

Autism spectrum disorder in Qatar: Profiles and correlates of a large clinical sample

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Abstract

Autism spectrum disorder (ASD) is an increasingly prevalent disorder. Although around 15% of cases are caused by specific genetic causes, most cases involve a complex and variable combination of genetic risk and environmental factors that are not yet identified. There is a paucity of studies on ASD in Qatar, mostly in the form of case reports and genetic causes. The current study was designed to describe the clinical characteristics of ASD and its correlates in Qatar. Individuals with ASD were recruited from the Shafallah Center for Children with Special Needs which is the largest special needs center in Qatar. Within the sample of 171 individuals with ASD, 47% were ethnic Qataris, while 53% were nonethnic Qataris (Arabs and other nationalities). The analysis included the following factors: nationality, age, gender, socioeconomic status, consanguinity, prenatal/postnatal complications, and comorbidities. Eighty percent of the identified cases were males, with a 4:1 male to female ratio. Additionally, 83% of the families had one proband, 9.9% with 2 probands, and 7.1% with more than two. Comorbid conditions included: intellectual disabilities (ID) in 83% and epilepsy in 18.8%. 76.6% of subjects were nonverbal. There were 3 (1.8%) children with Rett's syndrome, 3 (1.8%) with Fragile X, and 1 (0.6%) with tuberous sclerosis. There are currently no publications that clarify the mean age of diagnosis in Qatar, however, the present study showed that more than half of the diagnosed cases were among the ages of 7–14 years (56%). The effect of consanguinity as a risk factor was not found to be significant.

Keywords

Autism spectrum disorder (ASD), prevalence, causes, intellectual disability (ID), Qatar

Introduction

With the emergent global prevalence of ASD (Elsabbagh et al., 2012), research has rapidly advanced efforts to better understand the rise in occurrence, the possible causes, and the optimum interventions.

Additionally, research continues to focus on public education and the amelioration of the deficits related to ASD. Despite equal or similar prevalence of ASD in the Arab world compared to Western countries, research into the field is still in its initial stages and

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has only reached the Arab world's attention during the late 1990s (Taha & Hussein, 2014). According to the Center for Disease Control (CDC), about 150 per 10,000 children (1 in 42 boys and 1 in 189 girls) have been identified with ASD (CDC, 2014, 2015). Prevalence studies conducted to date within Arab countries yielded an estimate of the prevalence of ASD for Saudi Arabia, Oman, UAE, Jordan, Libya, Egypt, and Tunisia (Taha & Hussein, 2014). A systematic review of the epidemiology of ASD in the Gulf Cooperation Council (GCC) countries reported a prevalence rate ranging from 1.4 to 29 per 10,000 individuals (Salhia, Al-Nasser, Taher, Al-Khathaami, & El-Metwally, 2014). The difference in the prevalence rates compared to other countries does not prove that ASD is less prevalent in the Arab world, but rather reflects underdiagnosis, underreporting, and cultural attitudes (Taha & Hussein, 2014). Underdiagnosis and underreporting are attributed to the limited availability of quality specialized healthcare services for children with neurodevelopmental disorders (Hussein & Taha, 2013). Moreover, the cultural attitudes regarding disability are also related to the underreporting due to the stigma attached to most neurodevelopmental disabilities. In Qatar, ASD was added as a disability category after 2012, and used to be included within the intellectual disability reporting (Ministry of Development Planning and Statistics, 2016). To date, there are no studies clarifying the current diagnostic practice of ASD in Qatar. Yet, most of the centers in Qatar usually use the ADI-R or ADOS as diagnostic tools with the DSM-4 and DSM-5 criteria for diagnosis.

To date, no studies have explored the clinical characteristics in the ASD population in Qatar. The aim of the current study was to describe cases within one of the country's largest special needs centers, the Shafallah Center for Children with Special Needs. The current study evaluated clinical profiles of ASD and their correlates. Due to similarities in many demographic characteristics between Qatar and the neighboring Gulf States, we think that this study provides important insights to Autism not only in Qatar but also in the entire region. This added knowledge is important given the scarcity of ASD studies from this region. We also think that this study provides an important cross-cultural perspective on ASD from an underrepresented region that contributes to enhancing our understanding of ASD.

Methods

Subjects

The methodology in the current study was designed to review cases within the Shafallah Center for Individuals with Special Needs between the years 2011 and 2015.

