

Awareness and Knowledge of Autism Spectrum Disorders Among Community Pharmacists in Khartoum state(Sudan), 2018

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ABSTRACT

This study was conducted to assess awareness and knowledge of autism spectrum disorders (ASDs) among community pharmacists in Khartoum state. A cross-sectional study was conducted among 345 community pharmacists. All the data were collected from randomly selected by questionnaire. The results indicated gaps in participant awareness and knowledge regarding ASDs. The participant reported low familiarity with ASDs. The median score on 12 item knowledge section regarding ASDs was about 60%. Having continuing education(CE) or training program on ASDs was significantly associated with familiarity and confidence scores. About 64% of the participants reported as not feeling confident enough in their ability to counsel parents about medications used for their children with ASDs and their side effects. Pharmacists' awareness and knowledge regarding ASDs needs to be improved. Providing continuing education programs should be considered to increase pharmacist's awareness and knowledge regarding ASDs.

Keywords: Autism spectrum disorders, Community pharmacist, Behavioral disorders.

INTRODUCTION

Autism Spectrum Disorders (ASDs) are complex, lifelong neurodevelopmental and behavioral disorders manifests as difficulty communicating, abnormal social interaction, and delays in developmental skills⁽¹⁾. The first reported on ASDs was Kanner in 1943 and since then the global prevalence has been increasing consistently⁽²⁾, The Centers for Disease Control (CDC) estimated the prevalence of ASDs nationally as 1 in every 59 children⁽³⁾, it's 3-4 more prevalent

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among males than females⁽⁴⁾, and more prevalent than juvenile diabetes, pediatric cancer, and pediatric AIDS combined⁽³⁾. Because of increasing prevalence, ASDs is widely considered to be an emerging public health concern⁽⁵⁾, ASDs were not shown to be associated with a certain racial, ethnic and socioeconomic group⁽²⁾, it occurs because of an interaction of genetic and environmental factors⁽⁶⁾. Currently, there is no cure for autism⁽⁷⁾ but there are pharmacological and non-pharmacological treatment options to alleviate the symptoms associated with ASDs.⁽⁸⁾

Pharmacological treatment has become increasingly popular in managing behavioral symptoms of ASDs like aggressiveness, anxiety, hyperactivity, and tantrums⁽⁸⁻¹⁰⁾, Risperidone and aripiprazole are drugs approved by The Food and Drug Administration (FDA) for the management of behavioral symptoms associated with ASDs.^(11,12) Other pharmacological classes used to manage symptoms of ASDs include Central Nervous System (CNS) stimulants, antidepressants, and anxiolytics⁽¹²⁾. In today's healthcare system, the role of pharmacists goes beyond merely dispensing medications, they are considered as trusted and easily accessible health care providers⁽¹³⁾. Therefore, the community pharmacist could play an important role in the care of people with ASDs and help them achieve the best results from their medications. The pharmacological treatment of children with ASDs can be challenging. A previous study showed that children with ASDs are particularly susceptible to adverse effects and may exhibit paradoxical reactions to medications.^(14,15) Therefore, improperly trained pharmacists or those with less familiarity and knowledge would fail to do so. This might have consequences on their role in providing healthcare and might result in deteriorating the health and quality of life of their patients.

As the community pharmacist is the first line of interaction with families and/or caregivers in our community, they should be more familiar and knowledgeable about ASDs resources allocated for ASDs in their communities and should guide families of children with ASDs to relevant professional resources. Unfortunately, previous studies reported cases of pharmacists lacking knowledge and awareness of the ASDs area.⁽¹⁶⁻¹⁸⁾ Community pharmacists practicing in Khartoum(Sudan) were not previously assessed for their awareness and knowledge of ASDs. Therefore, this study aims to assess awareness and knowledge of autism spectrum disorders (ASDs) among community pharmacists.

METHODOLOGY

Study setting and population: This study was conducted in Khartoum state, the national capital of Sudan from April to August 2018. The study population was registered community pharmacists practicing in the Khartoum state.

