POLICY PAPER

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EXECUTIVE SUMMARY

Autism is a lifelong neurodevelopmental disorder that is characterized by impaired social interactions, verbal and non-verbal communication, and stereotyped, repetitive behaviors. While the Autism prevalence in the United Arab Emirates (UAE) is comparable to that observed in other countries, children in the UAE are being diagnosed later as their conditions are not being detected by the available pediatric healthcare oversight protocols or being reported by parents. Pediatricians and parents are at the best vantage point to spot the earliest warning signs of autism. If the disorder is detected in its infancy, early intervention programs can help ameliorate the symptoms significantly. This study provides insight into the important issues impacting autism's early detection in the UAE, using the emirate of Ras Al Khaimah as a case study to better understand and mitigate local phenomena that might be delaying diagnosis, negatively impacting the future of autistic children and their families.

Early Diagnosis of Autism in the United Arab Emirates: Autism Knowledge and Attitudes Among Primary Healthcare Providers in Ras Al Khaimah

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Introduction

An estimated one in 68 children in the United States is identified with autism, a neurodevelopmental condition that is part of a continuum of disorders collectively known as autism spectrum disorders (ASD). Autism is one of the most expensive medical conditions for the country and, furthermore, one of the most common causes of disability among children in the world (CDC, 2013). The World Health Organization (2019) estimates that an average of one in 160 children worldwide has ASD. However, this is only an average, and estimates of the prevalence of autism vary substantially across studies depending on diagnostic criteria, age of the children screened, and geographical location.

In addition, despite the fact that estimated prevalence rates of ASD vary across regions, and that the numbers from many low-and middle-income countries are still unknown, the global prevalence of ASD appears to be dramatically increasing. This increase is estimated, based on epidemiological studies that analyze the incidence and distribution of ASD conducted over the past 50 years (WHO, 2019). This apparent increase may be explained by improved awareness, expansion of diagnostic criteria, improved diagnostic tools and practices, and better reporting (Newschaffer, 2007). Another hypothesis is that all above-mentioned factors, including better ascertainment, especially for children at the less severe end of the spectrum, explain only a part of the linear increase observed. Indeed, numerous studies support the evidence suggesting a contribution of environmental risk factors (Chaste & Leboyer, 2012). Therefore, it is reasonable to assume that there may be both a real increase in the number of autism cases and an increase in the ASD detection in children.

"Autism" was first described, clearly defined, and used as a diagnostic term by Leo Kanner, a child psychiatrist from Johns Hopkins University Hospital in the United States in 1943 (Kanner, 1943). Since Kanner's first publication on autism over 75 years ago, the vast majority of the global research concerning the spectrum of autism has been conducted in the Anglo-Saxon world. This creates an illusory and fundamentally false impression suggesting that autism is a phenomenon the scale of which is alarming in the western world and virtually non-existent in non-western societies (Mostafa, 2011).

In the Arab world, ASD has been a topic of discussion since the late 1990s. Yet, the current state of epidemiological studies of autism conducted, especially in the Gulf

Cooperation Council countries (GCC), highlight that there are gaps in the literature, research agendas, and public health policies and practices related to the theoretical, practical, and therapeutic components of ASD diagnosis, management, and widespread familial and societal impacts. Furthermore, few researchers have addressed the issue of autism diagnosis in the GCC and the critical role of primary healthcare professionals in the process. Early detection is essential for early intervention, which can help ameliorate the symptoms significantly, improving the quality of life for families and the prognosis of ASD sufferers. In fact, one influential study in the United Arab Emirates (UAE) highlighted worrisome trends, such as the lack of timely diagnosis and a sustainable screening scheme (Eapen, 2007), which have negative impacts on the effect of subsequent interventions. Such impacts lead to lifelong impairments that were potentially treatable if caught early enough.

Early symptoms of autism and the awareness thereof among pediatricians and general practitioners, the use of screening tools,[1] and issues concerning timely referral to early intervention providers are a neglected area in the field of ASD research in the GCC and, as highlighted above, in the UAE. Thus, there is a need to better understand opinions, perceptions, and concerns of primary healthcare providers regarding autism spectrum disorders in order to fill the gaps in the screening and diagnostic processes of ASD.

