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# Identification of Autism Spectrum Disorders (ASD) in Africa: Need for Shifting Research and Public Health Focus

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# Identification of Autism Spectrum Disorders (ASD) in Africa: Need for Shifting Research and Public Health Focus

## Abstract

**Background:** Researches from Western culture have consistently demonstrated that Autism Spectrum Disorders (ASD) can be identified as early as during infancy. In spite of such observation, late identification of ASD and poor level of awareness are the findings from Africa. The importance of early intervention in children with ASD is well known, but there will be no possibility of active intervention in absence of early identification and appropriate diagnosis.

**Aim:** This chapter aims at discussing issues related to identification of ASD in Africa and the need for focusing research and funding on developmental disorders among African children because the condition is increasingly becoming of public health importance as more children below the age of 5 years survive infectious and communicable diseases following improvement in healthcare.

**Methods:** Aspects addressed include prevalence of ASD in Africa, characteristic features of ASD in African children, identification/diagnosis of ASD among African children and factors associated with late identification of ASD in Africa

**Conclusion:** Late identification of ASD is a common observation among affected children in Africa. Such finding suggests a dire need to address factors associated with late identification of ASD in Africa with a focus on more research and funding.

## 1. Introduction

Inspired by Ionian philosophy, Hippocrates abandoned temple medicine for a rational practice that embodied observation at the bedside of the patient, exact recording of the phenomena of disease, reasoning, and accumulating experience (Bloch, 1994). Hippocrates is known to pioneer clinical observation as bedrock of modern medical practice, a path also followed by the American psychiatrist Leo Kanner (Kanner, 1943) when he described his observation about children with infantile autism in his classical paper titled, "Autistic disturbances of affective contact".

Following Kanner's first description of characteristics of infantile autism in a group of children about seven decades ago (Kanner, 1943), documented evidence revealed that identification of ASD in Africa was not made until about three decades afterwards (Longe, 1976; Lotter, 1978). Though there were some reports of childhood conditions with features suggestive of current description of the spectrum of disorders that constitute ASD before the term "autism" was coined, this concept took a new dimension in 1943 when Kanner, the inaugural chair of child psychiatry at Johns Hopkins Hospital in Baltimore, Maryland, reported his observations, made over a period of 5 years, about eleven children with unifying behavioural features which he termed as "infantile autism". Kanner's ascription of infantile autism (Kanner, 1943) fits into the current description of the commonest and more severe form of ASD. Kanner's description of the core disorder, in subsequent decades, was followed by a period of a relative neglect, with the notion of the rarity of the disorder in Africa as in other parts of the developing world. Nonetheless, a notable recent upsurge in prevalence of ASD in Western culture (MMWR, 2012) has led to increased attention worldwide

ASD comprises a group of complex, lifelong, neuro-developmental disorders usually noticeable prior to 3 years of age. The conditions are characterized by qualitative impairments in reciprocal social interaction, impairments in verbal and non-verbal communication skills and a restricted pattern of interest or behaviour (WHO, 1992; APA, 1994). Spectrum of symptoms in ASD range from mild to severe and are often accompanied by abnormalities in cognition, learning and sensory processes. ASD is found in every race, ethnic group and socio-economic class. Despite the universality in occurrence, relatively less attention has been afforded to the identification and diagnosis of ASD in Africa.

Typically, signs and symptoms of ASD present during early childhood years with ensuing delays in emergence of specific skills in areas of social communication and adaptive functioning. A number of developmental milestones, tagged "red flags", have been suggested to be indicative of ASD. These warning signals include poor eye contact, reduced social responsiveness, reduced responsive smiling, diminished babbling, and overall poor language development. Across cultures, parents are remarkably the first to show concern about the unusual development or feature(s) in the affected child (AAP, 2001; Bello-Mojeed et al, 2011). It is now well recognized that the diagnosis of ASD can be made as early as

in the first year of life (Klin et al, 2004). However, there remains noteworthy disparities in the age of onset and identification of ASD with a prominent problem of late identification among affected children in Africa (Mandell, 2007; Bello-Mojeed et al, 2011; Bakare & Munir, 2011a).

In addition to poor outcome in the affected child, a delay in diagnosis could also impact on the health of the caregiver (Bouma & Schweitzer, 1990; McGrath, 2006; Bello-Mojeed et al, 2010a; Bello-Mojeed et al, 2010b), while early identification of ASD is pivotal to ensuring early entry into intervention programs with the aim of achieving better developmental outcomes.

