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## Autism Spectrum Disorders in Africa

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### 1. Introduction

*"..... Perhaps, in the future, there will be some African history to teach. But at present there is none, or very little: there is only the history of the Europeans in Africa. The rest is largely darkness..... And darkness is not a subject for history" – Hugh Redwald Trevor-Roper.*

This chapter is necessitated so that similar comments to Trevor-Roper's on African history would be avoided as it relates to autism spectrum disorders in Africa, even though there are limited research works relating to autism spectrum disorders in Africa at present.

Since Leo Kanner first reported autism in his classical paper titled, "Autistic disturbances of affective contact" in 1943 (Kanner, 1943), knowledge and research about autism spectrum disorder have been on the increase in Europe and North America. However, the situation in Africa had remained largely obscured until about the last decade.

The pioneer works on autism spectrum disorders in Africa had been by Longe and Asuni (Longe & Asuni, 1972) and Lotter (Lotter, 1978; Lotter, 1980) about three decades after the first report of autism spectrum disorder by Kanner in 1943 (Kanner, 1943). Lotter discussed cross-cultural perspectives on childhood autism. Africa, because of its peculiar socio-cultural environment may have divergent conception on various aspects of autism spectrum disorder compared to that envisaged in the Western culture (Bakare et al, 2009a). In the same vein, cultural factors have recently been documented to influence characterization, diagnosis and treatment of autism spectrum disorder worldwide (Bernier et al, 2010).

It may be important to recall therefore that until about two and half decades ago, autism spectrum disorder was thought to be exclusively an illness peculiar to Western civilization. The existing evidence then suggested that autism occurs mostly in countries with high technological development, high level of industrialization and with salience of nuclear family system. However autism spectrum disorder was also believed to be relatively uncommon even in Western Europe and North America at that time. Nevertheless, the idea that autism may not exist in Africa was further supported by very infrequent report of cases on the continent and other parts of the world outside the West. These observations led Sanua to raise a debate and a pertinent question in 1984 in a paper entitled, "Is infantile autism a universal phenomenon? An open question" (Sanua, 1984).

While Sanua's question (Sanua, 1984) is yet to be satisfactorily answered because of lack of large scale epidemiological study of autism spectrum disorders in sub-Saharan Africa, evidence accruing through case reports before and after Sanua's question suggest that autism spectrum disorders indeed also occur in the African continent (Longe & Asuni, 1972; Lotter, 1978; Dhadphale et al, 1982; Bakare & Ikegwuonu, 2008). However, many aspects of autism spectrum disorders in Africa remain obscured. Some aspects of autism spectrum disorders in Africa over the period of year 2000 to 2009 were recently documented in a review by Bakare and Munir (2011).

## **2. Epidemiology of autism spectrum disorders in Africa and among Africans**

Available literature revealed that the prevalence of autism spectrum disorders among Africans living in Africa differs from that among Africans living outside the continent and will be reviewed separately.

### **2.1 Epidemiology of autism spectrum disorders among Africans living in african continent**

In an attempt to answer the question as to whether autism spectrum disorders occurred in Africa prior to Sanua's important inquiry of 1984, Lotter (1978) screened children with intellectual disabilities in nine major cities of six African countries, which included Ghana, Nigeria, Kenya, Zimbabwe, Zambia and South Africa. Lotter found 9 out of the 1,312 children with intellectual disabilities studied in these countries to meet the eligibility criteria to be classified as having autism, a rate which was 1 in 145 (Lotter, 1978). Because the screening was among children with intellectual disabilities, Lotter (1978) had expected to find a rate of about 1 in 20 based on the then epidemiological data in the West (Lotter, 1966). In addition to the finding on prevalence of autism spectrum disorders in the 1978 study on African continent, which Lotter admitted fell short of epidemiological survey, a number of other observations were made as follows: First, the combination of behaviors constituting criteria for autism occur in African children (Lotter, 1980). Second, there was a preponderance of boys among children who exhibited such behavior combination and such presentation tended to be more common among African children with moderate to severe intellectual disabilities (Lotter, 1980). Third, there was overrepresentation of children of parents of high socio-economic class among the children described as having features of autism (Lotter, 1980). Fourth, there were certain differences in frequency of specific behaviors between African children and children from Western Europe and North America, notable of which is stereotypic repertoire of behavior which was observed to be less common among African children compared to their counterparts in the West (Lotter, 1980). This is important because the stereotypic repertoire of behavior is an aspect of the main criteria for diagnosing autism spectrum disorders (Lotter, 1980).

