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REVIEW

The Unmasking of Autism in South Africa and Nigeria

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Abstract: This review is of interest to researchers, policymakers, and healthcare professionals working in the field of autism in Africa. The review aims to describe autism in sub-Saharan Africa, focusing on South Africa and Nigeria regarding prevalence, incidence, identification, treatment, and attitudes towards autistic children. There are several challenges, such as lack of awareness, limited access to professional support and diagnostic tools, and cultural considerations in establishing the autism prevalence in the African region compared to other parts of the world. Additionally, South Africans and Nigerians exhibit diverse perspectives and attitudes that significantly influence the provision of treatment, including stigma and misconceptions held by healthcare professionals themselves. As a result, it is difficult to determine prevalence in South Africa and Nigeria. However, research has indicated that autism prevalence is rising globally, and in these contexts. Rising prevalence highlights the need to increase access to services, rehabilitation, and provide support to families of children with autism. Furthermore, research has emphasized the inequitable support and access available to families living in low-and high-income households and the need to provide contextually relevant and responsive interventions, education and training, research and policy in these countries.

Keywords: Africa, autism, Nigeria, South Africa

Introduction

Masking, a coping mechanism employed by many autistic individuals (and also observed in other marginalized groups), manifests itself in two primary ways: camouflage and compensation. Consequently, the process of unmasking calls for greater understanding, inclusivity, and amplification of voices within these communities that are frequently silenced. Autism, defined as a complex neurodevelopmental disability that affects individuals differently, results in specific deficits in interaction, communication, receptive language, and imaginative thinking or play.[1] Importantly, autistic children can be diagnosed as early as 18–24 months of age, as this is when autistic symptoms and characteristics can be differentially diagnosed from other developmental delays or conditions.[2] Autism is recognized as a global health concern, yet majority of information comes from high-income countries (HICs). It is estimated that approximately 95% of autistic individuals live in low-middle income countries (LMICs).[3,4] Research has indicated a high number of children with neurodevelopmental disabilities in LMICs, specifically in sub-Saharan Africa, with the prevalence increasing.[4] The increasing numbers are attributed to improved diagnostic testing and the growing number of children surviving their first 5 years. Moreover, Nigeria is one of the top ten countries with the highest prevalence of children with specific developmental disabilities under 5 years of age.[4] While, research on autism in Africa is growing, existing knowledge and available information remains limited, with an estimated 1% of autism research coming from sub-Saharan Africa.[3] This underrepresentation is an important consideration because of the disparities in identification and support for autistic individuals and their families in LMIC.

The awareness, support, and resources available for individuals with autism and their families vary across contexts, and the current lack of evidence in LMICs presents a substantial gap in our understanding of autism from majority world

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contexts.[2,4] While research on autism has increased exponentially in the last few years, it is important to note that the majority of this research is from the United States and other HICs.[5,6] Resources and intervention programs that have been developed in HICs are not transferable to other LMICs due to the limited availability of resources, shortage of trained healthcare professionals, limited awareness of autism, stigma around autism, and the need for contextually and culturally appropriate materials and procedures required for implementation.[7–9]

Meeting the needs of families with autistic children faces considerable challenges within existing systems, leading to unmet needs and a dearth of support from adequately trained specialists who comprehend the specific contextual requirements of these families.[7] Hence, there is a pressing need to gain a better understanding of autism within the sub-Saharan African context and to develop interventions that are responsive to the context and seamlessly integrated into existing care systems. Although, there are some studies in other low- and middle-income countries, these studies still appropriate diagnostic procedures, which impact on the prevalence and identification of autism.[3,10–12] In addition, there is a lack of generalizability to other contexts due to cultural and linguistic diversity and cultural differences in perceptions from other countries. These limitations are further compounded in Africa where there are additional health disparities and socioeconomic equalities prevalent.

