

Knowledge and awareness of autism spectrum disorder among Libyans

ARIEJ M. MUSTAFA^{1,2}, DHIBA S. GRIFA^{1,3}, AFAF SHEBANI^{1,2}, SALAH ALHARABI¹ and KHALID ALNAJJAR¹

¹National Center for Diagnosis and Treatment of Autistic Children; ²Department of Genetic Engineering, Biotechnology Research Center; ³Psychology and Education Department, University of Tripoli, Tripoli, Libya

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Abstract. Autism spectrum disorder (ASD) is a neurodevelopmental disorder characterized by the presence of delayed or defective development before the age of three years, as well as behavioral difficulties in social communication and interaction. To evaluate ASD knowledge and awareness, as well as ASD information sources in a sample of the Libyan general population, and to explore factors that could be associated with the knowledge and awareness. A cross-sectional study was carried out between 22 March and 13 August, 2022 using a self-administered questionnaire. The study included 2350 individual aged 18 and up from households living in different regions in Libya (eastern, southern, central, and western). Out of 2195 participants, 48.9% were females and 51.1% were males. Three-quarters of the participants (74.8%) presented a low level of knowledge about autism causes. Of those whose source of knowledge of autism was social media, 78.9% had a low level of knowledge. However, 57.9% of the participants showed a good level of awareness of autism symptoms and signs. The participants had a limited understanding of the causes and characteristics of ASD. Raising community awareness of the causes and characteristics of ASD is a priority.

Introduction

Autism spectrum disorder (ASD) was first described in the early forties by an American child psychologist named Leo Kanner. He displayed 11 children whose actions were distinct from other children, and he suspected that they had an innate characteristic that limited their regular sociability. Early

infantile autism, childhood autism, or Kanner's autism are all terms used to describe autism (1).

According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, ASD falls under the umbrella of neurodevelopmental disorders. It is characterized by impairments in social communication and interaction and by restricted, repetitive patterns of behavior, interest, or activities that are manifested during the first years of life. These two criteria exist on a continuum in terms of severity and dysfunction (2). The social interaction difficulties that autistic people face range from relatively minor difficulties to more serious behavioral problems, including not speaking, adhering to strict routines, and social isolation relies (3).

The diagnosis of ASD is complicated because there are no current direct diagnostics, such as blood tests or specific biomarkers to confirm the diagnosis. Therefore, autism is diagnosed by observing the child's behavior (3).

Although the causes of autism are unclear, several studies describe a strong genetic link because most cases of ASD are associated with a combination of genetic factors. However, it cannot be related to a single genetic mutation or chromosomal abnormality (4). Also, other risk factors are involved, such as sex. Autism is four times more common in males than in females (5). Other risk factors are family history, parents' ages, and the presence of other disorders such as fragile X syndrome, tuberous sclerosis, Tourette's syndrome, and epilepsy (6). Intrauterine viral infections or metabolic disorders might also have a role in ASD etiology, as well as exposure to teratogenic medicines during pregnancy. Thalidomide and valproate have also been linked to autism in a small number of children (1).

Changes in normal brain growth very early in development may be the cause of ASD. These abnormalities could be caused by errors in the genes that regulate brain growth and communication between brain cells (7).

Several myths and misconceptions concerning ASD have appeared, such as the belief that vaccines cause ASD. However, the World Health Organization (WHO) has stated that there is no documented link between any vaccine, including the MMR vaccine, and the development of ASD (8).

The estimated overall prevalence of ASD in children aged 8 years in 2018 was 23.0 per 1,000, with variations between the 11 Autism and Developmental Disabilities Monitoring

Correspondence to: Dhiba S. Grifa, Psychology and Education Department, University of Tripoli, Libya, National Center for Diagnosis and Treatment of Autistic Children, Tripoli, Libya
E-mail: d.grifa@uot.edu.ly

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(ADDM) Network sites. These estimates are higher than the estimates for the prevalence of ASD from the ADDM Network in previous surveillance years (5).

Expanded diagnostic standards and increased public awareness of the disorder are likely contributors to the rise in its reported prevalence. The public, parents, health professionals, and the scientific community have lately all observed an exponential increase in knowledge and awareness of the disorder. The world has started to understand the magnitude of this issue and has taken worldwide and local action to better the lives of the increasing number of people and families affected by this disorder (9).