According to the Sudanese General Directorate of Pharmacy, the number of registered community pharmacists when this study started is 2265.⁽¹⁹⁾

Study design and sampling: A descriptive cross-sectional survey design was used for this study. The sample size needed for this study was calculated according to this equation:

$$np = \frac{N}{1 + N(e)^2}$$

Where N= target population, n= sample size, e= margin of error (0.05). The sample size was estimated at 95% confidence interval with a default margin of error of 5%. The sample size was 345 pharmacists.

Sampling conducted by selecting individual units (Khartoum state pharmacies) by stratified sampling to ensure representativeness of the study. Khartoum state pharmacies were broken down into seven strata by the area (locality). Samples were randomly selected from each stratum according to their percent in the population as follow; Khartoum (23%), Khartoum North (14%), Omdurman (13%), Sharq an-Nil(13%), Jabal Awliya(14%), Om Badda, (11%), and Karari (12%). One of the pharmacists who are working in the selected pharmacy was randomly selected and included in the study.

Data collection: Face to face paper-based questionnaires were administered after obtaining participants' informed consent by the researcher itself and trained data collectors who visited the community pharmacists in their workplaces and explained the purpose of the study. The questionnaire sections were adopted from similar previous studies^(16,19-22). The questionnaire contained four sections, the first section collected demographic and practice details of the study participants, also pharmacist was asked if they had a course(s) or lecture(s) on ASDs during their pharmacy degree program and if they had continuing education (CE) or training program on ASDs. The second section contained six items to measure pharmacists' degree of familiarity with symptoms, treatment, and community resources of ASDs. The participant pharmacist had to indicate the degree of familiarity on each item on a Likert scale of five options. The third section contained 12 items to measure pharmacists' knowledge of the etiology, prevalence, and treatment of ASDs. The fourth section contained four items to measure pharmacists' training and confidence in medication management of ASDs. Pharmacists had to indicate the degree of their agreement with the 4 items on a Likert scale of five options. The questionnaire was tested in twenty community pharmacies as a pilot study, and these pharmacies were excluded when the study was conducted.

Statistical analysis: Statistical Package for Social Sciences software, version 21.0 (IBM SPSSInc., Chicago, IL) was used for the analysis of data. Initially, all information gathered via directly administered questionnaire are coded into variables. The normality of data was tested using the Kolmogorov-Smirnov test. Data that were not normally distributed expressed as medians then categorized into poor (less than the median) and good (median and above) and compared using Mann-Whitney U-Test. The reliability test of the questionnaire was tested using Cronbach's Alpha= 0.618 (62%), Spearman's rho correlation was used to investigate the correlation between familiarity, knowledge, and confidence scores. and binary logistic regression was used to present results. A *p*-value of less than 0.05 was considered statistically significant.

Ethical approval: This study received ethical approval from the ethical committee of the faculty of pharmacy, University of Khartoum. Pharmacists who participated in this study also gave informed consent before they took part.

RESULTS and DISCUSSION

Demographic and practice characteristics of the study participants

A total of 345 community pharmacist participants in the study giving a response rate of 100%. The study participants practicing in the 7 localities of Khartoum state was found between 1996- 2016. The demographic and practice-related characteristics of the participant pharmacists are listed in Table 1.

Table 1. Demographic and practice characteristics of the participant community pharmacists surveyed (n= 345)

Demographic variables	Number	Percentage
Age (Years)		
(≤35)	328	95.1%
(>35)	17	4.9%
Gender		
Male	93	27%
Female	252	73%
Number of years in practice		
(<5)	248	71.9%
(≥5)	97	28.1%
Job Title		
Staff pharmacist	271	78.6%
Others(manager,owner)	74	21.4%
Highest degree		
Higher degree (MSc and Ph.D.)*	70	20.3%
Basic degree (BSc)	275	79.7%
Had attend ASDs course(s) or lecture(s) during pharmacy degree		
Yes	34	9.9%
No	311	90.1%
Had attended ASDs CE program*		
Yes	23	6.7%
No	322	93.3%