The evidence base for autism intervention and treatment in Africa is inadequate, with a scarcity of published research in the region.[13,14] Notably, South Africa and Nigeria emerge as the focal points of research on autism in sub-Saharan Africa. Notably, South Africa and Nigeria emerge as the focal points of research on autism in sub-Saharan Africa. Therefore, this review aims to comprehensively outline the current understanding of autism in South Africa and Nigeria, proposing avenues for enhancing identification, assessment, management, and policy within these specific contexts. The article will discuss the following points in relation to South Africa and Nigeria to meet the aims of the review, (1) the prevalence and incidence of autism, including the obstacles and challenges around establishing prevalence in these countries, (2) the identification and assessment of autism that encompasses the tools, assessment procedures, and referral pathways that are being utilised, (3) perspectives and attitudes of autism and the influence of contextual and cultural considerations that impact on the identification, assessment and management for children with autism, (4) the access to support and services available for children with autism their families due to the challenges associated with the availability of resources, schools, and specialist healthcare professionals. Finally, a discussion on the (5) changing landscape of autism in Africa will be discussed regarding future directions and recommendations to promote awareness, reduce stigma, and to promote prioritised access to care that can inform changes to research, policy, and healthcare professionals working in the field of autism in Africa.

Prevalence and Incidence of Autism in South Africa and Nigeria

Autism presents with an increasing prevalence in children across contexts and countries and varies across different geographical locations and dependant on study methodology. Even with the increasing prevalence of autism globally and in Africa, it has been the subject of limited research. The first prevalence study documented about autism in Africa was a study by Lotter in 1978 among children with intellectual disability, which involved five sub-Saharan African countries, namely Ghana, Kenya, Zimbabwe, Zambia, and South Africa.[15] Lotter found a prevalence of autism to be about 1 in 145 among children with intellectual disabilities in these sub-Saharan African countries. According to the World Health Organization (WHO, 2022), the prevalence of autism is one in every 100 individuals worldwide. Prevalence estimates have increased over time, and vary across different socioeconomic groups.[2] However, the estimated global prevalence is currently underestimated since the prevalence of autism in the African region and other low-middle income countries is still unclear and underreported, which can be attributed to the paucity of epidemiological surveys.[16–18]

In Nigeria, autism prevalence has surged over the past decade, with estimated 600,000 affected children.[19] There has been some attempts to explore prevalence rates in Nigeria at a paediatric neurology clinic between 2007 and 2012. Studies revealed prevalence rates of 1:43.5 in South-West Nigeria and 1:125 in South-Eastern Nigeria.[18] A more recent study in 2014 reported a prevalence of 2.3% nationwide.[14] These hospital-based studies underscore the substantial burden of autism in Nigeria.

Comprehensive epidemiological studies on autism in Africa, including community and school-based research, are lacking, hindering the availability of accurate national statistics, particularly in South Africa.[16,18] Estimates suggest

approximately 270,000 individuals live with autism in South Africa, with around 5000 new cases annually.[20] However, these figures may be underestimated due to diagnostic challenges, stigma, and regional variations. Localized studies in the Western Cape province found prevalence rates ranging from 0.01% to 0.08% among school children, but these may not be representative of the entire country.[9,21] The overall prevalence of autism in South Africa, like other countries in Africa, remains unknown. The absence of data from large scale epidemiological studies is a possible reason for the perceived low incidence and/or prevalence of autism observed in both South Africa and Nigeria.

Limited awareness, underreporting, and diagnostic constraints contribute to the difficulty in assessing autism prevalence in both South Africa and Nigeria.[3,16] All studies reported more males than females being diagnosed and that children from middle-high income families had an improved likelihood of being evaluated for an autism diagnosis. Gender disparities and socioeconomic factors further impact diagnosis rates, highlighting the need for more inclusive research to understand the complex interplay of factors affecting autism prevalence across different contexts and populations in Africa.[22] Therefore, further research is required to better understand the complex relationship of the different factors that may contribute to the disparities in the prevalence of autism amongst different contexts and populations.

