Strategies for Autism Diagnosis and Care in Resource Deprived Settings in Africa: An Overview

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Abstract: Background and Goals: Autism Spectrum Disorders (ASDs) exist in Africa as they do everywhere in the world. Historically they have been under recognized and under studied. The aim of this paper is to review the existing challenges of ASD care and diagnosis in Africa, with a view to describing workable unique strategies deployable within the continent.

Methods: We present an overview of the existing medical literature and summarize key findings in relation to the topic of ASD in Africa. First, as a preliminary step, we highlight key findings from previous epidemiological surveys. Second, we undertook a review of relevant available evidence from the various African regions. When the authors were familiar with additional local or regional scientific works, these were also used and referenced.

Discussion: There has been a growing awareness of the extent to which ASDs exist and have an impact on affected individuals and their families. There are many barriers to diagnosis and effective interventions. These include lack of trained personnel, stigma and cultural beliefs regarding etiology, disparities in resources between urban and rural areas, and poverty. Nonetheless, partnerships to support research and the development of culturally appropriate interventions can be developed and strengths exist in the communities that can be harnessed to improve care.

Keywords: Autism, autism spectrum, Africa, children and adolescents, public policy, epidemiology.

1. INTRODUCTION

Autism has an onset in early childhood and is often associated with considerable morbidity and lifelong disability. Autism Spectrum Disorder (ASD) according to the Diagnostic and Statistical Manual for Mental and Behavioral Disorders (DSM 5; American Psychiatric Association, 2013) is classified as a neurodevelopmental disorder. The DSM 5 highlights that the core symptoms must be present in the early developmental period, but may not become fully manifest until social demands exceed limited capabilities, or may be masked by learned strategies in later life. Autism symptoms often cause global clinically significant impairments in child’s functioning, and in view of these potential impairments early recognition and intervention is recommended. However, in resource deprived settings, many persons with ASD are either not diagnosed, or when they are diagnosed there are no services within reach to meet their needs. Lack of suitable interventions is also a challenge in resource poor settings. These deficiencies, have implications for the long-term outcome and the burden of the disorder both on the individual and on the family. The socioeconomic costs to a nation can only be imagined, with lost man hours plus reduced income earning as a result of caring for persons with ASD.
ASDs are recognized as having global public health significance. There have been United Nations (UN) resolutions adopted following recognition of the need for effective and sustainable programs along with a call for greater attention to the problem of ASD by Member States (World Health Organization, 2013). A further reflection of a global drive is seen by the Comprehensive Mental Health Action Plan 2013–2020, which was developed by the World Health Organization (WHO) in consultation with member states and adopted by the World Health Assembly in May 2013. The plan highlights the urgent need to strengthen efforts to address the treatment gap for mental and neurological disorders inclusive of ASD. Member nations in Africa gave assent to and signed on to these resolutions, however, political willingness and policy implementation are crucial steps to making such laudable resolutions a reality.

2. WHAT DO WE KNOW ABOUT PREVALENCE?

Historically, from the days of Lotter’s work (1978) to date there is now sufficient evidence that shows that autism is present in Africa and is a disorder worthy of attention. The exact prevalence of autism and ASDs in Africa is unknown, as there are no published population based epidemiological studies to date. Modest efforts have been made by researchers to describe the prevalence of these disorders in Africa within various settings and from different countries, with widely varying results. For example, among the Arab nations a study by Seif Elden and colleagues (2008), found a prevalence of 11.5% and 33.6% among children with developmental disabilities in Tunisia and Egypt respectively. In a hospital based population study in Nigeria, West Africa, a prevalence of 0.08% was reported (Bakare et al., 2011). However, this was deemed likely unrepresentative due to non utilization of hospital services by majority of persons with ASD and their families, except when there are serious medical or behavioral problems. In contrast, a later study among school children with intellectual disabilities in Nigeria showed a prevalence of 11.4% (Bakare, Ebigbo & Ubochi, 2012). This extreme variability of prevalence figures can be attributed to the difference in study settings and non-uniformity of assessment methods. A review by Bakare and Munir (2011a) highlighted how most studies on ASD in Africa only looked at clinical presentations, comorbidities, etiological factors, and knowledge about ASD with little or no attempt to study exact prevalence figures.

