

AUTISM SPECTRUM DISORDER: THE SITUATION TODAY IN LIBYA – “A PERSPECTIVE”

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ABSTRACT

This perspective is to attract the attention of researchers, policymakers, and healthcare professionals working in the field of autism spectrum disorder (ASD). It aims to describe the ASD situation in Libya with regards to prevalence, attitude toward children with ASD, and challenges facing families in taking care of their children.

The prevalence of autism in developing countries is generally lower than in developed countries; however, it is important to note that this may be attributable to underdiagnosis, lack of knowledge, under-reporting, and the associated social stigma rather than true differences in prevalence.

In conclusion, inadequate resources, infrastructure, and setup have hampered large-scale epidemiological studies needed to obtain accurate data. There ought to be a need for more widespread and consistent epidemiological studies to obtain accurate and up-to-date prevalence data on ASD in Libya to schedule plans and allocate funds for diagnosis, treatment, and support services. In general, there are no clear policies regarding inclusive education and integration. It is very important that future researches should take into account the cultural, social, and socioeconomic elements that exist in Libya and may wish to use different approaches for data collection.

Keywords: Libya, Autism, Tripoli, Africa.

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INTRODUCTION

Libya is a country in North Africa. It is bordered by the Mediterranean Sea to the North. It covers an area of almost 1.8 million km² (700,000 sq mi). Libya is the 17th-largest country in the world. The capital of Libya is Tripoli. Libya is a developing country ranking 92nd by the Human Development Index, the highest score in mainland Africa. In spite of the ongoing challenges and political instability in the country, the World Bank surprisingly defines Libya as an “Upper middle-income country, along with only six other African countries” [1].

The population of Libya in 2011 was said to be about 6,597,960. This is not a large number for a country that has such a large area, so the population density of Libya is low. This is because much of Libya is in the Sahara Desert. Most people in Libya live in cities on the coast [2].

In 2010, spending on healthcare accounted for 3.88% of the country's GDP.

In 2023, the Libyan health ministry announced the launch of the National Strategy for Primary Healthcare 2023–2028 to improve services provided by group clinics and health centers.

Basic education in Libya is free for all citizens and is compulsory up to the secondary level. The adult literacy rate in 2010 was 89.2%. The majority of Libya's higher education has always been financed by the public budget. The budget allocation for education represented 38.2% of Libya's national budget. The educational infrastructure for children with special education needs in Libya faces significant challenges and obstacles [3].

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder characterized by communication difficulties, impaired social skills, and restricted and repetitive behaviors. Children with ASD may also struggle to connect with others on an emotional level and often exhibit certain common behaviors. These include strong interests in

a certain topic or activity, difficulties in generalizing new information, and obsessions with certain objects or topics. In addition to these behaviors, they may be hypersensitive to sensory input such as noise or light, which can pose unique challenges in daily life [4,5].

Autism is a widely recognized global health issue, but most of the information available originates from high-income countries (HICs). It is believed that around 95% of individuals with autism live in low- and middle-income countries (LMICs) [6,7]. While research on autism in Africa is increasing, present knowledge and information are still limited, with only about 1% of autism research originating from sub-Saharan Africa. This lack of representation is significant due to the inequalities in identifying and supporting individuals with autism and their families.

There is a shortage of published research on autism in Africa, making the evidence basis for autism intervention and treatment insufficient [8,9].

Thus, the purpose of this study is to provide a thorough overview of the state of knowledge on ASD in Libya, along with recommendations for improving identification, assessment, management, and policy in these particular circumstances [10].

EPIDEMIOLOGY AND BARRIERS ASSOCIATED WITH DETERMINING PREVALENCE

Various studies have shown a high prevalence of children with neurodevelopmental disabilities in LMICs, particularly in sub-Saharan Africa, where the numbers are increasing. This increase is linked to improved diagnostic testing and the rising number of children surviving beyond their first 5 years.

According to a study by the National Center for Biotechnology Information, the global pooled prevalence of ASD was 98/10,000, with a higher prevalence in males (90/10,000) than in females (21/10,000). In addition, the prevalence of ASD is higher in developing countries

(155/10,000) than in developed countries (85/10,000) [11,12]. Recently, 66 studies reported on the prevalence of ASD, screening 21,313,061 children worldwide. Among these, 25 studies were conducted in Europe, 22 in Asia, and 13 in America. In addition, 3 studies each were reported from Africa and Australia. According to a meta-analysis, 0.77% of children globally are diagnosed with ASD, with boys comprising 1.14% of this group [13].

