

Autism Knowledge among the public in Saudis Arabia

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Abstract

Autism is defined as a neurodevelopmental syndrome that starts early in life and manifests as an unusual behaviors of negligence, independence, isolationism, and constant repetition that believed to be held by a defect in special areas of the brain that assembles what is known as “the social brain”. The disease is found to be highly heritable, with strong genetic association evidence. The aim of this study is to measure the Saudis general knowledge of ASD, the causes, the treatment, and their attitude toward it in order to determine the level and significance of the educational interventions needed to raise the awareness of the Saudi society about the disease and the proper ways to deal with it.

Keyword: *Autism, Knowledge, Saudi Arabia*

INTRODUCTION

Autism is defined as a neurodevelopmental syndrome that starts early in life and manifests as an unusual behaviors of negligence, independence, isolationism, and constant repetition that believed to be held by a defect in special areas of the brain that assembles what is known as “the social brain”⁽¹⁻³⁾ and leads to a disturbance of the interpersonal emotional communications and failure to develop peer relationships^(4, 5), that neural defect starts by causing language delay in the majority of the patients and could cause mental retardation in some others⁽⁴⁾. It is also believed to be associated with other psychiatric comorbidities like anxiety, depression, attention deficit hyperactivity disorder (ADHD) and behavioral problems.^(6, 7)

The disease is found to be highly heritable, with strong genetic association evidence⁽⁸⁻¹³⁾ and increasing prevalence; in Canada the prevalence had increased by 63% in just 2 years, and it is on increase of 18-26% annually in the US according to official reports to Congress⁽¹⁴⁾, with a prevalence of 1 in 88 children (5 times higher in males) according to the CDC’s Autism and Developmental Disabilities Monitoring Network, 2008, in The United States⁽¹⁵⁾; in Saudi Arabia reports indicate 42,500 diagnosed children in the year 2002⁽¹⁴⁾ while unfortunately there is no estimating rates of the incidence could be obtained.

A study done by (Furnham & Buck, 2003) in London discussed the lay beliefs about the etiology and treatment of autism, and the results seemed matching experts’ opinions, in regard to the etiology, biomedical reasons (like genetics or congenital damage) were preferred by the participants over the psychogenic; While for the treatment psychogenic approach (like education and behavioral change) was little preferred, yet these results seem of low benefit since the authors indicated that their sample was not representative as it was small and the participants were mostly middle-aged, educated females⁽¹⁶⁾. Another study by (Campbell, 2011) in the US measuring middle school students’ knowledge, and it showed that

slightly more than half of the students (53.9%) haven't heard of autism before, with higher scores in correctly answering questions testing the knowledge among the counter group of whom had prior awareness of the disease⁽¹⁷⁾. In (Heidgerken, 2005) study among health care providers, it indicated that primary health care providers still have a confusion between autism and childhood schizophrenia, and also reflecting an outdated data like revealing the cause of autism to the failure of parenting.

In Saudi Arabia, the less-developed child psychiatric services in Saudi Arabia certainly hides the burden of the extent of ASD and the other important psychiatric co-morbidities among Saudi children, and that also could explain the high number of dropped cases in Saudi Arabia⁽¹⁸⁾.

Promising findings have shown that early diagnosis of autism will permit for Early Intensive Behavioral Intervention (EIBI) and that would help to create a friendly environment suitable for the autistic child resulting interestingly in a great improvement of the child's symptoms^(18, 19).

The aim of this study is to measure the Saudis general knowledge of ASD, the causes, the treatment, and their attitude toward it in order to determine the level and significance of the educational interventions needed to raise the awareness of the Saudi society about the disease and the proper ways to deal with it.

Methodology

Participants:

This is a quantitative, observational, cross-sectional study, studying citizens living in Saudi Arabia, and a convenient sampling technique was used, of the data received, only responses from Saudis older than 16 years of age were included.