It is clear that the exact burden for ASD in sub-Saharan Africa is not really known (Abubakar, Ssewanyana & Newton, 2016). Recent reviews of publications from the region (Abubakar, Ssewanyana, De Vries & Newton, 2016; Franz, Chambers, von Isenburg & de Vries 2017) have reiterated that there are very limited epidemiological data from Africa compared to other parts of the world. These amongst many others confirm the dearth of data emanating from Africa and the urgency to correct such a knowledge gap is constantly highlighted. So, the need for ASD epidemiological studies in Africa cannot be over emphasized to aid the planning for relevant services and policy development for persons with ASD and their families. There are, however, clear limitations as outlined by these researchers that make such research currently difficult, one of which is the lack of culturally relevant tools, as we will discuss further.

There is a need for resourced poor settings to look inward into exploring strategies that are adaptable to solving some of the ASD related challenges. This overview does not attempt to provide an exhaustive discourse on the subject matter but simply highlights some relevant literature for the discourse and further identify possible strategies that may be applicable in addressing the challenge of ASD diagnosis and care on the African continent.

3. CHALLENGES UNIQUE TO AFRICA

Africa is a massive continent made up of many countries with distinct differences in resources. Some countries are more challenged than others in terms of availability of skilled manpower, economic resources, or access to multidisciplinary team personnel. Nonetheless, there are some unique factors that contribute to the challenges of ASD care throughout Africa. The majority of the challenges in most resource poor countries are similar in many regards with slight variations in severity. A few common challenges which have been readily identified include the following.
3.1. Insufficient Numbers of Skilled Professionals

The lack of sufficient numbers of skilled professionals in many child mental health subspecialties on the African continent is a problem, and such a deficiency also exists in the field of ASD care and research. The strategies of “scaling up personnel” and of “task shifting” have been recommended for addressing the unmet treatment gaps in mental health in general and child adolescent mental health in particular (Patel, Flisher, Hetrick & McGorry, 2007). Task shifting is the name given to a process whereby tasks are moved, where appropriate, to less specialized health workers (WHO, 2009). Task shifting involves a deliberate process of increasing services in rural or low economic communities where there are inadequate numbers of skilled personnel by providing training to allow for increasing the scope of practice of existing health workers as well as creating new cadres of health workers (Dawson et al., 2014; Okyere et al., 2017). By reorganizing the workforce in this way, task shifting presents a viable solution for improving health care coverage by making more efficient use of the human resources already available and by quickly increasing capacity. Expansion of training and retention programmes are necessary components. Scaling up refers to expanding or replicating innovative pilot or small-scale projects to reach more people and/or broaden the effectiveness of an intervention (Simmons et al., 2007; World Health Organization, 2016). These strategies present valid mechanisms to improve services, which, when well executed could benefit many underserved areas.

3.2. Comorbidities

Individuals with ASD are known to have a variety of different comorbidities. In Africa, common comorbidities include intellectual disability and epilepsy (Bakare et al., 2012). Springer and colleagues (2013) found a high proportion of children with pervasive developmental disorders in South Africa had severe language impairment, behavioral problems and complex autism. Intellectual disability seems to be the most commonly diagnosed co-occurring condition in individuals with ASD in Africa (Bakare & Munir, 2011b; Belhadj, Mrad & Halayem, 2006; Lotter, 1980; Mankoski et al., 2006). The presence of co morbidities with ASD presents a unique challenge because the focus is often on the comorbidity and the ASD features are often missed or ignored. Having inadequately skilled personnel to identify ASD contributes to this difficulty in diagnosis especially in some remote/rural settings. As a result, it may not be unusual for persons living with ASD to be managed in clinic settings where at least their comorbidities are being attended to.

