

Assessment of Autism Spectrum Disorder: Improving Screening and Diagnosis in Kenya

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ABSTRACT

One hallmark feature of Autism Spectrum Disorder is poor socio-communication skills. Almost every individual with ASD exhibits this challenge. Diverse research-based intervention strategies exist to ameliorate that. Effective intervention starts with timely assessment and diagnosis. This article explores the different assessment procedures inclusive of screening and diagnosis of Autism Spectrum Disorder. Precisely, it reviews available assessment methods, screening tools, parental perception and the general global diagnostic criteria. The article also highlights the significance of timely and accurate diagnosis in improving the quality of life of a child with ASD. This is an in-depth qualitative research reviewing literature from research findings published in renowned peer-reviewed journals. Among the challenges faced in the diagnosis process are stigmatization, lack of trained personnel, and culturally insensitive assessment tools with the majority of parents registering their dissatisfaction with the entire diagnostic process. This paper ends by giving recommendations to the government and related stakeholders.

Keywords: Autism Spectrum Disorder, Screening, Diagnosis of Autism Spectrum Disorder

INTRODUCTION

Autism spectrum disorder (ASD) is a complex neurodevelopmental condition (Ochuka & Wairungu, 2023) characterized by difficulties in social communication and interaction skills with the presence of restricted and repetitive behavior (DSM-5; APA, 2013). The history of this condition dates back to the 20th century when Eugene Bleuler came up with the term autism in 1911. It described a withdrawal from social interaction as observed in individuals with Schizophrenia. Later on in 1943, the term *infantile autism* was coined by Leo Kanner and it marked the onset of the understanding of contemporary Autism (Ghazi, 2018). This term was used to describe a group of children who exhibited a distinctive pattern of social and communication impairment. A year later in 1944, Han's Asperger identified a similar condition which would later be referred to as Asperger's Syndrome. The studies by these two formed the basis of the current definition of Autism Spectrum Disorder (ASD).

Diagnostic criteria for Autism was first outlined in the third edition of the Diagnostic and Statistical Manual of Mental Disorders DSM-III in 1980 (APA, 1980). Subsequent revisions of DSM-IV in 1994 and DSM-5 in 2013 reinvented the current diagnostic criteria for ASD. DSM-5 saw the conceptualization of autism as a *spectrum* rather than a single entity. It recognized diversification of symptoms and severity across individuals with this condition. The current criteria combines DSM-IV's Pervasive Developmental Disorder (PDD) diagnoses; Autistic disorder, Asperger's disorder, Childhood Disintegrative Disorder and Pervasive Developmental Disorder not Otherwise Specified (PDD-NOS). Rett syndrome is now considered a neurological disorder by itself (Hodges et al., 2020). A new condition, Social Pragmatic Communication was introduced to represent individuals with poor socio-

communication skills but short of repetitive behaviors and restricted interests associated with ASD (Wairungu, 2020).

Autism Spectrum Disorder is a lifelong condition that is diagnosed by age 3 (Muthoni & Wairungu, 2023). Its hallmark symptoms are present in the early developmental period although they may not fully manifest until social demands exceed an individual's limited capacities (Crane et al., 2015). Among the common socio-communication challenges include deficits in social and emotional reciprocity, and deficits in non-verbal communication such as understanding and using non-verbal cues like facial expressions, gestures, and body language. Repetitive behaviors include stereotypical and repetitive motor movements like hand flapping, finger flicking, and echolalia. Children with ASD insist on sameness and inflexibly adhere to routines. They have fixated interests and exhibit hyper/hypo-reactivity to sensory stimuli (Muthoni & Wairungu 2023). Over 90% of them typically exhibit a dysfunction in one or more of the eight sensory modalities. These ASD symptoms lead to significant difficulties in daily life that affect social relationships in the child's environment and other areas of functioning. In school, learning is significantly affected especially if instructors are not effectively trained on intervention strategies. When diagnosed promptly, interventions are more effective although ASD is not a disease to be treated but a condition to be managed (Ndiema & Wairungu 2021).