Identification of Autism in South Africa and Nigeria

Research has indicated that early identification can improve long term developmental outcomes for children with autism.[23,24] The World Health Organisation[25] has been promoting developmental monitoring in order to ensure early identification for children with developmental disabilities, particularly in LMIC. In order to implement this, it has been suggested to incorporate screening into the child's routine health check-up, which can provide more accurate identification of children who may be on the spectrum and identify those children who are at risk. This process is beneficial, especially for countries where there is a shortage of specialists, and many working with children with autism are often less experienced.[23] Despite the research on early identification, challenges continue in LMIC. Durkin et al[5] and Abubakar et al[17] have highlighted the challenges in early identification due to the availability of tools that are sensitive to local variations, including cultural interpretations of disability in LMIC, with a particular focus on Africa.[23] There is a scarcity of tools that are both culturally sensitive and affordable. Furthermore, it is not often appropriate to utilise tools developed in HICs within LMIC settings. The application of Western-based norms to different cultural contexts can lead to issues of over-identification, where children may be incorrectly labelled.[23,24] Moreover, the restricted accessibility of these tools adds to the challenge. Many of them are copyrighted, necessitating permissions and payment for translation into other languages, which further limits their applicability in regions like South Africa and Nigeria.

Due to the difficulties with using standardised assessments, the utilisation of screening tools has continued to grow in popularity amongst health professionals in order to identify at-risk autistic children. Screening tools are questionnaires that are often completed by the health care provider, or the caregiver in order to identify if the child may have autism, before a full diagnostic assessment is completed.[26] Screeners allow for different healthcare professionals to identify autism, even if they are unable to provide a formal diagnosis. In South Africa and Nigeria, there is currently no mandate on when children should be screened and by who, with referrals for screening often coming from concerned parents.[21]

There have been a number of different screening tools being used, with the Modified Checklist for Autism in Toddlers Revised with Follow-up (M-CHAT-R/F) being one of the most commonly used assessment in many LMIC, such as South Africa.[22] The M-CHAT-R/F is a validated screening tool that can be used to identify autism in toddlers. It has been found to have preliminary reliability in the South African context.[27] However, there is limited evidence-based research on which screening tools are most effective at identifying children with autism in a different context, with majority of them coming from HIC such as the United States or the United Kingdom.[26] Recent research has highlighted the improvements on the development and validation of screening tools for the use in LMIC, and the linguistic and cultural adaptations required, although, there is still a limited amount of validated tools available with majority only being available in English.[17,26,28] Moreover, validation of tools is more than just linguistic adaptations but also the incorporation of cultural and contextual factors that are imperative to understand the population being studied.[26]

In South Africa, healthcare is accessed via the public sector or the private sector, with majority of South Africans using public healthcare services. Those accessing the public sector will access services at their primary health care clinic,

where they are seen by a nurse or medical officer. Following that, parents are then referred to a general paediatrician who may refer to a specialist (or team of specialist including a developmental paediatrician and/or a child psychiatrist) to provide a diagnosis of autism.[21] In the private sector, parents who are concerned about autism may go directly to their general practitioner, paediatrician, or other specialists (such as a speech language pathologist or occupational therapist). However, for all children diagnosed they will need to go on a waiting list in order to access special schools (both government and privately funded. In South Africa, there is no standardised referral pathway for receiving an autism diagnosis. Therefore, there is a pressing need to establish standardised assessment tools and diagnostic criteria that can be utilised to improve the assessment and management of children with autism.

Additional challenges in the identification and assessment of children with autism have been identified in Nigeria regarding the limited awareness and knowledge associated with autism amongst both healthcare professionals and the general public.[16,29,30] Unfortunately, this results in underdiagnosis and misdiagnosis of autism, as many medical doctors themselves, with many not providing any sort of assessment or intervention. Furthermore, unlike South Africa, many caregivers themselves are also not aware of autism, and therefore are not seeking a diagnosis, assessment or any type of intervention.[30] Nigeria also has a lack of therapeutic services such as SLPs and occupational therapists, and a lot of stigma around disability and autism, with many children not being provided with appropriate treatment.[31] The available literature suggests that there is a higher proportion of children with autism who are non-speaking than those who are speaking in Africa. Co-morbid disorders commonly associated with autism in Africa include intellectual disability, and epilepsy.[16] The lack of awareness and support, are key contributing factors in late diagnosis, and available supports for both autistic children and their families.[31]