A literature review to date shows no school or community based epidemiological studies of autism spectrum disorders in the African continent. The only available study that is closely related was focused on prevalence of autism spectrum disorder among children with developmental disorders in the Arab countries (Seif Eldin et al, 2008). This study (Seif Eldin et al, 2008), however included two Northern African countries, namely, Egypt and Tunisia, with predominantly Arabic populations. Prevalence of autism spectrum disorders among children with developmental disorders in Egypt and Tunisia were documented to be 33.6%

and 11.5% respectively (Seif Eldin et al, 2008). The prevalence figures are quite higher if compared against the earlier finding by Lotter who documented a prevalence of 9 in 1,312 (approximately 0.7%) among intellectually disabled children (Lotter, 1978).

In a clinic based population study in south-eastern Nigeria, prevalence of autism spectrum disorders had been noted to be 0.8% of the total population of children that attended the clinic over a one year period (Bakare et al, 2011a).

There is a need for both community and school-based studies on epidemiology of autism spectrum disorders in Africa. This is not only to know the present true prevalence in Africa to afford comparability with European and North American data, but to answer so many other questions on characteristics of African children with autism spectrum disorders as raised by Lotter in his paper on cross cultural perspectives on childhood autism (Lotter, 1980). Lotter (1980) observed, "These preliminary findings need to be corroborated and extended, in conjunction with better descriptions of normal early childhood development. Most of the children we saw in Africa were already over six years old, and little good information about early development could be obtained. We do not know therefore whether the age and pattern of onset of autism in Africa is similar to Western cases. ....Special difficulties arise also because the onset of autism coincides with a period of vulnerability to physical disease in the second year of life." Lotter (1980) further observed, "The African autistic children were all mentally retarded, with at best, very little speech. We do not know therefore whether the peculiar autistic patterns of speech use occur in Africa, or generally whether, and how, autism develops in African children of normal intelligence. All the children we saw were living in cities, most having been raised there. We know nothing therefore of the occurrence of autism in rural villages, in which most of the African populations still live." From Lotter's (1980) observations, there are therefore so many questions still awaiting answers on characteristics of African children with autism spectrum disorders.

## **2.2 Epidemiology of autism spectrum disorders among Africans outside african continent**

Prevalence of autism spectrum disorders among Africans living in Europe had also been examined by three studies (Gillberg et al, 1995; Gillberg & Gillberg, 1996; Barnevic-Olsson et al, 2008). Gillberg et al (1995) observed a higher prevalence of autism spectrum disorders among children in Goteborg, Sweden born to mothers from Uganda compared to children of the indigenous Swedish mothers in the general population. They (Gillberg et al, 1995) documented a prevalence of 15% autism spectrum disorders among children of mothers from Uganda, which was noted to be two hundred times higher than in the general population of children in Goteborg, Sweden. This trend of higher prevalence of autism spectrum disorders among children of African immigrants in Europe was further confirmed by Gillberg and Gillberg (1996).

