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Autism Spectrum Disorders in Nigeria: A Scoping Review of Literature and Opinion on Future Research and Social Policy Directions

Muideen O. Bakare, MD, Olufemi G. Taiwo, MD, Mashudat A. Bello-Mojeed, MD, Kerim M. Munir, MD

MUIDEEN O. BAKARE and OLUFEMI G. TAIWO are both affiliated with the Childhood Neuropsychiatric Disorders Initiatives, No. 28 and the Child and Adolescent Unit, Federal Neuropsychiatric Hospital, New Haven, Enugu, Enugu State, Nigeria. MASHUDAT A. BELLO-MOJEED is affiliated with the Childhood Neuropsychiatric Disorders Initiatives, No. 28 and the Child and Adolescent Centre, Federal Neuropsychiatric Hospital, Yaba, Lagos (Oshodi Annex), Nigeria. KERIM M. MUNIR is affiliated with the University Center for Excellence in Developmental Disabilities (UCEDD), Division of Developmental Medicine, Boston Children Hospital and the Department of Pediatrics and Department of Psychiatry, Harvard Medical School, Boston, MA.

Abstract

Introduction.—Research about autism spectrum disorder (ASD) in sub-Saharan Africa is sparse and limited. However, research studies coming from Nigeria in West Africa as a country have contributed significantly to the subject of ASD in sub-Saharan Africa.

Methods and results.—This study is a scoping review of research literature on ASD in Nigeria through June 2017 conducted by searching the key terms autism and Nigeria on PubMed and Google Scholar. Included in the review are works concerning case reports and co-morbidities associated with ASD in Nigeria; prevalence of ASD; genetic study of ASD; clinical characteristics of children with ASD; knowledge and awareness about ASD; sociocultural factors affecting ASD. Expert opinion on social policy and public health issues affecting ASD in Nigeria are discussed.

Conclusion.—Wide research and intervention gaps are noted and we suggest directions for future research, social policy development, and intervention services for individuals with ASD in Nigeria.

Keywords

Autism; Nigeria; West Africa; research; scoping review; social policy

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Please address all correspondence to Muideen O. Bakare, Child and Adolescent Unit, Federal Neuropsychiatric Hospital, New Haven, Enugu, Enugu State, Nigeria. mobakare2000@yahoo.com.

Conflict of Interest

Authors have declared no conflict of interest in connection with this article.

Ethics Approval

This article does not contain any studies with human participants or animals performed by any of the authors.

The notion that Autism Spectrum Disorder (ASD) may be a disorder of highly industrialized and developed countries that Sanua¹ once posited has now been debunked. Instead, ASD is now universally considered a neurodevelopmental disorder that can occur across cultures and geographical regions. Of more than two billion children and adolescents worldwide under 15 years, over 90% live in low and middle-income countries (LMICs) (Figure 1: World Bank Population 0–14 years, % of total, by country).² Knowledge and research about ASD globally is highly important and has been continually growing over the last four decades, including research on populations in sub-Saharan Africa, albeit at a much slower pace than research on populations in Europe and North America.

The Federal Republic of Nigeria is located in West Africa, bordered by the Republic of Benin in the west, Chad and Cameroon in the east, and Niger Republic in the North. The Nigerian coast in the south lies on the Gulf of Guinea on the Atlantic Ocean. The country consists of six geopolitical regions or zones, 36 states, and a Federal Capital Territory located in Abuja. Nigeria is the most populous country in sub-Saharan Africa, with an estimated population of over 170 million people; one in five Black Africans is a Nigerian. Children and adolescents under the age of 15 years account for about 35% of the total population. The country is home to over 250 ethnic groups, the three most populous ethnic groups being Hausa-Fulani, Yoruba, and Igbo.³

Research about ASD in sub-Saharan Africa remains limited,⁴ but recent research studies from Nigeria have contributed significantly to our knowledge of ASD in sub-Saharan Africa. The current study is a scoping review of literature on ASD in Nigeria with the goal of offering expert opinions on possible future research and social policy directions in the country.

Methods

Search strategy and selection criteria.