The center was established in 1999 to provide services for both citizens and expatriates with disabilities, mainly ASD, between the ages of 3 and 18 years of age. The criterion for admission to the center is for any individual diagnosed with ASD. All individuals undergo a full evaluation and assessment including IQ, ADOS, and ADI-R, and only those with a definite diagnosis of ASD are usually accepted to be admitted to the Autism Unit in the center. Depending on the severity of the case and family preference, the child may either get admitted to full-time intervention program, or part-time intervention sessions. A total of 171 cases of ASD were identified through a comprehensive record review which contained diagnostic, medical, and developmental history. This enabled access to information regarding comorbid conditions, intellectual ability, family history of ASD and consanguinity, prenatal and postnatal history, and other relevant information.

Definitions and instrument

ASD diagnosis. The ASD diagnoses for the majority of subjects were confirmed by utilizing the Autism Diagnostic Interview-Revised (ADI-R) and/or the Autism Diagnostic Observation Schedule (ADOS) (136 cases), or by using clinical diagnosis utilizing the Diagnostic and Statistical Manual of Mental Disorders (DSM-4) criteria (35 cases). All cases had a clinically confirmed diagnosis of ASD following an assessment by a multidisciplinary team including a child psychiatrist, neurodevelopmental pediatrician, and a psychologist.

Intellectual disability. Intellectual disability (ID) was diagnosed according to DSM-4 during the initial assessment period; where intellectual disability is considered to be two standard deviations or more below the population, which equals an IQ score of 70 or less. ID cases were categorized as mild (IQ Score 50–70), moderate (IQ score 35–49), and severe (IQ scores 20–34). The Stanford Binet IQ test was used by the assessment team.

Language level. Language level was measured using the ADI-R classification for verbal (i.e., when the patient used at least five different words other than “Mama” and “Baba” meaningfully on a daily basis). Cases were classified as verbal (uses 5+ functional words), delayed (starts using more than 5 words later than the normal developmental milestone), or nonverbal (uses less than 4 words).

Family history. Single families (simplex) and extended families (multiplex) were defined as having one or more than one sibling affected with ASD within the family. Consanguinity was defined in this study as marriage between first and second cousins.

Genetic testing. Blood samples were drawn from cases diagnosed with ASD for Fragile X (FMR-1) testing for males, MECP-2 testing for females, and testing for tuberous sclerosis when suspected in the diagnoses.

Ethical considerations

Qatar Biomedical Research Institute-Institutional Review Board (QBRI-IRB) approval obtained. Informed consents were obtained from the parents/legal guardians of the subjects who agreed to participate in this study.

Data analysis

The Statistical Package for the Social Sciences (SPSS) program was used for statistical analysis. Chi-square was used to ascertain the association between two or more categorical variables. The level $p < 0.05$ was considered as the cut off for statistical significance.

Results

Sociodemographic characteristics

Table 1 illustrates the distribution of families with children with ASD categorized by age (grouped into 5

years intervals), nationality (Qatari, non-Qatari Arabs, and non-Qatari other nationalities); in which nationality refers to ethnicity, that is, Qatari nationals were not selected by citizenship status. Additionally, the following factors were investigated; gender, income (monthly income in Qatari Riyals (QR) grouped into three groups; low ($<10,000$ QR), middle ($10-20,000$ QR), and high income ($>20,000$), number of ASD probands in the family (1, 2, or more than 2), and consanguinity. The largest age group was between 10 and 14 years of age (30.9%), while the lowest was between 0 and 4 years (2.3%). Eighty percent of the subjects in the sample were males, translating into a male-to-female ratio of our sample of 4:1. Within the sample, 47% of ASD cases were Qatari nationals, and 53% were non-Qataris (residents and expatriates). Results showed that 47.5% of families were in the highest income group ($>20,000$ QR per month), whereas 40.9% had a monthly income of $10,000-20,000$ QR, and only 21.5% had a monthly income of less than $10,000$ QR.

Language level and ID

In terms of language level and ID, 76.6% of the cases were nonverbal while 83% had ID. There were no significant gender differences in the incidence of ID and

Table 1. Sociodemographic characteristics of ASD cases by gender.

Variable	Total ($n = 171$)		Males: $n = 136$ (79.5%)		Females: $n = 35$ (20.5%)		p-Value
	n	%	n	%	n	%	
Age							
0–4	4	2.3	4	2.9	–	–	
5–9	44	25.7	31	22.7	13	37.1	
10–14	53	30.9	43	31.6	10	28.5	
15–19	49	28.6	42	30.8	7	20	0.379
>20	21	12.2	16	11.8	5	14.2	
Nationality							
Ethnic Qatari	80	47	58	42.6	22	62.8	NS
Non-ethnic (non-Qatari Arabs and non-Qatari other nationalities)	91	53	78	57.4	13	37.2	
Consanguinity							
Consanguineous	69	40.3	51	37.5	18	51.4	0.00
Nonconsanguineous	102	59.7	85	62.5	17	48.6	
Number of probands							
Single family (1 proband)	142	83	112	82.3	30	85.7	
Extended family (2 probands)	17	9.9	14	10.3	3	8.5	1.0
Extended family (>2 probands)	12	7.1	10	7.4	2	5.8	
Monthly family income (QR)							
<10,000	37	21.5	32	23.5	5	14.2	0.32
10–20,000	70	40.9	52	38.2	18	51.4	
>20,000	64	47.5	52	38.2	12	34.3	

language abilities; with females (91% with ID) only being slightly higher than males (81% with ID) (Table 4).

