

Assessment of Parental Knowledge, Awareness, and Perception About Autism Spectrum Disorders in Aseer Region, Southwestern Saudi Arabia

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Background: Autism spectrum disorder (ASD) is a neurodevelopmental condition that affects young children in social relatedness and communication besides other characteristics. A community's awareness and early intervention services in diagnosing and treating autistic children are essential for preventing the expected complications, eg language delay, social interaction, and intellectual ability.

Aim: To assess the parent's knowledge and perceptions regarding autism and its associated clinical features and effects.

Methodology: A cross-sectional study was conducted targeting all available parents aged 18 years or more living in Aseer region. Data were collected using a self-reported questionnaire from randomly selected parents who attended outpatient clinics at Abha Maternity and Children Hospital and Aseer Central Hospital. Parents' knowledge regarding autism was assessed covering general knowledge, clinical features, social effects, consequences, and curability.

Results: A total of 477 parents participated. Parents' ages ranged from 18 to 85 years. 261 (54.7%) parents were male and 216 (45.3%) were females. Nearly 65.6% of parents were university graduates and 28.3% had a secondary level of education. About 50.9% of the parents know that genetics play a major role in causing autism, 69.6% think that most children with autism have special talents or abilities, 64.2% know that delayed language development is one of the main symptoms of autism, 61.2% also know that repetitive movements of the hands and head are a common symptom of autism. About 36.9% of parents think that diagnosing a child with autism will lead to discrimination against the child, 33.3% of parents think that autism is a rare condition in this country compared to the West.

Conclusion: The study showed that parents had poor knowledge levels regarding autism and its related clinical features, especially male parents with low levels of education. On the other hand, their perception of the disease and its frequency in the study area was satisfactory.

Keywords: autism, children, parents, awareness, perception, Aseer, Saudi Arabia

Introduction

Autism is a neurodevelopmental disorder that is mostly diagnosed in the first three years of age and can be diagnosed after the age of three years old.¹ Autism classically alters the child's communication skills and relationship with others or the environment, in addition to other features.^{2,3} While the minority of autistic children may show relatively high-functioning speech and average intelligence, the majority of autistic children have intellectual disabilities and language delay. It is known that autism is more common in males and premature children, and it has a strong link to some genetic disorders.⁴⁻⁶

Studies estimate autism prevalence shows a high variability of prevalence rates with different reasons for the observed changes in prevalence and advise caution when claiming that there is an autism epidemic.^{7,8} Recently, a noticeable increase

in the magnitude of autism has been reported, making claims about an “epidemic” of autism.^{7,9} Others postulated this increment in autism prevalence is a reflection of high awareness levels among the physicians and the community in general. Insufficient studies in Middle East countries were shown to underestimate the prevalence of autism. Generally, these studies estimated prevalence as lower than in Western countries. In Iran, the most updated estimate of autism spectrum disorder (ASD) prevalence among a large-sample of the population about psychiatric disorders among Iranian children and adolescents aged 6–18 years were about 1.60/1000, compared to 2.90/1000 among 0–14 year old children in United Arab Emirates,^{10,11} and 0.14/1000 had been estimated in children aged 0–14 years in the Sultanate of Oman.¹² In Saudi Arabia, the prevalence of ASD was 2.618 per 1000 children in Jeddah, 3.68 per 1000 children in Makkah, and 2.81 per 1000 children in both Jeddah and Makkah.¹³

The early intervention programs implemented in the previous two decades aim to identify the autistic children as early as possible and reduce the possible complications if children are left unserved. It is found that children who undergo such interventions show better outcomes in language, motor skills and intelligence compared with their untreated peers. These results emphasize the strong need for the community’s awareness and therefore, prompting the early detection and interventions which will lessen the burden on the children, families, and society. There is no similar study in our region to the best of our knowledge which has assessed the parental knowledge, awareness, and perceptions about autism spectrum disorders. The current study aims to assess the parent’s knowledge, awareness, and perceptions about autism and its associated clinical features and effects among the parents in Aseer region, southwestern Saudi Arabia.