The literature search was conducted on PubMed and Google Scholar. The key words included autism, autistic disorder, ASD, and Nigeria. All available articles up until the end of June 2017 were included if they concerned the following (in Nigeria): (1) case reports and comorbidities associated with ASD; (2) prevalence of ASD; (3) genetic studies on ASD; (4) clinical characteristics of children and adolescents with ASD; (5) knowledge and awareness of ASD; (6) socio cultural factors affecting ASD; and (7) social policy and public health issues related to ASD.

Results

Case reports and comorbidities.

After Kanner's pioneer work in 1943,⁵ the subject of ASD was heralded in Nigeria by a case report by Longe and Asuni in 1972, read at the Third Pan African Psychiatric Conference in Khartoum, Sudan.⁶ Further case reports published subsequently include those of Onuora in Southeastern Nigeria,⁷ Bakare and Ikegwuonu in Southeastern Nigeria,⁸ and Bello-Mojeed and colleagues in Southwestern Nigeria.⁹

A common theme of these reports is the late presentation and diagnosis of ASD. All the reported cases had associated intellectual disability as a comorbid condition.^{7,8,9} One of the case reports highlighted an association of ASD with oculo-cutaneous albinism.⁸ Other associated comorbidities with ASD included seizure disorders and attention deficit/hyperactivity symptoms.^{7,8,9}

Prevalence studies.

The first prevalence study documented about ASD in Nigeria was a quasi-epidemiological study among children with intellectual disability conducted by Lotter in 1978, which involved five other sub-Saharan African countries, namely Ghana, Kenya, Zimbabwe, Zambia, and South Africa.¹⁰ Lotter found a prevalence of ASD to be about 1 in 145 among children with intellectual disabilities in these sub-Saharan African countries.¹⁰ This study however, is not specific to Nigeria, and can only serve as a guide to subsequent prevalence studies that focused specifically on Nigeria. Since then, pockets of other prevalence studies have emerged in different settings in Nigeria.

Prevalence of ASD in a clinic-based setting.—In a mental hospital clinic setting in Southeastern Nigeria, Bakare and colleagues recorded a prevalence of 0.8% for ASD among a total of 393 children attending the clinic over a one-year period.¹¹ Lagunju and colleagues in Southwestern Nigeria documented a prevalence of 2.3% for ASD among 2,320 new cases seen at child neurology and psychiatric clinics over a six-year period.¹²

Prevalence of ASD among children with intellectual disabilities or neurodevelopmental problems.—Prevalence of ASD among 44 children with intellectual disabilities in a privately-owned special school for children with neurodevelopmental disabilities in Southeastern Nigeria was recorded to be 11.4% by Bakare and colleagues.¹³ Bakare and colleagues also screened a group of children under the age of three years through the National Program on Immunization (NPI) in Lagos State, Southwestern Nigeria, and documented a prevalence of 14.8% for ASD among a group of children identified as having a neurodevelopmental delay.¹⁴ Oshodi and colleagues in a community-based sample of 85 children with neurodevelopmental problems documented a prevalence of 34.5% for ASD in Lagos State, Southwestern Nigeria.¹⁵

Prevalence of ASD in normal mainstream schools.—In a school-based epidemiological study conducted among mainstream elementary and secondary schools in Southeastern Nigeria, Chinawa and colleagues documented a prevalence of ASD to be 2.9% among children between the ages of 3 and 18 years.¹⁶

Genetic studies.

Only two studies were found that addressed the subject of the genetics of ASD in Nigeria. Included in these studies was a case report that documented co-occurrence of ASD and oculo-cutaneous albinism in a 13-year old Nigerian boy.⁸ This case report suggested that inherited hypomelanotic skin disorders such as oculo-cutaneous albinism among others could be associated with ASD among Nigerian children.⁸ This is an observation that requires further explorative research studies. Another hypothesis paper further buttressed the

possible association between ASD and hypomelanosis among Nigerian children and postulated that dysregulation in vitamin D metabolism may play a role in the etiology of ASD among Nigerian, as well as other sub-Saharan African children.¹⁷ This hypothesis also requires further testing.

Clinical characteristics of Nigerian children with ASD.