3.3. Stigma and Ignorance

Stigma and culturally determined prejudices play an important role in child and adolescent mental health disorders, including neurodevelopmental disorders. Some Africans believe that autism is caused by supernatural forces, making it unlikely they would seek help from mental health professionals (Lesi et al., 2014) or delaying their accessing services (Bakare et al., 2009). Such beliefs are not unusual in developing countries, having been reported in other studies within Africa relating to mental health conditions (Abasiubong, Obembe & Ekpo, 2008; Abiodun, 1995). Parental belief systems play an important role in the process of how stigma affects the child who suffers from a mental health condition. A conceptual framework by Mukolo and colleagues (2010) suggests that compared to adults, children are subject to unique stigmatizing contexts and suggests that stigma experiences may be linked to how parents/caregivers cope with children’s emotional and behavioral problems such as seeking professional help. Such delays in accessing services, where available, or denying symptoms, where evident, contribute to poorer outcomes in Africans with ASD.

3.4. Lack of Availability of Diagnostic and Research Tools

The high cost of standardized tools for diagnosing autism and the high cost of training of professionals and para-professionals to use the tools makes them out of reach, which then affects the subsequent ability to screen and diagnose autism in resource constrained settings. In addition, the use in Africa of the diagnostic tools that are commonly used elsewhere presents challenges in terms of cultural appropriateness, cost of translations and adaptations, and copyright-related costs (Ruparelia, 2014). The first population-based prevalence study of autism in India, a resource poor nation, illustrates that success can be achieved using cul-
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3.5. The Burden of Care

Caregivers of people with chronic disorders experience a huge burden of care. In resource poor settings poverty and lost wage-earning further compounds the caregiving pressure. The caregiver burdens for caregivers are both emotional and financial. Without schools or respite facilities many have to care for chronically ill relatives around the clock. Siblings also bear this burden even though there is evidence that their attitudes towards the affected sibling do change over time (Van der Merwe, Bornman, Donohue & Harty, 2017). This burden is also evident in the stigma and culturally determined prejudices against individuals with autism. Some of these manifestations of stigma include local appellations used to describe developmental disorders such as autism, and broader societal discrimination against not only sufferers but also their family members and caregivers, a phenomenon termed “courtesy stigma.” Abubakar, Ssewanyana, and Newton found in their systematic review (2016) that a significant proportion of the studies done on the African continent were on psychosocial issues. They concluded that this reflects the significant burden on quality of life that African communities are increasingly witnessing and appreciating as resultant from ASDs. Caregiver distress has been reported in community studies in relation to the many symptoms associated with autism and their comorbid conditions (Oshodi et al., 2017). Furthermore, there is a lack of support for many caregivers who have no alternative support, such as governmental financial aid, in caring for their ASD relatives. Countries such as South Africa award disability grants for carers of chronically ill family members, but this is not the case in most other African countries. The reality that there are generally no government social safety nets that provide support for families in Africa must be considered when planning interventions and designing policy, to avoid failure of such policies due to lack of affordability, and to also reduce the risk of inadvertently increasing the burden that families already experience.

3.6. Access Challenges

As with many other underserved conditions in Africa access to services for people with autism is an issue. Such access problems include geographical, cultural and economic hindrances. Novel innovative ways that are uniquely adapted to overcoming these challenges and catering to the needs of individuals with autism must be explored to address these challenges. Using local languages for awareness creation and information dissemination is essential. With the explosion of technology, mobile devices, apps and gadgets may find use in these settings. This is of particular relevance since the use of mobile hand-held devices now extends into the most remote regions on the continent.

3.7. Poverty and Opportunity Cost

The pervasive poverty and inequitable distribution of resources between urban and rural areas further compounds an already difficult situation when dealing with ASD and other non-communicable disorders. For families and caregivers to leave their jobs, farms or other sources of income to seek help in the cities where most of the specialist health care providers are located is a challenge. The opportunity cost will be often seen as too much, especially if the individual with ASD is seen as essentially normal but for the social and repetitive deficits. Developing models of care that reduce the need to make families and patient pay
such opportunity costs in getting services will be important in service planning.

