

# Perception and convenience of caring for children with autism spectrum disorder among family medicine residents in Riyadh 2018

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## ABSTRACT

**Background:** Autism spectrum disorder (ASD) is a group of childhood pervasive neurodevelopmental disorders characterized predominantly by persistent moderate to severe impairment in social skills, communication, and associated with restricted repetitive or stereotyped behaviors. Early diagnosis of this disorder is paramount, which then allows for a timely intervention to facilitate a positive prognosis. To the best of our knowledge, there is no study that has investigated the perception of ASD among family medicine residents in Saudi Arabia. **Objective:** To determine the level of awareness of childhood autism among family medicine residents in Riyadh. **Settings and Design:** A cross-sectional study was conducted in nine teaching primary healthcare centers in Riyadh. **Materials and Methods:** The questionnaire was adopted from Unigwe *et al.* study and distributed to 344 available physicians, of which 277 were received back completed. **Results:** Only 28 physicians (10.1%) answered positively if they had previously attended any ASD workshops or conferences. In addition, only 29 participants (10.5%) correctly answered 50% or more questions. The question that yielded the lowest scoring was "Recognizing the signs and symptoms of autism in individuals with good language and no apparent intellectual difficulties", while the question with the highest scoring was "Identifying stress in the parents and carers of my patients with autism." The regression analysis showed no association between the scores and the physicians' characteristics. **Conclusions:** The results show a low awareness level and moderate to low level of confidence in the physicians ability to recognize, identify, or communicate in regards to ASD. We recommend integrating lectures and clinical exposure of ASD to the residency training program curriculum.

**Keywords:** Attitude, autism, autism spectrum disorder, autistic disorder, awareness, health knowledge, knowledge, perception, practice, residents

## Introduction

Autism spectrum disorder (ASD) is a group of childhood pervasive neurodevelopmental disorders mainly characterized by persistent moderate to severe impairment in social skills and communication and is associated with restricted repetitive or stereotyped behaviors.<sup>[1,2]</sup> The symptoms are subtle in early childhood and may not become apparent until the child's limited capabilities cannot be disguised especially in a social setting.<sup>[2]</sup>

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ASD prevalence is increasing over time due to the advances in diagnosis and reporting system. A global estimation shows that 1 in 160 children have ASD with increased occurrences in boys.<sup>[3]</sup> A systematic review of the gulf region reported an estimated 0.14 to 2.9 in 1000 children had ASD.<sup>[4]</sup>

Previous studies had hypothesized that environmental factors may have a role in the etiology of ASD in genetically predisposed individuals. Genetic factors such as abnormalities in chromosomal structure and genes expression may also contribute to the

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development of ASD; an association was found between paternal age and an increased risk to develop ASD possibly due to de novo mutations that occur with age.<sup>[5]</sup> Furthermore, imbalances in biological systems (including metabolic and immune), imbalance between free radicals and antioxidant defenses, and environmental factors such as exposure to toxins (e.g. pesticides, polychlorinated biphenyls, solvents, toluene, toxic waste) may also contribute to the etiology. Furthermore, heavy metals, such as mercury, lead, and arsenic cross the blood brain barrier and affect neurodevelopment.<sup>[5]</sup>

The American Academy of Family Physicians and the U.S. Preventive Task Force do not recommend screening of healthy children for ASD due to insufficient data. However, routine developmental screening is recommended at 9, 18, 24, and 30 months of age.<sup>[6]</sup> The American Pediatric Association recommends a targeted screening using a validated tool at 24 and 30 months of age including a two-stage parent questionnaire, a modified checklist for autism in toddlers with follow-up (M-CHAT-R/F).<sup>[6]</sup> A physician experienced in evaluating patients with ASD may be sufficient; however, an interdisciplinary team consisting of a physician, audiologist, geneticist and genetic counselor, occupational therapist, psychiatrist, social worker, and speech language pathologist is preferred in assessment of ASD.<sup>[6]</sup>

Early intensive behavioral intervention and medical therapy that is the use of antipsychotics such as aripiprazole and risperidone is recommended. These medications were approved by U.S. Food and Drug Association for treating symptoms, such as irritability, aggression, explosive outbursts, and self-injury. However, subspecialty referral is recommended for serious side effects.<sup>[6]</sup> It has been suggested that nonstimulant-based therapies may show more effectiveness and less adverse effects in patients with comorbid attention deficit hyperactivity disorder (ADHD).<sup>[6]</sup>

## Literature Review

### PubMed, Google scholar

Several studies investigating ASD awareness have been performed in several populations.