Questionnaires:

Data collection sheet consists of 5 parts as follows, general demographic data, (including age, gender, residence, education, marital status, number of children, monthly income, and if the family has an autistic child among them); general knowledge of the public about autism, if they have heard of it, and how do they know about the different features of the disorder; the public knowledge about the causes of autism, and it included the common controversial believes, and a local religious/cultural question; the different treatment approaches in autism and how the public view and knowledge of them, and consisted of questions about the different management approaches found in the literature, and about the general course of the disorder with or without management; Finally, the last part focused on the attitude of the public toward people diagnosed with the disorder. The questionnaire was validated through a pilot phase of data collection conducted prior to the questionnaire distribution. (Table 1)

Table 1: this is the English version of the questionnaire distributed among the participants

Autism knowledge and attitude questionnaire			
Demographic data:			
Age	Average monthly income	having an autistic child in the family	Age
Residency	Marital status	Occupation	Residency
Nationality	No. of children	Level of education	Nationality

Knowledge questions:
<i>Generally about the disease:</i>
1. Have you heard about autism before?
2. Is autism a communicable disease?
3. Most children with autism do not show attachments, even to parents.
4. Autistic children are deliberately uncooperative (they can control their behavior).
5. Autism occurs more commonly among higher socioeconomic.
6. Autism tends to run in families.
<i>Regarding the cause:</i>
1. Is it organic in nature?
2. Is it caused by failure of parenting?
3. Is it caused by pregnancy's complications?
4. Is it caused by food or allergy?
5. Is it related to mother vaccination during pregnancy?
6. Is it related to child's vaccination?
7. Is it caused by Jinn "the devil" actions?
<i>Regarding the treatment:</i>
1. What is the best current treatment approach?
a. Educational
b. Behavioral therapy
c. Dietary interventions
d. Medical approaches (Drugs)
e. Surgical
2. Children with autism can grow up to live independently without treatment.
3. Early intervention can lead to significant gains in children's social and communication skills.
4. With the proper treatment, most children diagnosed with autism eventually can-outgrow the disorder.
5. There is one approach/program that works for all children with autism.
Attitude questions:
1. Is it important that all children diagnosed with autism receive some form of special education services at school?
2. Do you mind your child having an autistic friend?
3. Do you mind letting one of your sons or daughters marrying an autistic patient?

Data collection and analysis:

The questionnaire was distributed among Saudi citizens using SurveyMonkey®, throughout social media channels such as Twitter®, WhatsApp®. In addition to the paper-based method. Data collection was conducted during the period from April 2013 to March 2014. Data was entered in Microsoft Excel and analyzed using the SPSS® program version 19 year 2010. The data was presented as means ± standard deviation, frequency, median, maximum, minimum and percentage. Statistical differences will be ascertained by using the chi-square with significance set at a P value of 0.05 or lower.

Ethical consideration:

All participants consented through a fixed statement at the beginning of the questionnaire distributed, and the Institutional review board (IRB) approval was obtained prior starting data collection.

All data received are maintained confidential and in possession of Autism Research and Treatment center (ART) at King Saud University, Riyadh Saudi Arabia.

RESULTS

The Demographic data

A total of 367 participants have participated in the study, 37.3% who answered the survey were aging between (26 -35), 36.7% were between (16 – 25), 19.8 % were between (36 – 45) and only 4% were 46 and older. with the majority living in the central region 76.8%, and 20.4% were from the eastern region, 2.7% from the western region, and no participants were from the northern nor southern region. furthermore, 67 % of the participants have a bachelor degree, 22.6 % have secondary school degree or less. In addition, 56.4% of were married, 49% have one child only, 28.3% have between 2-3, and 22.6% have more than 4 children. Moreover, 23.4% of the participants have an autistic member, and 49.6% have a monthly income of 5000 riyals or less, 22.6 have more than 5000 to 10000, 16.6% have more than 10000 to 15000, and 11.2% earn more than 15000. (Table 2)