This study provides insight into the factors impacting autism's early detection in the UAE, using the emirate of Ras Al Khaimah as a case study to better understand local phenomena that might be significantly delaying diagnosis. The paper first provides an overview of what autism is, as well as its regional epidemiology and socioeconomic impacts. It then investigates the level of knowledge and awareness of the key aspects of autism among children's primary healthcare providers, which are pediatricians and general practitioners, practicing in various locations of Ras Al Khaimah. It also provides recommendations to address questions of access to continuing education on ASD-related subjects, the use of autism screening tools, and community awareness.

Overview of Autism and its Socioeconomic Impacts

With a growing body of research and frequent changes of diagnostic criteria, clinical definitions of autism constantly evolve. The current *Diagnostic & Statistical Manual of Mental Disorders*[2] (DSM-5) by the American Psychiatric Association describes autism as a lifelong neurodevelopmental disorder that is characterized by impaired social interactions, impaired verbal and non-verbal communication and stereotyped, repetitive behaviors (DSM-5, 2013). Symptoms may include, among others: unresponsiveness, self-abusive behaviors, learning to speak relatively late, intense focus on one item, avoidance of eye contact and social withdrawal. Autism may significantly limit the child's capacity to conduct daily activities and develop self-help skills such as self-feeding, independent dressing and grooming, hygiene and toileting, or helping with daily chores. The severity of these symptoms varies widely among affected individuals, and it is important to note that not all individuals with ASD experience all of the symptoms listed. This is because, as previously mentioned, the condition is part of a continuum of disorders collectively known as autism spectrum disorders (ASD) and is classified under the general category of pervasive developmental disorders (PDDs).

The etiology of autism is still a matter of speculation. Many researchers agree that the causes of autism are likely to be genetic[3], although the genetic linkage is complex and has been inconclusive. Others have suspected that the factors are biochemical, neurological, and environmental (Amaral, 2017). Most experts agree that there is no cure for autism. The current treatment options are limited to the management of core symptoms or development of skills, which includes behavioral and educational therapy. No medication is approved for use in treating the core symptoms of ASD. However, some evidence exists that one medication, risperidone[4], may be effective in treating the repetitive and restricted patterns of behavior in children with autism (DeFilippis & Wagner, 2016).

The most commonly used evidence-based treatments for children with autism are: Speech and Language Therapy,

[1] Screening tools can be specific to a disorder (for example, autism: STAT, MCHAT) or an area (for example, cognitive development, language, gross motor skills: PEDS, CSBS, ASQ). Screening tools, by definition, are not designed to provide a conclusive evidence of a disorder. Their aim is to help identify children who might have a disorder. A positive screening result should be followed by an in-depth assessment.

[2] DSM is the handbook used by healthcare professionals in the United States and much of the world to diagnose mental health conditions. An alternative classification system to DSM is International Classification of Diseases (ICD) by the World Health Organisation.

[3] The recurrence risk of autism in siblings of ASD-affected children is estimated to be between 10% and 20% (Szatmari et al., 2016).

[4] Risperidone appears on the list of restricted and controlled drugs in the United Arab Emirates. Retrieved from: https://www.government.ae/en/information-and-services/health-and-fitness/drugs-and-controlled-medicines/controlled-medicines-

Applied Behaviour Analysis (ABA), Cognitive Behaviour Therapy (CBT), and Occupational Therapy. All of these are legal and available in the UAE (Kelly, 2016). Regardless of the therapeutic option chosen, emphasis should remain on early detection of ASD that may provide an opportunity for early intervention, which has been considered 'essential to achieving the best outcomes[5] (Pierce, Courchesne, & Bacon, 2016). Early intervention may have the best chance of altering neural connectivity at a time of optimal brain plasticity (Pierce et al., 2016).

The disorder imposes significant economic burdens on countries and families of affected children. Autism's economic cost in the United States was estimated at $268 billion in 2015 and will potentially rise to $461 billion by 2025 in the absence of more effective interventions and support across the lifespan of the individual with ASD (Autism Speaks, 2017). In addition, a 2014 study on the economic costs of ASD in the United States and the United Kingdom found autism to be the fourth most expensive medical condition across the two countries, beyond only trauma, cancer, and cardiovascular disease (Buescher, 2014). The economic cost of ASD and its social implications in the UAE and the greater Gulf region remain unresearched. However, according to estimates by Dubai-based experts the costs can range from Dh 4,000 to as much as Dh 40,000 a month for every ASD-affected child (The National, 2014).