Having adequate public awareness and a good understanding of the symptoms of ASD is critical to the early detection of autistic children. Lack of awareness, particularly among parents, health professionals, and teachers, leads to a high risk of misdiagnosis or late diagnosis, as well as a negative attitude toward people with ASD (10). It has been found that the media is one of society's primary sources of information about ASD (10).

Based on this background, research is needed to assess the knowledge and awareness levels of ASD, as well as the knowledge of its signs and symptoms, and to discover any gap in awareness or lack of information in Libya. This is important for the implementation of any local ASD management strategy.

Material and methods

Ethical considerations. The study was approved by the local ethics committee of the Biotechnology Research Center, Tripoli, and written informed consent was obtained from all the participants.

Study design. The sample consisted of 2350 adults aged 18 years or over from households living in different regions in Libya (eastern, southern, middle and western).

To eliminate the selection bias for the study sample we obtained the study sample from various state institutions, companies and universities, as well as from public commercial markets and parks.

We used a cross-sectional sampling, in which the study instruments were distributed to people who agreed to take part in the research. The study was carried out between 22 March and 13 August, 2022.

Research tool. A questionnaire was developed by the authors in English after an extensive literature search. To ensure the accuracy and validity of the final Arabic version, a forward and a backward translation approach was used. The content validity of the translated questionnaire was evaluated by a team of experts in psychology, primary health care, and pediatrics.

The questionnaire consisted of three sections. The first part covered the demographic characteristics of the participants, such as age, gender, region of residence, and educational level. The second section consisted of seven questions to assess the participant's knowledge of the causes of ASD, suggesting ASD causes such as vaccines, watching TV, parental abuse (violence), and genetic factors, as well as whether it is a rare, long-life, or psychological condition. The third section consisted of nine questions exploring the participants' knowledge of ASD

symptoms, such as whether autistic children have communication difficulties, delayed name response, special abilities, and skills, etc. The multiple answers to the questions in the second and third sections were based on a three-point Likert scale: disagree, neutral, and agree.

The questionnaire was distributed to 2,350 participants living in different regions in Libya.

Statistical analysis. All statistical analyses were performed using the Statistical Package for Social Sciences (IBM SPSS Statistics for Windows, Version 26.0. Armonk, NY: IBM Corp). Participants' responses were descriptively analyzed as frequencies and percentages. A knowledge score was calculated to reflect a participant's opinions about ASD and its signs and symptoms by assigning one mark to each correct answer and zero for each incorrect or neutral answer. To determine the degree of knowledge of the study sample on their knowledge about autism causes, it was determined based on previous studies that everyone who answered 50% or more of the questions correctly had a good level of knowledge. We considered 4 out of 7 (57%) as a good score for the participant's knowledge about the etiology of autism and 5 out of 9 (55.5%) as a good score for their awareness of its signs and symptoms. Knowledge and awareness scores were then compared to other sociodemographic parameters like age, gender, education level, etc. To compare categorical variables, the Chi-square test was performed. A P-value less than 0.05 was considered to be a significant association.

Cronbach's alpha was calculated for all 2195 completed questionnaires to assess the internal consistency of the questionnaire. Its value was 0.83.

Results

Participants' demographic characteristics. Of the 2350 questionnaires, 155 were excluded due to missing information or failure to complete the questionnaire. Hence, the data were analyzed for 2195 participants. Table I presents the sociodemographic characteristics of the participants. The distribution of participants by geographic area was as follows: 852 (38.8%) in the western region of Libya while, 493 (22.5%) in the eastern region, 481 (21.9%) in the middle region, and 369 (16.8%) in the southern region. Females (n=1074) represented 48.9% of the sample and males (n=1121) represented 51.1%. Over half of the participants (56.8%) were aged 25-35 years. Age group ≥ 55 years represented only 8.7% of the sample. More than half of the participants (53.9%) had a bachelor's degree, 9.9% had a Master's degree, and only 1.8% had doctorate degrees. The rest had high school or intermediate school diplomas. About one-third of the participants (30%) had graduated in basic sciences, 28.7% in humanities, and 19 and 16.9% in medical sciences and applied sciences, respectively. The remaining 5.3% were from language departments.

Participants' knowledge and sources of information. The majority of the participants (82.2%) reported that they had previous knowledge of ASD, while (17.8%) stated that they did not. Table II shows the participants' sources of knowledge about ASD. Of those who knew of ASD, 29.8% reported that having a relative who has a child with ASD was their main

Table I. Sociodemographic characteristics of the participants.