Consanguinity

Consanguinity (1st and 2nd cousin marriages) among parents of children with ASD was reported by 40% of families. Nearly half (50%) of the consanguineous cases of ASD in this study were Qatari, compared to (32%) non-Qatari-Arabs, and (16%) other nationalities. Analysis of cases of ASD with epilepsy found that 50% of the cases within this sample were from both consanguineous and nonconsanguineous families. However, for ASD without epilepsy, 38% were consanguineous and 62% of the cases were nonconsanguineous (Table 3). Moreover, 87% of cases with ID were consanguineous, compared to 80% nonconsanguineous cases (Table 5).

Simplex and multiplex families

Autism spectrum disorder affected one sibling in 83% of the families with 9.9% of families having two offspring (extended families) affected by ASD and 7.1% of families had more than two siblings affected (Table 1).

Prenatal and postnatal factors

Prenatal and postnatal factors were analyzed including method of labor, neonatal complications, and postnatal complications. Unassisted vaginal delivery was the most frequently reported method of labor (70%). Of the sample, a combination of breast and bottle-feeding represented the majority of feeding practices (77%). Postnatal complications and injuries included: neonatal hypoxia (13%), jaundice (11%), and history of head trauma (5%) (Table 2).

Comorbidities

Comorbid conditions were reported in 24% of the sample (41 cases). Comorbid conditions included epilepsy (32 cases, 18.7%), Fragile X (2.9%; 3 cases with full mutation and 2 cases with premutation (55–200 CGG repeats), Rett's syndrome confirmed with MECP2 mutation (1.7%; 3 cases), and 1 case of tuberous sclerosis. Eighty-three percent of the ASD cases have some degree of ID, 47.9% of the cases were nonverbal, and 28.6% were language delayed.

Further analysis of the association of comorbidities and syndromic ASD showed that 90% of children with ASD and epilepsy had ID. Additionally, 69% of those with ID and epilepsy were nonverbal.

Table 2. Environmental and genetic risk factors' analysis of ASD cases; method of labor, feeding practices, prenatal and postnatal factors, syndromic, and other co-morbidities.

Variable	Total (n = 171)	
	n	%
Method of labor		
Normal unassisted delivery	120	70
C-section	38	22
Forceps/or suction	10	6
Protracted/induced	3	2
Feeding practices		
Breast feeding	38	22
Breast and bottle feeding	119	70
Bottle feeding	14	8
Prenatal and postnatal factors		
Hypoxia	23	13
Jaundice	19	11
Head trauma	8	5
Syndromic ASD and other comorbidities		
Fragile X		
Full mutation	3	2
Pre-mutation (55–200 CGG repeats)	2	1
Rett's syndrome		
MECP2 +ve	3	2
Tuberous sclerosis	1	0.5
Epilepsy	32	19
Total comorbidities	43	25

Epilepsy was the highest comorbid diagnosis found among cases with ASD (32 cases, 18.7%), 24 cases in males (17.6%), and 8 cases in females (22.8%). Analysis of cases of ASD and ID found that 83% of the sample had ID with slightly more cases among females (91%) than males (81%) (Table 2).

Discussion

Research on Autism Spectrum Disorders within a cultural context, and in developing countries, has received limited attention (Daley, 2002; Susser, 2014). The current study is the first attempt to characterize ASD in Qatar. This study gives insights to ASD in the entire Gulf region as there are many similarities in population characteristics between the Qatar and its neighboring Gulf States. This study also contributes much needed information to the cross-cultural understanding of ASD in developing countries. One of the main advantages of this study is the utilization of strict diagnostic methodology with the use of ADI-R/ADOS for the majority of the sample (136/171, 80%), and clinical diagnosis using strict DSM-4 criteria for the remainder.

Table 3. ASD with or without epilepsy.