Methodology

A descriptive cross-sectional study was conducted targeting all available parents attending the outpatient clinics at Abha Maternity and Children Hospital and Aseer Central Hospital (which are the largest governmental hospitals in the southern region of the Kingdom of Saudi Arabia) from October 2021 to November 2021. Persons of 18 years or more, living in Aseer region, having children less than 5 years old and attending the outpatient clinics of the two selected hospitals during the study period were invited to participate in the survey. Parents with children with ASD or mental retardation were excluded from the study. Parents who are medical professionals were also excluded. Out of a total of 600 eligible parents, 477 parents completed the study questionnaire with a response rate of 79.5%. Data were collected from participants using a self-reported questionnaire with randomly selected parents who attended outpatient clinics. To the best of our knowledge there is no validated awareness scale for autism, especially in Arabic language, and the related studies vary in the assessment of autism awareness in different study populations. Therefore we had to create our own awareness tool based on the existing literature review to be used in the selected study population. The questionnaire was constructed based on a comprehensive literature review and expert’s consultation in the study field.^{1,5,14} The tool was reviewed using a panel of 3 experts in developmental disorders from the medical college of King Khalid University to check the clarity and its content’s validity. Tool reliability was assessed using a pilot study of 25 participants with a reliability coefficient (α -Cronbach’s) of 0.76. The tool covered the following data: parents’ socio-demographic data, like age, gender, education, and having children with chronic health problems besides family size. The parents’ knowledge regarding autism was assessed using 31 questions covering general knowledge, clinical features, social effect, consequences, and curability. The last section covered parents’ perception regarding autism frequency in Saudi Arabia, stigma, and awareness level in the study region.

Data Analysis

After data were extracted, they were revised, coded, and fed into statistical software IBM SPSS version 22 (SPSS, Inc. Chicago, IL). All statistical analysis was done using two tailed tests. P-value less than 0.05 was statistically significant. For knowledge and awareness items, each correct answer was scored one point and total summation of the discrete scores of the different items covering general knowledge regarding autism and its related features. Parents with scores less than 60% of the total score were considered to have a poor knowledge level while good knowledge was considered if they had scores of 60% or more. Descriptive analysis based on frequency and percentage distribution was done for all variables including participants socio-demographic data and family size, and children’s medical history. Also, parents’ knowledge and perception regarding autism and its clinical features were shown in frequency tables. Cross-tabulation was used to assess the distribution of parents’ knowledge level regarding autism according to their personal data, and disease history. Relations were tested using Pearson chi-square test and exact probability test for small frequency distributions.

Results

A total of 477 parents completed the study questionnaire. Parents ages ranged from 18 to 85 years with a mean age of 39.6 ± 10.5 years old. 261 (54.7%) parents were male and 216 (45.3%) were female. As for educational level, 313 (65.6%) parents were university graduates and 135 (28.3%) had a secondary level of education. 84 (17.6%) families were 1–3 persons, 194 (40.7%) were 4–6 persons, 164 (34.4%) were 7–9 persons and 35 (7.3%) were 10 or more persons. A total of 44 (9.2%) parents reported that they had a child with a chronic health problem (Table 1).

Regarding parents knowledge about autism disorder, Aseer region, Saudi Arabia, a total of 69 (14.5%) parents had a good knowledge regarding autism and its related features but 408 (85.5%) had a poor knowledge level (Figure 1). About 75.5% of parents knew that autism has different levels of severity. Nearly 69.6% think that most children with autism have special talents or abilities, 64.2% know that delayed language development is one of the main symptoms of autism, 61.2% also know that repetitive movements of the hands and head are a common symptom of autism. Nearly 17.2% of parents thought that vaccinations contribute to autism while 16.4% of parents thought that most children with autism are also mentally retarded.

Only 15.1% of the parents thought that autism is a lifelong disorder and 15.1% of participants think that certain types of food can cause autism (Table 2).

Regarding parents' perception concerning autism disorder in Aseer region, Saudi Arabia (Table 3), 176 (36.9%) parents think that diagnosing a child with autism will lead to discrimination against the child, 159 (33.3%) parents think that autism is a rare condition in this country compared to the West, 164 (34.4%) reported that autism is unrecognized and often missed in general practice, and 301 (63.1%) think that there is a lack of awareness regarding autism among parents in the southern region.

