

Original Articles

Understanding Parent's Knowledge and Perception About Autism Spectrum Disorder (ASD) in the City of Jeddah, Kingdom of Saudi Arabia

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Abstract

Background

Autism spectrum disorder (ASD) has shown a dramatic rise in the past few years. It is one of the most common chronic neurodevelopmental disorders with strong genetic basis. As patients' outcomes are implicated by their parents' knowledge and perception about ASD. This study aimed to assess the knowledge and perception of childhood autism among parents in Jeddah, Saudi Arabia.

Methodology

This is a descriptive cross-sectional study that targeted all parents with at least one child in Jeddah, Saudi Arabia in 2020. An electronic self-administered questionnaire was distributed online. A total of 413 participants were included. To describe our study participants, we used frequencies for the categorical variables. Chi-square test was used to determine the presence of associations.

Results

A total of 413 respondents were included, most of them were females. The mean age of the sample was (41±11.35). After assessing the knowledge about ASD among our sample of patients, most of the participants showed good level of knowledge as the majority were able to identify ASDs' early symptoms and believe that early identification of the disease will improve the therapeutic outcome. The perception was also acceptable in our sample since more than half of the participants were able to define ASD and were aware of the possibility of early diagnosis. It was also remarkable that most of the participants in our sample were able to identify the features of a child with ASD.

Conclusion

The study demonstrates an acceptable fund of knowledge and perception among parents regarding facts and myths about ASD among parents in Jeddah, Saudi Arabia. Males answered better in both sections covering knowledge and perception about ASD. We also found out that the level of education had a significant positive influence on the level of knowledge and perception.

Keywords: autism spectrum disorder, Jeddah, parent's, knowledge, perception

Introduction

The psychologist Eugen Bleuler first formulated the concept of autism in the 20th century. He used the Greek term *autos* that means “by oneself”. Bleuler described autism as schizophrenia with severe symptoms (1) and since then, the concept was reformulated many times. Today we can define Autism Spectrum Disorder (ASD) as one of the most common chronic neurodevelopmental disorders that has an underlying genetic basis (2). The prevalence of ASD among children is estimated to be one in 160 around the world and, 1:167 in Saudi Arabia (3,4). A recent study reported that the rate of ASD is higher in males (0.031%) than females (0.004%) in Taif, Saudi Arabia (5). Patients with ASD typically suffer from three main symptoms: social interaction impairment, verbal and nonverbal communication disabilities, and a narrow range of activities that are unique and carried out repeatedly in a stereotyped manner (2). Furthermore, patients suffering from ASD may have other comorbidities including epilepsy, depression, anxiety and Attention Deficit Hyperactivity Disorder (ADHD) (6). Causative mechanisms are unclear. However, the hypothesis supports genetic contribution and carnitine deficiency in infants who are genetically normal (7,8).

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is used by healthcare providers to diagnose a variety of conditions including ASD. According to DSM-5, there are three levels of ASD: level 1- requiring support, level 2- requiring substantial support, level 3- requiring very substantial support (9). ASD is considered a chronic non-curable disease. Several treatment interventions have been developed and proved their efficacy in reducing ASD's symptoms such as; behavioral and communication therapies, educational therapies, family therapies, and other interventions that depend on the child's condition and case severity (10). Pharmacological medications that are specifically targeted for the treatment of autism are still not available. Haloperidol, Risperidone and Aripiprazol are antipsychotic medications that are effective in treating

aggressiveness, which is a common associated symptom of autism. Methylphenidate and Clonidine has shown an effective role in treating hyperactive symptoms associated with autism. However, neither social nor communication impairment seen in autism are proven to be treated effectively by pharmacological agents yet (11).

