

## **PREVALENCE AND SEVERITY OF ASD IN TWO SCHOOLS IN NAIROBI, KENYA**

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### **ABSTRACT**

Autism is a developmental disorder that impairs a child's abilities for social interaction, language development and communication. It is characterized by restricted/repetitive patterns of behaviour, interests, and activities during the early developmental period. Others exhibit hyperactivity, aggression and anxiety. ASD in Kenya has received very little attention from researchers when compared to other disabilities. This study looked at the prevalence of ASD in two schools among children and adolescents with ASD. The study used mixed method strategy that involves archival, observation, structured and unstructured interviews, and questionnaires. Quantitative data was analyzed using statistical package for social scientists (SPSS) and summarized in percentages.

**Keywords:** ASD, Prevalence and school children

### **1. INTRODUCTION**

Autism is defined as a disorder beginning in childhood, marked by the presence of markedly abnormal or impaired development in social interaction, communication and a restricted repertoire of activity and interest (ICD-10-CM). Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual. Globally, it is estimated that, one child in every 160 suffers from Autism (WHO, 2014). Studies conducted over the years have shown an increase in autism around the world.

ASD is usually seen as a life-long diagnosis. However, during various phases of development, the clinical picture often changes. For instance, there are children who fall just within the classification and who after some time can fall outside it (Helt, Kelley, Kinsbourne, Pandey, Boorstein, Herbert et al., 2008). Key predictors for long-term progression are language development (presence of communicative speech at the age of 5) and intelligence level. Early

detection of ASD is important to reduce the problems and to promote the child's development. Early diagnosis of ASD increases chances for children to access early intervention services, which is fundamental to achieving positive outcomes as early on as possible (Lovaas, 1987; Reichow and Wolery, 2009; Rogers and Vismara, 2008; Boyd, Hume, McBee, Alessandri Anibal, Johnson, 2014; Magiati, Tay, & Howlin, 2012; Prior, Roberts, Roger, & Williams, 2011).

## **2. LITERATURE**

The United States Centers for Disease Control and Prevention, CDC (2009) estimates that ASD affects one in every 110 children. According to the center, ASD usually appears early in life, often before the age of three, and is four to five times more common in boys than in girls (CDC, 2009). The prevalence of anxiety problems in school-age children and adolescents with ASD is in the range of 40–45 per cent (White et al., 2009b). This is noticeably higher than incidence of anxiety disorders in epidemiological studies of children and adolescents in the general population who are in the range of 5–10 per cent (Costello et al., 2004), and 31.9 per cent (Merikangas et al., 2010).

Studies show that the numbers of children with ASD in Africa are rising, estimating this at 116.1 per 10,000 (Riccio, 2011). In a developmental clinic in Johannesburg, South Africa, there was a 8.2% increase in the number of children presenting with features of ASD in the period from 1996 to 2005 (Springer, Laughton & Kidd, 2013). A study carried out in Egypt shows that the number of reported cases of autism increased dramatically in the 1990s and early 2000s (Chawarska, 2005). The estimated prevalence rate in the world is 1 in every 88 children (CDC, 2009).

Bakare and Munir (2011) in their book entitled "Autism spectrum disorders in Africa: A comprehensive Book on autism spectrum disorders" argues that there is presently limited research works relating to ASDs in Africa. According to Bakare et al., pioneer works on ASD in Africa had been by Longe and Asuni (1972). This was 30 years after the first report of ASD by Kanner in Europe and Northern America in 1943 (Bakare et al., 2011).

Bakare et al. (2011) further observes that cultural factors that influence characterization, diagnosis and treatment of ASD have recently been documented worldwide. Interestingly, until recently, ASD was thought to be an exclusive illness peculiar to western civilization (Ibid, 2011). 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 (Ibid, 2011).

In an attempt to answer the question of whether ASD occurred in Africa, children with intellectual disabilities were screened in a study by Lotter (1978) in Ghana, Nigeria, Kenya, Zimbabwe, Zambia and South Africa (Bakare et al., 2011). The study by Lotter found that 9 out of 1312 children had ASD. This study found among other things that there were certain differences in frequency of specific behaviours between African children and children from Western Europe and Northern America. This was noticeable with regard to stereotypic repertoire of behaviour which was observed to be less common among African children compared to their counterparts in Europe (Ibid, 2011). This finding justifies the need to conduct studies on African children where data is missing.

Bakare et al. (2011) also observe that to date there is no school or community-based epidemiological studies of ASD in the African Continent. The authors argue that the only closely related study was focused on prevalence of ASD among children with developmental disorders in the Arab countries that included Egypt and Tunisia (Ibid, 2011). In this study prevalence of children with ASD in Egypt and Tunisia were documented at 33.6 and 11.5 per cents respectively. In Nigeria, the prevalence rate was documented at 0.8 per cent of the total population of children that attended the clinic over one year period (Bakare et al., 2011). Bakare et al. therefore indicates that there is a need for both community and school-based studies on ASD in Africa.

In Kenya, ASD has not been well understood. Autism was traditionally seen as a psychiatric disorder, a curse or a consequence of witchcraft (Gona, 2010; Riccio, 2011). This has resulted to children with autism being hidden away in homes, locked behind doors, or chained for life and completely kept away from public eye. Researcher Jon Onala, in Riccio (2011), has estimated that given current world data on autism, the prevalence and the population of Nairobi, it is estimated that 25,000 children are affected by a disorder on the autism spectrum in this area alone in the ratio of boys to girls being 4:1.

Studies have shown that ASD is on the rise (Kim et al., 2011; US CDC 2012), but whether this is due to improved diagnostic methods or the reality that the condition is becoming rampant is yet to be established.