When studying ASD prevalence by country, it is essential to consider the divergent factors that might influence these statistics, such as healthcare access and diagnostic criteria.

In Libya, the prevalence of ASD has risen significantly since 2005. Efforts have been made to study prevalence rates in Libya, with studies conducted at the pediatric neuro-development clinics of the two main teaching hospitals in Tripoli between 2005 and 2009 [14]. These studies revealed prevalence rates between 3 and 4:1000 [15,16]. A more recent 2023 study conducted at the same clinic reported a prevalence of ASD among children was about 8:1000 and 12:1000. These hospital-based studies highlight the substantial burden of ASD in Libya [17,18].

Based on various research studies, the prevalence of autism is higher in boys compared to girls, with a median male-to-female ratio of 4.2. This statistic implies that for every 4.2 boys diagnosed with autism, there is one girl diagnosed. This discrepancy has been consistent across different regions and cultures, reinforcing the observation that autism is more common in males.

The first documented autism prevalence study in Africa was conducted by Lotter in 1978, focusing on children with intellectual disabilities in Ghana, Kenya, Zimbabwe, Zambia, and South Africa. Lotter's study revealed a prevalence of autism of approximately 1 in 145 among children with intellectual disabilities in these sub-Saharan African countries [19]. According to the World Health Organization (WHO, 2022), autism affects about one in every 100 individuals worldwide [20].

About 1 in 31 (3.2%) children aged 8 years across the USA have been identified with ASD according to estimates from the Centers for Disease Control and Prevention ADDM Network. Prevalence of ASD among children aged 8 years was higher in 2022 than previous years [21].

Delivering the right support for children with autism is imperative. This can stretch from speech therapy, occupational therapy, and psychological counseling, to applied behavioral analysis and specialized behavior support. Understanding these behaviors and features is the key to the diagnosis of ASD and consequently interpreting rates and prevalences. It's important to keep in mind the complexities of the disorder. Each individual with autism is unique, and the support and interventions required can vary significantly from one child to another.

The level of knowledge, assistance, and help for people with autism and their families differs depending on the region, let alone the shortage of trained healthcare professionals and the stigma associated with diagnosis.

Even if some researches have been conducted in various low- and middle-income nations, these studies nevertheless use acceptable diagnostic techniques that might have an impact on the identification and prevalence of ASD [6,22,23].

The prevalence of autism in children is on the rise in Libya, and despite the increasing global prevalence of autism, research on this topic in Africa, particularly in Libya, has been limited. The present reported prevalence is more likely to be underestimated due to the unclear and underreported cases of ASD in the country; this is probably due to the lack of epidemiological surveys in this area of the world [10,15-17].

There is a lack of comprehensive epidemiological studies on autism in Libya, including research in villages and schools, which hinders the availability of accurate national statistics. It is estimated that approximately 40,000 individuals live with ASD in Libya, and there

are around 500 new cases annually. However, these figures may be underestimated due to challenges in diagnosis, stigma, and the unavailability of specialized clinics. The overall prevalence of autism in Libya is probably similar or closer to other African countries. The perceived low incidence and/or prevalence of ASD observed in some African countries could be due to the absence of data from large-scale epidemiological studies.

The varying rates of autism prevalence in Africa reflect the different diagnostic practices, healthcare systems, and cultural attitudes toward ASD across the continent.

While the data may not be as comprehensive or as readily available as in HICs, it provides valuable insights into autism prevalence and the challenges associated with data collection in these regions [11,12].

Inadequate knowledge, underreporting, lack of well-trained professionals, and diagnostic constraints contribute to the difficulty in assessing ASD prevalence in Libya [6,10,24,25].

All previous studies reported more males than females being diagnosed. The effect of the family income on early detection and intervention has not been studied yet [26]. Therefore, further research is required for a better understanding of the complex relationship of the different factors that may contribute to the disparities in the prevalence of autism amongst different contexts and populations.

With a better understanding of the prevalence and impact of ASD, governments can develop resources that are more effective, services, and policies to support individuals on the autism spectrum and their families [11,12].

