

# Underlying Factors Behind the Low Prevalence of Autism Spectrum Disorders in Oman

## Sociocultural perspective

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## العوامل الكامنة وراء انخفاض معدل انتشار طيف اضطراب التوحد في عُمان

### منظور اجتماعي وثقافي

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**ABSTRACT:** Epidemiological surveys from various countries indicate an increased prevalence of autism spectrum disorders (ASD), leading researchers to debate whether there are now 'more affected' or 'more detected'. The epidemiology of ASD in developing countries, such as Oman, has generally indicated a lower prevalence compared to developed countries in the West. In Oman, the prevalence is low; however, this article highlights some of the factors that could contribute to the appearance of a low ASD rate: cross-cultural variations in the presentation of distress; a lack of reliable biological markers for diagnosing ASD, and a lack of health services for children with ASD, thus limiting the number of participants in epidemiological surveys. While the defining features of ASD have yet to be established, pilot studies in Oman indicate a substantial number of children with these disorders. Therefore, it is important that these discrepancies be addressed and the need for appropriate services for this patient population in Oman be highlighted.

**Keywords:** Autism; Prevalence; Culture; Oman.

**المخلص:** أشارت دراسات المسح الوبائي من مختلف البلدان إلى زيادة انتشار اضطرابات طيف التوحد، مما يطرح تساؤلاً في أذهان الباحثين حول ما إذا كان ذلك ناتجاً عن زيادة معدل حدوث الاضطراب، أم زيادة الكشف عنه. أظهرت الدراسات الوبائية في البلدان النامية، مثل عُمان، قلة انتشار اضطراب التوحد بالمقارنة مع الدول المتقدمة في الغرب. هذا المقال يسلط الضوء على بعض العوامل التي يمكن أن تسهم في ظهور ذلك المعدل المنخفض؛ الاختلافات بين الثقافات في عرض الشدة، عدم وجود "علامات بيولوجية" يمكن الاعتماد عليها لتشخيص الاضطراب، وعدم وجود الخدمات الصحية للأطفال المصابين بالاضطراب، مما يحد من عدد المشاركين في دراسات المسح الوبائي. في حين لم يتم بعد تأسيس السمات المميزة للاضطراب، أظهرت الدراسات التجريبية في عُمان وجود عدد كبير من الأطفال الذين يعانون من هذه الاضطرابات. ولذلك نرى من الأهمية بمكان أن يتم الالتفات إلى هذه التناقضات، والحاجة إلى تقديم الخدمات المناسبة لهذه الفئة من المرضى في عُمان.

**مفتاح الكلمات:** التوحد؛ انتشار؛ الثقافة؛ عمان.

IN MANY PARTS OF THE WORLD, PRIOR TO the introduction of modern healthcare and social and economic improvements, vulnerable children were often prone to an early death.<sup>1</sup> More recently, countries such as Oman have witnessed a dramatic decline in child mortality. Out of 230 countries, Oman is ranked 48<sup>th</sup> in the global population growth rate with a demographic profile characterised by a younger population; 44.7% of the population is under the age of 20 years.<sup>2</sup> Population growth means that the number of people afflicted by cognitive, emotional and social deficits is likely to be on the rise. Furthermore, Oman's

population is characterised by large family sizes and a preponderance of consanguineous marriages.<sup>3,4</sup> The latter is thought to trigger many developmental anomalies, including those that are likely to cause social and intellectual disabilities.<sup>4</sup>

Autism spectrum disorders (ASD) encompass five pervasive developmental disorders that are characterised by impairments in social interaction, impediments in communication skills and behavioural and emotional problems.<sup>3</sup> According to the available nomenclature, diagnoses of ASD are only made if symptoms are persistent and pervasive prior to the

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age of three years old.<sup>5</sup> While autism-like conditions may have always existed,<sup>3</sup> autism has only recently been featured in diagnostic nomenclatures such as the Diagnostic and Statistical Manual of Mental Disorders (DSM).<sup>6</sup> According to a review on the history of ideas surrounding autism, a child with symptoms akin to autism was previously perceived as a “soulless mass of flesh possessed by the devil”<sup>5</sup>

As with any condition that is culturally devalued, the societal perception of children with autism is often akin to ‘madness’ and demonic possession.<sup>7</sup> In recent history, various studies have explored the ignorance (knowledge), prejudice (attitude) and discrimination (behaviour) of the general public towards those with autism.<sup>8</sup> Many studies have indicated that the general public regard children with autism as less affable.<sup>9</sup> However, those who have previously had contact with autism sufferers—such as family members or those who provide them with social, education or medical care—have a less pervasively negative attitude towards such children.<sup>9</sup> On the whole, attitudes towards any culturally-devalued condition tends to be greatly influenced by the prevailing *Zeitgeist*.<sup>8</sup> Despite the increased awareness that autism is marked by both maladaptive behaviour as well as proficiency, there is little evidence that the concept of autism has not suffered effects of the ‘euphemism treadmill’ as in the case of those with marked intellectual disabilities.<sup>8</sup>