Perspectives and Attitudes of Autism in South Africa and Nigeria

Autism awareness is relatively low compared to some other countries. Many people have limited knowledge about autism and may hold misconceptions and stigmatizing beliefs around disability and autism.[8] These misconceptions contribute to the challenges faced by individuals and families affected by autism resulting in families not seeking a diagnosis or treatment for their child due to fears of isolation and discrimination.[8] There continues to be a lot of stigma surrounding autism in South Africa and Nigeria has been a significant concern, as highlighted by several studies. In Nigeria, there is a low level of knowledge and awareness about autism, even among healthcare workers who still exhibited misconceptions about autism.[30,31] A limited understanding amongst healthcare professionals can hinder early recognition and interventions for children with autism and highlights the need to increase awareness not only amongst the community but also those in healthcare.

There have been a number of studies that have explored the family experiences and perspectives of caring for a child with autism in South Africa and Nigeria. These studies shed light on the challenges faced by caregivers and the strategies they employ to support their children. Studies that have explored perspectives on autism in Nigeria have found similar findings to that of South Africa. However, it is important to note that perspectives on autism in South Africa and Nigeria are diverse, and individual experiences and beliefs can vary.

In South Africa, many caregivers face challenges related to the lack of awareness, limited intervention services, and lack of support.[32] The study found that caregivers experienced psychological stress, social stress, financial burden, and reported unavailability and inaccessibility of services. Caregiver stress was associated with comments when out with their child in public, and the future of their child.[32] These findings are similar to other studies that have reported on higher levels of parental stress, poorer psychological outcomes and higher levels of anxiety when caring for a child with autism.[33,34] However, it is important to note that many families in South Africa will also stay with family members, and in their communities many may experience continued social rejection and isolation as a result of this.[35]

Studies have also explored the experiences of caregivers feeding their child with autism in South Africa.[36,37] Children with autism are more likely to experience food selectivity and problematic mealtime behaviours compared to their neurotypical peers.[38,39] These difficulties encompass picky eating, limited independent feeding, longer feeding times, and a restricted food repertoire.[40,41] These difficulties can impact their overall food security and nutrition status. Inadequate dietary intake, characterized by limited consumption of fruits and vegetables and excessive intake of high-energy dense foods like sugar-sweetened beverages and processed snacks raises concerns about the development of diet-related non-

communicable conditions such as obesity.[42,43] Feeding difficulties are of particular concern in contexts such as South Africa where many families experience food insecurity making it difficult to provide appropriate support for their autistic children and associated feeding difficulties. Moreover, feeding difficulties in autistic children increased parental stress and anxiety, and the additional financial burden associated with feeding their child.[36] The study emphasized the importance of incorporating the family's beliefs, values, and needs into feeding management and highlighted the individualized strategies used by caregivers to deal with feeding difficulties.

Similarly to South Africa, Nigerian caregivers experience significantly high levels of psychological distress among mothers of children with autism, indicating the emotional toll of caregiving.[44] The study also highlighted the impact of caregiving on mothers' who are often the primary caregiver. Additionally, mothers were impacted financially regarding low-income employment and many mothers having to give up their jobs to take care of their child with autism due to lack of support and services available.[44] In both South Africa and Nigeria women often take on the primary role of caregiving, perpetuating gender-based stereotypical roles of parenting and are more susceptible to alleviated stress and significant caregiver burden.[45]

Studies conducted in South Africa and Nigeria have highlighted the unique experiences and challenges faced by caregivers of children with autism. Caregiver experiences of children with autism were strongly influenced by cultural and contextual factors.[46] Contextual factors such as culture, language, location of treatment, cost of treatment, type of service provider, support, parenting practices, and stigma emerged as important considerations in the adaptation of interventions. Caregivers expressed a preference for affordable, in-home, and individualized interventions where they have an active voice in shaping treatment goals. Autism places considerable emotional and financial burdens on families of autistic children, often leading to increases in stress and anxiety, with limited access to support services.[8] The findings emphasize the need for comprehensive support services, including accessible interventions, education, and financial assistance, to alleviate the burden on caregivers and improve the well-being of children with autism in these contexts. These interventions should be tailored to the specific needs and preferences of caregivers in both South Africa and Nigeria to effectively support them in their caregiving role.