*ASDs autism spectrum disorders, BSc bachelor degree in pharmacy, MSc master of science degree, Ph.D. doctor of philosophy degree, CE continuing education

The demographic and practice-related characteristics of the pharmacists from different localities were similar. About 73% of community pharmacists were female and Nearly 78% of community pharmacists identified themselves as staff pharmacists. About 77% of the community pharmacists had basic pharmacy degrees and about 80% had less than 5 years practicing pharmacy in Khartoum. Only about 10% had either course(s) or lecturer(s) on ASDs during their pharmacy school program, and about 6% had Continuing Education Programme (CEP) on ASDs as shown in Table 1.

The familiarity of pharmacists with Symptoms, Treatment, and Community Resources of ASDs

Table (2) describes the participant pharmacists' degree of familiarity with ASDs. Majority of the participants showed a low degree of familiarity (67.9%) with symptoms, treatment, and community resources of ASDs, the median score on the Likert scale was 13. Furthermore, about 74% of participants showed low familiarity with classes of medications used to manage symptoms of ASDs, and nearly 59% low familiar with their side effects. About 74% were not sufficiently familiar with the specific behavior that medication seeks to alleviate.

Table 2. Degree of familiarity with ASDs symptoms, treatment, and community resources of the participant community pharmacists surveyed (n= 345)

Familiarity variables (n=345)	Not at all familiar N(%)	Not familiar N(%)	Somewhat familiar N(%)	Familiar N(%)	Extremely familiar N (%)
Are you familiar with the different symptoms of ASDs*?	24	94	165	54	8
	7%	27.2%	47.8%	15.7%	2.3%
Are you familiar with different classes of medications? (e.g. antipsychotics, antidepressants, stimulants) that are used in treating the symptoms of ASDs?	127	128	76	12	2
	36.8%	37.1%	22%	3.5%	0.6%
Are you familiar with specific behaviors associated with ASDs that medications seek to alleviate? (e.g. hyperactivity, OCD, and self-injury)	124	131	72	16	2
	35.9%	38%	20.9%	4.6%	0.6%
Are you familiar with various side effects produced by medications used in the treatment of ASDs symptoms (e.g. sedation, irritation, and extrapyramidal symptoms)?	78	125	118	21	3
	22.6%	36.2%	34.2%	6.1%	0.9%
Are you familiar with how to help families sort through informed decisions about their children with ASDs?	61	172	76	34	2
	17.7%	49.9%	22%	9.9%	0.6%
Are you familiar with community resources in your region that can be used for the referral of a child who is exhibiting symptoms commonly associated with ASDs?	73	161	77	33	1
	21.2%	46.7%	22.3%	9.6%	0.3%

*ASDs autism spectrum disorders, OCD obsessive-compulsive disorder

Knowledge of Pharmacists of Etiology, Prevalence, and Treatment of ASDs

Table (3) describes a participant's knowledge of ASDs based on their response to a series of true/false statements. The median score was nearly 58%. About 95% of participants knew that the children with ASDs have impairment in so-

cial interaction, communication or language, and behavioral development (variable 1), and about 87% knew that ASDs are developmental disorders(variable 2). Only about 30% of participants knew that ASDs are more prevalent than down syndrome and juvenile diabetes (variables 5 and 4). About 51% knew that ASDs are not curable (variable 6), and 55% knew that risperidone and aripiprazole have been approved by the FDA for the treatment of irritability associated with ASDs (variable 7). Only 14% and 25% don't know that vaccine cannot cause ASDs and ASDs not exists only in childhood (variable 8,9 respectively). Nearly half of the participants knew ASDs are rare disorders (variable 12), and about81% knew that genetic factors play a major role in the etiology of ASDs(variable 11). Only about 29% knew that ASDs are not caused because of emotionally distant, rejecting parents(variable 10) and about 43% knew ASDs occur more commonly among males than females(variable 3).