Exploring culturally related factors regarding ASD in Africa could proffer solution to intriguing observation of a wide gap in the important period leading to ASD identification and onset of symptoms, while preparing the ground for instituting early intervention programmes. This chapter addresses prevalence of ASD among children living in Africa, characteristic features of African children with ASD, period of identification/diagnosis and possible predictive factors associated with late identification of ASD in African children.

## 2. Prevalence of ASD among African children

Over more than a decade, studies have consistently shown an increase in the prevalence of ASD worldwide (Yeargin-Allsop et al, 2003; Merrick et al, 2004; Charkrabarti & Fombonne, 2005; Fombonne et al, 2006; CDC, 2007; Newschaffer et al, 2007). Prevalence of ASD has been reported to have increased from 0.4 per 1,000 in the 1970s to the current estimate of up to 11.3 per 1,000 (MMWR, 2012). Despite the global seriousness of this problem, available data on prevalence of ASD is mostly from Western cultures, with epidemiological data on prevalence of ASD in African continent remaining direly limited. Such lack of epidemiological affirmation of ASD among African children is, in part, responsible for the persistence of the earlier, incorrect assumption that ASD is rare in Africa (Sanua, 1984).

### 2.1. Prevalence of ASD among African children living in Africa

Although previously described as a disorder of children living in Western industrialized countries, new evidence has underscored the occurrence of ASD among African children living in Africa (Bakare & Munir, 2011b; Bello-Mojeed et al, 2011). Yet, presence of ASD among African children was first reported in the 1970s with the work of Longe (1976) and Lotter (1978, 1980). Though not a thoroughly designed epidemiological study, Lotter (1978) carried out pioneering work in ASD in nine major cities of six African countries (Ghana, Nigeria, Kenya, Zimbabwe, Zambia & South Africa). Out of the 1,312 children with intellectual disability screened for ASD, Lotter found that only 9 met the criteria for ASD diagnosis, giving a rate of about 0.7% (Table 1). Three decades after Lotter's work in Africa (Lotter, 1978), further studies from Africa again addressed the issue of ASD prevalence among African children in particular with co-occurring intellectual disabilities (Seif Eldin, 2008; Bakare et al, 2012). Bakare et al (2012) reported a prevalence of 11.4% of ASD among 44 children with intellectual disabilities in a school for children aged 4 to 18 years with developmental disabilities in South Eastern Nigeria (Table 1). Though limited in sample size, this remains the only study at present, three decades after Lotter (1978, 1980), that has directly looked at ASD prevalence among African children with intellectual disabilities and serves as an important reference point for future studies on the African continent

In a prevalence study of ASD among children with developmental disabilities, Seif Elden et al (2008) used the M-CHAT to screen for young children with ASD in a multinational Arab population in Tunisia and Egypt, two Northern African countries. Seif Elden et al (2008) reported the prevalence of ASD in their study to be 11.5% and 33.6% among children with developmental disabilities in Tunisia and Egypt, respectively (Table 1).

Both the Bakare et al (2012) and Seif Elden et al (2008) recent studies clearly demonstrate an increase in prevalence rate of ASD among African children with intellectual /developmental disabilities when compared with the earlier results documented by Lotter (Lotter, 1978; 1980). Observations from these recent research findings on prevalence of ASD among African children with intellectual disabilities therefore are in keeping with phenomenon of a worldwide increase in reported prevalence of ASD.

Despite the Bakare et al (2012) and Seif Elden (2008) studies on prevalence of ASD among children with intellectual disabilities, the literature remains deficient of information on prevalence of ASD especially among African children without intellectual impairment.

A hospital-based study by Bakare et al (2011a) also examined prevalence and pattern of neuro-psychiatric diagnoses among 393 Nigerian children in a child and adolescent clinic over a period of one year. A rate of 0.08% was documented

for ASD among the children studied (Table 1). While the study provided useful information on characteristics of children with ASD encountered in a clinical setting in Africa, there is limited generalization in terms of prevalence, given issues of related stigma and help seeking for children who do not appear to be developing according to community norms. To date, a representative community-based epidemiological study on prevalence of ASD among African children is not available. There is a dire need for large scale community-based studies in order to determine the prevalence of ASD among African children living in the continent. This is particularly remarkable as the proportion of children and adolescents living in Western Africa represent more than 45% of the overall proportion, compared to 18% in Western Europe; it would appear that this is inconsistent with the principle of distributive justice (Yan, Munir, 2004) emphasizing conditions affecting child development worldwide.