### **3. METHODOLOGY**

*Recruitment.* To be eligible for the study, children had to be within the schooling age and in a learning institution. The two schools visited had an age group from five to 21 years of age. Both DSM-V and Autism Behaviour Checklist (Krug et al., 1993) were used to confirm ASD. Due to limited schools with children with ASD, all the available cases that met the inclusion criterion formed the sample. The sample included the children and adolescents with ASD.

### The Autism Behaviour Checklist (ABC)

Tools that help with assessment of generalization may evaluate collateral skills such as problem behaviours that occur as a result of social or communication deficits. Hence pre and post measures of problem behaviours can help determine treatment effectiveness. The ABC is a 57-item informant-based measure of problem behaviours of individuals with developmental disabilities, rated on a 4-point Likert scale (Aman, Singh, Stewart, & Field, 1985). There are five subscales: "Irritability" (15 items); "Lethargy, Social Withdrawal"(16 items); "Stereotypic Behaviour" (7 items); "Hyperactivity" (16 items); and "Inappropriate Speech" (4 items).

The scores for each of the five domains are tallied, giving a partial score for each domain, as well as an overall score. When the overall score is 68 points or higher, the child is classified as autistic (Krug et al., 1993). Scores between 54 and 67 indicate a moderate probability of autism; scores between 47 and 53 are considered dubious for the classification of autism; and scores below 47 indicate that the child is typical (Krug et al., 1980, 1993). The checklist has been widely used in a number of countries by professionals both in research and clinical practice due to its ease of application and low cost.

### **4. RESULTS / DISCUSSION AND CONCLUSION**

Slightly below half of the children were found to have severe level of autism in both experimental 10 (50%) and control school 13 (65.0%). Those with moderate autism were 14 (70%) in both schools at baseline. Only 5 (12.5%) had low level of autism in experimental school compared to 2 (5%) in control school, as presented in Table 1.

**Table 1: Demography and Severity of Autism amongst children presenting with ASD**

Background Variables	Labels	Control School		Experiment School		Overall			
		Number	Percent	Number	Percent	Number	Percent		
Sex	Male	13	65.0%	14	70.0%	27	67.5%		
	Female	7	35.0%	6	30.0%	13	32.5%		
Level of Schooling	Junior	11	55.0%	8	40.0%	19	47.5%		
	Middle	3	15.0%	6	30.0%	9	22.5%		
	Senior	6	30.0%	6	30.0%	12	30.0%		
Age	< 10 Yrs	5	25.0%	7	35.0%	12	30.0%		
	10-14 Yrs	7	35.0%	6	30.0%	13	32.5%		
	15-19 Yrs	6	30.0%	4	20.0%	10	25.0%		
	20 - 24Yrs	2	10.0%	3	15.0%	5	12.5%		
Autism Level	Autism Level	Control School		Experimental school		p-value			
		Number	Percent	Number	Percent				
		Parents Rating	Severe	13	65.0%	10	50.0%	0.603	
		Moderate	6	30.0%	8	40.0%			
		Mild	1	5.0%	2	10.0%			
Total	20	100%	20	100%					

**DISCUSSION**

The social demography of children under study gave rich information in the population of ASD. Out of the 40 children in the study, 26 of them were males and 14 were females. The high numbers of males with ASD is consistent to other parts of the world where the global impression has confirmed that ASD is more prevalent in males than females (4:5) ratio. In the study population there is clear evidence that there were more adolescents than children. This could mean a number of explanations. One is confirming late diagnosis in Kenya, consistent with Cohen (2012) who registered a similar finding. Due to lack of awareness, parents get to problems in their children late and probably when they cannot perform certain tasks as their peers in the general population.

There were more parents with high education from college degree. A clear indicator that awareness was high in the educated population compared to lowly educated in this study. This might have been contributed by the fact that this study was done in the urban are where the high population are educated and working. As gathered the focus discussion with parents, many relocated to the city for better facility of their ASD children. The finding is consistent with the

findings of Gona (2016) where little help for ASD is available in the villages. More facilities and awareness is needed in the outskirts of cities for ASD cases.

In Africa, as noted earlier there is limited research work in this area. Although ASD characteristics may not be outright in this context, there are prevalent comorbidity conditions in relation to ASD among children in Africa (Bakare & Ikegwuonu, 2008; Belhadj et al., 2006). This finding corroborated with the observation made by Mankoski et al. (2006) in their study in Tanzania. Similarly, this study found out that ASD was not easily recognized by the caregivers. This may be contributed by a number of factors such as the inclusive African culture.

As many have ascertained, differences exists in signs presented as shown by literature originating from Africa on (Bakare et al., 2011; Lotter, 1980). Further outcomes indicate poor awareness and knowledge on ASD among the healthy workers and the general populace in Africa thus hindering early identification of ASD (Bakare et al., 2008; Bakare et al., 2009; Igwe et al., 2010; Igwe et al., 2011; Maulik & Darmstadt, 2007; Riccio, 2011). Additionally, the diagnosis of anxiety especially in ASD is complicated (Joshi et al., 2010; Leyfer et al., 2006; White, 2010). Thus, lack of awareness explains why ASD continue to receive no attention in identification and treatment as well.

Culture is an aspect that has recently drawn interest worldwide as worthy noting in ASD presentation across bounders (Bakare et al., 2011; Lotter, 1980). Different cultures have different ways of explaining ASD behaviour which limit identification. From the tools of measure used, more prevalent indicators for ASD in the study population were realized, creating further knowledge in this populace.

## **CONCLUSION**

Education and awareness of the caregivers and the public at large is vital. People who deal with children living with ASD should be aware of this condition (characteristics and treatment), their needs, and the part they (parents, teachers, medical doctors, education officers, and the society at large) can play in the lives of the ASD child. The stigma that comes with ASD would also be done away with as a result of awareness campaigns.

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