Furthermore, while all of the evidence-based therapies are available in the UAE, a major difficulty for families is access to them, as they are often unaffordable and inflexible (e.g. not being home-based or close-to-home). Most specialized autism centers (such as the Dubai Autism Center founded in 2001 and the largest facility of its kind in the UAE) operate at full capacity, have long waiting lists, and only offer care until the child turns 18 years of age. As mentioned earlier, autism is a lifelong condition. Individuals with ASD do not 'outgrow' autism. They need services and support throughout their lifetime.

Despite the increasing media attention autism spectrum disorders have gained both around the world and in the UAE over the years, many ASD-affected families face a societal lack of compassion and understanding. Common reactions of mainstream society include staring, making hurtful remarks, and interpreting some of the typical ASD-related behaviors as outcomes of poor parenting. These reactions and stigmas surrounding autism further deepens the distress experienced by the individuals with ASD and their families. During an emotional interview given to Gulf News, a UAE-based family of a child with ASD pleaded that, "we are already struggling physically, spiritually, mentally, financially. These are burdens enough. Do not add to them by staring, commenting and making our life more difficult...Perhaps you can't say a few good words. You can't help [us]. But please don't criticise or judge" (Gulf News, 2016).

Many children with ASD living in the UAE do not attend special needs schools because their caregivers cannot afford the extremely high school fees. Regarding inclusive education for ASD-affected children, one parent stated that "as for inclusion, we're so far behind. We've been rejected from so many schools without them even giving a chance for assessment. As soon as they hear 'autism', it's a 'no' or 'we're full' " (Arab News, 2019). In order to solve this problem, the Knowledge and Human Development Authority (KHDA), Dubai's education regulator, has launched new guidelines stating that all private schools in Dubai must be able to cater for special needs children by 2020 (The National, 2019).

ASD Prevalence Rates in the GCC

Statistical studies concerning autism prevalence rates in the GCC states – Bahrain, Kuwait, Qatar, Oman, Saudi Arabia, and the UAE – have only been conducted in half of the countries. The published statistics of the epidemiology of autism concern Bahrain (Al-Ansari & Ahmed, 2013), Oman (Al-Farsi et al., 2011) and the UAE (Eapen et al., 2007), and are the first, and to date only, studies of their kind in the history of the region. A lack of publications persist concerning the scale of the phenomenon in Kuwait, Qatar, and Saudi Arabia.

Table 1 presents a comparison of the size of population with the number of diagnosed cases of autism in each GCC state. The lack of data in three cases, as well as the markedly low statistics for prevalence in the other three (in comparison, the median for Europe is 18.75 per 10,000 individuals; for the United States. it is 21.6 per 10,000), clearly show that our knowledge of autism spectrum disorders' epidemiology in the Arab Gulf region is based on very limited data.

In the case of the UAE, the first and only report on the epidemiology of autism in the community reported a weighted prevalence of 29 per 10,000 among three-year-olds (Eapen et al., 2007). While the rate reported from the UAE is comparable to that observed in other countries worldwide, none of the UAE children diagnosed during the study had a prior diagnosis. All of them escaped detection by the available and required pediatric healthcare oversight protocols. It is, however, critical to detect the disorder in its infancy - behavioral signs and delays associated with autism can be identified at 18 months of age, if not earlier (Bryson, 2004).

[5] Sustained improvements after early intervention have been indicated by recent follow-up data. For example, two-year follow-up postintervention with the Early Start Denver Model (ESDM) found improved core autism symptoms at six years of age (Estes et al., 2015). See also research by Green et al., 2017; Pickles et al., 2016) for randomised controlled trials (RCT) demonstrating symptom reduction at long-term follow-up.

Table 1. Epidemiology of autism in the GCC states

GCC state	Estimated population (in millions), 2017 (source: World Bank)	Published statistics for the epidemiology of autism
Bahrain	1.49	4.3 per 10,000 (Al-Ansari & Ahmed, 2013)
Kuwait	4.13	13
Oman	4.63	1.4 per 10,000 (Al-Farsi, Al-Sharbati, Al-Farsi, Al-Shafaee, Brooks, & Waly 2011)
Qatar	2.63	-
Saudi Arabia	32.94	-
UAE	9.4	29 per 10,000 (Eapen, Mabrouk, Zoubeidi, & Yunis, 2007)

Methodology

This cross-sectional study evaluates the level of knowledge and awareness about the various aspects of ASD among pediatricians and general practitioners practicing in urban and semi-urban/rural areas of the emirate of Ras Al Khaimah.[6] The study included 87 doctors practicing in both private and public outpatient clinics and hospitals and all those surveyed specialized in one of the two fields, pediatrics and general practice, which together form a very important professional group with regards to autism spectrum disorders' screening and referral for a further diagnosis. Pediatrics and general practice are usually the first and most commonly used point of access to healthcare for parents of young children.