Populations' knowledge and perception regarding ASD could enhance the treatment outcomes. A study was conducted in 2012 among 85 Saudi parents of children who suffer from ASD in order to evaluate their perceptions and beliefs about autism showed that 47 (55%) out of 85 parents had misperceptions regarding the cause of ASD. Vaccination was the most common reported misconception as a causative factor of ASD. Other parents believed that nonmedical or cultural reasons such as evil eye and black magic could cause ASD. Few parents reported using alternative medical intervention, such as diet program and hyperbaric oxygen therapy to heal their children from autism. The results of the mentioned study suggested that further awareness is required in order to correct the misconceptions and lack of awareness about ASD (12). In 2019 a study was conducted in the Holy city of Makkah, Saudi Arabia, assessing the knowledge about childhood ASD among healthcare workers. The results of the study were displayed in scores, the overall mean score was (9.80±0.32), and although psychologists had higher scores, the overall fund of knowledge amongst healthcare professionals was insufficient with mean score of (9.6±3.28) compared to non-physicians (11.2±4.41) (p=0.113)

(13). In the year 2020 multiple studies were conducted in the UK and USA to explore the knowledge and beliefs among the families of children suffering from ASD prior to their children's diagnosis in which a common theme in many papers stated that there was a lack of knowledge among parents in the past. Findings also highlighted those familial perceptions of ASD were influenced by social stigma. Furthermore, it was common for parents of children suffering from ASD to approach members of

their relatives first before seeking professional advice. This approach might be based on viewing ASD as an anonymous impairment and mental illness rather than a well known neurodevelopmental disorder. Therefore, parents misunderstanding the nature of ASD has obstructed them from seeking medical advice. Those findings indicated the need to carefully develop culturally sensitive interventions and provide simplified guided information for parents to strengthen social support (14).

ASD is a common disease that affects children worldwide, with an annual increase in its incidence rate. As patients' outcomes are implicated by their parents' knowledge and perception about ASD, understanding populations' awareness about the diseases is essential. Recent studies about parents' knowledge and perceptions toward ASD were limited in the literature, especially in Jeddah, Saudi Arabia. In this context, this study aimed to assess the knowledge and perception of childhood ASD among parents in the city of Jeddah, Saudi Arabia during the year of 2020.

Methodology

Study participants and data collection

Understanding parent's knowledge and perception about Autism Spectrum Disorder (ASD) in the city of Jeddah, Kingdom of Saudi Arabia is a descriptive cross-sectional study that put as a target any parent with at least one child in Jeddah, Saudi Arabia. The study was conducted over a period of three months (June-August 2020). An online questionnaire was distributed and was used to assess the parents' knowledge and perception about childhood's ASD. We used a self-administered questionnaire that was developed and obtained from a previous study (15). The questionnaire consists of three sections: the first section includes the socio-demographic data of the participants including age, gender, having children, the presence of a child suffering from ASD in the family, and their experience with ASD. The second part was concerned with parent's general knowledge about ASD in which this section participants completed 19 multiple-choice questions. The last part of the questionnaire is concerned with parents' perception of ASD which included 13 items; with responses ranging from 1-strongly agree to 5-strongly disagree. The data was collected and submitted through an electronic form. The sample size was calculated by using Raosoft sample size calculator and it was determined to be 385. The study proposal was reviewed and approved by the institutional review board (IRB) of Fakeeh College of Medical

Science (FCMS) approval number:114/IRB/2020. The primary outcome was the assessment of the parents' general knowledge and perception about childhood ASD.

Statistical Analysis

Microsoft office Excel version 2020 was used for data entry. The data were analyzed using Statistical Package for Social Sciences (SPSS) V25.0. To describe our study participants, we used frequencies for the categorical variables. For continuous variables, the mean, median, and standard deviation were used. Chi-square test was used to determine the presence of associations between knowledge and perception regarding ASD in relation to the level of education and gender. P value of 0.05 was considered statistically significant.