In Table 4, about the distribution of parents' knowledge of autism by their personal data, 18.5% of mothers showed a good knowledge level compared to 11.1% of fathers with recorded statistical significance ($P = 0.022$) using Chi squared test. Also, 16.9% of university graduated parents had a good knowledge level regarding autism versus none of the parents

Table 1 Socio-Demographic Data of Study Parents, Aseer Region, Southwestern Saudi Arabia

Socio-Demographic Data	No	%
Age in years		
20–29	94	19.7%
30–39	141	29.6%
40–49	153	32.1%
50+	89	18.7%
Gender		
Male	261	54.7%
Female	216	45.3%
Educational level		
Below secondary	29	6.1%
Secondary	135	28.3%
University / above	313	65.6%
Family size		
1–3	84	17.6%
4–6	194	40.7%
7–9	164	34.4%
10+	35	7.3%
Have a child with chronic health problem		
Yes	44	9.2%
No	433	90.8%

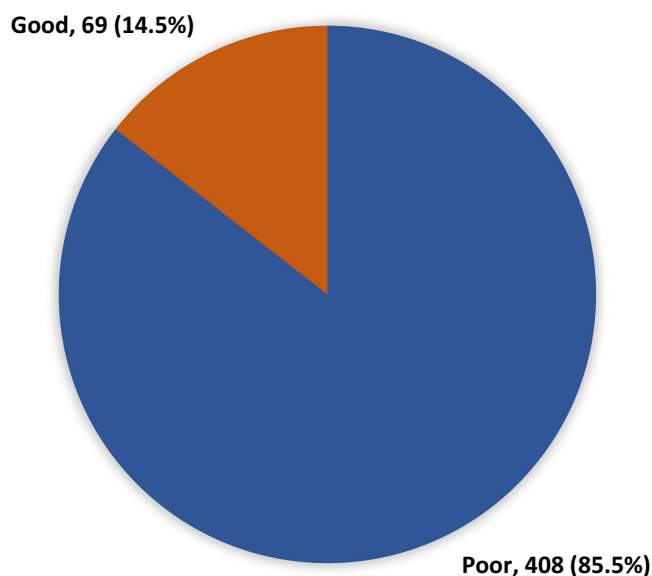


Figure 1 Overall parents knowledge regarding autism disorder, Aseer region, Saudi Arabia.

with below secondary level of education ($P = 0.027$). Good knowledge was also detected among 18.9% of parents who think that there is a lack of awareness regarding autism among parents in the southern region compared to 8.7% of others who think they have a good knowledge level ($P = 0.001$).

Table 2 Parents Knowledge Regarding Autism Disorder, Aseer Region, Saudi Arabia

Knowledge Items	Yes		No		Do not Know	
	No	%	No	%	No	%
Does autism have different levels of severity?	360	75.5%	42	8.8%	75	15.7%
Most children with autism have special talents or abilities?	332	69.6%	57	11.9%	88	18.4%
Delayed language development is one of the main symptoms of autism?	306	64.2%	82	17.2%	89	18.7%
Repetitive movements of the hands and head are a common symptom of autism?	292	61.2%	63	13.2%	122	25.6%
Autism is often attributed to parental neglect of the child.	279	58.5%	111	23.3%	87	18.2%
Is autism curable?	278	58.3%	72	15.1%	127	26.6%
One of the symptoms of autism is a preference for a certain type of food and a certain game?	277	58.1%	74	15.5%	126	26.4%
Imaginative play is an important trait among people with autism?	274	57.4%	60	12.6%	143	30.0%
Autistic children use body language and symbolic finger gestures to communicate?	269	56.4%	82	17.2%	126	26.4%
There is a link between the financial condition of the family and autism?	258	54.1%	142	29.8%	77	16.1%
Can children with autism study within public education?	247	51.8%	140	29.4%	90	18.9%
Genetics play a major role in causing autism?	243	50.9%	95	19.9%	139	29.1%
Is autism preventable?	238	49.9%	101	21.2%	138	28.9%
Of the most prominent cases similar in symptoms of autism, hearing impairment and mental retardation?	227	47.6%	114	23.9%	136	28.5%

(Continued)

Table 2 (Continued).

