagnostic decisions of ASD. However, these results agree with Whiteley's et al. findings (1998) which indicated that the lack of specialists and the difficulty in identifying the appropriate specialists were significant factors that affected the parent's experiences towards diagnosing ASD. Dosreis et al. (2006) found that many clinicians and professionals working in the field of ASD might not be familiar with screening procedures or requirements related to sensitivity and specificity of diagnostic instruments.

In addition to the challenges related to specialists, the participants discussed the challenges related to diagnostic instruments, the specialist's responses agreed that there is a significant lack of standardized diagnostic instruments for ASD in KSA and a lack of many instruments in diagnostic clinics. Furthermore, there are no available modified instruments for the diagnosis of ASD. An accurate diagnosis requires using a number of valid and reliable diagnostic instruments. The quality of diagnostic instruments plays an important role in determining the nature of the problem. The invalid and inaccurate instruments affect the results and decisions of diagnosis (Hus & Segal, 2021). Bryson et al. (2003) confirmed that the quality and accuracy of the instruments play an important role in decision of diagnosis.

On the other hand, more than half of the specialists discussed another challenge related to overlapping symptoms of ASD and other conditions. Undoubtedly, many conditions overlap with symptoms and characteristics of ASD. These conditions lead to difficulty in distinguishing symptoms of ASD (Thabtah & Peebles, 2019). Diagnostic instruments designed for ASD may not adequately differentiate characteristics of comorbidities and can result to misdiagnosis (Heidi et al., 2019). However, Hus & Segal (2021) indicated that the disorders associated with ASD, such as hyperactivity and attention deficit disorder, intellectual disability, developmental language disorder, and others may affect the diagnosis of ASD.

The other participants' responses showed that symptoms of ASD vary among children and they differ between both genders. Dwyer (2020) suggests that gender differences are one of the challenges that affect the diagnosis of ASD. Females with ASD may exhibit socially efficient behavior and communication skills more than males. On the other hand, females may display internal behavioral problems, such as anxiety, depressive symptoms, loss of identity, and others which may lead to difficulties in diagnostic process. In addition, the nature of ASD and its unique characteristics may lead to variance and disparity in symptoms through different environments, situations, and circumstances (Hus & Segal, 2021).



As for the challenges related to time of diagnosis, the participants provided different responses. Some participants indicated that diagnostic process takes a long time, others indicated otherwise. Werner et al. (2005) found that the later diagnosis of ASD and the length of time that parents wait to receive the diagnosis for their children were the biggest challenges and the most factors that lead to negative perspectives towards diagnostic process. Stozler (2011) also found that the diagnosis of ASD takes more time than other disabilities.

Finally, the participants reported other challenges related to results of diagnostic report, which included difficulty with understanding results, lacking information, the unreliability of reports, and the interventions were not explained in reports. This kind of challenge may be due to a number of factors as reported by Freedman et al. (2012), including the lack of qualified specialists who provide diagnostic services, the differences in specialization, the quick judgment of diagnosis, and the disappearance of symptoms of ASD. Furthermore, the missed information that parents give about their children may also be another factor that affects the differences in the report results. Prizant (2012) also indicated that the lack of training, the diagnostic settings type, and the presence of a parent/caregiver during diagnostic process may decrease the diagnostic accuracy that affects the report results. However, These findings agree with some previous studies. For example, Braiden et al. (2010) found that parents of children with ASD didn't receive enough support after diagnosing their children and they didn't aware about the services available in their community. Also, Mockett et al. (2011) confirmed that families of children with ASD hadn't had good knowledge of appropriate programs and services provided to their children after the end of the diagnostic process. Furthermore, Lavik & Sansosti (2012) reported that parents of children with ASD may receive missed information about the effective interventions for their children that are usually provided in diagnostic reports.

## **CONCLUSION**

It is very clear that the challenges of diagnosing children with autism spectrum disorder is a matter of many challenges for both parents and specialists. Although ASD is a complex disorder and has different and specific characteristics, it leads affect the diagnosing process. However, the challenges related to the settings of diagnosis were the most important challenges of diagnosing ASD. There were also other important challenges reported by the participants in this study, including the challenges related to diagnostic instruments and the lack of these instruments, the challenges related to the overlapping symptoms of ASD with other conditions, the challenges related to heterogeneity of symptoms between both genders, the challenges of the time of diagnosis, and the challenges related to diagnostic reports. This study suggests number of recommendations, including the need for increasing the establishment of diagnostic clinics specialized in ASD in KSA, especially in the Tabuk region, the need for developing and translating the modified diagnostic instruments to the Saudi environment, and the need for training workshops in administrating the diagnostic instruments of ASD, using the differential diagnosis of other disorders, and preparing formal diagnostic reports.

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