Despite early parental concerns about delay in normal development of their children, the children with ASD in Nigeria often tend to present very late to clinical practice settings, with an average age of about 7 years. This observation is supported by various case reports and cohort studies of clinical population samples of Nigerian children with ASD.^{7,8,9,12,18,19} Earlier reports documented a number of factors that may be responsible for such an observed late diagnosis and presentation of Nigerian children with ASD. These included stigma, ignorance about ASD, negative cultural practices, tortuous or delayed pathways to care, inadequate number of trained personnel, inadequate health care facilities, poor access to existing facilities, and burden of care which may include both financial and psychological factors.^{20,21,22,23}

One approach to mitigate the trend of late diagnosis of ASD among children with neurodevelopmental disorders has been the implementation of early screening and provision of core packages of intervention services to primary health care centers at the National Program on Immunization (NPI) clinics.¹⁴

We documented that late diagnosis of ASD among Nigerian children and limited interventions for them often coincide with the period of peak vulnerability to salient infectious diseases with neurological consequences, such as cerebral malaria, meningitis, and other post-encephalic infections prior to five years of age,^{20,22} and that this may indeed be responsible for the excess of non verbal presentations observed among Nigerian children presenting to routine medical practices.^{12,19,21} We also observed that diagnosis of ASD in sub-Saharan Africa, including Nigeria, is rarely made exclusive of intellectual disabilities—a phenomenon that possibly explains that the most severe spectrum of ASD cases present to medical practices in Nigeria, as well as in other sub-Saharan African countries.²¹

The cohorts of Nigerian children with ASD included in the studies by Lagunju and colleagues¹² and Bello-Mojeeed and colleagues¹⁹ corroborate the observation that more than half the children diagnosed with ASD in Nigeria have comorbid intellectual disabilities. Bello-Mojeeed and colleagues¹⁹ in their study also showed that the symptoms of stereotypic repetitive repertoire of behaviors and activities occurred infrequently among cohort of Nigerian children with ASD. Other common comorbidities observed among Nigerian children with ASD include seizure disorders, attention deficit hyperactivity symptoms, and some cases of self-injurious behavior.^{12,18,19}

Knowledge and awareness about ASD and associated socio cultural factors.

A handful of studies have been carried out in Nigeria to assess the knowledge and awareness among the general population and health care workers.^{24,25,26,27,28,29,30} These studies consistently showed the low level of knowledge among the general population, and the low to moderate level of knowledge among health care workers.^{24,25,26,27,28,29,30}

Knowledge and awareness about ASD has important implications for help-seeking behavior. In cases where etiology of ASD is attributed to spiritual causes as reflected by study findings,²⁶ it is obvious that the first point of contact in the process of help-seeking would be traditional or religious healers—a practice commonly observed among children with ASD in Nigeria. Stigma and derogatory comments from neighbors have actually made many parents with children with ASD to lock up or hide such children away in their homes, thus depriving them of needed early interventions that have been shown to improve prognoses in many cases.^{20,21}

Existing social policies and current controversies.

Despite the adoption of the Child Rights Act in 2003 that promised equal opportunities to every Nigerian child,²⁵ full implementation has reached an impasse because not all of the Nigerian States have adopted the act, and among those that have done so, its implementation has been hindered by a number of cultural and socio-political factors. Many children with ASD and other neurodevelopmental disabilities are still being locked up or hidden away in their homes and have subsequently been prevented by desperate parents and relatives from accessing any form of intervention. This is largely because of common derogatory comments and stigma associated with having such children that parents often have to face with little advocacy. In addition, health insurance is not available for most parents, and when available, it may still not cover chronic and long-term care for children with ASD and other serious neurodevelopmental disorders. This exposes parents to out-of-pocket costs and huge costs of care for their children with ASD and other neurodevelopmental disabilities. Therefore, a mixture of stigma and psychological and financial burdens have combined to prevent many children and adolescents with ASD from having the opportunity for any form of intervention, either medical or special education services, despite the existence of the federal law that promises equal opportunities for every Nigerian child.^{23,25}

Adults with ASD and intellectual disability are also denied access to basic rights. Many face exclusion in employment opportunities despite being qualified to take available positions due to stigma and discrimination. Unlike the children that have the advantage of availability of Child Rights Act, the Nigeria Disability Bill that it is believed would cater to the needs and rights of adults with any form of disability is yet to be passed in Nigeria.^{31–33}

Future research and social policy directions.