Results

A total of 413 responds were included, who were all parents of one or more children. Most of the respondents (287) were females, which represent 69.5% of the sample size. Among females 79.5% had a bachelor's degree or higher, whereas among males, 89.8% had a bachelor's degree or higher. In our sample, the level of education was significantly influenced by gender ($P=0.004$). The mean age of the sample was (41 ± 11.35). In this study, only a minority, 57 (13.8%), had at least one child suffering from ASD. and almost third of them 131 (31.7%) had a communication or a dealing experience with a child suffering from (ASD) (Table 1).

Table 1 Demographic characteristics of study population

		Percentage from the total sample	All (N)				
Presence of a child suffering from (ASD)							
Yes		13.8%	57				
No		86.2%	356				
If participants have an experience with a child suffering from (ASD)							
Yes		31.7%	131				
No		68.3%	282				
Level of education							
Gender	PS	MS	HS	BD	MD	PhD	Total
	2	5	52	191	24	13	287
Female	0.7%	1.7%	18.1%	66.6%	8.4%	4.5%	69.5%
	0	1	11	56	26	32	126
Male	0%	0.8%	8.7%	44.4%	20%	25.4%	30.5%

PS= primary school, MS= middle school, HS=high school, BD= bachelor's degree, MD=master's degree, PhD=doctor of philosophy, N=numbers

Parents' knowledge about ASD

Participants were asked some questions to assess their knowledge about ASD. The prevalence of ASD was identified correctly only by (41%) of the patients. However, most of the participants (82%) knew that the number of children diagnosed with ASD has increased in the last two decades, also (53%) of the participants knew that ASD is more common in males than females. Regarding the causes of ASD, most of the participants did not believe that it was caused by vaccines or poor parenting (54% and 78 % respectively). Approximately almost half of the participants (47%) did not think that environmental factors alone could predispose to ASD, and (53.3 %) of our sample thought that the family history increases the risk of ASD. Almost forty one percent of the participants knew that there is no medical test or biological marker to diagnose ASD, and only (24.9%) think that the children suffering from ASD can't

outgrow autism with proper treatment or intervention. On the other hand, the majority (70%) of the participants answered that the behavioural therapy is the appropriate treatment option. Participants were also asked about signs of ASD, (74.8%) knew that the delays in the development of early language and communication, repetitive and stereotyped behaviours are early signs and symptoms of ASD. Most of the participants (69.7%) thought that not all patients suffering from ASD have comorbid mental disabilities. Almost half (49.4%) of the respondents believed that patients with ASD can live independent lives, and (52.1%) think that ASD is a lifelong disorder. Also, most of the parents in our study (92.5%) knew that early identification and intervention could improve patients' outcome for most young children (**Table 2**).

Table 2: The knowledge section of the survey

Knowledge questions	1 in 1000	1 in 100	1 in 10
How common do you think autism is?	54%	41.4%	4.6%
When was autism first diagnosed?	1943	1970	1990
	21.5%	42.1%	36.3%
The treatment option is	PT	BT	BI
	17.9%	70%	12.1%
	Yes	No	Not sure
Autism is caused by vaccines.	6.1%	54.7%	39.2%
Autism is caused by poor parenting.	7.7%	78%	14.3%
All individuals with ASD have mental disabilities.	14.3%	69.7%	16%
People with autism can live independent lives.	49.4%	25.7%	24.9%
Autism is more common in males than females.	53%	9.2%	37.8%
Children can outgrow autism with proper treatment.	56.9%	24.9%	18.2%
Environmental factors alone predispose to ASD.	24.7%	47.2%	28.1%
Family history increases the chance of having ASD.	53.3%	23.2%	23.5%
The social communicative impairments in ASD causes inability to use information from face.	63.7%	13.1%	23.2%
There is no medical test that can diagnose autism.	40.7%	31%	28.3%
Number of children diagnosed with autism has increased exponentially in the last two decades.	82.8%	4.1%	13.1%
ASD patients can't continue studying to bachelor's degree?	20.3%	59.6%	20.1%
Delay in the development of early language, repetitive and stereotyped behaviors are early signs of ASD.	74.8%	7%	18.2%
ASD is a lifelong disorder	52.1%	29.1%	18.9%