Table 3. Knowledge of etiology, prevalence, and treatment of ASDs of the participant community pharmacists surveyed (n= 345).

Knowledge variables (n=345)	True N (%)	False N (%)
1- ASDs are developmental disorders	302	43
	87.5%	12.5%
2- Children with ASDs have impairments in social interaction, communication or language, and behavioral development	330	15
	95.7%	4.3%
3- ASDs occur more commonly among males than females	151	194
	43.8%	56.2%
4- ASDs is more prevalent than juvenile diabetes	97	248
	28.1%	71.9%
5- ASDs is more prevalent than down syndrome	115	230
	33.3%	66.7%
6- ASDs is curable	168	177
	48.7%	51.3%
7- Risperidone and aripiprazole have been approved by the FDA for the treatment of irritability associated with ASDs	191	154
	55.4%	44.6%
8- Vaccines can cause ASDs	50	295
	14.5%	85.5%
9- ASDs exists only in childhood	89	256
	25.8%	74.2%
10- ASDs are caused because of emotionally distant, rejecting parents	243	102
	70.4%	29.6%
11- Genetic factors play a major role in the etiology of ASDs	281	64
	81.4%	18.6%
12- ASDs are rare disorders	171	174
	49.6%	50.4%

ASDs autism spectrum disorders, FDA food, and drug administration
Correct answers are in boldface

Training and Confidence of Pharmacists in Medication Management of ASDs

Table (4) described the training and confidence of pharmacists in medication management of ASDs. About 64% of the participants reported as not feeling confident enough in their ability to counsel parents about medications used for their children with ASDs and their side effects, and about 54% reported not feeling comfortable enough dispensing medications for individuals with ASDs. But 89% agreed that they would benefit from taking CE or training programs in the ASDs area, and nearly 91% agreed that pharmacy curricula should include courses or lectures on ASDs.

Table 4. Training and confidence of the participant community pharmacists surveyed in medication management of ASDs (n= 345).

Confidence Variables (n=345)	Strongly disagree N (%)	Disagree N (%)	Neutral N (%)	Agree N (%)	Strongly agree N (%)
I feel confident in my ability to counsel parents about the medication profile and side effects of prescriptions being used for the treatment of their child with ASDs	47	176	68	43	11
	13.6%	51%	19.7%	12.5%	3.2%
I feel comfortable dispensing medications used in the treatment of ASDs	32	152	74	75	12
	9.3%	44.1%	21.4%	21.7%	3.5%
I feel that I could benefit from taking a continuing education or training program in the area of ASDs	14	10	13	179	129
	4.1%	2.9%	3.8%	51.9%	37.4%
I feel that the pharmacy school curriculum should include a course or lecture in the area of ASDs	11	6	12	179	137
	3.2%	1.7%	3.5%	51.9%	39.7%

ASDs autism spectrum disorders

Association of characteristics of the participants and familiarity and knowledge

Comparing the characteristic of the participant using the Mann-Whitney *U* test, a certain variable like having a CE program on ASDs was significantly associated (p value<0.05) with familiarity score and confidence score, as shown in Table 5. On the other hand, age, gender, practice setting, number of years in practice, job title, and a degree in pharmacy were not significantly associated with familiarity score.

Table 5. Association of characteristics of the study pharmacists with familiarity, knowledge and confidence scores

