Identifying Gaps in Knowledge, Prevalence and Care of Children with Autism Spectrum Disorder in Tanzania – a Qualitative Review article

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Abstract

Introduction: Autism Spectrum Disorder (ASD) is a severe neuro-developmental disorder with onset in childhood and is being increasingly recognized worldwide. Recent statistics indicate an increase from 1 out of every 90 children to almost one out of every 60 children in USA. It has also been increasingly recognized in many African countries. In Tanzania, we are noticing a large gap in information on the knowledge, prevalence and care of children with ASD.

Methods: A systemic search and an extensive survey of the existing information about ASD in Tanzania was done using various tools, including interviewing key persons, visiting facilities and identifying potential resources available for improved care of children with ASD.

Results: There is very limited information available on children with Autism in Tanzania. There have been scattered information and no concerted efforts for these children. There are about 8 public schools registered with Ministry of Education and Vocational Training (MEVT) and about 8 centers, privately owned and not yet registered by the MEVT. The prevalence in these centers was 437 children which may be a gross underestimate, since these are predominantly in Dar-es-Salaam and the North-Eastern Regions in Tanzania. Information from other areas is not available. The education and care in the public facility is meager and the private facilities have a huge burden of costs, and are mainly donor dependant. There is also a lack of trained human resources to cater for these children.

Conclusion: There is need to draw attention to the policy makers on the need to identify, screen, increase trained human resources and provide quality care to these children with special education needs.

Introduction

Autism is a severe neurodevelopmental disorder with onset during early childhood. Children affected with autism have variable presentations and therefore the disorder is now termed as Autism Spectrum disorder (ASD). ASDs also called pervasive developmental disorders constitute a group of neurodevelopment disorders that coalesce around a common theme of impairments in social functioning, communication abilities, and repetitive or rigid behaviors. The ASDs considered in this paper include autism/autistic disorder, asperger disorder/asperger syndrome (AS), and pervasive developmental disorder not otherwise specified. Autistic disorder, sometimes called autism or classical ASD, is the most severe form of ASD, while other conditions along the spectrum include a milder form known as asperger syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). Although ASD varies significantly in character and severity, it occurs in all ethnic and socioeconomic groups and affects every age group. Experts estimate that 1 out of 88 children age 8 will have an ASD. Males are four times more likely to have an ASD than females [1].

The hallmark feature of ASD is impaired social interaction. As early as infancy, a baby with ASD may be unresponsive to people or focus intently on one item to the exclusion of others for long periods of time. A child with ASD may appear to develop normally and then withdraw and become indifferent to social engagement.

Children with an ASD may fail to respond to their names and often avoid eye contact with other people. They have difficulty interpreting what others are thinking or feeling because they can't understand social clues, such as tone of voice or facial expressions, and don't watch other people's faces for clues about appropriate behavior. They lack empathy and have poor social interactions.

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Many children with an ASD engage in repetitive movements such as rocking and twirling, or in self-abusive behavior such as biting or head-banging. They also tend to start speaking later than other children and may refer to themselves by name instead of "I" or "me". Children with an ASD don't know how to play interactively with other children. Some speak in a sing-song voice about a narrow range of favorite topics, with little regard for the interests of the person to whom they are speaking.

Children with characteristics of an ASD may have co-occurring conditions including Fragile X syndrome (which causes mental retardation), tuberous sclerosis, epileptic seizures, Tourette syndrome, learning disabilities and attention deficit disorder. About 20 to 30% of children with an ASD develop epilepsy by the time they reach adulthood.

ASD varies widely in severity and symptoms and may go unrecognized, especially in mildly affected children or when it is masked by more debilitating handicaps. Very early indicators that require evaluation by an expert include no babbling or pointing by age 1 year, no single words by 16 months or two word phrases by age 2 years, no response to name, loss of language or social skills, poor eye contact, excessive lining up of toys or objects and no smiling or social responsiveness. Later indicators include impaired ability to make friends with peers, impaired ability to initiate or sustain a conversation with others, absence or impairment of imaginative and social play, stereotyped, repetitive, or unusual use of language, restricted patterns of interest that are abnormal in intensity or focus, preoccupation with certain objects or subjects and inflexible adherence to specific routines or rituals.

Health care providers will often use a questionnaire or other screening instrument to gather information about a child's development and behavior. Some screening instruments rely solely on parent observations, while others rely on a combination of parent and doctor observations. If screening instruments indicate the possibility of an ASD, a more comprehensive evaluation is usually indicated [1, 2].

A comprehensive evaluation requires a multidisciplinary team, including a psychologist, neurologist, psychiatrist, speech therapist and other professionals who diagnose children with ASDs. The team members will conduct a thorough neurological assessment and in-depth cognitive and language testing. Because hearing problems can cause behaviors that could be mistaken for an ASD, children with delayed speech development should also have their hearing tested.

Children with some symptoms of an ASD but not enough to be diagnosed with classical autism are often diagnosed with PDD-NOS. Children with autistic behaviors but well-developed language skills are often diagnosed with Asperger syndrome. Much rarer are children who may be diagnosed with childhood disintegrative disorder in which they develop normally and then suddenly deteriorate between the ages of 3 to 10 years and show marked autistic behaviors.