Knowledge Items	Yes		No		Do not Know	
	No	%	No	%	No	%
With proper intervention most children with autism eventually “get out” of autism.?	214	44.9%	89	18.7%	174	36.5%
People with autism do not have the ability to make eye contact with the public?	209	43.8%	141	29.6%	127	26.6%
Autistic children show emotional separation from their parents?	207	43.4%	149	31.2%	121	25.4%
Symptoms of autism begin to appear at school age (6–12 years)?	191	40.0%	143	30.0%	143	30.0%
The intelligence level of the majority of people with autism is within the normal limits?	189	39.6%	161	33.8%	127	26.6%
Children with autism do not show any social relations, even to their parents?	164	34.4%	173	36.3%	140	29.4%
It's impossible to tell if a child has autism before the age of four?	144	30.2%	164	34.4%	169	35.4%
Do children with autism usually grow up to be adults with schizophrenia?	130	27.3%	122	25.6%	225	47.2%
There is a relationship between the occurrence of autism and the religious level of the parents?	123	25.8%	256	53.7%	98	20.5%
In general, children with autism have good social communication skills and a good ability to interact with others.	110	23.1%	289	60.6%	78	16.4%
Autistic children are not affectionate?	100	21.0%	225	47.2%	152	31.9%
Males get autism more than females?	118	24.7%	104	21.8%	255	53.5%
Autism exists only in childhood?	88	18.4%	250	52.4%	139	29.1%
Vaccinations contribute to autism?	82	17.2%	254	53.2%	141	29.6%
Most children with autism are also mentally retarded?	78	16.4%	297	62.3%	102	21.4%
Autism is a lifelong condition?	72	15.1%	212	44.4%	193	40.5%
There are certain types of food that can cause autism?	72	15.1%	249	52.2%	156	32.7%

Table 3 Parents Perception Concerning Autism Disorder, Aseer Region, Saudi Arabia

Perception Items	No	%
Do you think that diagnosing a child with autism will lead to discrimination against the child?		
Yes	176	36.9%
No	200	41.9%
Do not know	101	21.2%
Autism is a rare condition in this country compared to the West.		
Yes	159	33.3%
No	155	32.5%
Do not know	163	34.2%
Autism is unrecognized and often missed in general practice.		
Yes	164	34.4%
No	190	39.8%
Do not know	123	25.8%
Is there a lack of awareness regarding autism among parents in the southern region?		
Yes	301	63.1%
No	69	14.5%
Do not know	107	22.4%

Table 4 Distribution of Parents' Knowledge about Autism by Their Personal Data

Personal Data	Knowledge Level				p-value
	Poor		Good		
	No	%	No	%	
Age in years					
20–29	74	78.7%	20	21.3%	0.065
30–39	125	88.7%	16	11.3%	
40–49	128	83.7%	25	16.3%	
50+	81	91.0%	8	9.0%	
Gender					
Male	232	88.9%	29	11.1%	0.022*
Female	176	81.5%	40	18.5%	
Educational level					
Below secondary	29	100.0%	0	0.0%	0.027* [§]
Secondary	119	88.1%	16	11.9%	
University / above	260	83.1%	53	16.9%	
Family size					
1–3	69	82.1%	15	17.9%	0.198 [§]
4–6	172	88.7%	22	11.3%	
7–9	135	82.3%	29	17.7%	
10+	32	91.4%	3	8.6%	
Have a child with chronic health problem					
Yes	37	84.1%	7	15.9%	0.775
No	371	85.7%	62	14.3%	
There is a lack of awareness regarding autism among parents in the southern region?					
Yes	244	81.1%	57	18.9%	0.001*
No	63	91.3%	6	8.7%	
Do not know	101	94.4%	6	5.6%	

Notes: P: Pearson χ^2 test. [§]Exact probability test. *P < 0.05 (significant).