Table 1: An Overview of Studies on Prevalence of ASD in African children

Reference	Study location	Study population	Prevalence
Among Africans living in Africa			
Lotter, 1978	Ghana, Nigeria, Kenya, Zimbabwe, Zambia, South Africa	Children with Intellectual disability	0.7%
Seif Elden, 2008	Egypt, Tunisia	Children with developmental disability	33.6% 11.3%
Bakare et al, 2012	Nigeria	Children with Intellectual disability	11.4%
Bakare et al, 2011(b)	Nigeria	Children with mental health problems (Clinic Based Population)	0.08%
Among Africans living outside Africa			
Gilberg & Gilberg, 1995	Sweden	population-based	15%
Bernevik-Olsson et al, 2008	Sweden	Autism habilitation centre (population-based birth records)	0.7%

Table 1 shows an overview of studies on prevalence of ASD conducted among Africans living in and outside Africa

## 2.2. Prevalence of ASD among African children living outside Africa

Studies have also examined prevalence of ASD among children born to African parents and living outside the continent. Both prospective and retrospective studies were conducted to assess prevalence of ASD among children of African immigrants living in Sweden (Gilberg et al, 1995; Gilberg & Gilberg 1996; Barnevik-Olson et al, 2008; Bejerot & Humble, 2008). 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. Gilberg et al (1995) reported a rate of 15% of ASD among children of African mothers residing in Sweden but who were born in Uganda (Table 1). The reported prevalence rate of 15% among African children was said to be about 200 times higher than what obtained in the general population of children in Sweden. Gilberg and Gilberg (1996) in another study again endorsed that ASD was commoner among African children living in Sweden than the host indigenous population.

Possible reasons for the higher prevalence of ASD among African immigrants outside the continent are not clear but such findings may not be entirely unrelated with the Vitamin D etiological hypothesis of ASD (Grant & Soles, 2009; Bakare et al, 2011b). Therefore, large scale community-based epidemiological research on prevalence of ASD in Africa stand to

give important insights into possible variations in prevalence of ASD across cultures as well as in helping address issues of possible aetiological factors that are yet unravelled. Findings of such research in ASD will also bring into government notice policy implications for children with neuro-developmental disorders in Africa.

### 3. Characteristic Features of African children with ASD

As noted earlier, ASD is a disabling childhood condition with deficits in 3 core areas of functioning which are social skills, communication, and areas of interest or behaviour. Though core symptoms of ASD as described by Kanner (1943) are present in African children with ASD, such core characteristic features in African children may however be associated with some notable differences.

#### 3.1. Age of onset of ASD Symptoms and Infections with Neurological Consequences in African children

ASD is a spectrum of conditions with no definitive biological diagnostic marker at the present. In addition to genetic and epigenetic factors, environmental factors including influence of infections with neurological complications have received attention in multiplex aetiology of ASD (Bakare & Munir, 2011b). Age range below five years is an important period of childhood infections associated with neurological complications in Africa (Table 2). This age period among African children is characterized by significant childhood morbidity and mortality. In as much as there is competing morbidity and mortality related to infections as well as other forms of physical illness with neurological complication, for surviving children in this early age group, ASD remains a major clinical concern (Lotter, 1980; Bakare & Munir, 2011b). In an attempt to examine aetiology of ASD among Tanzanian children, Mankoski et al (2006) reported that onset of ASD followed recovery from infection/physical illness in about 50% of the studied population. Association of post encephalitic infection and physical illness among African children with onset of ASD symptoms is less researched and warrants further exploration to define the nature of a putative association. Findings from such research could be very helpful in unravelling many complexities presently associated with the aetiology of ASD as a complex set of conditions affecting early child development.