Like Gillberg et al (1995) and Gillberg & Gillberg (1996) studies, Barnevic-Olson et al (2008) study was conducted outside African continent and also in Sweden. Barnevic-Olsson et al (2008) documented significantly higher prevalence of autism spectrum disorders among children of Somali parents living in Sweden compared to non-Somali group. Children of Somali parents living in Sweden were found to have a prevalence of 0.7% autism spectrum disorders compared with approximately 0.2% in non-Somali group. Barnevic-Olsson et al (2008) concluded that their findings warrant further investigation into why children of

Somali parents living in Sweden tend to have higher prevalence of autism spectrum disorders, suggesting possible vitamin D etiological hypothesis among other factors might be responsible for this findings ([Bakare et al, 2011b](#)).

While [Zaroff and Uhm \(2011\)](#) recent review supported the evidence that there is variation in prevalence of autism spectrum disorders across cultures and regions, a standard community based epidemiological data for African sub-region is presently lacking.

### **3. Diagnosis of autism spectrum disorders in Africa**

Diagnosis of autism spectrum disorders in Africa follows the criteria for diagnosing autism spectrum disorders specified in International Classification of Diseases, tenth edition (ICD – 10) (WHO, 1992) and Diagnostic and Statistical Manual of Mental Disorders, fourth edition, Text Revision (DSM – IV-TR) (APA, 2000). These criteria are based on impairments in areas of social interaction, communication and restricted repetitive and stereotyped patterns of behavior, interests and activities.

However, variations do exist as shown by literature originating from Africa on symptoms presentation and co-morbid conditions.

#### **3.1 Symptoms presentation**

Aside from the core symptoms of autism spectrum disorders in the areas of impairments in social interaction, communication and restricted, repetitive repertoire of behavior, one common presentation of symptoms found in over fifty percent of the cases reported in literature coming from Africa is lack of expressive language, i.e., predominantly non-verbal cases ([Belhadj et al, 2006](#); [Mankoski et al, 2006](#)).

[Belhadj et al \(2006\)](#) reported 51.2% of non-verbal cases of autism spectrum disorders in their clinic. [Mankoski et al \(2006\)](#) observed 71.0% of non-verbal cases of autism spectrum disorder in the cohort of patients in their study. The trend of excess non-verbal cases of autism in African children as observed by [Belhadj et al \(2006\)](#) and [Mankoski et al \(2006\)](#) concurred with the trend of observation documented by [Lotter \(Lotter, 1980\)](#) . However, [Mankoski et al, \(2006\)](#) concluded that this observation might be as a result of local diagnostic practice. The inference of these findings is that based on population of children with autism spectrum disorders presenting to orthodox medical care and current diagnostic practice in Africa, the population of non-verbal cases diagnosed with autism spectrum disorders out-stripped those who are verbal.

The true picture of autism spectrum disorders in the general population of African children needs to be ascertained; whether there is an actual overrepresentation of non-verbal cases or that the population of children who were referred to orthodox medical care was likely to be skewed towards being non-verbal cases. Again, future epidemiological studies of characteristics of children with autism spectrum disorders in Africa might be the sources of answer to this unresolved question.

#### **3.2 Co-morbid conditions associated with autism spectrum disorders in Africa**

Of the co-morbid conditions diagnosed in association with autism spectrum disorders among African children and documented in the literature coming from Africa, intellectual disabilities are more common.

[Belhadj et al \(2006\)](#) found co-morbid intellectual disability in over 60% of cases in their clinic. Other noted co-morbid conditions in association with autism spectrum disorders among African children included epilepsy ([Belhadj et al, 2006](#)) and oculocutaneous albinism (Bakare & Ikegwuonu, 2008). Co-morbidity of epilepsy and intellectual disability in association with autism spectrum disorders found by the study from Tunisia is an interesting finding ([Belhadj et al, 2006](#)) as it corroborated the observation of [Mankoski et al \(2006\)](#) from Tanzania, that autism spectrum disorder in Africa is rarely diagnosed exclusively of intellectual disability. This observation is also in tandem with that of Lotter documented about three decades earlier ([Lotter, 1980](#)). Therefore, the relationship between autism spectrum disorder and intellectual disability among African children need to be further explored in well designed clinical and epidemiological studies.