ASD prevalence is consistent across different ethnic and racial groups though some literature indicates potential variations (Becerra et al., 2014). A recent study by the Center for Disease Control (CDC) and Autism and Developmental Disabilities Monitoring (ADDM) (2023) estimated that 1 in 36 children are diagnosed with ASD in the United States of America (Ochuka & Wairungu 2023). The current prevalence of ASD in Kenya remains unknown with suggestions of 4% of the general population by Autism Society of Kenya in 2013. Additionally, a study by Baio et al. (2018) notes that ASD variations in racial, ethnic and socio-economic groups could be a result of stigma, lack of access to health care services as well as a patient having a primary language other than English. Unfortunately, most of the ASD assessment tools are in English. ASD is more frequently diagnosed in males than females with the ratio generally reported at 4:1 (CDC, 2020). This ratio can always vary depending on the study population. Male predominance may be partly due to the differences in symptom manifestation otherwise known as protective biological factors in females (Navarro et al., 2021), and bias in the referral and assessment process in the diagnosis between genders (Loomes et al., 2017). This is echoed by Navarro's postulation on the lack of sensitivity of the evaluation instruments for detection and diagnosis. Other than this, studies have tried to explain (Faras et al., 2013) the relationship between female autism phenotype, ASD misdiagnosis and late diagnosis or overlook of ASD in girls altogether. This theory postulates that females are less likely to present apparent ASD symptoms but mask them through camouflage. This to some extent explains the high prevalence rates in males. Over time, there has been an alarming rate of increase in new ASD incidences. Studies have tried to explain this occurrence, with some (Hodges et al., 2019) linking the increase in prevalence to the change in diagnostic criteria. Change from DSM-IV to DSM-5 has led to the broadening of the diagnostic concept. Other factors include the presence of insurance companies that are now covering ASD in developed countries. These services have ultimately led to the diagnosis of even milder cases of ASD and a wider public awareness of these disorders (Wang'ang'a, 2023).

To date, the exact cause of ASD remains unknown. It is a topic of ongoing research but studies point (Hodges et al., 2019) towards a complex interaction between genetics and environmental factors thought to affect a child's developing brain. Research shows that siblings of patients with ASD are more susceptible to ASD compared to the population norm and even higher in monozygotic twins (Kim et al., 2019). While this is the case, it is important to note that in some monozygotic twins, only one of the twin-lets can have ASD. Advanced parental age has also been shown to have an increase in the risk of having a child with ASD. This

partially explains the role of genetics as a risk factor. Environmental factors like maternal infection during pregnancy have also been associated with increased risk (Ester & McAllister, 2016). This is thought to be related to the activation of maternal immune responses leading to neurodevelopmental alteration in the fetus. However, this study remains inconclusive. Precisely, no one knows what causes ASD beyond reasonable doubt (Ndiema & Wairungu, 2021).

METHODOLOGY

This is an in-depth qualitative research. Recent research findings on the Assessment of ASD were reviewed and purposively analyzed. A descriptive research design was utilized. The research focused on scholarly articles, reports and relevant documents retrieved from reputable academic databases such as EBSCO, Eric, Science Direct, PubMed, and Research Gate. The utilization of a descriptive research design facilitated and allowed for the identification of trends within the qualitative data (Hatch, 2002).

Limitations

While this study presents valuable insights, it is important to acknowledge inherent limitations in the study (Muthoni & Wairungu, 2023). Foremost, the absence of direct engagement with individuals affected with ASD or healthcare professionals in Kenya could limit the depth of understanding as their personal experiences and perspectives are not captured directly. Other than this, the scope of a desktop research approach may limit the exploration of real-time challenges and developments in the field of Autism in Kenya. Reliance on existing literature may introduce a potential bias. This is because the quality and availability of relevant information may vary (Wairungu & Ochuka, 2024). On the same note, not all research findings are published online. Many hardcopy documents exist but were not reviewed. Further, some abstracts were written in English showing the potential of relevant literature but the Text bodies of the articles were in languages other than English. Finally, some databases required one to pay expensively to access critical information.

Inclusive and Exclusive Criteria

By use of Google Scholar, ask.com, and Microsoft Bing search engines, relevant terms such as Autism Spectrum Disorder, Autism Screening, Autism assessment, and Autism Prevalence were searched. Most results came from popular data bases such as EBSCO, Jstor, and Science Direct and Eric. Due to budget constraints, only sources that did not require payments were accessed. Further, any literature that was not relevant to screening and assessment of ASD was not considered.

RESULTS

Screening and Assessment of Autism Spectrum Disorder

There are no biological markers for ASD and therefore no laboratory test exists. Children can take long before assessment and that is why screening is recommended in every child. Usually, it is parents and guardians who raise the first alarm. Detection and diagnosis of ASD is developed based on the observation of symptoms in the diagnostic manual (DSM-5) (Alonso-Esteba et al., 2022). In developed countries, the evaluation of ASD begins with screening of the general pediatric population (Hodges et al., 2017). This helps identify children who are at risk of developing the condition. After this, a diagnostic evaluation is recommended for individuals whose screening results identified an area of concern (American Academy of Pediatrics, 2013). Accurate screening, assessment and diagnosis of ASD is vital in enabling

timely interventions (Jullien et al., 2021). Intensive Early Intervention makes a big difference in the outcome for people with ASD in the long run.