A mixed-method, social scientific, case study approach was also used in order to collect the data for this study. This included semi-structured interviews with all the doctors, as a follow-up procedure to the questionnaire utilized[7] , as well as semi-structured and more in-depth interviews with seven key stakeholders, including employees in the health and higher education sectors in Ras Al Khaimah.

Findings

Despite the fact that over 70 years have passed since Leo Kanner first described and defined autism, the disorder still has not been examined thoroughly, especially in countries such as the UAE, where the impact of culture and traditions on public healthcare is more significant. While there has been much progress in understanding autism and the critical role of the early diagnosis and intensive early interventions, this knowledge, however, often does not necessarily 'filter down' to primary healthcare providers (Levy, 2009).

Pediatricians and/or general practitioners are the first group of medical professionals that parents report to with all health-related concerns. These professionals are also responsible for required ASD screening protocols. It is therefore crucial for pediatricians and general practitioners to have adequate knowledge of developmental disorders, use screening tools, and refer cases to early intervention providers, as it can enable the timely and correct diagnosis of autism and help ameliorate the symptoms significantly. In order to better understand the factors impacting autism's early detection in the UAE, this section reviews the level of knowledge about ASD among pediatricians and general practitioners in Ras Al Khaimah, as well as their opinions and perspectives regarding ASD-related topics.

Level of knowledge about ASD among pediatricians and general practitioners in Ras Al Khaimah

To better understand the knowledge and awareness of ASD among healthcare providers in Ras Al Khaimah, a questionnaire on key concepts of autism was administered to the participating pediatricians and general practitioners. Table 2 shows the numbers and percentage (n, %) of respondents who gave correct answers, wrong answers, or did not respond to the questionnaire's questions[8]. Additional context and implications of the findings are discussed.

[6] Apart from the capital city, Ras Al Khaimah, the study included some of the most important towns and settlements of the Ras Al Khaimah emirate, namely Al Jazirah Al Hamra, Al Rams, Khatt, Diqdaqah, Al Qir and Sha'am.

[7] It consists of 22 statements, one could choose either 'agree' or 'disagree', depending on the answer one considered to be correct. The questions 1-14 and 22 referred to some of the key issues in autism's etiology, symptoms, diagnosis, comorbid disorders and prognosis. The questions 15-21 concerned opinions and perspectives based on individual experience of the respondent and are included in Table 3.

[8] Statistical test results for questions 1-14 & 22: 1. $\lambda 2(2)=45.31$; $p<0.001$, 2. $\lambda 2(2)=62.55$; $p<0,05$, 3. $\lambda 2(2)=38.55$; $p<0.001$, 4. $\lambda 2(2)=79.1$; $p<0.01$, 5. $\lambda 2(2)=57.38$; $p<0,05$, 6. $\lambda 2(2)=69.59$; $p<0.001$, 7. $\lambda 2(2)=61.31$; $p<0,00$, 8. $\lambda 2(2)=72.62$; $p<0.001$, 9. $\lambda 2(2)=56.48$; $p<0.001$, 10. $\lambda 2(2)=46.83$; $p<0.001$, 11. $\lambda 2(2)=38.55$; $p<0,05$, 12. $\lambda 2(2)=38.55$; $p<0.001$, 13. $\lambda 2(2)=124.62$; $p<0.001$, 14. $\lambda 2(2)=69.59$; $p<0.001$, 22. $\lambda 2(1)=29.9$; $p<0.001$

Table 2. Knowledge and awareness about ASD among primary healthcare providers in Ras Al Khaimah[9]