Table 2: Characteristic Features of African Children with ASD

Variables	Characteristic Features
Age of onset	<ul style="list-style-type: none"> <li>• Childhood infections/illnesses</li> <li>• Neurological complications</li> </ul>
Stereotypes	<ul style="list-style-type: none"> <li>• ?less common</li> <li>• Stereotypic repertoire of interest or behaviour : -                             <ul style="list-style-type: none"> <li>• Hand flapping</li> <li>• Rocky body movements</li> <li>• Spins objects</li> <li>• Spins self</li> <li>• Repetitive play</li> <li>• Obsessive routines or schedules</li> <li>• Repeating words or actions</li> </ul> </li> </ul>
Communication	<ul style="list-style-type: none"> <li>• Excess of non-verbal presentations</li> <li>• Features of non verbal communication : -                             <ul style="list-style-type: none"> <li>• Inability to speak</li> <li>• Pointing</li> <li>• Poor eye contact</li> <li>• Unresponsive to name</li> <li>• Not smiling</li> </ul> </li> </ul>
Co-morbidity	<ul style="list-style-type: none"> <li>• Intellectual disability frequently reported</li> </ul>

Table 2 shows characteristic features of African children with ASD. Examples of non-verbal communication and stereotypic repertoire of interest/behaviour are illustrated.

### 3.2. Stereotypic repetitive repertoire of interest / behaviour in African children with ASD

Earlier studies conducted among African children with ASD documented that stereotypic repetitive behaviour such as hand flapping & rocking (Table 2) are less common when compared with Caucasian children (Lotter, 1978; 1980). Suggesting that repetitive repertoire of behaviour may be a less common presentation among African children with ASD.

### 3.3. Excess of non-verbal cases over verbal cases in clinical population of African children with ASD

A consistent and important finding in the clinical presentation of ASD among African children is an excess representation of non-verbal cases over verbal cases (Table 2). For example, most of the children presenting to an orthodox clinical practice setting lacked or had limited expressive language abilities (Bakare & Munir, 2011a; Bello-Mojeed et al, 2011). Bakare & Munir (2011a) noted that this pattern of presentation might be connected to late presentation and diagnosis. It is however unclear whether the same trend will be observed in the community; this again calls for a need for large scale representative epidemiological study of ASD among African children.

### 3.4. Intellectual disability and ASD among African Children

Having a delay in both verbal and non-verbal communication abilities among children with ASD is not equivalent to co-presence of intellectual disability. However, research findings, to date, have reported a rate as high as 70% of intellectual disabilities among children with ASD (La Malfa et al, 2004; de Bildt et al, 2005; Belhadj et al, 2006). Findings from studies conducted in Africa among African children with ASD have shown that intellectual disability is the commonest co-occurring diagnosed condition among the children (Lotter, 1980; Mankoski, 2006; Belhadj et al, 2006) (Table 2). From available literature on the relationship between ASD and intellectual disabilities, it is observed that there is little documentation in both directions on the rate of ASD in children with intellectual disabilities (Lotter, 1978; Seif Elden et al, 2008; Bakare et al, 2012) as well as on rate of intellectual disabilities among children with ASD (Belhadj, 2006; Mankoski et al, 2006).

#### 3.4.1. Co-morbid Intellectual Disabilities in African children with ASD

Nevertheless, in studies that emanate from Africa the diagnosis of ASD in children often are reported to co-exist with intellectual disabilities (Mankoski et al, 2006). In keeping with findings of Mankoski et al, (2006), Belhadj et al (2006) reported a rate of 60.8% of intellectual disabilities among a clinical population of Tunisian children with ASD. A rate of 60.8% of co-existing intellectual disabilities was almost twice that of co-existing epilepsy (33.3%) in the Tunisian population studied by Belhadj et al (2006).

#### 3.4.2. Co-morbid ASD in African children with Intellectual and Developmental Disabilities

The earliest documented work on co-morbid ASD in African children with intellectual disabilities was again the landmark study conducted by Lotter (1978) among African children in six major cities in sub-Saharan Africa (Ghana, Nigeria, Kenya, Zimbabwe, Zambia & South Africa). Lotter (1978) reported a rate of about 0.7% ASD in African children with intellectual disabilities. More recently, Seif Elden et al (2008) study reported rates of 33.6% and 11.5% rate of ASD, among children from Egypt and Tunisia respectively. Bakare et al (2012) reported a rate of 11.4% ASD among group of Nigerian children with intellectual disabilities.

#### 3.4.3. Other Co-morbid conditions among African children with ASD

Other co-morbid conditions among African children with ASD have included epilepsy (Lotter, 1978; Belhadj et al, 2006; Bello-Mojeed et al, 2011) and oculocutaneous albinism (Bakare and Ikegwuonu, 2008) [Fig 1]. There is a need for future research to more meaningfully examine the broad clinical pattern of ASD presentation and co-morbidity among African children.



