

Current Situation of Autism Spectrum Disorders (ASD) in Africa – A Review

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An Open Question

-Sanua, V.D (1984): Is infantile autism a universal phenomenon? An open question; Int J Soc Psychiatry; 30(3): 163 – 177:

-Sanua (1984) opined that ASD may largely be a disorder of children living in Western Industrialized Countries with high technological development . As a result, may be uncommon among African Children.

-Three decades after (2014), we know otherwise.

Cooking Play: An Example of Social & Communication Interactions among African Children



Historical Evidence & Prevalence of ASD among African Children living in Africa

- **First Report of ASD Globally was by Kanner in 1943 (Kanner, 1943).**
- **Three Decades Later in 1970s, Longe (1976) and Lotter (1978) reported ASD among African Children in African continent, covering countries such as Ghana, Nigeria, Kenya, Zimbabwe, Zambia & South Africa.**
- **In 1970s, the prevalence of ASD in Africa was about 0.7% among children with Intellectual Disability (ID) (Lotter, 1978).**

Prevalence of ASD among African Children Living in Africa : Recent Pockets of Studies

- Seif Elden et al (2008), though an Arab Study involves two Northern African Countries (Tunisia & Egypt).**
- Prevalence of ASD were 11.5% and 33.6% among children with developmental disabilities in Tunisia and Egypt respectively (Seif Elden et al, 2008).**
- A Hospital Based population study in Nigeria found prevalence of ASD to be 0.08% (Bakare et al, 2011) - Most likely influenced by low help seeking behavior for Childhood Neurodevelopmental Disorders (NDD).**
- Prevalence among School Children with Intellectual Disabilities in Nigeria was 11.4% (Bakare et al, 2012).**

Prevalence of ASD among African Children Living Outside Africa

Notable Studies are from African Immigrants living in Sweden:

- The prevalence rates of ASD among children of African immigrants living in Sweden were consistently higher when compared with prevalence of ASD among indigenous Swedish population.
- For Instance, Gilberg et al (1995) reported a rate of 15% (**200 times greater than that of Indigenous Swedish Population**) of ASD among children of African mothers residing in Sweden but who were born in Uganda.
- Reasons for the higher prevalence of ASD among African immigrants outside the African continent are not clear but such findings may be related to the Vitamin D etiological hypothesis of ASD among other reasons (Grant & Soles, 2009; Bakare et al, 2011b).

Characteristic Features of African Children with ASD

Age of Onset:

- Period of onset of ASD symptoms among African children coincide with the period of less than five years that is characterized by vulnerabilities of African children to physical illness and infectious diseases associated with neurological consequences.
- Mankoski et al (2006) reported that onset of ASD followed recovery from infection/physical illness in about 50% of the studied population of Tanzanian children.

Characteristic Features of African Children with ASD - Contd

- Stereotypic repetitive repertoire of interest / behavior may be less common among African children with ASD (Lotter, 1978, 1980).**
- There are excess of non-verbal cases over verbal cases in clinical population of African children with ASD (Bakare & Munir, 2011a; Bello-Mojeed et al, 2011) – May be as result of late diagnosis and interventions.**

Intellectual Disability and ASD among African Children

- **Studies originating from Africa among African children with ASD suggest that intellectual disability is the commonest co-occurring diagnosed condition among the children (Lotter, 1980; Mankoski, 2006; Belhadj et al, 2006; Bakare & Munir, 2011b).**
- **Diagnoses of ASD in Africa is therefore rarely made exclusively of Intellectual Disability (Bakare & Munir, 2011b).**

Other Co-morbid Conditions among African Children with ASD

Other documented co-morbid conditions among African children with ASD include epilepsy ((Lotter, 1978; Belhadj et al, 2006; Bello-Mojeed et al, 2011), oculocutaneous albinism (Bakare & Ikegwuonu, 2008) among others.

Fig 1: Co-morbid Conditions among African Children with ASD



Identification and Diagnosis of ASD among African children

- Late diagnosis had been found to characterized ASD and other Neurodevelopmental Disorders (NDD) among African children in spite of early parental concerns about development (Bakare & Munir, 2011a). Possible factors identified as being responsible for late diagnosis of ASD include:
- Poor knowledge/awareness about ASD (Bakare et al, 2009a; Igwe et al, 2011).
- Negative cultural beliefs and practices (Bakare et al, 2009a)
- Tortuous pathway to care/help-seeking behavior (Bakare & Munir, 2011a).
- Inadequate number of trained personnel (Bakare et al, 2009a)
- Inadequate healthcare and intervention facilities (Bakare et al, 2009a).