Mann-Whitney U-Test							
Variables Mean Rank		Familiarity		Knowledge		Confidence	
		P-Value	Mean Rank	P-Value	Mean Rank	P-Value	
Age (Years)	(≤35)	170.62	0.051 *	174.24	0.301 *	173.17	0.889*
	(>35)	218.85		149.03		169.76	
Gender	Male	180.47	0.396*	184.01	0.205*	184.11	0.201*
	Female	170.24		168.94		168.9	
Number of years in practice	(<5)	170.96	0.541 *	169.9	0.347*	170.04	0.370*
	(≥5)	178.23		180.94		180.57	
Job Title	Staff pharmacist	167.2	0.038**	168.88	0.135*	174.45	0.599*
	Others	194.25		188.1		167.68	
Highest degree	MSc and PhD	190.61	0.096*	188.39	0.141*	161.33	0.265*
	BSc	168.52		169.08		175.97	
Had attend ASDs course(s) or lecture(s) during pharmacy degree	Yes	201.25	0.081 *	187.85	0.352*	187.26	0.371*
	No	169.91		171.38		171.44	
Had attended ASDs CEP	Yes	215.52	0.033**	194.63	0.273*	213.22	0.042**
	No	169.96		171.45		170.13	

**P-value ≤ 0.05 that's considered as statistically significant.

*P-value >0.05 that's considered as statistically insignificant.

Confidence scores significantly correlated with familiarity scores (spearman's rho=0.312, *p*-value < 0.01) and knowledge scores (spearman's rho=0.169 *p*-value <0.01), also there were significant correlation between familiarity and knowledge scores (spearman's rho=0.227 *p*-value<0.01). Binary logistic regression analysis was conducted to know factors that could be associated with the low familiarity, knowledge, and confidence scores. The analysis revealed that older age is significantly associated with poor knowledge (*p*-value 0.037). Moreover, participant's poor knowledge and poor familiarity was significantly contributed to poor confidence with *p*-value 0.001 and 0.047 respectively.

To the best knowledge of the investigators, this is the first study to assess community pharmacist's awareness and knowledge regarding Autism Spectrum Disorders(ASDs) in Sudan. The present study used variables from previous studies that were used to measure similar constructs among healthcare provid-

ers. ^(16,18, 20-22). As shown in Table 3, about 87% of participants knew that ASDs are developmental disorders. This finding was higher than the result observed in studies from Palestine⁽¹⁸⁾ and Mississippi⁽²⁰⁾, in which the percentage was 40% and 76% respectively.

In agreement with the studies from Mississippi surveyed pharmacists and pharmacy students ^(16,20), in the current study, about 96% of the participants knew that children with ASDs have impairments in social interaction, communication or language, and behavioral development. However, only about 44% of the participant knew that ASDs are more common in males than in females. This finding is close to the study conducted in Palestine ⁽¹⁸⁾, but lower than the findings obtained from the pharmacists and pharmacy students from Mississippi were about (85%) of participants correctly answered this statement ^(16,20). On the other hand, only about 30% of the participants knew about the prevalence of ASDs compared to juvenile diabetes and Down syndrome, respectively. This finding is consistent with a study carried out in Palestine, However, it is contrary to the study from Mississippi ⁽²⁰⁾.

Although the primary duty of the community pharmacist is not diagnosis, participant pharmacists were somewhat familiar with the different symptoms of ASDs. About 34% of the participant were minimally familiar with signs and symptoms of ASDs, our results were consistent with those reported among nurses in the state of Virginia and pharmacists in Palestine ^(22, 18). However, pharmacists and pharmacy students in Mississippi were relatively more familiar with the signs and symptoms of ASDs as only 25% of them reported as either not familiar at all or not familiar with the different symptoms of ASDs. ^(16,20).

Pharmacists assuming educative roles might need to educate families of people with ASDs on these symptoms. Pharmacists who are not familiar with symptoms of ASDs cannot assume this role. This can be even worse when pharmacists are not familiar with how to help families sort through information to make informed decisions about their child with ASDs. This study revealed that about 67% of the pharmacists reported themselves as either not familiar at all or not familiar with how to help families sort through information to make informed decisions about their child with ASDs (Table 2). This percentage was comparable to those reported by Palestinian pharmacists and Mississippi pharmacists and pharmacy students. ^(16,18, 20). Moreover, about 68% of the pharmacists in this study were not familiar with community resources in their region that can be used for the referral of a child who was exhibiting symptoms commonly associated with ASDs. These results were comparable to those reported by Mississippi pharmacists and pharmacy students ^(16, 20) and similar to the studies done on Palestinian pharmacists ⁽¹⁸⁾.