### Internationally

A cross-sectional study performed by Unigwe *et al.* in the United Kingdom showed high ASD knowledge scores in general practitioners (M [mean] = 88.1%, correct standard deviation [SD] = 9.2, range = 36.4-100%), but reduced confidence in identifying and managing autistic patients (M = 4.8, SD = 1.5, range = 1.50-9.07).<sup>[7]</sup> In contrast, a questionnaire-based study by Esegbe *et al.* conducted in Nigeria showed lower knowledge and misconception regarding ASD among general practitioners ( $P < 0.05$ ). However, pediatricians and psychiatrists displayed increased knowledge when compared ( $P < 0.05$ ). The mean knowledge score of the overall participants was  $13.5 \pm 3.7$ .<sup>[8]</sup> Additionally, a cross-sectional study performed in

the United States (U.S.) by Broder-Fingert on pediatrics residents showed low levels of perception in the caring of ASD patients. The overall comfort level in caring for children with ASD was low (mean Likert score = 2.21/5, SD = 0.86).<sup>[9]</sup>

### Regionally

A survey-based study by Imran *et al.* in Pakistan recruited healthcare professionals (psychiatrists, pediatricians, neurologists, family physicians, psychologists, and speech therapists), and the results showed misconceptions regarding ASD.<sup>[10]</sup>

In addition, a cross-sectional study on general practitioners in Pakistan by Rahbar *et al.* showed misconceptions and knowledge deficits in the etiology and diagnosis of ASD.<sup>[11]</sup>

Furthermore, a cross-sectional study was conducted by Hidiroglu *et al.* in Turkey involving the recruitment of residents of varying specialties including psychiatry, child and adolescent psychiatry, neurology, pediatric neurology, pediatrics, family medicine, public health, physical therapy and rehabilitation, dermatology, internal medicine, emergency medicine, obstetrics and gynecology, ophthalmology, urology, otorhinolaryngology, general surgery, biochemistry, microbiology, and anatomy. The results indicated that residents belonging to the non-neuropsychiatric disciplines display a moderate awareness of childhood autism.<sup>[12]</sup>

### Nationally

A survey-based study by Helmy which recruited medical students in Saudi Arabia showed that final year students had a better knowledge and positive attitude toward children with ASD in comparison to second year students.<sup>[13]</sup> The mean knowledge scores were  $8.99 \pm 1.91$  and  $6.44 \pm 2.24$  for final, and second year students respectively ( $P < 0.001$ ). Also, in agreement, the comparison of the attitude scores of the final year students ( $3.92 \pm 0.97$ ) and the second-year students ( $3.29 \pm 1.33$ ) showed statistical significance ( $P < 0.001$ ).<sup>[13]</sup>

ASD is a burden and negatively impacts on the emotional capacity of affected children and caregivers, as well as economically.<sup>[3]</sup> ASD was found to be the leading cause of disability in children that are less than 5 years old, and the 4<sup>th</sup> in children aged between 5 and 14 years old in terms of years lived with disability.<sup>[14]</sup> In the United Arab Emirates, the health loss due to morbidity and mortality, referred to the disability adjusted life years was estimated to be 137 per 100 000, and thus the highest globally.<sup>[14]</sup>

Since family doctors are the first point of contact with the community, it is crucial to identify ASD patients and initiate timely and appropriate referrals for definitive diagnosis, as early intervention may improve outcomes.

Currently, the literature is lacking investigations into this topic especially in Saudi Arabia, and to the best of our knowledge, there is no study that has investigated the perception of ASD among family medicine residents in Saudi Arabia.

The aim of this research is to investigate potential approaches of family medicine residents towards ASD to improve the outcome of the patients. Our objective is to determine the current knowledge of ASD among family medicine residents. The research question is what is the level of awareness of family medicine residents in regards of ASD?

## Subjects and Methods

### The study design

A cross-sectional was conducted between the 10<sup>th</sup> of April and 20<sup>th</sup> of May 2018 over two waves.

### Study Area

The study was conducted in nine teaching primary healthcare centers (PHCs) in Riyadh. These centers are operated by the Ministry of Health (MOH), and the Medical Service Department of the Military. The MOH and the military are the two largest healthcare providers in the Kingdom of Saudi Arabia (KSA).

### Inclusion criteria

Family medicine residents in Riyadh city.