Poor Knowledge and Awareness about ASD

- Review of literature reveals low level of knowledge and awareness about ASD among African parents and health care workers (Bakare et al, 2008; Bakare et al, 2009a; Igwe et al, 2010; Igwe et al, 2011).**
- Lack of knowledge and awareness about ASD interacts with many other factors in late identification and diagnosis.**
- Continuous education to increase knowledge and awareness about ASD is required in African countries, this will enhance early recognition and interventions in affected children.**

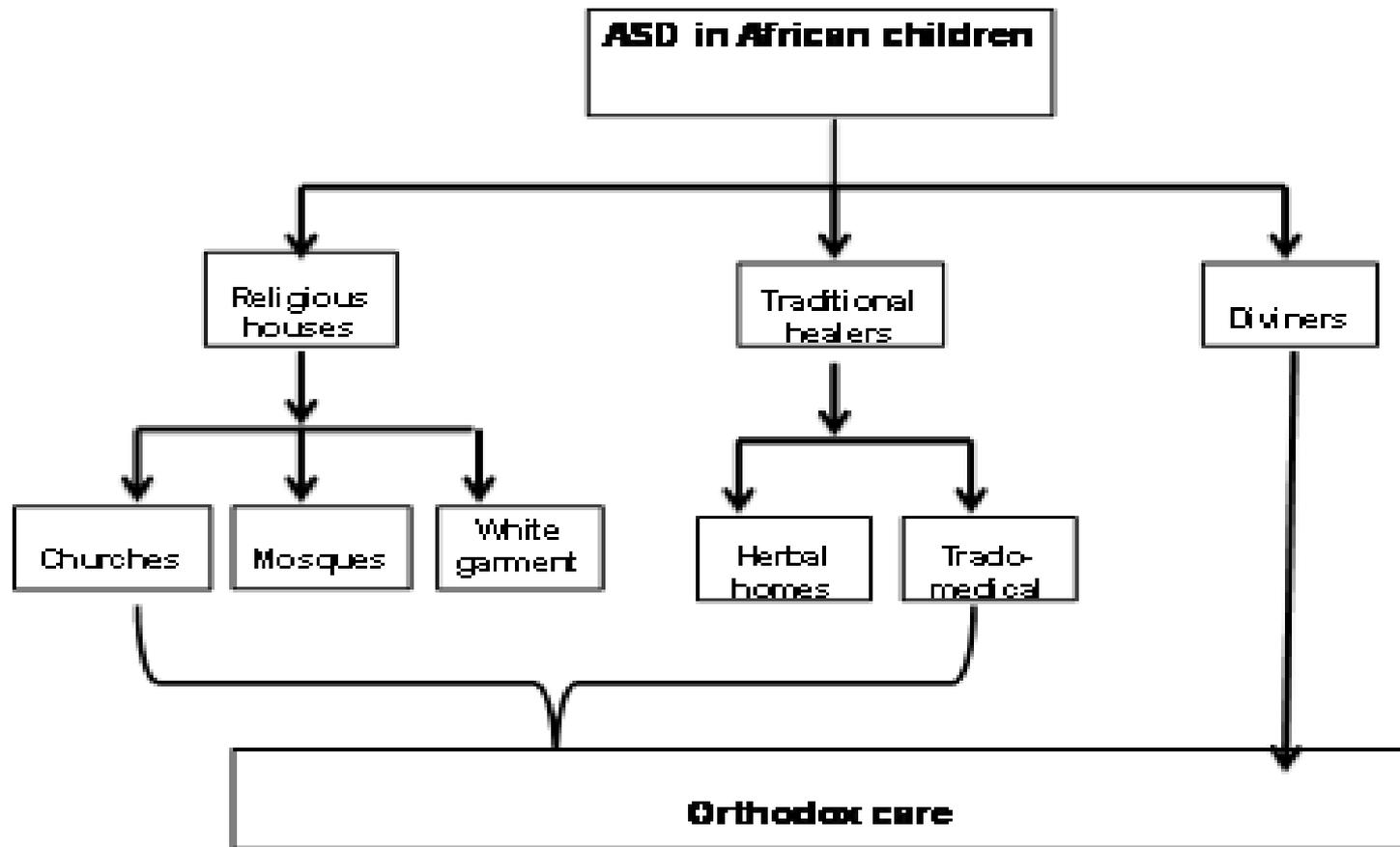
Negative Cultural Beliefs and Practices

- Research finding observed that the aetiological basis of ASD is still being explained by supernatural causes (Bakare et al, 2009b).
- In Africa, witchcraft, demonic afflictions, evil spirits are common acceptable mode of explaining aetiology of ASD and other childhood NDD.
- Individuals with ASD and their families are often faced with rejection, negative and derogatory comments, further promoting stigma.
- To avoid stigma, families tend to hide away the affected children from the society. This may lead to late presentation and diagnosis of the disorder among African children.