Although it has been widely broadcast that ASD, like other neurodevelopmental disorders, are debilitating and impervious to available medical interventions,<sup>10</sup> there is a strong indication that early diagnosis, coupled with early intervention, can be good prognostic indicators.<sup>11</sup> Against such a background, the focus has been on lessening the associated impairments and disabilities of those with ASD while improving their quality of life and facilitating functional independence and psychosocial skills.<sup>10,12</sup> This means that early recognition is essential, if not paramount, in order to safeguard the path of such children to a meaningful and comfortable future. Furthermore, in order to improve the educational, social and medical remedial services for these children, it is essential to quantify the magnitude of the problem in order to allocate appropriate resources. It is well known that an incentive for establishing services for those affected by ASD will stem from the recognition that there is an increasing number of children with ASD in Oman. Thus, quantifying the rate of ASD in the community is crucial for ensuring the welfare of this patient population.

The aim of the present discourse, therefore, is to highlight some of the factors that could contribute to a lower prevalence of ASD in Oman.

## Prevalence of Autism Spectrum Disorders

ASD constitute a global challenge as it appears that a proportion of children in all societies will be affected by these disorders in the future.<sup>13</sup> In a recent systematic review of ASD epidemiological surveys conducted in various parts of the world, it was estimated that the worldwide prevalence was 77/10,000.<sup>13,14</sup> The review also noted both an increasing prevalence as well as variations among different populations.<sup>14</sup> Without making a blanket generalisation, most studies from emerging-economy countries have reported prevalence estimates that, with a few exceptions,<sup>15</sup> are skewed towards the lower limit.<sup>16</sup> The prevalence of ASD in Oman was estimated to be 1.4 cases per 10,000 0–14-year-old children.<sup>16</sup> On the other hand, in Saudi Arabia, the prevalence of autism was 18 per 10,000 children,<sup>17</sup> while in the United Arab Emirates, from a representative random sample of three-year-old Emirati children, 29 per 10,000 children had autism.<sup>18</sup> In Libya, of 38,508 children who attended a paediatric clinic in Tripoli, 128 children were autistic, thus giving a prevalence of one in 300.<sup>19</sup> Furthermore, in Egypt and Tunisia, the autism frequency rate among children with developmental disorders was documented as 33.6% and 11.5%, respectively.<sup>20</sup> It appears that there is a wide discrepancy in the magnitude of ASD, even among countries with similar sociocultural characteristics; therefore, it is essential to discuss factors that may have contributed to such variations.

## Potential Factors Underlying the Low Prevalence of Autism in Oman

Compared to the international trend, an ASD prevalence of 1.4 cases per 10,000 in Oman would likely convince policymakers that Oman has been spared the global ‘epidemic’ of ASD. Although differing study methodologies could have led to this variability, other factors may have significantly contributed to the lower prevalence of autism in Oman. These are summarised in the following sections.

### CROSS-CULTURAL VARIATIONS

Studies from populations outside of North America and Western Europe have indicated that some of the core symptoms of ASD do not mimic the ASD symptoms linked to African populations.<sup>21,22</sup> This suggests that there are cultural variations in the expression of ASD. A study carried out in sub-Saharan Africa demonstrated that there was a lack of non-verbal aspects within the expressive language of predominantly sub-

Saharan children diagnosed with ASD.<sup>23</sup> This means, as has been shown in other psychiatric conditions, that distress, disability or illness are often expressed within sociocultural contexts.<sup>23</sup> It has been well-established that applying Euro-American expectations of human nature to people in other parts of the world constitutes a 'category of fallacy' or, simply put, like using the same yardstick to measure two different situations.<sup>21</sup> This is an example of the pan-human predisposition to neurogenetic determinism that is often applied to such developmental disorders. The argument that ASD should display a similar degree of prevalence worldwide stems from the misconception that these disorders are rooted in biology.<sup>24</sup> Another view is that the phenotypical features of ASD stem from pathoplastic cultural factors and individual idiosyncrasies.<sup>25</sup> Therefore, the high variability of the rate of ASD in different populations suggests that both sociocultural and ecological factors play a substantial role in shaping the features of ASD, while existing evidence points to complex interactions between the nature versus nurture dichotomy.<sup>26</sup>