Fig 1: Reported co-morbid conditions in African children with ASD

Figure 1 illustrates conditions reported to co-exist with ASD among affected children in Africa

#### 4. Identification / Diagnosis of ASD among African children

Until recent times, it was uncommon to recognise and diagnose disorders among ASD children before the third year of life. With specialized screening tools and enhanced training of healthcare professionals and improved resources available for them, ASD can now be increasingly recognized and valued earlier as a highly important developmental condition affecting children that deserved urgent attention. However, a trend of late diagnosis/identification continues to be observed in Africa (Bakare & Munir, 2011a; Bello-Mojeed et al, 2011) with resistance expressed by funding agencies in recognizing ASD on an equal footing with other important public health issues facing children in developing countries.

Possible factors identified in the literature that are associated with late identification and diagnosis of ASD among African children include poor knowledge/awareness about ASD, cultural beliefs and practices, non-specific pattern of clinical presentation, a delay in presentation, tortuous pathway to care/help-seeking behaviour, inadequate number of trained personnel, inadequate healthcare and intervention facilities (Bakare et al, 2009a; Bakare & Munir, 2011a; Bello-Mojeed et al, 2011; Igwe et al, 2011). These are precisely the same conditions that present to public health of developing children and represent opportunities for future partnerships to address in large scale epidemiological research studies.

#### 5. Factors associated with late identification of ASD in Africa

##### 5.1. Poor knowledge/awareness about ASD:

Current literature reveal a low level of awareness and knowledge about ASD among African parents and health care workers (Bakare et al, 2009a; Igwe et al, 2010; Bello-Mojeed et al, 2011). This state of affairs continues to impede early identification for ASD in Africa. .

Among healthcare workers and the general populace in Nigeria, Bakare et al, 2008, 2009a and Igwe et al (2011) not only found a very low level of knowledge and awareness about ASD among the general population, but a low to average level

of understanding among health care workers with the highest level observed among those in psychiatric facilities in Nigeria.

Lack of knowledge about ASD interacts with many other factors in late identification and diagnosis. African mothers have been observed to exhibit concern over delayed development and presence of features suggestive of ASD in their children as early as the first two years of life but fail to recognise those signs as ASD (Bello-Mojeed et al, 2011). Continuous education to increase knowledge and awareness about ASD is required in African countries to encourage better cultural acceptability of affected children, enhance early recognition of ASD and enhance advocate for development of appropriate and effective interventions.

## 5.2. Cultural beliefs and practices

Africa is endowed with a rich culture of immense benefits to both children and their caregivers as exemplified in the African extended family support system in care-giving. At the same time, African cultural practices and belief system about aetiology of complex disabling developmental disorders such as ASD could serve as an impediment to early identification of signs and symptoms of ASD. In African culture, a child with ASD is often viewed as defective and possibly having ASD as a result of some mishaps or wrongdoings by the parents or the ancestors in the family lineage. Recent research findings observed that the aetiological basis of ASD is still being explained by supernatural causes (Aina, 2004; Bakare et al, 2009b). In Africa, witchcraft, demonic afflictions, evil spirits are common acceptable mode of explaining aetiology of childhood developmental disabling conditions such as ASD. The belief system that individuals with ASDs are being possessed with evil spirit that still exist in Africa has a huge implication. Rather seeking medical help in orthodox settings, witchdoctors and spiritualists are often consulted before contacting orthodox medical practitioners (Bello-Mojeed et al, 2011). Complications often occur when such cases finally appear later at the doorstep of the orthodox facility.

In Africa, a child with a disabling condition such as neuro-developmental disorders is seen as a mark of shame on the family. Often, Individuals with ASD and their families are faced with negative attitude, avoidance, rejection, as well as negative and derogatory comments. To avoid the experience of stigma, the family tend to hide the affected child from the society. This may lead to late presentation and therefore late diagnosis of the disorder among African children.