Tortuous Pathway to Care & Help Seeking Behavior

With a background of supernatural etiological explanations, families of children with ASD often go through a tortuous pathway in search of non-orthodox or spiritual help before seeking help from orthodox clinical practice (Bakare & Munir, 2011a) – Figure 2.

Fig. 2: Tortuous Pathway to Care & Help Seeking Behavior among African Children with ASD



Inadequate Trained Personnel in Africa

- **Primary health care workers in Africa do not routinely undergo training in identification of neurodevelopmental disorders (NDD) such as ASD.**
- **Relatively few physicians equipped with some knowledge about NDD are those with specialization in medical fields such as Psychiatry, Pediatrics and Neurology.**
- **Inadequate trained personnel contributes to late diagnosis and interventions for African children with ASD.**

Inadequate Healthcare Facilities and Intervention Centers

- **Compared with the western countries with trained professionals, better access to child care facilities and available intervention services, African children are seriously underserved, and have limited access to the few available child health care facilities (Bakare et al, 2009a; Bakare & Munir, 2011a).**
- **Documented benefits of early identification of ASD include early entry into appropriate treatment programs with the aim of improving developmental outcomes such as language, social, cognitive and motor skills.**

Fig. 3: Factors associated with late identification of ASD among African Children - Addressing these factors is important in guiding development of interventions and provision of support services in the management of ASD among African children.



Multidisciplinary & Inter-disciplinary Management

The objective is to ameliorate impairment in the three domains of **social interaction, communication and stereotypic behavior.**

- **Behavioral modification:** ABA, Positive reinforcement; Prompting; Shaping & breaking down complex task into steps.
- There are communicative functions of difficult behavior. **Difficult Behavior** may be meant to communicate **needs & wants** of the child in **language deficit.**

Multidisciplinary Management

- **Teaching and Special Education:** Should be tailored to individual child. May be home based or school based.
- **Communication skill programs in Language Deficit:** Sign Language; Computer generated pictures; Photographs. All these are aimed at symbolizing desire or needs.
- **Social Skill Training:** Examples include, Picture script; Social skills group.
- **Pharmacotherapy:** As indicated in treating associated behavioral problems like; Aggression, Disruptive behavior, Mood disorders, Attention deficits hyperactivity symptoms & Self Injurious behavior.

Summary 1

- Despite worldwide reports of increase prevalence of Autism Spectrum Disorder (ASD), there is no large scale community based epidemiological data on ASD in Africa.
- Recent studies on ASD among African children with intellectual and developmental disabilities suggest an increase in prevalence of ASD in Africa. However, there is need for a population based epidemiological study of ASD in Africa to confirm this trend.
- Period of onset of ASD symptoms among African children coincide with the period of less than five years that is characterized by vulnerabilities of African children to physical illness and infectious diseases associated with neurological consequences.

Summary 2

- When compared with children in Europe and North America, it has been observed that stereotypic repetitive repertoire of interest/behavior may be uncommon among African children with ASD. Large scale community based epidemiological study is needed to confirm this observation.
- There is an over-representation of non-verbal cases of ASD among African children presenting to orthodox medical facilities. This lack of or limited expressive language ability could be related to late intervention, resulting from late presentation/identification of ASD among African children.
- In Africa, it has been observed that ASD is rarely diagnosed exclusively of intellectual disabilities.

Summary 3

- There is a wide gap between age of onset of symptoms and diagnosis of ASD in Africa.
- Identification/diagnosis of ASD has been observed to be late among African children.
- Possible factors identified from the literature that are associated with late identification of ASD in Africa include: Poor knowledge and awareness about ASD, negative cultural beliefs and practices, tortuous pathway to care and help-seeking behavior, inadequate number of trained personnel, inadequate healthcare facilities.
- There is scarcity of intervention programs for children with ASD in Africa. The few available services are very expensive with huge unaffordable cost to most of the parents of affected children.

Ways Forward

- Research Funding for Childhood Neurodevelopmental Disorders (NDD) needs to get some more priority in Africa as more African children survive beyond the age of 5 years.
- Legislation and Policy Papers against Stigma to promote **community inclusion** and **human rights** of Individuals with Neurodevelopmental Disorders in Africa.

Conclusions

- Late identification of ASD is a common observation among African children.
- Late identification of ASD among African children suggests the need to intensify effort at addressing associated factors to improve overall prognosis.
- It is important to improve assessment and diagnostic services for ASD in Africa and also increase the level of knowledge and awareness of parents and health care professionals about ASD in Africa through continue massive education, as well as provide enabling environment for training of different professionals that will be involved in multidisciplinary approach of managing African children with ASD.

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THANK YOU!