Early identification of ASD and intervention during the toddler and preschool years improves outcome.	92.5%	1.9%	5.6%
There is an increased risk of having another child with autism (recurrence)?	32%	37.8%	30.3%

PT=psychotherapy, BT= behavioral therapy, BI=biochemical interventions

Parents of children with ASD had better knowledge and awareness about the early features of ASD (P= 0.006), and the absence of cure for ASD (P=0.001),when compared to parents who don't have children with ASD (Table 3).

Parent's perception about ASD

The participants showed variable levels of perception about ASD. Almost half of the patients (54.5%) strongly agreed/agreed that ASD is a neuro-developmental disorder with a strong genetic basis. Only (16.7%) of the parents had good perceptions about the age groups that can be affected by ASD who strongly disagreed/disagreed on the statement "ASD only affects children". More than half (58.4%) of the respondents know that ASD can be diagnosed as early as 18 months and (67.8%) believed that children with ASD are not necessarily intellectually disabled. Also, almost half (52.8%) of the patients had good perception about the fact that children with ASD have poor eye contact. Almost half (49.1%) of the patients thought that ASD is a non-curable disorder. The majority 85.2% of the parents answered positively when asked whether early intervention could significantly impact the social and communicational skills of children with ASD. Most of the respondents (78.2%) answered positively when asked whether children suffering ASD could grow to become constructive individuals in their society (Table 4).

Table 3: Comparison between ASD vs. Non- ASD parents

Parent of a child with autism	Delay in communication and stereotyped behaviors are early symptoms of autism.			P-value
	YES	NO	NOT SURE	
YES	5	0	52	0.006*
NO	70	29	257	
TOTAL	75	29	309	
Parent of a child with autism	There is a cure for autism			P-value
	YES	NO	NOT SURE	
YES	5	42	10	0.001*
NO	111	161	84	
TOTAL	116	203	94	

* p-value < 0.005 is statistically significant

Table 4: The perception section of the survey

Perception questions	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Autism is a neuro-developmental disorder with strong genetic basis.	20.6%	33.9%	30%	11.4%	4.1%
There is a cure for Autism.	3.6%	19.1%	28.1%	27.6%	21.5%
Autism affects only children.	24.7%	36.8%	21.8%	11.9%	4.8%
Autism can be diagnosed as early as 18 months.	18.2%	40.2%	25.9%	14.8%	1%
People with Autism are intellectually disabled.	3.1%	9.4%	19.6%	43.8%	24%
Autistic individuals are violent and aggressive.	7%	24%	32.2%	29.1%	7.7%
ASD patients are unable to form social relationships.	15.5%	37%	26.2%	16.5%	4.8%
Autistic children display poor eye contact.	18.2%	34.6%	25.4%	15.7%	6.1%
Early interventions have a great impact on communicational skills of ASD patients.	50.8%	34.4%	11.6%	1.2%	1.9%
ASD children perform better if tasks are presented visually rather than verbally.	27.1%	42.6%	24.9%	3.6%	1.7%
ASD children can become constructive individuals.	35.1%	43.1%	14.5%	6.3%	1%
ASD children do not show affection.	8.7%	24.2%	26.6%	28.3%	12.1%
Chances of a child being diagnosed with ASD depend on his socioeconomic class and education level.	31.7%	35.4%	23%	8.2%	1.7%

Knowledge and perception of parents in relation to their level of education

The parents' knowledge and perceptions about ASD were significantly affected by their education level as the number of correct answers increased with higher levels of education. Knowledge questions that were significantly affected by the level of education include the question asking if ASD is a lifelong disorder (P-value = 0.003), the questions about causes of ASD; "if vaccines can cause ASD" (P=0.033), and "if family history increases the risk of having a child with ASD" (P=0.005).