Questions (answer) (n = 87)	Correct answer n=	Correct answer %	Wrong answer n=	Wrong answer %	No answer given n=	No answer given %
1. Autism is a lifelong condition (yes).	56	64%	26	30%	5	6%
2. Autistic children's withdrawal is mostly due to cold, rejecting mother (no).	62	71%	22	25%	3	4%
3. Autism is an emotional disorder (no).	46	53%	39	45%	2	2%
4. It is impossible to tell if a child is autistic before 4 years of age (no).	67	77%	18	21%	2	2%
5. Autism is a developmental disorder (yes).	61	70%	21	24%	5	6%
6. Autism exists only in childhood (no).	64	74%	21	24%	2	2%
7. Even with early intervention, the prognosis for independent community functioning of autistic individuals is poor (no).	61	70%	24	28%	2	2%
8. With the proper treatment, most autistic children eventually "outgrow" autism (no).	20	23%	65	75%	2	2%
9. The onset of autism occurs before 36 months (yes).	59	68%	26	30%	2	2%
10. Most autistic children are also intellectually disabled (no).	54	62%	31	36%	2	2%
11. Most autistic children are nonverbal (no).	39	45%	46	53%	2	2%
12. Language delays in autism are due to intellectual disability (no).	46	53%	39	45%	2	2%
13. Autism can occur in mild as well as extreme forms (yes).	78	90%	7	8%	2	2%
14. Most autistic children have special talents or abilities (no).	21	24%	64	74%	2	2%
22. Autistic children are "untestable" (no).	69	79%	18	21%	0	0%

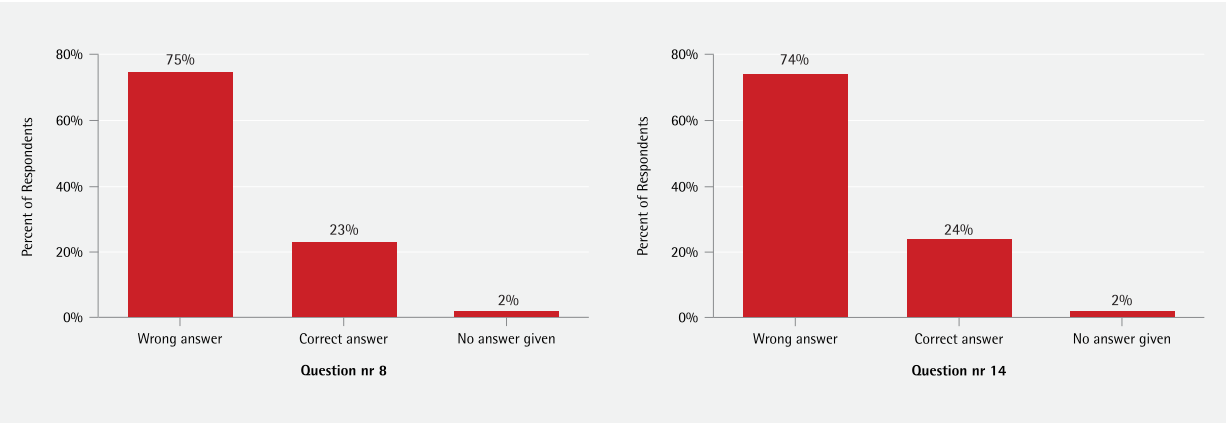
In the first question of the questionnaire, 64% of the respondents marked correctly that autism is a lifelong condition. As much as 6% felt that they didn't know the correct answer. It is extremely important for the primary healthcare providers to deeply understand the persistent nature of this developmental disorder in order to provide a more informed guidance for the families who often fall victim to fraudulent therapies and false claims of con artists who prey on desperate parents by promising them a 'cure' for autism. Regarding the second question concerning causes of autism, one quarter of respondents wrongly indicated a causal association between autistic behaviors and lack of love on mothers' part. Refrigerator mother theory, according to which autism was primarily caused by emotional neglect and withholding of affection, was formed in the 1950s and early 1960s, in the absence of any biomedical explanation of autism's cause. It went unchallenged into the mid-1960s until researchers ultimately refuted and discredited this theory.

Questions 8 and 14 had the highest percentage of incorrect responses (see Figure 1). The current state of scientific knowledge on curability of ASD is that a cure for autism is not available. Autism is a pervasive disorder, which begins in childhood and tends to persist into adolescence and adulthood. However, numerous evidence-based interventions exist, such as behavioral treatment, speech-language therapy and skills training programmes that can significantly reduce difficulties in social behavior and communication, improving child's well-being and quality of life.