Characteristics	N	(%)
Sex		
Male	1121	51.1
Female	1074	48.9
Age group (years)		
25-35	1246	56.8
36-45	486	22.1
46-55	272	12.1
>55	191	8.7
Educational level		
Intermediate diploma	253	11.5
High school diploma	500	22.8
Bachelor's degree	1184	53.9
Master's degree	218	9.9
Doctorate	40	1.8
College specialization		
Basic sciences	371	16.9
Humanities	659	30
Applied science	631	28.7
Medical science	418	19
Languages	116	5.3
Residence		
Eastern region	493	22.5
Southern region	369	16.8
Middle region	481	21.9
Western region	852	38.8

source of knowledge, followed by social media (27.8%). TV (20.8%) came in the third place, and the remaining responses were the literature (11.7%) or a friend (9.9%).

Additionally, 78.9% of those whose source of information about ASD was social media had a poor level of knowledge of its causes. On the other hand, 37.8% of the participants whose source of information was having an autistic child or a relative whose child has ASD had a high degree of knowledge of the causes of ASD. There was a highly significant association between the source of information and the level of knowledge about the causes of ASD ($P=0.000$).

Contrarily, it was evident that participant's awareness of the signs and symptoms of ASD was higher than their knowledge of its causes, as evidenced by the high awareness levels of 74.5% of participants whose source of information was television, 62.9% of those whose information was social media, and 57% of those whose information came from having an autistic child or a relative whose child has ASD, with a significant association ($P=0.000$).

Participant's knowledge about the etiology of ASD. More than half of the participants (58.2%) correctly agreed with the absence of a connection between vaccines and ASD (Table II). Only 20.3% disagreed with the statement that watching TV causes ASD.

Half of the participants (50.8%) believed that ASD has a genetic cause, but only 25.1% knew that ASD is not a rare disorder. Only 16.1% believed that ASD is not a psychological condition and only 19.8% agreed with the statement that ASD is a life-long condition. Moreover, 40.2% disagreed with the existence of a link between parental abuse and autism. Overall, 74.8% of the participants showed a poor level of knowledge about autism causes. The scores for knowledge of the causes of ASD ranged from 0/7 to 5/7, with a mean \pm SD of 2.46 ± 1.18 .

Participant's awareness about symptoms and signs of ASD. As for awareness, 65.5% of the participants agreed with the notion that the autistic child has difficulty communicating with others (Table III). Almost half of the participants (49.1%) were aware of the repetitive actions of some autistic children, such as hand flapping and spinning. While 63.1% of the participants knew that autism can be diagnosed before the age of three, 44.6% correctly answered that autistic children exhibit some strange patterns of speech and sounds. One of the potential signs of ASD is avoiding eye contact with others and not responding when they hear their names called; 46.2 and 62.6% of the participants were aware of these two respective signs. On the other hand, a small percentage of participants (13.2%) disagreed with the statement that autistic children have mental retardation, more than the half of them (57.2%) agreed that autistic children have special abilities and skills, and 65.8% disagreed that all autistic children can to integrate into schools. Overall, 57.9% of the participants showed a good level of awareness of ASD signs and symptoms, with a mean \pm SD score (for correct answers) of 2.44 ± 0.099 out of a total of 9. In contrast, 42.1% needed more awareness about it. The range of scores was 0-9 out of a maximum of 9.

Factors related to participants' scores on knowledge and awareness of ASD. There were statistically significant associations between the participants' sociodemographic characteristics and their level of knowledge of the causes of autism, as well as with their level of awareness of its signs and symptoms (Table IV). A larger percentage of females received high scores than males on knowledge (27.4% vs. 23.3%; $P=0.027$) and on awareness (69.1% vs. 47.4%; $P=0.000$). As for age, the frequency of participants with high scores on knowledge and awareness dropped significantly after the age of 55 years. As expected, those who studied medical or other applied sciences had better scores on knowledge and awareness, whereas those in humanities had the worst. For educational level, the results were less clear, with few participants with a higher diploma (4.4%) scoring high on knowledge but most of them (74.6%) scoring high on awareness.

Discussion

Knowing the causes of ASD and being aware of the most significant indicators of signs and symptoms of this disorder in children at a young age is important for early intervention. Our findings show that the majority of the study participants were aware of ASD. About half of them knew what ASD is, and nearly one-third reported that they had some knowledge about it. Notably, more than half of the participants had a child with ASD or a relative with a child with ASD. It has

Table II. Frequency of correct answers on the causes of ASD.