Screening for ASD

Autism Spectrum Disorder screening tool is a formalized brief questionnaire completed by a parent or health care provider. This is before an in-depth diagnostic evaluation is done. As stated earlier, screening tools do not diagnose ASD, they only identify whether a child meets the criteria for diagnosis of Autism Spectrum Disorder (Jullien, 2021). This is done when a child visits the primary care provider. The American Academy of Pediatrics advocates that children be screened for developmental delays and disabilities during regular well-child clinic visits at 9, 18 and 30 months respectively. There are two levels of screening. Level one screening is universal screening where a whole, unselected population is screened for Autism Spectrum Disorder. Level two screening known as selective screening is where children with developmental concerns or high-risk children are screened for ASD. High-risk children are those with siblings who already have ASD diagnosis, children born pre-term or children with developmental delays.

The most commonly used and studied screening tool is the Modified Checklist for Autism in Toddlers M-CHAT and its subsequent versions (MCHAT-R/F). This tool is designed to screen children between the ages of 16 and 30 months (Sobieski, 2021). It assesses communication skills, joint attention, repetitive movement and pretend play. If the screening results turn out positive, the child is referred for a full assessment. There is evidence that ASD screening tools administered accurately between 12-36 months correctly identifies those with ASD (Jullien et al., 2021). After screening the child is then referred for a full diagnosis.

ASD Diagnosis

ASD diagnosis is clinically based on the presence of core symptoms found in the Diagnostic Statistical Manual (DSM-5). These include deficits in socio-communication skills and the presence of restricted, repetitive patterns of behavior, interests or activities (Barasa, 2021). To meet the criteria for ASD, these symptoms must be present in early childhood. They should cause clinically significant impairment in social, occupational, or other important areas of functioning (Regier et al., 2013). The DSM-5 emphasizes a dimensional approach, recognizing the spectrum of severity in symptoms and highlighting the importance of individualized assessment. Specific criteria include impairments in social-emotional reciprocity, nonverbal communication behaviors, and challenges in developing, maintaining, and understanding relationships. The goal of a diagnostic assessment is not only to clarify the diagnosis but also to help caregivers and children understand the diagnosis and direct them to the appropriate support (Penner & Zwaigenbaum, 2018). The gold standard diagnostic practice integrates several sources of information including the child's developmental history from the caregiver, opinions of the members of a multidisciplinary team, observations of the child in multiple settings, results of standardized assessment and the diagnostic criteria provided by DSM-5. According to research done by Behavioral Innovations in (2021) Texas, the most commonly used diagnostic tools include Autism Diagnostic Observation Schedule (ADOS-2) and Autism Diagnosis Interview-Revised (ADI-R). Behavioral Innovations is an organization with global recognition founded over 20 years ago (in the United States) to provide diagnostic services and Evidence-Based Behavior Analysis (ABA) to kids diagnosed with ASD. Several challenges however face effective assessment.

Barriers to Timely ASD Assessment

Screening, diagnoses and treatment of ASD have increased in recent years in high-income countries (Kamau, 2017). There is however little or no available research in Africa. In

2008, UN member states were advised to regard ASD as a public health concern and take necessary measures to combat it. In Kenya just like in the rest of the developing world, measures to address ASD in terms of resources, planning and training do not or minimally exist (Cloete & Obaigwa, 2019). It is public knowledge that lack of diagnostic services hinders early intervention.

A study by Markino et al. (2021) identifies inadequate professional training in conducting ASD assessment, challenges with disclosing diagnoses to families and concerns on how to help families access resources in a fragmented system as some of the limitations to conducting ASD diagnostic assessments. In addition to this, Kamau (2017) identifies the following as barriers to the diagnosis, treatment and management of ASD in Kenya. Lack of awareness, limited research, lack of treatment protocols, lack of governmental support in the diagnosis, treatment and management of ASD, Cultural factors and financial factors in receiving ASD treatment and finally late age of diagnosis due to lack of awareness of the diagnostic and treatment avenues for ASD in Kenya. The steady increase in ASD prevalence has led to growing pressure on professionals to provide timely and accurate diagnoses for the treatment and management of ASD (Manner et al., 2020).

Parental Perspectives on ASD Diagnosis

Parental perceptions of the assessment process is the most studied aspect of ASD (Jacobs et al., 2018). Parents note that this journey is marked by significant delays between raising initial concerns and receiving a formal diagnosis. In the United Kingdom, parents reported consistent frustrations and dissatisfaction with ASD diagnostic services (Crane et al., 2015). A study by Bello Majeed et al. (2017) in Nigeria reports that the average diagnostic age for ASD is 9 years which is 7years later after the parent's initial concern was raised. This is attributed to the shortage of facilities and qualified personnel to conduct ASD assessments (Sengupte et al., 2017). Parents also note that there is little support offered in regard to treatment and management after the diagnostic process. Likewise, professionals also face limitations in delivering ASD diagnosis to caregivers (Markino et al., 2021). Some of the challenging aspects include; ensuring the understanding of the diagnosis by caregivers, communicating comprehensible information to the family and management of familial distress (Rogers et al., 2016). Ultimately, disclosure of ASD diagnosis should not be a negative experience for parents.