### Sampling method

A comprehensive survey was conducted in nine teaching PHCs in the Riyadh region. The questionnaire was distributed to 344 available physicians, of which 277 were received completed (80.5% response rate).

### The research tools

The research tool is a self-administered questionnaire. The first section of the questionnaire involved collating the sociodemographic and participants characteristics. The second and third sections were adopted from the investigation of Unigwe *et al.*<sup>[7]</sup> The first part asked the participants about prior training with respect to ASD, and also 19 questions regarding their perception about ASD. The final part consisted of seven questions to elucidate the participants' convenience of caring toward ASD patients. The questionnaire was piloted through 34 resident physicians outside Riyadh city to assess the questionnaire applicability and to obtain feedback on the language and questions. Once the questionnaire was deemed suitable for use, the researcher distributed the questionnaire over two waves in April and May 2018.

### The participants

The questionnaire was distributed to recruited family medicine residents in Riyadh without restrictions on age, gender, or any other factors.

### Statistical analysis

The statistical methods used were adopted from the scoring techniques utilized in the original questionnaire. For the first part, descriptive statistics was employed to summarize

the participants' sociodemographic and characteristics. The second part of the questionnaire was scored based on the following:

- A correct answer received 1 point.
- An incorrect answer received -1 point.
- If the participants answered "I do not know", then no marks were provided.

The association between scores and the characteristics was analyzed using regression analysis. The model utilized the score percentage as the dependent variable and the participants' characteristics as independent variables.

For the assessment of medical practitioners' convenience of care for ASD, descriptive statistics was used to provide an overview of the distribution of the participants' answers on each question.

### Ethical consideration

The study was approved by the Institutional Ethics Committee, all questionnaires were collected anonymously, and informed consents were obtained from participants.

## Results

As discussed in the previous section, the first part of the analysis involved assessing the participants' characteristics which is illustrated in Table 1. The average age of the participants was 27.5 years. The sample population was divided into males and females. Only one participant was a non-Saudi national. The positions were almost uniformly distributed in the first 3 years of residency, with the fourth (final) residency year having the lowest number of participants 45 (16.2%). Prince Sultan Military Medical City (PSMMC) contributed the most participants as 26% of the residents were training there. The lowest number of participants originated from King Fahad Medical City and Prince Mohammad bin Abdulaziz Hospital (PMAH) 9 (3.2%) Figure 1. Physicians who expressed previous experience with ASD represented approximately 10% of the recruited physicians.

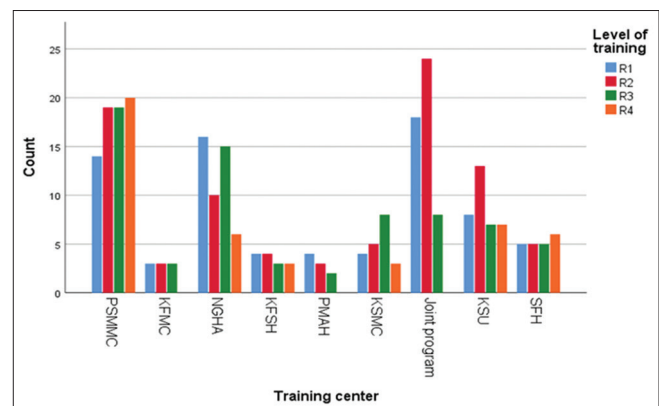


Figure 1: Clustered bar count of training center by level of training

**Table 1: Participants' characteristics (n=277)**

Characteristic	Mean±SD*	Frequency	Percentage
Age	27.5±2.4		
Gender			
Male		142	51.3
Female		135	48.7
Nationality			
Saudi		276	99.6
Non-Saudi		1	0.4
Position			
R1		76	27.4
R2		86	31.0
R3		70	25.3
R4		45	16.2
PHC**			
PSMMC		72	26.0
KFMC		9	3.2
NGHA		47	17.0
KFSH		14	5.1
PMAH		9	3.2
KSMC		20	7.2
Joint Program of ministry of health		50	18.1
KSU		35	12.6
SFH		21	7.6
Previous experience in another specialty			
Yes		47	17.0
No		230	83.0
Do you have personal experience with ASD - either through being autistic yourself, or through having a family member, a relative, a friend, or a colleague with ASD?†			
Yes		28	10.1
No		249	89.9

\*SD: Standard Deviation; \*\*PHC: Primary Healthcare Center; †ASD: Autism spectrum disorder