No. of Question	Question	Correct answers (%)	Mean score	Standard deviation S.D.
1	Vaccines cause autism	58.2	2.50	0.645
2	Watching T.V. is the main cause of autism	20.3	2.27	0.778
3	Genetic cause	50.8	2.21	0.871
4	Autism is rare	25.1	2.15	0.795
5	Autism is a psychological condition	16.1	2.35	0.741
6	Autism is a life-long condition or can be treated	19.8	2.26	0.765
7	Parental abuse causes autism	40.2	2.00	0.900

Table III. The correct answers of the participants regarding the symptoms and signs of ASD.

No. of Question	Questions	Correct answers (%)	Mean score	Standard deviation
1	The autistic child has difficulty communicating	65.5	2.54	0.696
2	Has hand flapping and spinning movements	49.1	2.36	0.699
3	Autism appears before the age of three	63.1	2.52	0.680
4	They have peculiar speech and sound patterns	44.6	2.31	0.699
5	They have difficulties in eye contact	46.2	2.30	0.725
6	Delayed name response	62.6	2.53	0.669
7	Most of them have mental retardation	13.2	2.43	0.713
8	Some of them have special abilities and skills	57.2	2.45	0.707
9	All autistic children can integrate into schools	65.8	2.55	0.682

been reported that individuals who had direct interaction with ASD patients had better knowledge than participants who had not (3,11). However, the level of knowledge observed among Libyans was not as high as that reported in developed countries (12-15). Nevertheless, it was above that reported in some Arab countries (3,16,17).

Surprisingly, though most of the participants reported that they had prior knowledge about ASD, most of them had a low level of knowledge. This was verified by deeper questions that revealed misconceptions about the etiology of ASD. However, participants who claimed to have prior knowledge about ASD showed a high level of knowledge of ASD signs and symptoms. This result is in line with previous research indicating that participants who claim to have prior knowledge about ASD exhibit low levels of knowledge of the causes of ASD but a high level of knowledge of its features (18-20).

The causes of ASD are still not clear and there are misconceptions about its causes. This study revealed a highly significant association between the source of information and the level of knowledge about the causes of autism ($P=0.000$). In particular, 78.9% of the participants in this study whose source of ASD knowledge was social media had poor knowledge of its etiology. This is likely because social media do not always contain accurate scientific information. Moreover, it has been noticed that health-related information on social media often contradicts scientific findings (21). On the other hand, (37.8%) of our participants whose source of information was having

an autistic child or a relative whose child has ASD had a high degree of knowledge of the causes of ASD. This finding is consistent with previous studies (3,20). In Libya, knowledge of ASD among the population can be strengthened by activating the pages of the National Center for Diagnosis and Treatment of Autistic Children on social networking sites or the official page of the Center, and disseminating information about ASD based on research findings.

The World Health Organization (WHO) has clarified that there is not sufficient evidence linking any vaccine to ASD (22). More than half of the participants (58.2%) answered correctly that there is no such link. Notably, this result differs from an Australian survey, which indicated that the majority of the participants considered vaccination as a cause of ASD (11).

The WHO and the American Academy of Pediatrics recommend that children younger than two years should not spend any time in front of a screen (23,24). The participants in this study could have been influenced by this recommendation, as about 80% of the participants agreed with the statement that watching TV causes autism.

The current consensus is that ASD has a multifactorial etiology, with environmental factors interacting with genetic factors (25,26). Yet, half of our participants (50.8%) believed that ASD has a genetic cause, and 74.8% of the participants showed a poor level of knowledge about its etiology, with a mean score of 2.46 ± 1.18 SD, (range 0/7 to 5/7). This finding is consistent with a Saudi Arabian study (3). It is also consistent

Table IV. The distribution of sociodemographic characteristics among participants achieving high scores on knowledge and awareness.

Characteristics	Total no.	High knowledge score	P-value	High awareness score	P-value
Sex					
Male	1,121	23.3%	0.027	47.4%	0.000
Female	1,074	27.4%		69.1%	
Age group (years)					
25-35	1,246	23.1%	0.000	60.2%	0.000
36-45	486	33.1%		64.2%	
46-55	272	27.2%		58.5%	
>55	191	16.8%		27.2%	
Educational level					
Intermediate diploma	253	24.5%	0.000	56.5%	0.000
Higher diploma	500	4.4%		74.6%	
Bachelor	1,184	34%		49.8%	
Master	218	26.6%		58.3%	
Doctorate	40	27.5%		100%	
College specialization					
Basic sciences	371	14.8%	0.000	55.5%	0.000
Humanities	659	11.7		50.4%	
Applied science	631	35%		68.6%	
Medical science	418	41.6%		58.6%	
Languages	116	24.1%		49.1%	
Residence					
Eastern region	493	39.6%	0.000	56.2%	0.000
Southern region	369	15.4%		72.6%	
Middle region	481	21.6%		35.8%	
Western region	852	23.4%		65.3%	

with an Australian study reporting a high level of awareness of ASD combined with the existence of a knowledge gap about its etiology. In contrast, a study conducted in the United States found that most of the participants showed a high level of knowledge of ASD etiology (13).