4. ENVISIONING SOLUTIONS

In spite of the resource constrained nature of many African nations, the continent is rich in some key areas. It is important as we try to explore solutions that we take cognizance of the wealth that may be found within its borders and may prove useful in planning workable strategies for ASD diagnosis and care on the African continent. A conversation has already begun by researchers recognizing the need for creative solutions for meeting the needs of persons with ASD and their families on the African continent (Abubakar, Ssewanyana, de Vries & Newton, 2016). Some workable relevant strategies that may be considered for use in Africa include the following.

4.1. Utilising Existing Primary Health Care Structures

There have been some successes achieved via the primary health care delivery structures in promoting infant survival and maternal child wellbeing programs. These primary health care structures have proven useful for preventable diseases and for immunization programs and can be further explored as a backbone for autism screening and linkages to early interventions. Omigbodun (2014) showed a cost effective strategy for improving access to mental health care using the existing primary care services. Such a model also becomes worth considering for ASD care delivery. In this manner ASD care can be included into the primary health care structure beginning with screening and including referring for definitive diagnosis, and coordination of long term care, while ensuring there is a linkage also with the few ASD experts in the community. As highlighted by Patel and colleagues (2007), delivery of services has to begin with primary care services. Reichow and colleagues (2013) found that the delivery of psychosocial interventions, including parent training, by non-specialist providers to children who have intellectual disabilities or lower-functioning autism spectrum disorders and their families was effective in improving developmental behavioral, and family outcomes. Although these authors noted that few studies have been done in resource poor areas, they felt that such scaling up interventions could be an option in many low and middle income countries where there is a scarcity of specialists.

4.2. Collaborative Research

Until fairly recently, much of the knowledge on ASDs and other developmental disorders was drawn from research conducted in high income countries. It is crucial to learn what works and what doesn’t in terms of interventions in low resource settings. There is always a need to balance the use of scarce resources for public health care delivery and for research (Bakare, Munir & Bello-Mojeed 2014). The need for large scale clinical, training and research to increase the capacity of researchers in the field of autism has been strongly recommended (Bakare, Munir & Bello-Mojeed, 2014; Franz et al., 2017). Scientific cooperation between the industrialized countries and the Less Developed Countries (LDCs), known as “north–south collaborations” has grown. Such collaborations range from technical assistance to collaborative research partnerships. In the field of autism research collaborative research partnerships can hold real value and allow for generation of locally relevant data while providing experienced technical assistance and increasing the competence of in-continent researchers. Within the continent south-south collaborations between researchers from countries within the continent will allow for comparison of research findings and testing of interventions in very similar populations for efficacy and replicability.

4.3. Increased Advocacy

Despite the generation of good evidence and well-meaning efforts by health care professionals and non-governmental agencies, there is still a great need for government buy in and political will to ensure policies are not only put in place but are also implemented. Advocacy is an important tool that is still underutilized in these settings. Consumer-led groups are only just evolving in some African countries. It has been a slow process due to the stigma associated with having an emotional disorder and the courtesy stigma extended to their family members. Organized ASD caregiver advocacy drives can be encouraged in a culturally appropriate manner by and for parents/caregivers of persons with ASD. Empowering them and granting them a voice via advocacy can be expected to build confidence and competence around the fact
that they have a child or ward on the spectrum. The use of TV programs, advertisements and television drama series in the local dialect can be a powerful tool in community enlightenment activities where the funding permits.

4.4. Culturally Appropriate Tools

There are ongoing discussions amongst stakeholders in the field of autism care and research on the need for increasing the availability of assessment measures and resource development for low and middle income countries. A few researchers in recent times have commented on the inappropriateness of some of the Western diagnostic and assessment tools in sub-Saharan Africa (Abubakar, Ssewanyana, & Newton, 2016). Issues around the context of language, training of users and proprietary costs continue to limit the use of such standardized tools in research. As a result, few studies are found on the continent that use these standardized tools in research (Franz et al., 2017). The use of open access and open source models can help solve this problem and also encourage collaboration and training internationally in the field of ASD diagnosis and care (Durkin et al., 2015). The need to think globally and embrace the use of such open access models has been identified as one of the several novel ways to ensure efficiency and high standards of care (de Vries, 2016). The ideal open source global screening tool will need to be well thought out to accommodate varied literacy levels and culturally relevant applicability.

