

The contribution of sub-Saharan Africa to autism spectrum disorders

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Introduction

Autism spectrum disorder (ASD) is one of the most prevalent neurodevelopmental disorders in high-income countries, but little is known about it in Africa or other low- and middle-income countries^{1,2}. A recent review of the global prevalence of autism did not identify any data from sub-Saharan Africa (SSA)³, even though this region has a population of nearly 1 billion, of whom 40% are children aged less than 14 years. To date the public health emphasis in SSA has been on communicable conditions such as HIV, malaria and tuberculosis⁴. However, with the reduction in childhood mortality in recent decades, non-communicable diseases (in particular neurodevelopmental disorders) are likely to become a greater burden on the health system of these countries⁴. Given these circumstances there is an urgent need for studies on ASD and other neurodevelopmental disorders in Africa.

Challenges for ASD research and management in SSA

One of the major barriers to research and management of autism has been the lack of validated tools in Africa. Well established standardized tools for ASD such as Autism Diagnostic Observational Schedule (ADOS/ADOS-2) have contributed significantly to knowledge about ASD in high-income countries¹. However, the use of these tools in Africa poses significant challenges in terms of cultural appropriateness, the cost of translations and adaptations, as well as the expense associated with copyright of these measures². Additionally, although awareness of ASD has been increasing in low- and middle-income countries in recent years⁵, there are still significant challenges arising from limited awareness in many communities in SSA, especially among families living in rural areas. Without awareness, families may not seek or be referred to appropriately-skilled staff for a comprehensive assessment to confirm a diagnosis. Inadequacies in the educational sector such as limited knowledge and awareness about ASD and lack of an inclusive curricula poses similar challenges.

Why should we urgently invest in ASD research in Africa?

Early studies suggested that ASD may be a culturally-bound condition, and that ASD might be rare in regions such as SSA. In the 1970s, Lotter, a psychiatrist, identified 9 children with autism in hospitals in six African countries.⁶ Subsequently there have been case reports of autism reported from Kenya, Zimbabwe, Nigeria and Ghana among others. Therefore given the sheer numbers of African children, there is a need to estimate the burden of neurodevelopmental disorders, including ASD.

Evidence from immigration studies suggests that autism may be common in Africa. For instance, initial studies of women who migrated from Somalia to Sweden reported the frequency of autism in their children as three or four times that of children born to Swedish mothers.⁷ It is suggested that various risk factors associated with immigration may predispose them to ASD (e.g. lack of vitamin D especially for immigrants with dark skin in places with less sunshine or perinatal infections in mothers) though the evidence for most of the hypothesized pathways remains weak. Nevertheless, to date, it is not clear whether or not African immigrant populations have a prevalence of ASD similar to populations in their countries of origin. Until such data are collected, it cannot be confirmed that factors inherent in the immigration process contribute to increased prevalence of ASD.

ASD is a highly heritable neurodevelopmental disorder⁸. More than 100 genetic polymorphisms have been associated with ASD^{9,10}, although many of these have not been replicated in other datasets. Africa has greater genetic diversity than any other continent¹¹ and genetic studies of ASD in Africa may provide unique insights to the pathogenesis of autism .

The environmental risk factors for ASD are poorly understood, but the incidence of the risk factors associated with autism in high income countries associated with ASD, such as pre-eclampsia, placental insufficiency, prolonged labour, induced labour, birth asphyxia, pre-term birth, and low-birth weight¹² are more common in Africa. Thus Africa may provide unique insights into the gene-environment interactions.

What is the way forward?

There is no doubt that progress and developments are needed at multiple levels, and that involvement from numerous stakeholders is required.

There is an urgent need to increase awareness about ASD at all levels. Clearly this needs working in partnership with parent support groups, not-for-profit organisations, private sector, governments, international autism organisations, media, the World Health Organization and funders such as National Institute of Health and the Wellcome Trust. Programmes such as the Autism Speaks Global Autism Public Health (GAPH)⁵ initiative that have expanded to SSA countries could potentially play an important role in bridging the gap in Africa.

With awareness comes advocacy. It is encouraging that there is an increasing number of parent/user/carer groups in Africa; but these are still very limited, and where they exist many prioritise supporting individuals and families in local communities rather than building national

and continental advocacy. Access to research and materials is being promoted through websites (e.g. <https://grand.tghn.org/>, <http://aut2know.co.za/>), but in many rural areas of Africa, access to the internet remains limited. Harnessing more accessible technological platforms such as mobile phones may provide lasting solutions

Education and training clearly links awareness and advocacy. The goal should be to embed ASD training into curricula of healthcare, education and social care trainees, to increase the baseline level of knowledge and expertise across the continent. There is an urgent need to develop appropriate educational services for children with ASD in the African context as this is currently lacking.

We need significant enhancement of research on autism in Africa. In particular tool development and evaluation are key steps in SSA. Thereafter epidemiological research to assess the burden of ASD in Africa and define the clinical features of ASD on this continent.

Many will agree that we have an ethical duty to develop post-diagnostic interventions - from psycho-education, to community-based and more specialist programmes. Linking educational, health and social care systems to generate co-ordinated knowledge, policies and plans would ensure efficacy and cost-effectiveness of the programmes an important consideration in resource-poor settings.

The needs of Africa are great, but at the same time the world has much to learn from Africa in terms of the interplay between nature and nurture in the pathway to ASD and neurodevelopmental disorders, and in finding creative ways to meet the needs of individuals and families in low-cost, high impact ways.

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