In an earlier report, we advocated a more proportionate balance in priority-setting for public health policy and funding for research on childhood neurodevelopmental disorders compared to communicable diseases on which attention had been focused in Nigeria and other sub-Saharan African countries.^{22,34} However, with improved childhood survival, and a dire need for developmental services across the lifespan, the research and policy landscape must change. With improvements in under-five mortality across Nigeria and other sub-Saharan African regions, there will be a steady rise in the numbers of children and adolescents, as well as adults, living with neurodevelopmental disorders.^{22,34}

For cases of ASD in Nigeria, the need to involve parents and non-specialists in providing interventions to reduce direct and indirect cost of care, as well as productivity losses, has

been emphasized and should be given due consideration, even as the capacity of other multi disciplinary health care professionals is being developed.^{35,36}

At the present time, there is no established or nationally adopted research and social policy direction on ASD in Nigeria. We therefore recommend a number of important steps to be taken to improve the status of care for ASD among Nigerian children, adolescents, and adults, and their families:

Define the magnitude of the problem of ASD (and other associated neurodevelopmental disorders) and conduct needs assessment for affected individuals through a well-implemented nationwide epidemiological study, or national network of studies.³¹

Carry out genetic and environmental studies of ASD in Nigeria, which are of importance in understanding the various risk factors. Lagunju and colleagues found that 22.6% of their sample had family history of ASD.¹²

Build capacity for training of health care personnel, promoting human resource development in the area of interventions for ASD, and other associated neurodevelopmental disabilities.³¹

Establish special education facilities incorporated into normal mainstream schools with the aim of promoting inclusionary educational practices, social stimulation, and community inclusion to reduce stigma. This is based on the fundamental principle that social inclusion is an important remedy for reduction of stigma through experience of coping with disabilities in the community.³⁷ This process would be enhanced by appropriate legislation and policy formulation.³¹

Implement existing legislation fully, including the commendable Child Rights Act and passage of pending bills such as the Nigeria Disability Bill. These would promote education and employment opportunities for people with various disabilities, including ASD.³¹

Formulate social policy to address the financial side of health care and special education provision for individuals with neurodevelopmental disabilities, since this is not presently covered under the Nigeria National Health Insurance Scheme (NHIS) or any existing social policies.³¹

Finally, focus research and social policy on public health education campaigns to positively influence help-seeking behavior for children, adolescents, and adults with ASD, and other neurodevelopmental disorders, to reduce the social and economic burdens of late diagnosis and interventions, and improvement of quality of life across the lifespan in the country.³¹

Conclusions.

The distribution of child and adolescent mental health service resources across the globe remains vastly unequal, especially given the majority of youth under age 15 years living in low-income and middle-income countries. This manifests in the treatment gap of major childhood onset mental health problems not only in Nigeria, but across sub-Saharan African countries, with the gap being most pronounced for neurodevelopmental disorders. The need is urgent to balance public health priorities and to provide research funding in sub-Saharan

Africa. This must be reflected in pragmatic health care planning, policy formulation, and implementation.³¹

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Boundaries, colors shown do not imply any judgment on the legal status of any territory or endorsement of such boundaries

Figure 1.

Population estimates ages 0–14 (% of total).

Source: World Development Indicators. World Bank, 2016. (Available from: <https://data.worldbank.org/indicator/SP.POP.0014.TO.ZS?type=shaded&view=map0>).

Figure 2.

Factors responsible for late diagnosis of ASD at orthodox medical care facilities.

Notes: ASD = Autism Spectrum Disorder

Table 1.**PREVALENCE OF ASD IN NIGERIA**

Settings		Prevalence	Prevalence Range
Clinic-Based Population	Bakare et al ¹¹	-.8%	.8–2.3%
	Lagunju et al ¹²	–2.3%	
Among Children with Intellectual Disability/Neurodevelopmental Problems	Bakare et al ¹³	–11.4%	11.4–34.5%
	Bakare et al ¹⁴	–14.8%	
	Oshodi et al ¹⁵	–34.5%	
Normal Mainstream School-Based Population	Chinawa et al ¹⁶	–2.9%	2.9%