The possibility also exist that more severe non-verbal cases of autism spectrum disorders with intellectual disability are likely to present to orthodox medical practice for help, largely because the symptoms may become intolerable to the parents. Many of the cases that are often less severe are likely to seek help from prayer houses, spiritualists and traditional healers (Bakare, 2006). This, possibly stemming from lay etiological explanation of autism spectrum disorders among Africans and African health care workers as documented by Bakare et al (2009a) in a study done in Nigeria.

Oculocutaneous albinism, though infrequently reported in association with autism spectrum disorder, had been observed to occur co-morbidly with autism spectrum disorder in Africa (Bakare & Ikegwuonu, 2008). The co-morbidity of autism spectrum disorders and oculocutaneous albinism had also been reported in some cases outside the African continent ([Rogawski et al, 1978](#); [DeLong, 2007](#)). Bakare and Ikegwuonu (2008) suggested that further embryo-genetic studies into relationship between autism spectrum disorder and associated hypomelanotic skin disorders, including oculocutaneous albinism may provide useful clues to understanding etiology of autism spectrum disorders.

#### **4. Etiology of autism spectrum disorders in Africa**

Many etiological explanations have been proposed for autism spectrum disorders based on a number of studies coming from African continent. Discussion on these etiological explanations would be based on two major categories: etiological explanation based on opinions and etiological explanations based on scientific and clinical evidences.

##### **4.1 Etiological explanation based on opinions**

One study in Nigeria assessed the opinion of health care workers, specifically nurses, on their perceived etiology of autism spectrum disorders (Bakare et al, 2009a). A very significant proportion of 26.9% of the health care workers are of the opinion that etiology of autism spectrum disorders can be traced to supernatural causes. About fifty eight percent of these health care workers subscribed to natural causes as explanation for etiology of autism spectrum disorders, while 14.2% subscribed to preternatural causes, with rational explanations as yet unknown (Bakare et al, 2009a). The preternatural and supernatural etiological explanation for autism spectrum disorders as found in this study (Bakare et al, 2009a) is further substantiating the inseparable spiritual beliefs of Africans as it relates to etiological explanations for neuro-psychiatric disorders.

## **4.2 Etiological explanation based on scientific and clinical evidences**

Several etiological hypotheses had been put forward for autism spectrum disorders and to date no definitive one is proven. Among the etiological hypotheses proposed by literature coming from Africa are post-encephalitic infections or sepsis preceding the onset of autism spectrum disorder symptoms, genetic factors, auto-immune factors, and vitamin D etiological hypothesis.

### **4.2.1 Post-encephalitic infections or sepsis preceding the onset of autism spectrum disorders**

Mankoski et al (2006) in a case series documented cases of autism spectrum disorders following post-encephalitic infection/sepsis in a population of children from Tanzania. Because physical illnesses such as cerebral malaria and infectious diseases are common occurrence in African children under the age of five years, population of African children with symptoms of autism spectrum disorder setting-in following post-encephalitic infections may be substantially higher compared to that in high income developed countries where infectious diseases in children are not of public health significance. This brings to fore the observation of Lotter about three decades ago, that the age of onset of autism spectrum disorder may coincide with period of vulnerability to infectious diseases and other physical illnesses which may have greater likelihood for risk of infection and therefore neurological consequences among African children (Lotter, 1980). The specific roles played by post-encephalitic infection/sepsis on onset of autism spectrum disorders symptoms among African children need to be further examined.

### **4.2.2 Genetic factors**

Genetic factors had been known worldwide to play a significant role in occurrence of autism spectrum disorders (Smalley, 1991; Muhle et al, 2004). Although the heritability of autism has been estimated to be as high as 90%, the genetic factors are heterogeneous, complex, and for the most part poorly understood. Epigenetic and environmental factors are also etiologically significant in autism (Muhle et al, 2004). The precise mechanisms of genetic inheritance of autism are presently being explored through methods of genome-wide screening, cytogenetic studies, and evaluation of candidate genes (Muhle et al, 2004). Evidence is accruing of similar genetic influences among African children as well (Arieff, 2010; Mostafa & Shehab, 2010). Although strong genetic association in etiology of autism spectrum disorders had been established, the specific model of inheritance is still unclear.