We found the highest frequencies of correct answers in the domain related to knowledge about the signs and symptoms of ASD, with 57.9% of the participants showing a good level of awareness of symptoms and signs; the mean score for correct answers was 2.44 ± 0.099 SD out of a total of 9. This result is consistent with findings from a study carried out in Saudi Arabia showing that the highest percentages of correct answers were on items related to ASD symptoms in children (3). Recognizing the signs and symptoms of ASD in children is crucial for early detection of the disorder and evidence-based interventions that may prevent the development of the disorder, lead to better outcomes, and reduce long-term consequences.

Consistent with a study conducted in Northern Ireland (14), more than half of our participants (57.2%) thought that children with autism have special abilities and skills. On the other hand, it has been reported that only 0.5% of people with ASD have special abilities (27). The participants have probably been affected by the media (e.g., the TV series Good Doctor, Mucize Doctor and Extraordinary Attorney Woo, and the film

Rain Man), which was the source of information about autism for the majority of the participants.

Our findings show that demographic characteristics were associated with ASD knowledge and awareness levels. Sex, age, and college specialization correlated significantly with ASD knowledge and awareness. In line with previous research indicating that females are more aware of ASD than males (4,8,12,13,28), there was a statistically significant association of sex with the level of knowledge ($P=0.027$), as well as awareness of the causes, signs, and symptoms of ASD ($P=0.000$). The knowledge scores of males and females were 23.3 and 27.4%, respectively. The awareness scores had a similar pattern. The notion that females might have been more concerned about diseases than males is consistent with earlier research (11,12,18,29,30).

Participants holding bachelor's degrees had higher levels of knowledge and awareness (72.4%) than the other participants. In addition, those who were 25-35 years old had a higher level of knowledge and awareness than younger and older participants. This is in agreement with reports that adults younger than 24 years or older than 36 years showed lower levels of knowledge and awareness (12,28). It should be noted that most of our participants who had Master's or doctoral degrees were older than 35 years. This may explain

why they had lower levels of knowledge and awareness than participants holding bachelor's degrees. Consistent with the finding that most of the participants' primary sources of information were social media, it is likely that those aged 25-35 years used the internet more frequently than the other age groups. As expected, participants specializing in medical and other applied sciences had the highest level of knowledge and awareness, likely because the syllabi in applied sciences may include topics related to ASD.

The participants' knowledge and awareness of ASD were also associated with geographic regions. Participants in the western region had significantly higher knowledge and awareness levels than those in the other three regions. The western region has the largest population, it has several universities and other educational institutions, in addition to many centers for the rehabilitation of children with ASD, and it has the best internet services. People in this region have likely more opportunities to learn about ASD, whether through formal studies or from the internet, and they might also get more exposure to autistic children.

The findings of this study revealed that Libyans are aware of ASD and its signs and symptoms. However, there is a gap in the knowledge of its etiology and some misconceptions concerning its features. These findings indicate that it is time to focus more on local ASD awareness through campaigns that have been proven to be successful in increasing public awareness and knowledge. Policymakers and healthcare practitioners should invest more effort into educating the public about ASD. As the findings show that most of the participants relied on social media and television as a source of information about ASD, health professionals should also use these channels to enhance the knowledge of the public about ASD.

Limitations

This study is the first to explore Libyan community knowledge and awareness about ASD. One limitation of this study is that the great majority of participants had a university qualification, which could result in an overestimation of the level of awareness and knowledge of the community at large.

Conclusions

Social media was the main source of information about ASD among the study participants. The participants had an acceptable level of knowledge about ASD but a limited level of awareness of its etiology. Government, academic institutions, and professional societies should focus on enhancing the community's knowledge about ASD etiology and features through different means.

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Contributions

All authors contributed equally.

Conflict of interest

All authors declare no conflict of interest.

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