Table 2: this table summarizes the demographic data found in this study

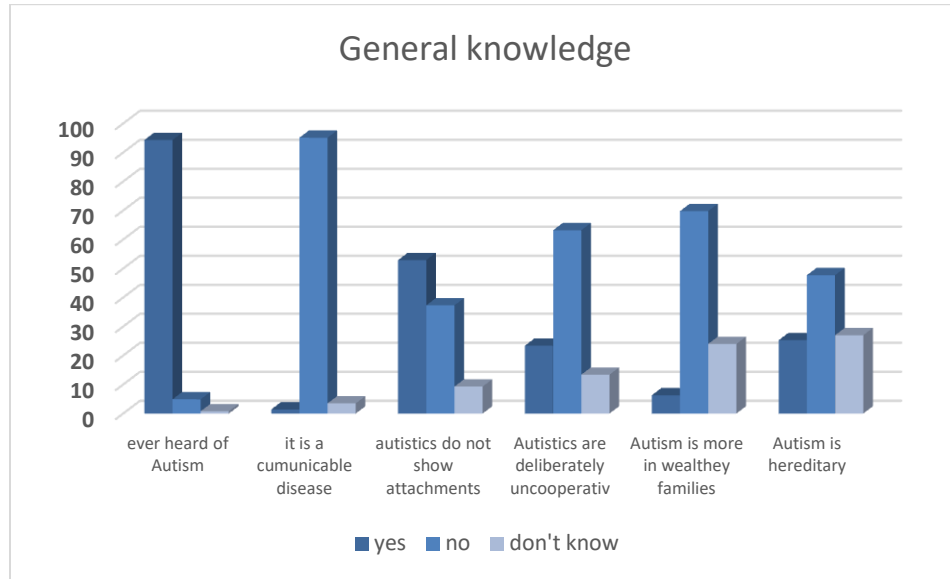
The demographic data				
Age	16-25	26-35	36-45	46 and older
	37.30%	36.70%	19.80%	4%
Residency	central	western	eastern	Northern and southern
	76.80%	2.70%	20.40%	0
Education	secondary school and below	higher Edu.	bachelor	
	22.60%	10.40%	67%	
Marital status	married	single		
	56.40%	43.60%		
Number of children	0	1 to 3	more than 4	
	49%	28.30%	22.60%	
Families with an autistic child	yes	no		
	23.40%	76.60%		
Monthly income	5000 or less	5000 to 10000	> 10000 to 15000	> 15000
	49.60%	22.60%	16.60%	11.20%

General knowledge about autism:

Regarding Autism knowledge among Saudis, 94.3 % have heard of the disorder before, and 5.7% are not sure if they know it. Further, 95.1% don't agree that autism is a communicable disease, while 4.9% don't know. 53.2% agree that most of the autistic children don't show attention to the people and the environment surrounding them, while 37.5% don't agree with that statement, and 9.3% don't know. Moreover, 63.2% think that they are not deliberately uncooperative, and 23.4% think they are and assume they can manage their emotions and behavior, and 13.4% don't know. Furthermore, 69.8% don't link families with higher socioeconomic status to the emergence of the disorder occurrence, 24% don't know, and 6.3 % see an association between autism and wealth in families. Additionally, 47.7% don't agree that

there is a genetic factor in the disease process, 25.3% agree, and 27% don't know if there is a link between genetics and Autism. (Figure 1)

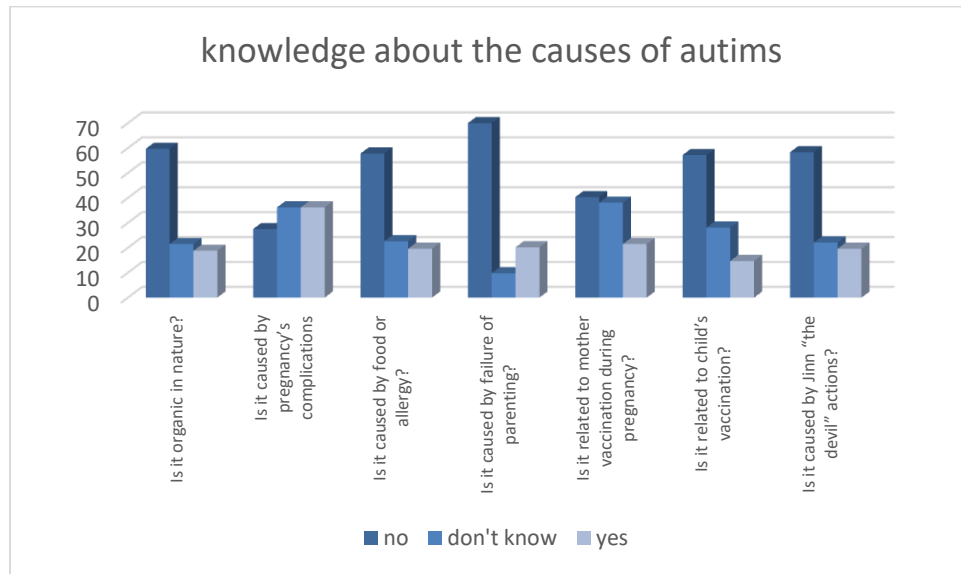
Figure 1: this figure is showing the percentage of different responses to the questions addressing the general knowledge of Saudis toward autism



General knowledge about the causes of autism:

When asking Saudis about the causes of autism, 59.7% believe that it's a non-organic disorder, 21.5% don't know, 18% agree that it is organic. In other respect, 36.2% think it is caused as part of a sequelae complication during pregnancy, 36.2% didn't know, while 27% don't agree. Furthermore, 57% don't think it is due to food allergy, 22.6% don't know, while 19.6% think of it as a cause. Moreover, 70% don't accuse the parenting ways of raising the child for the occurrence of autism, while 20.2% agree that parenting has a causation effect to autism, and 9.8% don't know. Additionally, 40.3% don't agree that the mother vaccination could be a potential cause of autism, 38.1% don't know, and 21.5% agree that it could be a cause. Furthermore, 57.2% don't think the child's vaccination could cause the disorder, 28.1% don't know, while 14.7% think it is linked to the disorder. Finally, 58.3% don't believe that it is a type of the devil's action "Jinn" on the child, 22.1% don't agree, and 19.6% believe it can be a cause. (Figure 2)

Figure 2: this figure is showing the percentage of different responses to the questions addressing the general knowledge of Saudis about the causes of autism



General knowledge about the treatment of autism:

49% don't think that Autistic children will outgrow the disorder and live independently without treatment, while 24.8% don't know, and 26.2% agree that it could pass away naturally. Additionally, 96.5% agree that early intervention can lead to significant gains in children's social and communication skills, 2.5% don't know, and 1.1% don't agree. Furthermore, 51.2% agree that with the proper treatment, autistic children will outgrow the disease, while 27.2% don't agree, and 21.5% don't know. In other respect, 76.8% think that there is no one management approach that works for all autistic children, 18.8% don't know, while 4.4% agree. Moreover, when asked about the best approach treatment, 72.8% have chosen behavioral, 16% educational, 3.3% nutritional, and 2.5% have chosen drug medications, while 5.4% thought there is no effective intervention. (Figure 3) and (Figure 4)

The general attitude of Saudis to toward autism:

When enquiring about the attitude of Saudis, 82.8% agreed on that autistic children need special educational services. Moreover, 69.2% will allow their children to have an autistic friend, while 24.5% stayed neutral. In another note, 69.2% would hesitate before allowing their siblings marrying and autistic patient.

Figure 3: this figure is showing the percentage of different responses to the questions addressing the general knowledge of Saudis about the treatment of autism

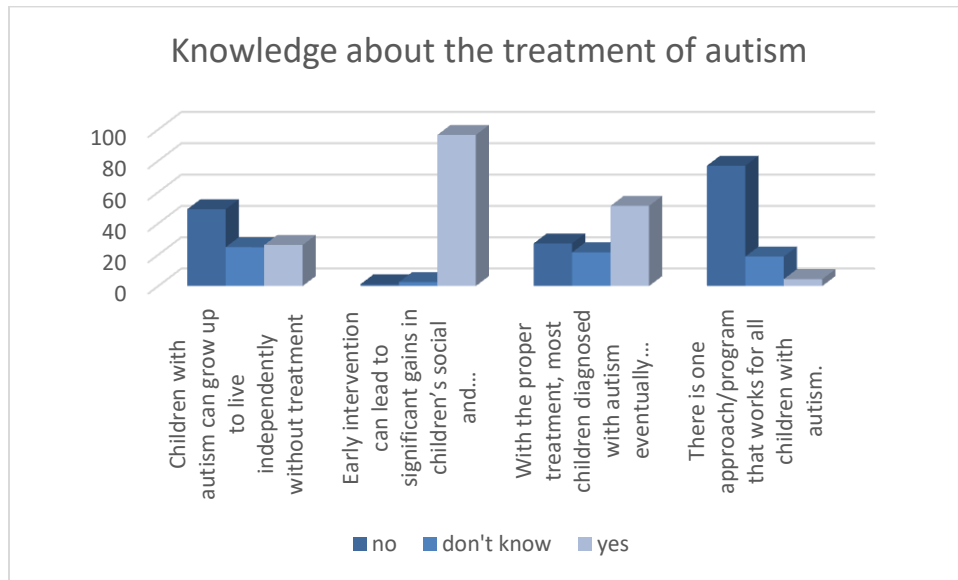
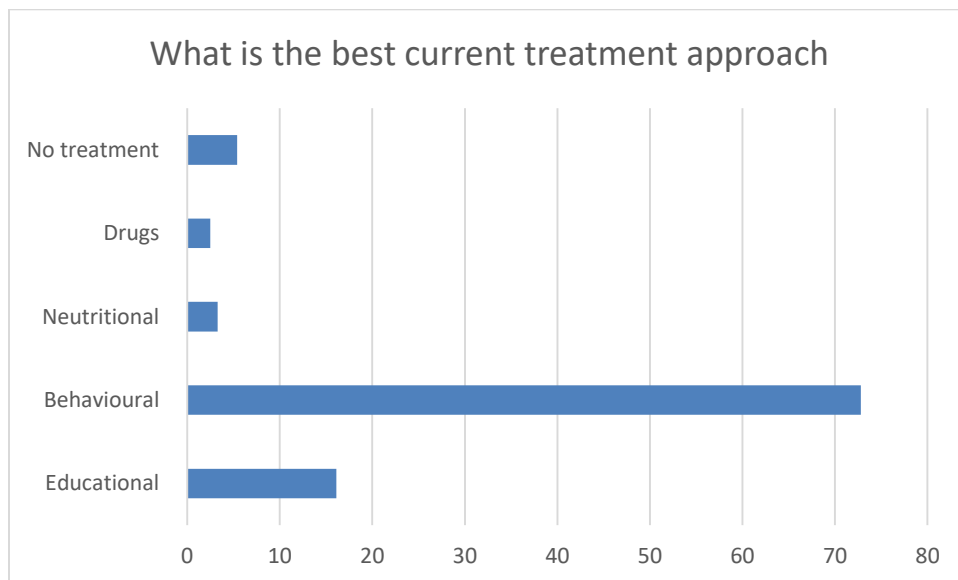