African belief system and cultural practices could shape the pattern or expression of signs and symptoms of ASD. Often, African value system is usually noted with expressions laden with proverbs or idioms which may influence the interpretation of given information or description of characteristic features of ASD in an African child. It is crucial to understand African culture in order to understand features suggestive of ASD and to understand the type of treatment plan suitable for the affected child in the African context. African culture uses "positive" or "denial" terms to represent "negative" experiences or events especially when it has to do with their children or other love objects in their life; "it is not allowed to say or utter negative statements about your child", many African mothers will caution. Often, the clinician had to explore for symptoms while at the same time needs to give assurance to parents that talking about the impairments in their children will in no way add to the problem at hand. Such African culture of denial of negative experiences among African parents may contribute to late identification of ASD among African children.

Families may also differ in their perception of the symptoms of neuro-developmental disorders. For example, African parents have some tolerance for developmental abnormalities which may be interpreted and accepted as variants of normality, with the belief that affected child will sometimes catch up with peers in developmental milestones (Bello-Mojeed et al, 2011).

## 5.3. Pathway to care / Help seeking behaviour

As noted therefore ASD and other neuro-developmental disorders are highly stigmatised condition associated with a belief system of the condition arising as a punishment from maleficent god. With a background of spiritual causation, 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 settings (Bakare & Munir, 2011a; Bello-Mojeed et al, 2011) (Figure 2). In challenging this belief system we ought to also address the appropriate research needs in Africa within the broader context, valuing the importance of children's social and cognitive development, and the core importance of ASD as a set of conditions that need to be better understood and cared for in the African setting.

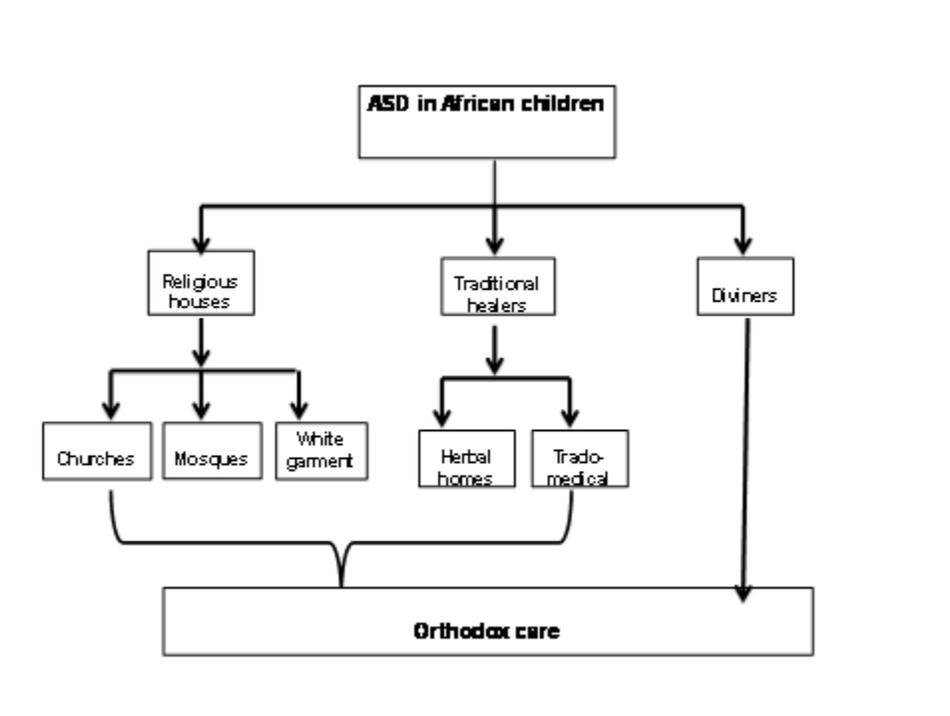


Fig 2: Tortuous Pathway to care among African Children with ASD

Figure 2 shows pathway to care in ASD among African children. The figure illustrates a tortuous pathway to care and contact of affected African children with spiritualists/traditional healers before contact with orthodox care.

#### 5.4. Non-Specific Pattern of Presentation:

Information made available to physician and other health workers on signs and symptoms of ASD in African children mainly come from parental recollections of child's early developmental events. Often, parents of affected children give the most distressing or culturally unacceptable symptoms which could be non-specific to ASD (Bello-Mojeed et al, 2011). In addition to the presence of impairments in social and communication, children with ASD also exhibit behavioural features including sensory difficulties, impulsivity, hyperactivity, self-mutilation/self-injuriousness and aggression. At presentation to orthodox facilities, Bello-Mojeed et al (2011) observed that caregivers often choose most distressing behavioural symptoms, which is not specific to ASD, as reason for bringing affected children to orthodox facility. The types of presenting complaints given by the parent of a child often play a vital role in making a diagnosis.