Question 14 was on a savant syndrome, a condition where prodigious talents and unique abilities co-occur with autism. Savant syndrome concerns not more than approximately 10% of the entire ASD-affected population. Portrayals of autism in popular culture, mainly in film and television, often depicting autistic children as individuals being able to crack advanced codes, play music by ear

[9] The intensity of the colour used in the table is directly proportional to the number of wrong answers given by the respondents. 50% and above of incorrect answers: light grey, 30%-50%: gold, 29% and below: light gold.

Figure 1. Percentage of incorrect responses on questions 8 and 14



after a single hearing, or draw highly detailed scenes from memory, contribute to dangerous generalizations and false perceptions of autism also among primary healthcare providers.

Question 9, pertaining to the early onset of ASD, was marked correctly by 68% of respondents, while 30% found that the symptoms occur after three years of age, and a further 2% didn't know how to respond. The timing and intensity of early symptoms vary widely, which is why professional evaluation is crucial. In the next question, 36% of respondents wrongly linked the majority of autism cases with intellectual disability. Only about 31% of children with autism have an intellectual disability (intelligence quotient [IQ]<70) (Autism Speaks, 2019).

It is interesting to note that both questions pertaining to language and communication in children with ASD, namely questions 11 and 12, revealed the highest percentages of divergence. 90% of respondents indicated correctly that autism can occur in mild as well as extreme forms. 21% were in favor of the false statement that autism spectrum disorders can't be tested in any way.

In conclusion, physicians' knowledge about autism spectrum disorder varies depending on the topic and is, in many aspects, insufficient to competently carry out an autism screening procedure that is required for every child in Ras Al Khaimah visiting a doctor at 18 months.

The lack of rural/urban disparities in autism knowledge and awareness among doctors in Ras Al Khaimah

An important socioeconomic public health consideration is location, such as the comparison of the quality and availability of services provided in rural or urban settings. Analysis[10] of participants' responses did not show the presence of statistically significant differences between the level of knowledge about ASD presented by the primary healthcare providers practicing in the main metropolis and by the doctors working in more remote areas of Ras Al Khaimah. This finding indicates the lack of significant rural-urban disparities in autism knowledge and awareness among doctors. However, there may be other factors potentially obstructing preventive services such as the ASD screening procedure in the rural/suburban context. For example, greater distance to healthcare services may reduce visit frequency, or access to resources and care coordination may be inadequate, as some interviewed doctors suggested (personal communication, 2019). In conclusion, efforts to improve early ASD detection should consider the barriers and challenges unique to rural, suburban, or urban areas.

Opinions and perspectives regarding ASD-related topics among pediatricians and general practitioners in Ras Al Khaimah

To better understand the opinions of healthcare providers in Ras Al Khaimah, the statements seen in Table 3[11] were included in the questionnaire. These perspectives are important to understand, as they highlight the perceived status of the field, and allow for a tailored dialogue that increases the buy-in of practitioners for potential reforms and capacity building. Table 3[11] presents the numbers and percentage (n, %) of respondents who agreed, disagreed, or gave no answer to each statement.[12]

The study found that three-quarters of respondents did not feel that ASD cases occur less frequently in the UAE compared with western countries, while 6% of respondents did not provide comment. Four decades ago, researchers

[10] Mann-Whitney U test: U = 567.5; p> 0.05; Out of 15 possible correct answers to give, the average of correct responses in the study group was 9.23 ± 2.11 points, which is 61.53 ± 14.08%

[11] The intensity of the colour used in the table is directly proportional to the number of 'agree' statements given by the respondents. 50% and above of agreeing responses: gold, 30%-50%: light grey, 29% and below: light gold.

[12] Statistical test results for statements 15-21: 15. $\lambda^2(2)=69.52$; $p<0.001$, 16. $\lambda^2(2)=89.86$; $p<0.001$, 17. $\lambda^2(2)=75.41$; $p<0.001$, 18. $\lambda^2(1)=0.02$; $p>0.05$, 19. $\lambda^2(1)=17.48$; $p<0.001$, 20. $\lambda^2(2)=52.14$; $p<0.001$, 21. $\lambda^2(1)=79.18$; $p<0.001$

Table 3. Opinions and perspectives on autism spectrum disorders among primary healthcare providers in Ras Al Khaimah