### **4.2.3 Auto-immune factors**

Auto-immune factors have also been hypothesized as possible etiological explanations for autism spectrum disorders. The proposition of auto-immune factors as etiological explanation for autism spectrum disorders in Africa had largely been derived from studies coming from Egypt (Mostafa et al, 2008; Mostafa & Kitchener, 2009; Mostafa et al, 2010).

### **4.2.4 Vitamin D etiological hypothesis**

Several studies had linked Vitamin D with autism and hypothesized that etiology of autism might be as a result of maternal and /or fetal Vitamin D deficiency (Grant & Soles, 2009;

[Meguid et al, 2010](#)). Most of these studies suggest that evidence for this hypothesis could be found in higher prevalence of autism spectrum disorders in higher latitudes, urban areas, and regions with intense air pollution and high precipitation where Vitamin D deficiency is likely to be common because of the reduced ultraviolet-B radiation essential for endogenous Vitamin D production ([Grant & Soles, 2009](#), [Bakare et al, 2011 b](#)). Further observation that supports this etiological hypothesis of Vitamin D deficiency for autism spectrum disorder included the findings that autism may be more common in dark-skinned individuals living at higher latitudes compared to the light-skinned indigenous inhabitants ([Gillberg et al, 1995](#); [Barnevik-Olsson et al, 2008](#)). The deduction is that at higher latitudes, dark-skinned individuals are less likely to maximize utilization of ultraviolet-B radiation in production of Vitamin D because of their skin color and therefore greater predisposition to risk of Vitamin D deficiency ([Gillberg et al, 1995](#); [Barnevik-Olsson et al, 2008](#)). A number of these studies addressed Vitamin D etiological explanation for autism spectrum disorders in relation to Africans and African continent ([Gillberg et al, 1995](#); [Barnevik-Olsson et al, 2008](#); [Meguid et al, 2010](#); [Fernell et al, 2010](#)).

## 5. Knowledge and awareness about autism spectrum disorders in Africa

The findings of many studies in Nigeria show a low level of knowledge and awareness about autism spectrum disorders in Africa, thereby compromising early recognition of the disorder and intervention to alleviate symptom severity ([ANPPCAN, 2007](#); [Bakare et al, 2008](#); [Bakare et al, 2009b](#); [Igwe et al, 2010](#); [Igwe et al, 2011](#)). African Network for the Prevention and Protection against Child Abuse and Neglect (ANPPCAN), Nigeria chapter, in a World Bank sponsored program carried out a survey to determine the level of knowledge and awareness of health care workers and the general public in Enugu, south-eastern Nigeria about autism spectrum disorders ([ANPPCAN, 2007](#)). The findings of the survey showed that there is very low level of knowledge and awareness about autism spectrum disorders among the general populace and a low to average level of knowledge and awareness among various categories of health care workers, with highest level of knowledge and awareness found among those health care workers working in psychiatric facilities ([ANPPCAN, 2007](#)). Using the template of findings and observations made during the ANPPCAN's study, a standard questionnaire for assessing knowledge of health care workers about autism spectrum disorders, aimed at early recognition was designed and validated ([Bakare et al, 2008](#)). Subsequent study done following ANPPCAN survey consistently was showing the same trend of low level of knowledge and awareness about autism spectrum disorders among the healthcare workers ([Bakare et al, 2009b](#)). It was further established that the ability of healthcare workers working in psychiatric facilities to recognize symptoms of autism spectrum disorder was better than their counterparts working in pediatric units/departments ([Bakare et al, 2009b](#)). [Igwe et al \(2010\)](#) examined level of knowledge about autism spectrum disorders among potential health care workers presently undergoing their training; they compared final year medical, nursing and psychology students of University of Nigeria in Enugu State, south-eastern Nigeria. Medical students were more likely to recognize symptoms of autism spectrum disorders, followed by nursing and then psychology students. Overall however, the level of knowledge of symptoms of autism spectrum disorder was low in