Access to Supports and Services in South Africa and Nigeria

The availability and access to treatment for autism is limited in both South Africa and Nigeria. Families are unable to access appropriate specialists, schools, or rehabilitation services.[3,17,47] These problems are exacerbated with late diagnosis, and lack of awareness of autism and the supports that are required. Reduced access to services and supports has been recognized by the World Health Organization as a global public health concern (WHO, 2013). In LMICs, services and supports for individuals with autism are often limited or unavailable.[3,46–48] Many families face challenges related to reduced awareness and education, financial implications, geographical location and availability of services, as well as the availability of resources and appropriate healthcare professionals.[16,17,49] Early intervention for autism is considered imperative, as it can improve clinical outcomes and support development in language, communication, cognition, social skills, and adaptive behaviours.[46,50–52] Research indicates the importance of feasible early interventions that can be integrated into systems of care to address implementation gaps. Early intervention also provides the opportunity for involving caregivers and family members in the planning and delivery of therapy, as well as extending support to the home environment.

In recent years, South Africa has made significant strides in improving autism support and awareness. There is a growing understanding of the importance of early intervention for individuals with autism in South Africa. Efforts have been made to improve early screening and assessment services to facilitate early intervention through organisations such as the Centre for Autism Research in Cape Town, South Africa.[53] South Africa has also witnessed the growth of advocacy organizations and support groups dedicated to autism, such as Autism South Africa (ASA), Mothers of Children with Autism (MOCWA), and Fathers of Children with Autism (FOCWA). These organizations raise awareness, provide support services, and advocate for the rights of individuals with autism. Additionally, they offer resources, information, and a network of support for individuals with autism and their families. They also play a crucial role in educating communities and dispelling myths and misconceptions surrounding autism. Moreover, South Africa has prioritized policies that focus on early childhood development, which mandate better funding for services and ensure

accountability in caregiving.[7] Policies like the National Integrated Early Childhood Development Policy guarantee equitable access to services for children with disabilities, including those with autism. Diagnostic facilities and specialized clinics have been established in major cities, enabling families to obtain proper evaluations and access-appropriate interventions. Despite these advancements, challenges in access to services, support, and early intervention still persist, particularly regarding the significant economic disparities for different people in the country.[7,54]

Access to supports and services in Nigeria for children with autism and their families continues to be a problem.[55] As mothers are often the primary caregivers, this places them in an important position in the delivery of interventions and ways to improve access to service delivery. There have been a number of advocacy and awareness campaigns, such as the Ike Foundation for Autism (IFA) in order to reduce stigma and promote acceptance amongst Nigerians. In order to assess the feasibility and effectiveness of involving parents in delivering behavioral interventions, a pilot study was conducted focusing on mothers and children with autism.[55] The results indicated the feasibility of this approach, highlighting both the importance and potential for involving caregivers in the treatment process.

In both South Africa and Nigeria, access to affordable and comprehensive therapies remains a challenge, particularly for families living in remote or rural areas. Considering the barriers to intervention in these contexts, it may be important to consider different service delivery models that can provide more equitable access to services, resources and supports for children with autism and their families. Research has provided a number of different options, including the stepped care approach, which is one that requires the least amount of resources, is low-intensity and can be delivered by non-specialists first before referring for specialised care.