Variables	With epilepsy (n = 32)		Without epilepsy (n = 139)		p-Value
	n	%	n	%	
Consanguinity					
Consanguineous	16	50	53	38	0.235
Nonconsanguineous	16	50	86	62	
C-section					
With C-section	9	28	29	21	0.357
Without C-section	23	72	110	79	
Hypoxia/and or jaundice					
With	11	34	31	22	0.174
Without	21	66	108	78	
Gender					
Male	24	75	112	80	0.473
Female	8	25	27	20	
Intellectual disability (ID)					
With ID (including mild, moderate, and severe)	29	90	113	81	0.297
Without ID	3	10	26	19	
Communication (language)					
Verbal	10	31	30	22	0.253
Nonverbal (including delayed (28.6%))	22	69	109	78	
Syndromic ASD (FRX, Rett's, TS)					
With	3	9	3	2	0.08
Without	29	91	136	98	
Single or extended families					
Single families (one proband)	27	84	127	91	0.321
Extended families (>one)	5	16	12	9	

Table 4. Gender differences.

Variables	Female (n = 35)		Male (n = 136)		p-Value
	n	%	n	%	
Intellectual disability (ID)					
With ID	32	91.4	110	81	0.206
Mild	10	28.5	27	20	
Moderate	18	51.4	65	47.8	
Severe	4	11.4	18	13	
Without ID	3	8.6	26	19	
Communication (language)					
Verbal	8	22.8	32	23.5	1.00
Nonverbal	16	45.7	66	48.5	
Delayed	11	31.4	38	28	
Epilepsy					
With epilepsy	8	22.8	24	17.6	0.481
Without epilepsy	27	77.2	112	82.4	

The enrolment of subjects from the main center for ASD in Qatar which is government supported, that accepts both citizens and expatriates, is thought to yield a representative sample of ASD in Qatar.

However, the sample under discussion may not be representative of the broader population in Qatar due to the fact that most of the cases referred to Shafallah Center are older than 5 years of age (only 4 cases were 0–4 years of age). Additionally, most of the cases with high functioning ASD attend mainstream schools. The implication of this misrepresentation may have caused the high percentage of cases affected with ID in our sample. Although the study utilized retrospective review of charts, there were consistent clinical data available for each individual, which allowed a detailed analysis of the subjects' clinical characteristics and comorbid conditions.

The findings of this study of male predominance (4:1) support previous research findings regarding the sex differences in ASD (Werling & Geschwind, 2013). In terms of income, only 21.5% of families in our sample were of low income which probably reflects the general high income in Qatar (Snoj & Tina, 2014) but could also be indicative of the lack of association of autism and low income (Elsabbagh et al., 2012). The nationality distribution indicates that almost half of the samples were ethnic Qataris, which is not reflective of the fact that out of the estimated 2.2 million people

Table 5. Intellectual disability with consanguinity.

Variables	With intellectual disability (<i>n</i> = 69)		Without intellectual disability (<i>n</i> = 10)		<i>p</i> -Value
	<i>n</i>	%	<i>n</i>	%	
Consanguinity					
Consanguineous	60	87	9	13	0.261
Nonconsanguineous	82	80	20	20	

living in Qatar, only 12% are citizens (Snoj, 2013). Further studies are needed to evaluate whether the prevalence in Qatar is higher than Western countries. The impact of high rates of consanguinity and large family size could cause increased prevalence in Qatar (Mezzavilla et al., 2015), however, this needs to be further evaluated on larger samples. The potential effects of consanguinity and family size on prevalence couldn't have been evaluated on our sample. The consanguinity rates in our study (40%) is slightly lower than that reported in the general population in Qatar (54%) but is still higher than that reported in Western countries (Al Ali, 2005). The percentage of multiplex families in our sample was 17%; which is toward the higher end of reported rates of having more than one person with ASD in the family which ranges from 3% to 18% (Ozonoff et al., 2011). One potential explanation is that a high rate of consanguinity is generally associated with a higher incidence of autosomal recessive genetic conditions and may conceivably be a factor in ASD incidence (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009; Salhia et al., 2014). However, the current study identified no significant effect of consanguinity on the occurrence rate of ID in this relatively small sample (Table 5).

The rate of epilepsy in our sample (18.7%) was comparable with other reports (22%) although the reported rate of epilepsy in autism is quite variable (20–40%) due to many factors including case ascertainment and inclusion of syndromic autism (Bolton et al., 2011). In our sample, 83% of subjects had some degree of ID which is significantly higher than recent estimates which is between 40% and 55% (Chakrabarti & Fombonne, 2001; Edelson, 2016). The high percentage of ID within our sample might reflect a higher percentage of severe ASD and/or under-diagnosed syndromic ASD. The percentage of nonverbal individuals was found to be consistent with what is reported in literature (48% vs. 25–50%) (Tager-Flusberg & Kasari, 2013).

In conclusion, the current study is the first attempt of clinical characterization of ASD in Qatar. This study provides insights to the similarities and discrepancies to what has been noted in other parts of the world. Additionally, it supports the need of a prospective

epidemiological study in this population which might contribute to expanding our knowledge of ASD.

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