Discussion

Autism is considered as a spectrum which means a child's symptoms can exist in a varied spectrum of combinations ranging from mild to severe. Autism is featured by a child's difficulty to communicate and interact with others.¹ Additionally, autism can make a child perform repetitive activities and movements, become distressed with changes in daily routine, and have unusual responses to certain circumstances.⁵ In some children, signs of autism can be seen as early as 12 months with babies that do not babble, other children may develop normal language and social skills for a time, but then begin to regress with autism which is called “regressive autism”.¹⁵ Early identification and diagnosis will help parents in planning a proper and efficient intervention plan, with releases in stress, as they will discuss and share their burden with the specialized physicians to reach a correct diagnosis. Lack of awareness increases the chance of misdiagnosis or late diagnosis especially the signs of this disorders parents who are the first to see any unfamiliar behaviour compared to other children or siblings of the same age group.^{16,17} The current study aimed to assess parents' awareness and perception of autism in Aseer region, Saudi Arabia. Other studies have assessed the knowledge regarding autism spectrum disorders with a lower number of participants than our study and have used lesser variables in their questionnaire.^{12,18,19}

As for parents' knowledge of autism and its associated features, the study showed that parent's knowledge was poor, as less than one fifth of the parents (15%) had good knowledge levels in total. Our findings are in agreement with

Alsehem et al that more health campaigns that target the level of awareness of the families of autistic child and the general population are needed.¹⁸ Our study revealed a higher knowledge level among the mothers and those educated upto the university level. Similarly, females were more knowledgeable about the disorder when compared to males in a prior study from Saudi Arabia in the general population.¹⁸ This is also comparable to the findings of another study from Saudi Arabia where males were less likely to be knowledgeable about autism spectrum disorder compared to others, and participants with a Master's Degree and those who work in the healthcare field were more likely to be knowledgeable about autism spectrum disorder compared to others.¹⁹ This may reflect improved exposure to the condition among the females or their interest towards the condition. Future studies should focus on the exact reason for greater knowledge among females and higher educational levels such as the effect of social media or more contact by the mothers with the child's teachers or service providers, etc. During the COVID-19 pandemic and quarantine all autistic children stayed in their homes with no contact with their teachers which made the role of their families to teach them and care about them more important due to the absence of their teacher's effect.^{12,19}

A much higher level of parental knowledge regarding autism was reported by Kandice J. Benallie²⁰ where 43.9% of the parents showed good knowledge levels regarding the disorder. Similarly low levels of knowledge among parents was detected in Pakistan by Anwar et al²¹ who reported that poor knowledge scores, with a mean score of 5.59 in the section concerning correct opinions on autism and that of 6.84 in the section testing knowledge of signs and symptoms. Another study in Pakistan among pre-school teachers, where 50% were able to identify a majority of disease characteristics and about 17% of pre-school teachers being interviewed in China could answer more than 50% of the items accurately.^{22,23} In Nepal, Heys et al showed the prominent lack of awareness of autism by parents and professionals alike.²⁴

As for parents' perceptions, the study results showed that more than one third of parents think that diagnosing a child with autism will lead to discrimination against the child, and autism is a rare condition in this country compared to the West. Besides, one third of children reported that autism is unrecognized and often missed in general practice, while two thirds of them think that is a lack of awareness regarding autism among parents in the southern region. Gray shows that parents of children diagnosed with ASD experience considerable stigmatisation due to the socially inappropriate behaviour of their children.²⁵ In a recent study from Saudi Arabia it was reported that caregivers of children with ASDs showed lower scores in most quality-of-life domains compared with those of caregivers of children without ASDs ($p < 0.05$, except for one domain).²⁶ As per a recent Saudi expert consensus - ASD requires evaluation and intervention by a range of professionals working in coordination. Parental involvement in interventions is vital to sustain therapeutic gains.²⁷ Enhancing the ongoing public services for individuals with autism in Saudi Arabia is the need of the hour.

Conclusions and Recommendations

In conclusion, the study showed that parents had poor knowledge levels regarding autism and its related clinical features especially male parents with a low level of education. On the other hand, their perception about the disease and its frequency in the study area was satisfactory. An early and accurate diagnosis plays a significant role in outcomes and development of behaviour in the child. If the parent recognizes the symptoms of autism in their child, like lack of eye contact, hyperactivity, increased attachments to toys, and lack of reactivity to verbal cues then they can seek medical help.

Ethical Considerations

The study was conducted in accordance with the Declaration of Helsinki, and the Ethics and Research Committee of the College of Medicine of King Khalid University approved on 12 September 2021 (REC # 16-09-21). Informed consent was obtained from the study participants prior to study commencement.

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Disclosure

The authors report no conflicts of interest in this work.

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