Although, some studies concluded that early diagnosis improves the prognosis of ASDs in children⁽²³⁾. Unfortunately, in many cases there were significant delays in diagnosing children with ASDs⁽²⁴⁾. In modern healthcare delivery systems, the role of pharmacists in caring for patients with chronic diseases is expanding. Subsequently, patients often report a good relationship with their pharmacists⁽¹³⁾ previous research showed that both patients and primary healthcare physicians wanted pharmacists to play a larger role in providing information to patients.⁽¹³⁾⁽²⁵⁾ When asked to indicate the degree of familiarity of participants with the different classes of medications (e.g. antipsychotics, antidepressants, stimulants) that are used in treating the symptoms of ASDs, nearly 74% of the participants in this study reported themselves as either not familiar at all or not familiar. This value was quite higher than that reported in study conducted in Palestine, where 62% of the pharmacists reported as not feeling confident enough in their ability to counsel parents about ASDs medications¹⁸. This finding highlight the need to increase knowledge of pharmacists on the classes of medications used to treat symptoms of ASDs.

Furthermore, about 58% of the pharmacists were either not familiar at all or not familiar with various side effects produced by medications used in the treatment of symptoms of ASD. These results are worrisome, as pharmacists are expected to be familiar with medications used in the management of different diseases and the side effects associated with the use of these medications. Therefore, it was not surprising that nearly 64% of the pharmacists in this study were not confident in their ability to counsel parents about the medications being used for the treatment of their child with ASDs. Previous studies reported that children with ASDs are prescribed psychotropic medications^(11,12) These medications are associated with weight gain, sedation, and/or tardive dyskinesia which might further complicate the management of ASDs in children⁽²⁶⁾.

Approximately 49% of the participant in this study thought ASDs were rare disorders, 70% thought ASDs are caused because of emotionally distant, rejecting parents, 25% thought that ASDs exist only in childhood, and about 18% did not know that genetics play a major role in the etiology of ASDs. About 14% believed that the vaccine causes ASDs. Pharmacists and other healthcare professionals are in a position to influence parent's decisions on vaccinations⁽²⁷⁾. Previous studies showed that believing in this myth had negatively affected vaccination rates in the US and UK.^(28,29)

Having CEP in the area of ASDs was significantly associated with familiarity and confidence scores. In this study, confidence scores correlated with both familiarity and knowledge scores. Despite the obvious low Spearman's rho, there

was a significant positive correlation between the scores. This indicates that the pharmacists who were relatively familiar and knowledgeable of ASDs were more confident in their ability to counsel parents about the medication profile and side effects of prescriptions being used for the treatment of their child with ASDs as well as dispensing medications used to treat symptoms of ASDs. A previous study showed that on many occasions, education increases familiarity and knowledge in certain domains⁽³⁰⁾. In this study, about 89% of the participants agreed that they could benefit from taking a CE or training program in the area of ASDs. Similarly, about 95% agreed that the pharmacy curriculum should include a course or lecture in the area of ASDs.

These results highlight the need to integrate educational interventions on ASDs in pharmacy curricula. Policymakers and health authorities should consider educational interventions to increase awareness and knowledge of pharmacists on ASDs. Similarly, pharmacy schools should revise, widen, and deepen educational materials on ASDs in the current curricula.

Community pharmacists are in a key position to provide crucial information to individuals with chronic disease and disabilities, including ASDs. The current study revealed gaps in awareness and knowledge of ASDs among community pharmacists in, Khartoum state, Sudan. Participants in this study reported low confidence in their ability to dispense and counsel individuals with ASDs and their families on medications used to alleviate symptoms of ASDs. Community pharmacists reported low familiarity with resources devoted to ASDs in their community, these gaps could be filled by specifically designed educational interventions.

CONFLICTS OF INTEREST

Nadine Hassan Ali and Ahmed H. Arbab report no conflicts of interest associated with this article.

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