Figure 4: this figure is showing the answers of the best current treatment approach/approaches; participants were able to choose more than one answer



DISCUSSION

As the results shows, the majority of Saudis have heard of autism, and the general knowledge seems to be adequate to the popularity of the disease, as almost all Saudis know that it doesn't spread with contact, or it's associated with families with higher socioeconomic status, but the community splits on the

facts that the autistic are not deliberately uncooperative rather it's the nature of their disorder⁽²⁰⁾, and if it's a hereditary disorder, which recent data addresses some strong hereditary association in autism rather.^(10, 21)

Many etiologies have been linked to autism, the genetic involvement is one of the strong associated aspect as many investigations are established in that perspective, though the food allergy might not be accurate words describing other etiologies other aspects discussed environmental factors such as the possibility of immune-mediated neuroinflammation process in the autistic child's neuronal system during development, as a result, from an imbalanced or inadequate nutrition.⁽²²⁾

As the heavy discussion of vaccines and Autism, the literature concludes no relation between the MMR vaccine and the disorder, other aspects have raised the concern of Ethylmercury containing vaccine, and since 2001, the U.S. food and drug administration have reduced the use of this metal in vaccines and got limited only in the Influenza vaccine, and a review article showed that it mostly has no strong linkage with the disorder.⁽²³⁾

In our survey, the community showed less attention the organic cause of Autism and reflect a believes that it is only a pure psychiatric process, less than half (36.2 %) don't relate pregnancy complications as a cause while the literature indicates the opposite and indicates the importance of pregnancy nutrition and the avoidance of some metals and environmental exposure during pregnancy in the prevention of Autism,⁽²⁴⁻²⁶⁾. our survey also shows more than the half still doubt on the causative relation of the mothers and the child vaccination to Autism. Remarkably 42% of the participants can link some religious interpretation to the cause of Autism as the devil's act on a human is not unpopular in the country.

Early intervention suggests positive outcomes⁽²⁷⁾ and the current literature suggests many approaches, of the ones applied commonly to Autism, are the applied behavioral analysis and the early intensive behavioral intervention^(28, 29), while some practitioners encourage the enrolment of Autistic children in a special learning program such as the TEACCH project (treatment and education for Autistic and related handy-caped children) which targets promoting the child's independence, and other interventions targeting the child's social interaction improvement.⁽³⁰⁾

Those different interventions mainly aiming at increasing the independence of the autistic child when growing up. In our survey, almost 50% of Saudis believed that autistic children can't outgrow the disorder by themselves, while 51% were optimistic and believed that they can outgrow the disorder with the proper intervention, either ways, nearly all of the participants agreed that early intervention has positive potentials in improving the child's condition, when asked more about the intervention, majority (76%) agree that not all Autistic children should get the same interventional approach, and behavioral intervention was believed to be the most effective by a great majority (72%) and 82.8% agreed on that they need a special educational services at school.

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