Question No. (n = 87)	Agree n=	Agree %	Disagree n=	Disagree %	No answer given n=	No answer given %
15 Autism is a rare condition in this country as compared with the West.	17	19%	65	75%	5	6%
16 There is a lack of awareness regarding autism among healthcare professionals in the UAE.	70	81%	15	17%	2	2%
17 Autism is under-recognized and often missed in general practice.	84	96%	3	4%	0	0%
18 Pediatricians and GPs are taught how to spot early autism symptoms.	43	49%	44	51%	0	0%
19 I have tools to diagnose autism.	24	28%	63	72%	0	0%
20 There are workshops and trainings on autism available for professionals in Ras Al Khaimah.	23	26%	59	68%	5	6%
21 A cooperation and exchange of information with speech language pathologists and psychologists would be useful.	85	98%	2	2%	0	0%

associated ASD mainly with technologically developed nations. The current evidence of increased prevalence of autism in developing countries proves this assumption wrong. In addition, the majority of respondents (81%) believe that, in general, awareness regarding ASD among healthcare professionals in the UAE is lacking, and that ASD is under-recognized and often missed in general practice. Only very few study participants (4%) disagreed with the latter statement. These numbers underline the importance of continuing education on ASD for primary healthcare providers across the emirate.

In response to statement 18, respondents gave divergent answers. Forty-nine percent of respondents replied that pediatricians and general practitioners are taught how to spot early ASD symptoms, but just over half (51%) of those surveyed did not share this view. These differences can be accounted for in part by different educational experiences of participants and different standards in medical schools' curricula, but they highlight the need for standardization across curriculums, certification requirements, and regulations.

Seventy-two percent of respondents indicated that they do not have tools to diagnose ASD. When respondents were asked whether they use or are familiar with any ASD screening tools, the answer was negative for all of 87 subjects. Alarmingly, all interviewed doctors said that they do not use any ASD screening tools in their daily practice, meaning that many young children in the emirate may remain undiagnosed and untreated. In addition, only 26% of respondents indicated that there are workshops and trainings on ASD related subjects available for them in Ras Al Khaimah, suggesting that training needs among doctors remain largely unmet. Furthermore, nearly all of the subjects who completed the questionnaire (98%), commented that cooperation and exchange of information with speech language pathologists and psychologists would benefit their practice.

Analysis on Question 16 on autism awareness found statistically significant differences.[13] Doctors who disagreed with this statement and felt that the overall autism awareness of local healthcare professionals is sufficient, obtained statistically significantly higher percentage of correct answers given[14] compared to doctors who expressed doubts about the level of autism awareness within their professional field.[15] This finding demonstrates a noteworthy association between self-perceived and objectively measured knowledge.

The results of this part of the study seem to demonstrate that the majority of pediatricians and general practitioners in Ras Al Khaimah do not feel sufficiently equipped with knowledge about childhood ASD and do not have or know of any easy-to-use screening tools they could confidently administer in their daily practice. Also, an overwhelming sense among respondents was that there are unmet needs in terms of continuing medical education and policy making with regards to ASD, especially, as far as early detection is concerned. The results also indicate that there is openness toward a more multidisciplinary approach (a closer cooperation and exchange of information with other specialists such as clinical psychologists and speech-language pathologists working closely with autistic individuals and their families).

[13] $U = 711.5$; $p < 0.05$

[14] $M = 65$, $SD = 12.38$

[15] $M = 57.98$, $SD = 14.95$

Recommendations for Key Stakeholders

This policy paper highlighted results from a study assessing the level of knowledge, perspectives and opinions about autism spectrum disorder among those who are the first point of contact for children affected by ASD and their families in Ras Al Khaimah, namely, pediatricians and general practitioners. This study may be the beginning of a new body of research into autism diagnosis and therapy in Ras Al Khaimah, the UAE, and the broader Gulf region. The findings could have considerable managerial implications for all decision makers and stakeholders involved.

The following recommendations could help implement the much-needed changes and improvements of policies, regulations, and guidelines, as well as inspire effective networking between local policymakers, researchers, and medical practitioners on the subject of timely autism detection and provision of early intervention services within the emirate and beyond.