#### RELIABILITY OF DIAGNOSTIC TOOLS

Diagnosing ASD is challenging as there are no biochemical tests or neuro-imaging techniques that can be reliably employed to establish the presence of autism. There are, however, many symptom checklists that are largely accepted as accurate in ensuring improved diagnoses of ASD.<sup>27</sup> One important point about these available checklists is their tendency not to detect higher-functioning individuals with autism, as opposed to moderate and severe cases.<sup>24</sup> In such cases, the experience and skills of the clinician are the sole influential factors in determining the accuracy of the diagnosis. There is a dearth of studies examining the psychometric properties of these symptom checklists.<sup>28,29</sup> It is possible, therefore, that there is a conceptual issue in adopting verbal or non-verbal scales from Euro-American populations for cross-cultural populations. This issue is relevant for studies examining the epidemiology of ASD. Related to this, estimating the 'true' prevalence of ASD is likely to be hampered by the fact that the 'true' signs and symptoms of ASD may be submerged by their resemblance to other childhood conditions. The very fact that some of the hallmark symptoms of ASD are without central features means that diagnoses of ASD are often confused with mental retardation. The difficulty of distinguishing between 'true' mental retardation and ASD is compounded by the fact that a significant number of children with autism are also likely to have mental retardation.<sup>17</sup>

Similarly, many psychiatric disorders have been reported as the 'twin sisters' of ASD, including social anxiety disorder, oppositional defiant disorder, childhood-onset schizophrenia and social communication disorder, as well as those child disorders characterised by inattention and hyperactivity.<sup>15,16</sup> One way to circumvent such a problem is to establish a genetic marker for ASD. As yet, identifying a genetic signature for ASD has remained an elusive search. Most experts agree that biological markers for autism are likely to owe their origin to spontaneous mutation.<sup>16</sup> Therefore, without a validated genotype, diagnoses of ASD often hinge on a phenotypical presentation such as the symptom checklist which is featured in some of the common nomenclatures, including the DSM and the International Statistical Classification of Diseases (ICD). It is worth noting that some critics have indicated that both DSM and ICD fail to recognise that disease, distress and disability is often expressed in a sociocultural context. In the available literature, there is a lack of discussion on how sociocultural context may shape the 'content' of ASD.<sup>30</sup> Such issues are likely to contribute to the disparity in reported rates of ASD in different parts of the world.

#### SERVICE MISDISTRIBUTION AND SOCIETAL COPING

Ideally, appropriate developmental evaluation and early intervention by a team of dedicated multidisciplinary professionals can aid in providing services to children with special needs. In Oman, however, services for children with special needs generally do not exist or are only rudimentary. Despite the fact that Oman has a geographical area of 310,000 km<sup>2</sup> and a population of 3.5 million, to date, there is only one child and adolescent mental health service unit in the country (located in a tertiary care setting in an urban area of Oman).<sup>31</sup> In the rest of the country, there are no dedicated centres for diagnosing children with developmental disorders. This is likely to contribute both to the under-diagnosis and to the under-reporting of ASD cases.

With no one to address affected children's symptoms, 'doctor-shopping' is a common method for parents to find a 'cure' for their children.<sup>32</sup> Since the modern healthcare system often cannot meet their needs, alternative or traditional healing systems are filling the vacuum. There is evidence to suggest that pathways to care for people with behavioural and emotional disorders in Oman are often seen as the prerogative of traditional healers.<sup>18,19</sup> In the Omani community, emotional and cognitive impairments are often perceived as a manifestation of possession

by spirits or supernatural forces, such as *hassad* (contemptuous envy), *sihr* (sorcery) or the 'evil eye'.<sup>4,18</sup> Little documentation exists regarding the role of traditional healing processes in families caring for children with ASD. In reference to other conditions, the traditional healing system tends to allay the 'guilt' often found among caregivers of children with intractable conditions. The family caregiver may resort to any means at their disposal to find a 'cure' for their autistic child. The use of traditional healers may also result from the frequent lack of mental healthcare services available in most Omani communities. Given this situation, it is difficult to quantify the true prevalence of children with ASD in the country.

## Conclusion

In the available literature on ASD in populations from North America and Western Europe, there is debate regarding whether the rising tide of children with ASD is because there are more children affected or more cases detected. Others have pointed out that the recent increase may stem from a broadening of the diagnostic criteria, greater service availability and an increased awareness among both professionals and the general public. On the other hand, although conditions akin to ASD have been reported in different parts of the world, including Oman, the prevalence of ASD varies from culture to culture. In Oman, the lower reported rate of ASD could be directly related to various sociocultural factors. This potential discrepancy in the prevalence rate of ASD may stem from cross-cultural variations in the manifestation of behavioural and emotional disorders. If the current, apparently low prevalence in Oman is in fact just a consequence of under-diagnosis and under-reporting, a concerted effort is needed to increase public awareness of ASD. Additionally, an attempt should be made to institute services for the welfare of such children. This would require training healthcare practitioners to provide the necessary services and remedial interventions for children with ASD.

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