Some resource poor nations on the continent have already deployed some unique solutions to assist them in caring for persons with ASD. For example, in Uganda, Kakooza-Mwesige and colleagues (2013) developed a 23-question screener (23Q) for neurodevelopmental disorders. The 23Q is built upon an instrument that had been previously validated in low resource countries, the Ten Questions Screener (Durkin et al., 1995) and includes additional questions on behaviors typical of autism spectrum disorders. The 23Q has been found to be modestly successful in identifying a subgroup of children at a high risk of autism spectrum disorders. Instruments such as this are few and need to be replicated and or improved upon. Continuous effort toward the further development of standard culturally suitable, reliable, and easily administered tools is urgently needed. This may take the form of developing new tools or modifying existing tools.

4.5. Intersectoral Collaboration

As with other conditions of public health significance, ASD cannot remain a problem of only one sector, specifically, the health sector. To mobilize and ensure effective delivery of any program in low resourced settings there is a need for stakeholders to be involved in the process. Effective intersectoral collaboration ensures sustainability and far reaching impacts even of little effort. In the case of autism screening if the local ministries of health train and deploy health care workers to rural settings for identification of ASD, there will also be a need to have a linkage between the educational systems and health for referrals back and forth for needed educational input and vice versa. Colleagues and I have called for frequent large scale community based screening along with autism awareness exercises, possibly using intersectoral collaboration as a strategy in communities with limited resources (Oshodi et al., 2017). Others have recommended clearly spelt out ASD focused policies (Lesi et al., 2014); such policies could serve in providing a road map as to how service delivery and collaborations should occur.

4.6. Community Leaders--Using Mothers and Snowballing Techniques

In many African traditional rural and low resourced communities, the role of older women who serve as community and religious leaders is very important, as is a high level of community involvement in individuals’ lives, particularly in the rural as compared with urban communities. Older women are often held in high regard, trusted and listened to by other parents. These women could be trained to help families who have a family member with ASD. Trainings ideally would be basic and also include provision of useful information about the condition and skills for some home based interventions. Such training can then be passed down from the mothers of children with ASD in the community to other mothers just learning of their child’s ASD condition, who will eventually pass on what they know to other mothers, thus having a snowballing effect. In addition, community support group fora where the women meet regularly can be encouraged; an ideal approach for rural communities. A model like this, if
proven workable, would save caregivers a lot in terms of time and cost of regular visits to urban settings for the support their child needs.

4.7. Parent/informal Caregiver Led Interventions and Groups

It follows from the above discussion that simple parent-led interventions can be taught to parents and at regular scheduled times the parent and child return for review and updates of the therapy. These sorts of interventions are successfully being carried out in a few non-governmental organizations in South Africa. A few examples include the Association for Autism, Autism Western Cape, and the Ernie Els Centre for Autism. Similar models can be explored for other parts of Africa. In addition, parent support groups can provide a place of solace learning and exchange of ideas among parents of individuals with autism. The role of informal family caregivers, such as parents and siblings, who often serve as primary caregivers and are ready resources that can be harnessed must be recognized. They are willing to be trained, they are committed to their wards and would be cost effective options for care delivery. This emphasizes the need to organize and accommodate parents much more in the work around autism care in Africa.

CONCLUSION

The impacts of ASDs on individuals living with these disorders and their caregivers are enormous. The burden in Africa is further increased by varied challenges found in the many resource poor nations within the continent. These include not only inadequacies in terms of trained personnel and services, but limitations on help-seeking caused by geography, culture and financial duress. Western methods of screening and intervention may require modification before use, while still maintaining the integrity of the methods. In addition, there is a need for further exploration of novel diagnostic processes and interventions that can be evaluated for efficacy. At the same time, there are many strengths among the communities and people that could be harnessed to provide support and training to families

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