### Perception of ASD

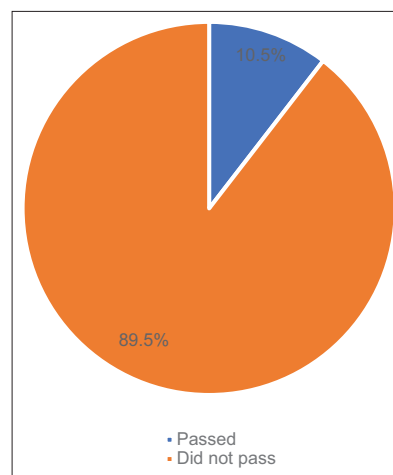
The perception of ASD among the residents was investigated by administering 20 questions. The first question quizzed the physicians about any prior attendance to ASD workshops or conferences; only 28 participants (10.1%) answered positively to this question. The second part consisted of 19 questions which assessed the perception and knowledge of the participants. The results in Figure 2 show that only 29 participants (10.5%) obtained 50% or more correct answers.

The correct answers of each question are presented in Figure 3. Most of the questions received less than 50% correct answers and seven questions received 50% or more correct answers. The question with the highest correct answer was “The behaviors of autism can only be managed with medications” (77.3%). The question with the lowest answer is “people with autism always display challenging behavior” (20.2%).

The regression analysis showed no association between the scores and the physicians' characteristics. No statistically significant associations were found as the *P* value were larger than the predetermined alpha ( $\alpha$ ) value of 0.05 [see Table 2].

### Convenience of caring for ASD patients

The distribution of the answers concerning the Convenience of caring for ASD patients of the physicians is shown in



**Figure 2:** Pie chart represents the percentages of physicians who passed or equaled the 50% correct answers vs. physicians who did not pass

Table 3. The most common answers provided to the questions can be divided into several categories (not confident, neutral, and confident). The question with the lowest confidence level is “Recognizing the signs and symptoms of autism in individuals with good language and no apparent intellectual difficulties.” The question with the highest level of confidence is “Identifying stress in the parents and carers of my patients with autism.”

## Discussion

Advances in the methodology of diagnosing autism have resulted in a rise in the reporting of individuals (especially children) with this disorder. Family physicians are the first point of contact with the community, thus it is critical for these practitioners to be able to detect autism in its early stage in order to promote early intervention and a better outcome.<sup>[6]</sup>

Similarly, the study done in Taif targeting medical students showed minimal attendance to ASD activities with 19.6% of 2<sup>nd</sup> year students and 10.7% of 6<sup>th</sup> year student stating attendance of an autism campaign.<sup>[12]</sup>

In this cross-sectional study, we surveyed 277 resident physicians about their perception and attitude toward ASD in a primary care setting.

The results show a low level of perception among the family medicine residents; only 10% answered more than 50% of the questions correctly. Most of the questions received less than 50% correct answers. Several studies also showed limited knowledge; a study performed in Nigeria among general practitioners indicated a basic and limited knowledge of this topic.<sup>[8]</sup> In a Pakistan study, some general practitioners (55.4%) reported that they had no knowledge of autism.<sup>[11]</sup> In contrast, a UK study that was done among general practitioners generally scored high

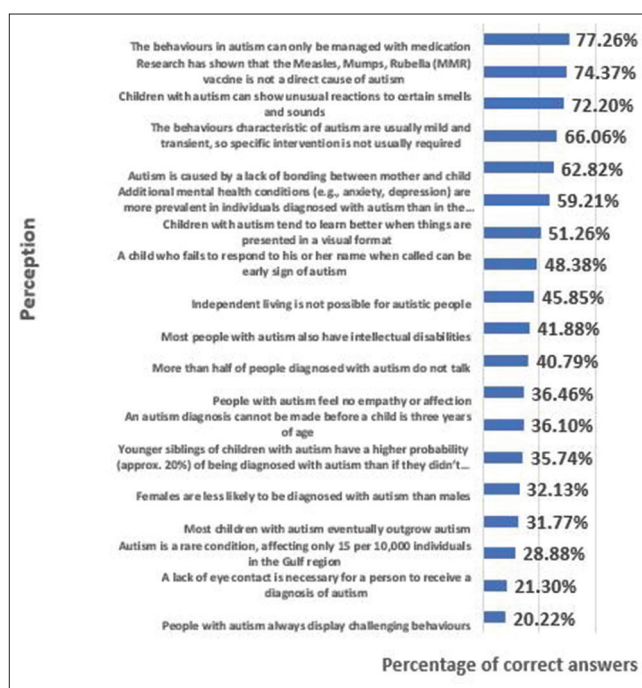
in ASD knowledge with a mean of 88.1%, correct standard deviation [SD] =9.2, range = 36.4-100%.

