Autism Spectrum Disorder (ASD) in Kenya: A neglected none communicable disease

In the commentary section of this issue, The Autism Society of Kenya (ASK) describes its role and objectives to sensitize and promote levels of awareness on Autism Spectrum Disorder (ASD) and to advocate for policies that would enhance the existing disease interventions. The syndrome is widely spread in Kenya but in the write up this is a neglected none communicable disease that is not well understood neither by the public health authority nor by the general community. Unlike malaria and other tropical infectious diseases, Autism Spectrum Disorder (ASD) is a worldwide health burden which is well understood and addressed in the developed world but there is no clear data in Africa [1].

The author paints a gloomy picture of ASD as a major health problem which the public healthcare authority in Kenya appears to have ignored or neglected, the community seem to have nothing to offer because it doesn't understand the syndrome and the only solution it may offer is the patient to be committed to the "mad house". Many a times, the parents of the autism child, in their desperation have no alternative but to lock the child indoors and in case of severe autism the child is chained inside for protection and safety. The author cites total lack of commitment and lack of specialist as the major health concerns related to autism in Kenya.

There is no locally generated clear data on prevalence of autism for Kenya but the staggering figure of 19,235 callers who responded after an awareness TV campaign presentation by ASK Director in June 2017 could shed light on the national burden of autism. The TV show presentation was in a vernacular Television Station and only those who could understand the language responded. By extension, therefore the population of autism children in Kenya could be extrapolated considering the fact that there are 42 ethnic groups in the country and that the probability of being born with autism is equal in all ethnic groups. Report of 2007 by ASK gave an estimated 4% prevalence rate [2] but again this was without research data. World Health Organization estimates the global autism population to be about 2% or 1 in 160 children suffer from the syndrome [1] but this is an under estimation because the prevalence data from sub-Saharan Africa is not clear, with little or none concrete medical research information available [2,3]. This gives a window of research opportunities in medical sciences and social sciences.

Late diagnosis may affect onset of treatment management and may result in complications [1, 2,]. This is also a common problem in Kenya mainly due to lack of a national policy which would establish specialized diagnostic training programmes. Increased awareness campaigns have caused an increase in the number of autism children. This is an indicator that with the proper support would lead to increased coverage of parents with autism in children which means increase in diagnosed cases.

According to Autism speaks [2] an estimated 50,000 teens with autism become adults – and lose school-based autism services in America– each year. Strong Transitional Stage programmes for such young adults must exist to enable a follow up into adulthood. This transitional stage is not catered for in Kenya and may leave the young adults at the mercy of the public. Such active young adults could be misdiagnosed for psychiatric cases and end up in the asylum.

Lack of autism specialists in Kenya could also contribute to incorrect records of autism a state that could be due to low levels of awareness of autism in the country as in many other sub-Saharan African countries. According to Autism Speaks [2] most-obvious signs of autism tend to appear between 2 and 3 years of age. Late diagnosis was reported to be common in African autism children because of delayed reporting by the parents [4].

The ASK efforts to reduce the levels of late diagnosis by introducing

sensitization programmes in mainstream public school is commendable but the efforts are frustrated by issues like lack of government policy on autism, which, in turn affect good management, diagnosis and treatment of syndrome as well as the choices by physicians and sociologists. There is a need to start a forum for autism research with a full support of the government and other stake holders, national and international.

The choice of autism for the editorial page in this issue was an effort to bring to the attention of the scientific community, physicians and relevant government authorities to look at autism as a major health problem in the country that inevitably deserves attention. I caught the interest after listening to the Director's explanation of the problem on the TV show. I invited her to write in this issue a synopsis of the extent of autism in Kenya in relation to the activities of the society. It was not so much as to the science in it but the role the society plays in sensitization of the public on autism. From the short write up we see a neglected none communicable disease that attracts no medical scientific research. Total lack of literature about autism in Kenya tells the story on the neglect.

Malaria mortality is the only infectious disease appearing in this issue. This is an acute infectious disease with high mortality rate in Homa Bay County as described by Kodhiambo and others. Autism, on the other hand is a neurodevelopmental disorder with no direct mortality except from related accidents and other secondary infections. Certain medical and mental health issues such as gastrointestinal disorders, seizures, sleep disturbances, attention deficit and hyperactivity disorder, anxiety and phobias may be experienced in autism patients [1] but such may not be life threatening. Unlike malaria, however, ASD has a lifelong impact in the family and as described by ASK it should be given the right attention and researched like any other disease in the communities. The relationship that ASK has with the Internationally recognized Autism Speak's Global Public Health must be exploited for medical research benefits on autism in Kenya. There is also a need to bridge the gap of information that exists between Africa and the rest of the world.

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