Also, the question regarding the treatment options for ASD was answered more correctly by those with a Ph.D. degree who achieved the highest percentage of correct answers compared to others with lower levels of education (P=0.025) (Table 5). Similarly, in the perception section, the percentage of correct answers was increasing with higher level of education, those questions include: "autism is a neurodevelopmental disorder" (P=0.001), "Autism affects only children" (P=0.002), and the question asking whether early intervention significantly impacts ASD patients' social and communication skills (P=0.034).

Table 5: knowledge and perception data in relation to the level of education

Knowledge section	P- value in relation to the level of education
	P - value
ASD is a lifelong disorder?	0.003*
Family history increases the risk of having autism.	0.005*
Can vaccines cause autism?	0.033*
Early interventions have a great impact on communicational skills of ASD patients.	0.003*
Is there an increased risk of having another child with ASD (recurrence)?	0.0003*
The treatment option is?	0.025*
Children can outgrow autism with the proper treatment.	0.010*
	P- value in relation to the level of education
Perception section	
Autism is a neurodevelopmental disorder with strong genetic bases.	0.001*
There is a cure for ASD	0.002*
Autism affects only children	0.001*
Early interventions have a great impact on communicational skills of ASD patients.	0.034*
ASD children perform better if tasks are presented visually rather than verbally.	0.047*

* p-value of <0.05 is statistically significant

Knowledge and perception assessment among males and females

Male participants had sufficient information in critical questions regarding both knowledge and perception. For instance, when asked "if vaccine causes autism" 62.7% of males answered this question correctly compared to 51.2% of the females. Also 37.3% of males vs 19% of females knew that children can't outgrow autism (P=0.001).

In the question asking whether a medical test or a biological marker could diagnose autism, 54.8% of males answered correctly, compared to 34.5% females (P=0.001). Finally, 64.3% of males answered that autism is a lifelong disorder compared to only 46.7% of females (P=0.003). Similarly, male participants answered better in the perception section. They showed

a higher percentage (71.4% males vs. 47.1% females) of correct answers to the question asking about: whether ASD is a neurodevelopmental disorder with strong genetic bases (P-value of 0.006). When asked if patients with ASD display poor eye contact, 63.5% of males answered correctly vs. 48.1% females (P= 0.03). Similarly, most males 58.7%, knew that there is no cure for autism compared to 45% of females (P= 0.014). On the other hand, 63.1% of females knew that autism can be diagnosed at 18 months, while only 46.7% of males answered this question correctly (P=0.003).

Discussion

We had evaluated the parents' current knowledge and perception towards autism by a self-administered questionnaire. Regarding assessing their knowledge, our participants had adequate knowledge in general. Since

almost three quarters of our sample (74%) could identify ASD's early symptoms, (76%) believed that children can outgrow autism with proper treatment, and 92% believed that early identification would improve the therapeutic outcome. Also, 82% of the parents knew that the prevalence of ASD has dramatically increased in the past two decades. Similar rates were obtained in a study conducted in Malaysia among university students in 2018, where 87% were aware of the early symptoms of ASD, 73% thought young patients with ASD could outgrow this disorder with proper treatment, and 83% believed that early identification would positively affect the outcome (16). We believe that awareness has risen along with autism's prevalence. As autism is no longer a rare disorder, it is possible to have a child with autism, to deal with a child with ASD, or to merely hear about autism in social media, which makes nowadays most parents able to identify its unique characteristics and enhance their general knowledge in its regards.

Although our participants were not completely unaware of the causes of ASD, since 78% of parents believed that poor parenting does not cause ASD, they still displayed insufficient knowledge in identifying the actual causative factor, since 46% either believed or were not sure whether vaccine caused ASD, 53% either believed or were not sure whether environmental factors alone predisposed to ASD and only 53% knew that family history increased the risk of ASD. This was consistent with a previous study conducted among Saudi parents during the year of 2012, when 55% of the parents were unable to identify the causes of autism (12). Knowledge did not rise among the Saudi population about this topic since 2012, and parents were still not very aware of the actual causes of ASD. We believe that further awareness is required in order to correct these misconceptions.