Finally, limited resources and infrastructure can hinder large-scale epidemiological studies needed to obtain accurate data. There is a need for more comprehensive and standardized epidemiological studies to obtain accurate and up-to-date prevalence data on ASD across Libya, as understanding the accurate prevalence of ASD in the country is crucial for planning and allocating resources for diagnosis, treatment, and support services.

IDENTIFICATION AND ASSESSMENT OF ASD

The WHO has been advocating for developmental monitoring to ensure the early identification of developmental disabilities in low- and middle-income countries. The new Global Scales for Early Development allow for comprehensive assessment of the development of young children up to 36 months of age, capturing cognitive, socio-emotional, language, and motor skills, which will lead to more accurate identification of children on the autism spectrum and those at risk [27].

This process is especially beneficial for countries with a shortage of specialists, and where those working with children with ASD may have fewer skills. Despite the research supporting early identification, challenges persist in low- and middle-income countries [28-30].

The difficulty in early identification is brought about by the lack of valid, standardized, and reliable questionnaires that are written in Arabic. A large number of these tools are copyrighted, which further restricts their availability and application in different places, in addition to the fact that a license and payment are required before translation to another language.

There is currently no legislation in Libya dictating when or by whom children should be examined; instead, referrals to the neurodevelopment clinics for screening and diagnosis are frequently made by worried parents and doctors.

The validated modified checklist for autism in toddlers revised with follow-up is one of the most widely used questionnaires in the neurodevelopment clinics in Tripoli.

The majority of the evidence-based researches on which screening instruments are most useful for diagnosing children with ASD in LMICs, such as Libya, are inadequate [31].

The creation and validation of screening instruments for use in LMICs have improved recently, according to many studies, and furthermore, tool validation involves not just language modifications but also the inclusion of appropriate cultural elements that are essential for comprehending the group under study [31,32].

The bulk of Libyan people use national public healthcare services, while access to healthcare can also be obtained through the private sector. There is no established referral process in Libya for ASD assessment and diagnosis. Parents who are worried about their child usually come directly to the neurodevelopment clinic for assessment.

The lack of awareness and knowledge of ASD among medical professionals and the general population has been noted as one of the additional problems in Libya. Unfortunately, many medical professionals themselves misdiagnose or underdiagnose ASD, which delays early detection and early intervention [33,34].

Furthermore, many caregivers themselves, for no obvious reasons, are also not aware of ASD, and therefore are not seeking a medical opinion early.

The department of education and integration of disabled groups (EIDG), within the Ministry of Education, works to "assist students with ASD to complete their education within the public school system". The department provides "direct support to students by assigning shadow teachers and supplies them with tools, equipment, and training necessary to do so." The EIDG also works on preparing the appropriate schools, centers, infrastructure, and other means of learning for each segment of people with disabilities [35].

Comorbid disorders commonly associated with ASD in Libya include intellectual disability, learning difficulties, and epilepsy [36].

AUTISM PERSPECTIVES AND ATTITUDES

Some evidence and data indicate that some children with ASD or learning difficulties can also access formal education in mainstream schools. Education services for disabled children are provided through schools affiliated with the Ministry of Education and Rehabilitation Centers affiliated with the Social Solidarity Fund Authority. In general, there are no clear policies regarding inclusive education and integration [35].

Many families may have stigmatizing ideas and pre-judices regarding ASD and disabilities in general, in addition to the fact that their awareness and knowledge on the condition is limited.

The viewpoints and experiences of most of the Libyan families raising a kid with autism have shown that they are not satisfied about the services their children are receiving. More studies are needed to pinpoint the difficulties encountered by caregivers and ways to improve these services and consequently help the children to achieve their potential.

Many families, as a result of caring with a child with ASD, experienced psychological stress, social stress, financial strain, and reported unavailability and inaccessibility of services. These results are consistent with previous published research showing that raising a child with ASD is associated with greater levels of parental stress, worse psychological outcomes, and anxiety [37,38].

The financial impacts were also felt by many families, some of whom had to quit their jobs to care for their children with ASD because there were insufficient assistance and support available to them. It is crucial to remember, though, that many of these children continue to face social rejection and isolation in their communities.

AVAILABILITY OF RESOURCES, AND SPECIALIST HEALTHCARE PROFESSIONALS

Although there is no definition of inclusive education in the laws and policies that were reviewed, the vision of the Libyan Ministry of Education through the EIDG is "Access to education for all without discrimination". The Ministry of Education focuses on "working to raise the efficiency of the integrated educational process for all students, including special groups, and providing special educational needs for that" [35].