Navigating the Changing Landscapes of Autism in Africa

Currently, there are very limited data on autism from Africa compared to other parts of the world, with majority of information coming from HIC.[8,9] There are a number of challenges in establishing the prevalence of autism, as well as early identification. Challenges are a result of a lack of awareness and knowledge amongst healthcare professionals and the public, and limited validated tools that can be used to identify autism with many not being linguistically or culturally adapted to the specific populations and contexts. Additionally, reduced support for families who do receive a diagnosis in terms of access to resources, specialist care, schools, and treatment limits early identification and intervention.[16,17,49] Therefore, efforts should be made to promote autism awareness in different communities and to develop linguistically appropriate and culturally responsive resources and educational materials that better reflect the needs and sociocultural context.

It is important to note that cultural factors and language barriers can influence the diagnostic process and require culturally sensitive approaches. There is still a lot of stigma surrounding autism in many African communities and it can provide numerous challenges and barriers in receiving support and care for the autistic individuals and their families.[56] Efforts are being made to train professionals and raise awareness about autism diagnostic criteria and appropriate assessment tools to improve the accuracy of diagnoses in Nigeria.[30] Additionally, it is important to acknowledge the financial strain for many families in these contexts, particularly those form lower socioeconomic backgrounds and those living in remote or rural areas regarding the types of support required for these families.[57,58] Reduced support and access to services will continue to result in limited or inadequate treatment and increased caregiver burden. Research has also indicted the financial strain placed on families and their autistic children regarding access to services, resources and treatment.[3,36,49,59] Limited funding is available for these families living in South Africa and Nigeria and appropriate finding support services should be made available. Furthermore, collaboration between key stakeholders, including; healthcare providers, educators, and support organizations are essential to ensure timely and accurate diagnoses and to provide appropriate interventions and support for individuals with autism in South Africa and Nigeria. The advocacy groups in these contexts have played an important role in raising awareness and providing support to autistic individuals and their families. These groups should also be involved in partnerships and collaborative efforts to address the challenges faced by these individuals.

In order to improve the ways in which autism is diagnosed, assessed and managed in Africa, it is important to change current policies. Funding for autism should be prioritised in order to facilitate improved access to care such as trained healthcare professionals, specialised centres and schools, and availability of appropriate tools and resources. Moreover,

support should also focus on advocacy and awareness campaigns, as well as the provision of community-based support and training for autistic individuals and their families. It is imperative that stigma surrounding disability a autism is reduced in order to promote diagnosis and early intervention. Each country needs to establish appropriate service delivery models and referral pathway systems for autism at the different levels of care.

Conclusion

The research article discusses the challenges and nuances surrounding autism in the specific contexts of South Africa and Nigeria. It addresses several key aspects, including the prevalence and incidence of autism, the identification of autism, perspectives and attitudes towards autism, and access to support and services not just on individuals with autism but also on their families and communities. This review emphasised the importance of collaborations between governments, communities, and organizations to create inclusive societies that empower individuals with autism and their families in order to provide them with the support they need. The research underscores the critical importance of future studies and interventions that consider the unique cultural, contextual, and socioeconomic factors in South Africa and Nigeria. Collaborative efforts between researchers, policymakers, healthcare professionals, and advocacy organizations are essential for bridging the existing gaps. Future research may want to employ different methods to collect data, to fill in the various gaps in this area and to develop clinical guidelines that are applicable to these contexts. Moreover, the article emphasizes the need for ongoing awareness campaigns to destigmatize autism and promote understanding within the broader community.

Learning Outcomes

1. To describe autism prevalence, incidence, identification, treatment, and attitudes in South Africa and Nigeria.
2. To explore the ways in which we can provide contextually relevant and responsive interventions, education and training, research and policies to autism in South Africa and Nigeria.
3. To improve our understanding of autism in low-middle income contexts and bring awareness to those living with autism in South Africa and Nigeria.

Abbreviations

ASA, Autism South Africa; FOCWA, Fathers of Children with Autism; HICs, high-income countries; LMICs, low-middle income countries; M-CHAT-R/F, Modified Checklist for Autism in Toddlers Revised with Follow-up; MOCWA, Mothers of Children with Autism; WHO, World Health Organization.

Disclosure

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