Almost half of the parents (49%) believe that a child with ASD can live an independent life. Similarly, a study was conducted in the United Arab Emirates among university students in 2016, in which 50% believed that ASD patients could live independently (15). We were expecting this variation which depends on the severity of ASD in an affected child, the skills he/she has gained, and their desire either to live independently or among their family members. Our results also illustrate that the education level significantly affects the level of knowledge. Particularly, when the patients were asked about ASD's causes, chronicity, and treatment since our study pointed that higher education was associated with better knowledge about the mentioned aspects of ASD.

As for perception, we found an acceptable level among parents in our sample. Since more than half of the participants, 54.5% either agreed or strongly agreed that ASD is a neurodevelopmental disorder, 58.4% knew that ASD can be diagnosed as early as 18 months. Also, most of the sample were able to identify the features of a child suffering ASD since 67.8% did not agree that people who have ASD are intellectually disabled, 52.8% knew that children suffering ASD display poor eye contact, on the other hand, only 49% knew that ASD had no cure which was less than the expected. Those result were somewhat higher than the reported outcome in a paper conducted among medical and non-medical students in Malaysia in 2018, where 57.4% knew that ASD is a neurodevelopmental disorder, 37.9% believed that patients who have ASD are intellectually disabled. Only 32.3% of participants knew that poor eye contact is a sign of ASD. Finally, 46.7% of the Malaysian sample thought there is a cure for ASD (16). Since our target sample was parents, we assume that they care more to know about a disease that might affect their children. 85.4% of our sample agreed or strongly agreed that early intervention could significantly impact an ASD child's social and communicational skills. 78.2% agreed that children suffering from ASD could grow to become constructive individuals in society. 69.7 % agreed that children who have ASD perform better if tasks were presented visually rather than verbally. And 67.1 % of parents thought that the chances of a child being diagnosed with ASD depend on his/her socioeconomic class and education level. Those results are like the results observed in a previous study in UAE, 2016 where 75.9% of the participants agreed that early intervention could improve the outcome of a patient with ASD (15).

Our results suggest that the level of education affected participants' knowledge and perception, which was expected, but we unexpectedly found out that males have slightly better knowledge and perception in some questions when compared to females, which is non-compatible with a previous study conducted in Jordan during the year of 2016, where the level of education did not affect the level of knowledge about ASD, and females had higher knowledge than males (18). This can be explained by the fact that in our sample, most males had a higher level of education than females, which allowed them to gain knowledge from reliable sources, and therefore, have fewer misconceptions and a higher level of understanding of ASD.

A major limitation is that the questionnaire was distributed through electronic forms since it was done

during the COVID-19 pandemic's quarantine so, our research team didn't have the chance interview the participants in person and make sure that the participants understood all the questions and clarified the vague questions. Also, our team couldn't distribute our survey equally neither between males and females nor between parents of children suffering ASD and parents of children who are not affected, in order to have more accurate results. Also, there was a severe lack of data about this topic in Jeddah Saudi Arabia, which made it very difficult to compare our results to previous data in the same settings.

Conclusion:

This study demonstrates an acceptable level of knowledge and perception among parents in Jeddah, Saudi Arabia about ASD. Males answered better in both knowledge and perception sections. Also, the level of education had a significant positive influence on both sections. There was an insufficient knowledge regarding the disease's causes. We suggest educating the society about ASD features and concepts through awareness campaigns and to encourage celebrating yearly Autism Day.

Disclosure statements:

Conflict of interest:

There is no conflict of interest

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Ethical consideration:

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Data availability:

Data that support the findings of this study are embedded within the manuscript.

Author contribution:

All authors contributed to conceptualizing, data drafting, collection, analysis and final writing of the manuscript.

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