Cultural Implications

Developmental disabilities in Africa carry a societal stigma often attributed to a curse (Cloete & Obaigwa, 2019). Many Kenyan communities link disabilities to supernatural causes like witchcraft and evil spirits (Bunning et al., 2017). According to Wang'ang'a (2023), learners with ASD in Africa are socially isolated and never diagnosed or treated. It is noted that the diagnostic pathway for children with neurodevelopmental disorders in the Kenyan Coastal region is to seek guidance from a traditional healer and then later to hospitals (Gona et al., 2016). A study in Nairobi found that parents or caregivers with children who have ASD tend to close off due to social stigma. Cloete and Obaigwa (2019) reported maternal blame, extramarital affairs and strained relationships as some of the challenges faced by families having a child with ASD. Parents also feel that even if they were to seek medical assistance, many medical professionals do not have adequate training in the assessment of ASD (Riccio, 2011).

Cultural Adaptation of Assessment Tools

Most assessment tools (screening and diagnostic) are created in English and later translated to other languages. The problem of Assessment in Africa is greatly linked to the large rural populations with different languages, dialects and cultures (Franz et al., 2016)

coupled with limited resources to translate and validate the tools (Abubakar et al., 2016). McPheelers et al. (2016) notes that the appropriate utilization of assessment tools goes beyond the translation to identify incongruities and modify the tool to be understood by the target population. Despite raising early developmental concerns reduced access to appropriate assessment resources ultimately delays the entire diagnosis (Bakare et al., 2022).

DISCUSSION

It is quite evident that the status of Autism Spectrum Disorder diagnosis in Kenya and Sub-Saharan Africa by extensions is way behind compared to the high-income developed Western Countries (Obaigwa, 2019). In Kenya, like in the rest of the developing world, developmental disorders attract little attention from the government. This is indicated by the lack of statistics on the country's prevalence of ASD, the impact of ASD on individuals and the improper resource allocation for research and training of professionals to support ASD. According to Wang'ang'a (2023), if indeed the prevalence of ASD is increasing then there is a need to increase support services for ASD. Unfortunately, this is not happening and neither is there evidence of a major government concern in developing countries like Kenya.

Cultural perceptions also play a role in inhibiting timely diagnosis. This is primarily due to lack of information and awareness on ASD mostly in the rural parts of the country. Furthermore, the assessment tools largely adopted from the West more often than not do not meet the specific needs of the target population. This is majorly due to cultural and linguistic variances and they have a high possibility of misdiagnoses. Insufficient training of professionals on the diagnostic methods and criteria of ASD and the general lack of financial and material resources negatively impact timely diagnosis. Assessment requires adequate financial and human-resource support for implementation.

A study by Dr. Lincoln Kamau in (2020) in Garissa County highlighted the experiences of parents and caregivers as they go about diagnosis and treatment. Parents reported their children's developmental delay as early as 18 months but were ignored or concerns were not adequately addressed by the health caregivers. The Parents were therefore dissatisfied with ASD related professionals for not providing a coherent diagnostic pathway and in some cases for giving incorrect diagnoses.

CONCLUSION/RECOMMENDATION

Obtaining a diagnosis is the first step to accessing support services for ASD. Therefore, the Government of Kenya should endeavor to develop a national policy on early diagnosis, support and treatment for children with ASD. It should also raise awareness through policies and initiatives advocating for awareness at all levels. On the same, the government should look for strategies to promote an inclusive society that accepts and appreciates coexistence with individuals with Autism Spectrum Disorder among others. Studies in developed countries have shown that availing adequate information through the training of healthcare professionals alleviates confusion (Wang'ang'a, 2023). There is also a need for all ASD stakeholders to develop their diagnostic tools to serve the diverse population in Kenya. According to Baio et al. (2018) advancing on diagnostic tools facilitates the availability of relevant information concerning ASD. Moreover, the financial impact of caring for individuals with ASD is substantial (Levelle, 2014), therefore there is a need for the government and all ASD stakeholders to avail resources to support children and their families and also to facilitate efficient service delivery (Ochuka & Wairungu, 2023). There should also be professional capacity building to invest in workforce development and to ensure a collaborative effort in the diagnosis and treatment of ASD. Insurance companies as well should also consider supporting parents with ASD for the needs of screening, assessment and diagnoses. Finally, there is need

to promote collaboration and a multidisciplinary team approach among parents, therapists and other related stakeholders.

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