the three groups of students (Igwe et al, 2010). In furtherance to this, Igwe et al (2011) examined knowledge of specialist pediatric and psychiatric nurses in Ebonyi State also in south-eastern Nigeria, establishing the same trend of low level of knowledge. They found association between improved knowledge and previous experience of participating in management of children with autism spectrum disorders and also noted that the ability of specialist psychiatric nurses in recognizing symptoms of autism spectrum disorders was slightly better than those of specialist pediatric nurses (Igwe et al, 2011).

The need to engage in education of health care workers and the general population in Africa on autism spectrum disorders cannot be ignored. This would enhance early recognition and interventions which had been observed to improve prognosis in individuals with autism spectrum disorders.

## 6. Summary

- It is established that symptoms of autism spectrum disorders occur among African children.
- To date, there have been no large scale epidemiological study on autism spectrum disorders in the African context. It is unclear whether the prevalence of autism spectrum disorders is different in rural and urban areas of Africa.
- The prevalence of autism spectrum disorders among children living in African continent is possibly lower than the prevalence among African children living in Europe and other high income developed countries. This disparity in prevalence need to be explained by future studies. The prevailing hypothesis of vitamin D etiological explanation for autism spectrum disorder is unlikely to explain the disparity in prevalence in its entirety.
- Period of onset of autism spectrum disorder symptoms among African children often coincides with period of vulnerability to physical illnesses and infectious diseases with neurological consequences, usually between the ages of two and five years. Etiology theory of post-encephalitic infection/sepsis preceding the onset of symptoms of autism spectrum disorder as observed in Tanzania study (Mankoski et al, 2006) may be reflecting this fact. This observation may also be confounded by the greater likelihood of exposure to infection/sepsis among African children in general. Given the high level of etiological and diagnostic heterogeneity implicit in autism spectrum disorders, these presentations may scientifically be highly informative.
- Based on presently available data, non-verbal cases of autism spectrum disorders outnumbered verbal cases in rate of presentation to orthodox medical care in Africa.
- Diagnoses of autism spectrum disorders in Africa are rarely made exclusively of intellectual disability. Therefore the relationship between autism spectrum disorders and intellectual disability need to be particularly explored in Africa.
- There are probable differences in clinical presentation of autism spectrum disorders among African children compared to that observed in Europe and North America. The symptoms of stereotypic repetitive repertoire of behaviors and activities which is one of the symptom domains for diagnosing autism spectrum disorder may be a less common occurrence in most African children with autism spectrum disorder.

- Etiology and pathogenesis of autism spectrum disorder in Africa and other parts of the world are still obscured, but complementary evidence point to both genetic and epigenetic factors.
- Level of knowledge and awareness about autism spectrum disorder is low among the general population and health care workers in Africa. There is need for community education of the general population and continuous medical education for health care workers on issues relating to autism spectrum disorder. This would enhance early recognition and interventions and in turn improve prognosis.

## 7. Conclusions

Based on present state of knowledge and situation in Africa, more studies are needed to address the issue of epidemiology of autism spectrum disorder in Africa and characteristic presentation of autism spectrum disorders among African children. Genetic studies to unravel the etiology and pathogenesis of autism spectrum disorders are areas of research that also need to be focused on in Africa. Policy making attention to ease the burden of autism spectrum disorder and other childhood neuro-developmental disorders among affected African children and their care-givers is of import considering the observation of Mung'ala-Odera et al (2006) that burden of childhood neuro-developmental disorders is likely to increase in Africa as more children of age five years and below continue to survive because of anticipated improved health care system directed at infectious and communicable diseases.

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