Services and supports for people with autism are frequently limited and inadequate or non-existent in some districts and this has been reported in other LMICs [39-41,39,42,43].

Many families encounter difficulties with lower knowledge and education, the financial consequences, the location and accessibility to services, the availability of resources and qualified medical personnel, and geographic location.

The Libyan government is committed to ensuring the educational rights of persons with disabilities on an equal basis with others. The Ministry of Education and National Guidance is responsible to ensure the establishment of classes and schools necessary for the education of students with disabilities, and where they receive the appropriate instruction and curriculum [35].

The law also stresses the importance of the fact that children with disabilities have the right to education in proportion to their conditions and the degree of disability. The EIDG aims to integrate disabled and special groups into the education system.

Libya has no national education monitoring report for children with ASD; however, Efforts are underway to identify and respond to children's needs. Children with ASD are granted a monthly cash allowance to help them to receive the appropriate interventions; nevertheless, there are still obstacles to early detection and early intervention, and service accessibility, especially in light of the financial obscurities the country has been passing through.

Libya signed the UN Convention on the Rights of Persons with Disabilities in 2008 and ratified it in February 2018. It also ratified the Convention against Discrimination in Education in 1973. In general, there are no clear policies regarding inclusive education and integration.

Early intervention for ASD is essential since it can enhance the outcome and promote the development of language, communication, cognition, social skills, and adaptive behaviors [39,42,43].

Early intervention offers the chance to strengthen the home environment and include family members and caregivers in the planning and execution of therapy. It is still difficult for families with an autistic child in Libya to get the proper assistance and services.

Generally speaking, access to comprehensive and reasonably priced special schools is still a problem in Libya, especially for families that reside in rural or distant locations.

WAY FORWARD

There is currently a shortage of data on autism in Libya, with most of the information originating from HIC, for example, USA and Europe. Verifying the exact incidence and prevalence of ASD and facilitating early detection programs pose several difficulties. The public and healthcare professionals lack awareness and information about ASD, and there are few proven methods available for identifying the condition-many of which are not linguistically or culturally appropriate for the communities and circumstances in which it is utilized.

To better understand the problem, efforts should be undertaken to raise awareness of ASD among families and to produce resources

and educational materials that are both linguistically and culturally acceptable.

It is noteworthy to remember that language and cultural limitations might affect the diagnosis process and necessitate the need the use of culturally sensitive methods. In Libya, ASD in children is still highly stigmatized, which can present a number of difficulties and obstacles to children and their families. Efforts are being made to educate and train people to deal with children and adults with ASD.

It is also critical to recognize the financial burden that many families in these situations face, especially those from lower socioeconomic classes.

Meeting with families have revealed the financial burden that they suffer when trying to get their kids the services, resources, and therapy they need. It would be beneficial to provide local suitable support services for them. In addition, cooperation and interaction amongst important sectors-such as medical professionals, educators, and support groups-is necessary to guarantee prompt and precise diagnosis as well as suitable interventions and assistance for people with ASD (children and adults).

Prioritizing funding for ASD will help to increase access to care, through the use of qualified medical personnel, specialist centers and schools, and the availability of relevant equipment and resources. In addition, aids ought to concentrate on raising awareness, offering community-based support and education to children with autism and their families.

Reducing the stigma associated with disabilities such as autism is essential to encourage early diagnosis and intervention. There should be a suitable service delivery models and referral pathways.

CONCLUSION

This review addresses the complexities and difficulties of ASD in Libya. It covers a number of important topics, such as the incidence and prevalence of autism, how to diagnose the condition, attitudes and viewpoints toward ASD, and how to get resources and support for people with ASD, as well as their families. To develop inclusive communities, children with ASD and their families should be given the full support they need. This review has also emphasized the significance of partnerships between the government, the public sectors, and civil services.

The review highlights how crucial it is that future researches should take into account the cultural, social, and socioeconomic elements that exist in Libya, and may wish to use different approaches for data collection.

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CONFLICT OF INTEREST

There is no conflict of interest to declare with respect to the research, authorship, and/or publication of this article.

ETHICS STATEMENT

No permission is required from the ethical committee because the review is based on a re-analysis of published data.

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