Regulated and Unified ASD Screening Procedure

Seventy-two percent of respondents indicated that they do not have tools to diagnose ASD. When respondents were asked whether they use or are familiar with any autism screening tools, the answer was negative for all of 87 subjects. All interviewed doctors admitted that they do not use any ASD screening tools in their daily practice, although there is an obligatory 'Autism Screening' procedure for every 18-month child in Ras Al Khaimah. According to well-informed healthcare practitioners from Ras Al Khaimah, the above-mentioned procedure is listed as part of an obligatory checklist scheme. However, it is not clearly stated how the procedure should be conducted and with what tools. There are no concrete guidelines provided. In reality, it was reported that the procedure is either skipped, or limited to a couple of random questions asked by a doctor to a visiting parent. Regulators should provide unified guidelines with regard to this procedure, listing at least one chosen screening tool that is available in the spoken languages of the populations being served.[16]

Medical Education Curriculum Revisions

Medical students in Ras Al Khaimah would highly benefit if additional coursework on ASD were to be implemented into the Bachelor of Medicine and Bachelor of Surgery (MBBS) curriculum, with special focus placed on early symptoms and detection, as well as the use of evidence-based early interventions.

It is critical, however, for such coursework not to become part of general education (alongside computer studies, Arabic, English, etc.). According to interviewed students and faculty, general education courses tend to be trivialized and neglected by the students (personal communication, 2019). Therefore, such subjects should be introduced in the third (clinical) year for MBBS students, as one of the core subjects.

Continuing Education Courses

Public health professionals and policymakers should make regular continuing education courses on ASD and its early symptoms in toddlers available and easily accessible for primary healthcare professionals in Ras Al Khaimah and the broader UAE. Special focus should be placed on providing these opportunities for (1) pediatricians, (2) general practitioners, and (3) nurses, as research suggests that they are often the primary point of contact for families with young children, providing initial information regarding developmental milestones, nutrition, immunizations, etc. Their role is also to build awareness with parents and beyond, and to provide basic health education.

Strategic Professional Group: Nurses

Owing to time and logistical constraints, it was not possible to include nurses in the research. This is an important limitation of this study to be highlighted and addressed in the future. Pediatric, psychiatric, and community nurses, as members of multidisciplinary teams, are expected to provide holistic care and adequate counseling to children with childhood autism and their families. It is critical not only to facilitate nurses' education by providing continuing medical education on the subject of ASD, but also to introduce new contents into the basic curriculum as the current curriculum does not include courses on screening, assessment, leadership, advocacy, and the practice of integrated nursing care of ASD (personal communication, 2019). Nurses, if adequately trained on the subject, are in a position to successfully conduct ASD screening procedures, which could be a huge time-saver for doctors, making the entire ASD early screening procedure more efficient.

Community Awareness Sessions

Early identification and diagnosis of childhood autism, and subsequently early interventions and better prognosis for the child, depend not only on the competence of medical

[16] The author of this study suggests using Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F, Robins, Fein, Barton, 2009) as it is recommended by American Academy of Pediatrics (AAP), free of charge for doctors to download, and most importantly, available also in Arabic as well as in other languages widely spoken in Ras Al Khaimah (e.g. Tamil, Urdu, Hindi, Tagalog). In a study conducted in nine Arabic speaking countries by Seif Edin et al. (2008), M-CHAT proved to be an effective tool to use in the early screening of autism (Seif Eldin et al., 2008).

professionals such as pediatricians, general practitioners, and nurses, but also are strongly linked to attitudes and awareness of parents and the entire community. Having emirate and nation-wide awareness and informational campaigns would help build minimum, foundational understandings of ASD, helping to combat misinformation and stigmas, encourage the development and prioritization of resources, and ensure higher percentages of early detection and diagnosis. Building parental and community buy-in is critical for building trust in the patient-provider relationship and for creating and maintaining culturally specific methods of communication between healthcare providers and families.

Additionally, various targeted awareness-raising events and meetings could be organized for pregnant women, young parents, siblings of ASD-affected children, and various professional groups such as nannies and nursery teachers. Suggested key locations for such events for medical workers and those that spend a significant amount of time taking care of newborns and toddlers are: neonatology departments, outpatient pediatric clinics (private and public), public Ras Al Khaimah health centers, nurseries, or even popular shopping malls in order to reach a wider audience.

Conclusion

Autism is one of the most severe developmental disorders. Pediatricians and general practitioners are a group of special importance because of the responsibility they bear and of the trust parents place in them, before they decide to consult other specialists (e.g. psychiatrists or neurologists). Parents turn to them first, and therefore their knowledge must be adequate to help families recognize the first symptoms. The study conducted in Ras Al Khaimah showed that the knowledge of primary healthcare professionals is dangerously insufficient to meet this challenge and that they should be continually educated on the disorder and how not to miss its early onset in outpatient practice.

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