#### 5.5. Inadequate trained personnel in Africa

Primary health care workers in Africa do not routinely undergo training in developmental disorders such as ASD. The relatively few physician equipped with some knowledge about ASD are those with specialization in medical field such as Psychiatry, Paediatrics and Neurology. Lack of or inadequate knowledge about developmental disorders in Africa, especially at primary care level (Bakare et al, 2009a) could lead not only to late identification but also misdiagnosis and inadequate intervention for affected children (Bello-Mojeed et al, 2011), while avoidable suffering and burden of care persist (Bello-Mojeed et al, 2010b).

### 5.6. Inadequate healthcare facilities/Intervention

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 & Munir, 2011a; Bello-Mojeed et al, 2011).

The non availability of child health care services and poor access to the few available services, which are concentrated in the urban areas, could result in late presentation. On a background of stigma, coupled with scarce intervention services and out-of-pocket payment for health care financing in Africa, families of African children with ASD may be reluctant to bring their children to the available facilities, partly because of expensive cost related to intervention programmes.

Documented benefits of early identification of ASD include early entry into appropriate treatment programmes with the aim of improving developmental outcomes such as language, social, cognitive and motor skills. It could give a relief of parental burden associated with caring for children with ASD. Early identification of ASD could help sensitise and prepare families of affected children, especially parents, to join support group for respite. This is pivotal in forming advocacy groups for guiding families with affected children across Africa. Unfortunately, there are wide gaps in area of ASD research in Africa when compared with developed countries of the world.

Attending to the factors identified as being associated with late diagnosis of ASD in Africa (Fig 3) is important in guiding development of interventions and provision of support services in the management of ASD among African children.



Fig 3: Factors associated with late identification of ASD among African Children

Figure 3 depicts factors reported to be associated with late identification of ASD among African children.

## 6. Summary

- Symptoms of Autism Spectrum Disorders occur among African children
- Despite worldwide reports of increase prevalence of Autism Spectrum Disorders, there is no large scale community based epidemiological data on Autism Spectrum Disorders in Africa.
- Recent studies on Autism Spectrum Disorders among African children with intellectual and developmental disabilities suggest an increase in prevalence of Autism Spectrum Disorders in Africa. However, there is a need for a population based epidemiological study of Autism Spectrum Disorders in Africa to confirm this trend.
- Period of onset of Autism Spectrum Disorder 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 disease associated with neurological consequences.
- When compared with children in Europe and North America, it has been observed that stereotypic repetitive repertoire of interest/behaviour is possibly uncommon among African children with Autism Spectrum Disorders. Large scale community based epidemiological study is also needed to confirm this observation.
- There is an over-representation of non-verbal cases of Autism Spectrum Disorders 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 Autism Spectrum Disorders among African children.
- In Africa, it has been observed that Autism Spectrum Disorder is rarely diagnosed exclusively of intellectual disabilities.
- There is a wide gap between age of onset of symptoms and diagnosis of Autism Spectrum Disorder in Africa. Identification/diagnosis of Autism Spectrum Disorder has been observed to be late among African children.
- Possible factors identified from the literature that are associated with late identification of Autism Spectrum Disorder in Africa include: Poor knowledge /awareness about Autism Spectrum Disorders, cultural beliefs and practices, non-specific pattern of clinical presentation, a delay in presentation, tortuous pathway to care/help-seeking behaviour, inadequate number of trained personnel, inadequate healthcare facilities.
- There is scarcity of intervention programmes for children with Autism Spectrum Disorders in Africa. The few available services are very expensive with huge unaffordable cost to most of the parents of affected children.

## 7. Conclusion

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. As part of this effort, 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. Despite the importance placed on ASD in Europe and North America, many international and research funding agencies still continue to view ASD as a secondary public health concern with a focus on primary and more traditional approach to public health. There is a need for a shift in this line of thinking. Research on ASD is also ethically justified in that it is more likely to redress this imbalance that is also reflected by the much larger proportion of children and adolescents in Africa compared to Europe and North America (Yan, Munir, 2004). An emphasis on ASD is likely to be innovative and stands to redress misperceptions of developmental disabilities, address children's special educational needs, and reduce stigma and feelings of shame and guilt beset upon families in Africa.

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