The low perception of ASD may potentially be as a result of deficient autism professional training in residency programs. Only 28 (10.1%) answered positively if they had previously attended ASD workshops or conferences. Similarly, the study done in Taif targeting medical students showed minimal attendance to ASD activities with 19.6% of 2<sup>nd</sup> year students and 10.7% of 6<sup>th</sup> year student stating attendance of an autism campaign.<sup>[13]</sup> In the UK, almost two-thirds (63.5%, *n* = 193) of general practitioners have not received any training on autism during their primary medical degree or specialist GP training. Overall, 39.5% (*n* = 120) of participants reported to have never received any training about autism.<sup>[7]</sup>

**Table 2: Regression analysis showing the relationship between the score and the participants' characteristics**

Factor	P*
Age	0.430
Years of experience	0.469
Gender	0.764
Position	0.640
PHC	0.505
Experience with another specialty	0.326
Experience with ASD	0.161

\* The P value is considered significant when less than 0.05 R<sup>2</sup>=8%



**Figure 3: The percentages of correct answers received for each question in the perception part of the questionnaire (n=277)**

**Table 3: The resident physicians' convenience of caring for ASD patients (n=277)**

Question	Extremely not confident (%)	Not confident (%)	Neutral (%)	Confident (%)	Extremely confident (%)
Recognizing the signs and symptoms of autism in children	16 (5.8)	66 (23.8)	114 (41.2)	71 (25.6)	10 (3.6)
Communicating with parents about a suspected diagnosis of autism	12 (4.3)	86 (31.0)	99 (35.7)	69 (24.9)	11 (4.0)
Recognizing the signs and symptoms of autism in individuals with good language and no apparent intellectual difficulties	18 (6.5)	112 (40.4)	95 (34.3)	46 (16.6)	6 (2.2)
Recognizing additional mental health conditions (e.g., anxiety, depression) in my patients with autism	13 (4.7)	85 (30.7)	100 (36.1)	69 (24.9)	10 (3.6)
Knowing the relevant care pathways/services for people on the autism spectrum	23 (8.3)	94 (33.9)	107 (38.6)	48 (17.3)	5 (1.8)
Knowing which community resources in my area are available for children with autism	38 (13.7)	98 (35.4)	93 (33.6)	40 (14.4)	8 (2.9)
Identifying stress in the parents and carers of my patients with autism	9 (3.2)	53 (19.1)	84 (30.3)	114 (41.2)	17 (6.1)

The regression analysis showed no statistically significant associations between the score and the physicians' characteristics. Whereas the study conducted in Nigeria showed a significant association of good knowledge and the male gender.<sup>[8]</sup> Researchers in the UK study found that personal connections of general practitioners with autism affected their scores of knowledge positively ( $P = 0.001$ ); approximately, 47.7% had personal experiences of autism, either through being autistic themselves ( $n = 3$ ), having an autistic child ( $n = 52$ ), an autistic relative ( $n = 44$ ), or an autistic colleague/friend ( $n = 37$ ).<sup>[7]</sup> Furthermore, in our study, only 28 individuals (10.1%) had a personal connection with autism.

Additionally, the convenience of caring for ASD patients' assessment section showed moderate to low level of confidence in the physicians ability to recognize, identify, or communicate with ASD patients. The question with the highest level of confidence is "Identifying stress in the parents and carers of my patients with autism." similarly to the UK study.<sup>[7]</sup> In a U.S. study on pediatrics residents, a low overall comfort level in caring for children with mean Likert score = 2.21/5, SD = 0.86 was observed.<sup>[9]</sup>

### Limitations

This is a descriptive study and may not be entirely representative of the care provided by residents. Additional studies are required to include multiple areas and several professional levels including consultants, senior registrars, registrars, and house officers. Another limitation relates to the questionnaire which was originally developed internationally (adapted from stone) and modified to current knowledge by Unigwe *et al.*; although we did a pilot study done on residents outside Riyadh.

### Conclusion

The results suggest low knowledge and low to moderate confidence of family medicine residents on the topic of ASD. We recommend integrating lectures and clinical rotations specializing in ASD including early diagnosis and intervention during residency training programs. Further studies are required which will extend into multiple areas and involve diverse medical practitioners of distinct hierarchies.

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### Conflicts of interest

There are no conflicts of interest.

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