Scientists aren't certain about what causes ASD but it's likely that both genetics and environment play a role. Researchers have identified a number of genes associated with the disorder. Studies of people with ASD have found irregularities in several regions of the brain. Other studies suggest that people with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that ASD could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that regulate how brain cells communicate with each other, possibly due to the influence of environmental factors on gene function. While these findings are intriguing, they are preliminary and require further study. The theory that parental practices are responsible for ASD has long been disproved.

Twin and family studies strongly suggest that some people have a genetic predisposition to autism. Identical twin studies show that if one twin is affected, there is up to a 90 percent chance that the other twin will also be affected. There are a number of studies in progress to determine the specific genetic factors associated with the development of ASD. In families with one child with ASD, the risk of having a second child with the disorder is approximately 5% or one in 20. This is greater than the risk for the general population. Researchers are looking for clues about which genes contribute to this increased susceptibility. In some cases, parents and other relatives of a child with ASD show mild impairments in social and communicative skills or engage in repetitive behaviors. Evidence also suggests that some emotional disorders

such as bipolar disorder occur more frequently than average in the families of people with ASD.

There is no cure for ASDs. Therapies and behavioral interventions are designed to remedy specific symptoms and can bring about substantial improvement. The ideal treatment plan coordinates therapies and interventions that meet the specific needs of individual children. Most health care professionals agree that the earlier the intervention the better. For many children, symptoms improve with treatment and with age. Children whose language skills regress early in life before the age of 3years appear to have a higher than normal risk of developing epilepsy or seizure like brain activity. During adolescence, some children with an ASD may become depressed or experience behavioral problems and their treatment may need some modification as they transition to adulthood. People with an ASD usually continue to need services and supports as they get older, but many are able to work successfully and live independently or within a supportive environment.

Therapists use highly structured and intensive skill oriented training sessions to help children develop social and language skills such as applied behavioral analysis. Family counseling for the parents and siblings of children with an ASD often helps families cope with the particular challenges of living with a child with an ASD. Doctors may prescribe medications for treatment of specific autism related symptoms such as anxiety, depression, or obsessive-compulsive disorder. Antipsychotic medications are used to treat severe behavioral problems. Seizures can be treated with one or more anticonvulsant drugs. Medication used to treat people with attention deficit disorder can be used effectively to help decrease impulsivity and hyperactivity. There are a number of controversial therapies or interventions available but few if any are supported by scientific studies. Parents should use caution before adopting any unproven treatments. Although dietary interventions have been helpful in some children, parents should be careful that their child's nutritional status is carefully followed [1].

Due to these variable presentations, these children are also subject to myriad of professionals as well as therapies specially because there is no single method of treatment which is considered gold standard [3,4]. Likewise, the available resources, diagnostic tools as well as support once diagnosis is established, notwithstanding the impact of social stigma, the eventual diagnostic label with which it is associated makes the diagnosis of ASDs a matter of significance. For instance, the unconfirmed reports and misconceptions on vaccine relation to ASD may be associated with decline in vaccination rates. In one study in Los Angeles County, USA, half of the parents discontinued or changed vaccination practices, and this was associated with a belief that vaccines contributed to ASDs indicating a potential subset of under-vaccinated children. Educational tools should be designed to assist physicians when talking to parents of children with ASDs about vaccination [5].

There has been an increasingly high prevalence reported from several resource-limited countries. The question raised is that is it a silent epidemic or increased awareness? There is therefore need to establish early diagnosis, map out possible resources and identify any potential predictors as well as therapies [7]. What is known and what are the facilities existing in Tanzania about autism? In order to highlight this, we conducted review and a qualitative assessment of the gaps in knowledge, and care on autism.

Materials and Methods

An extensive literature review was done using various search engines, textbooks, journals and interviews with several people. The existing facilities were mapped from the sources at the Ministry of education and from Department of Psychiatry at Muhimbili National Hospital. Various special schools were visited and data on autism obtained and documented in a semi-qualitative manner. These were also done over emails, telephone conversations. Standard questions were asked to each of the facilities. Data from a private pediatric clinic (author) were also included. The results have been described in a qualitative as well as semi-qualitative manner.

Results

1. Literature Review

a. Tools for assessing ASD

Several tools have been developed such as the Modified Checklist for Autism I Toddlers (M-CHAT), Autism Diagnostic Observation Schedule – Toddler Module (ADOS-T), Social Communication Questionnaire (SCQ), Social Responsive Scale (SRS), Autism Diagnostic Interview-revised (ADI-R), and

Autism –Spectrum Quotient (AQ), the recent addition of DSM V and so on. These clinical diagnostic tools may be self-administered by caregivers or by health workers at different levels. Since early detection and intervention is associated with institution of early therapy, the need for screening toddlers is considered very important [6-12].

Duarte et al. 2003 used the Child Behavior Check List (CBCL) to identify autism among a population of 101 children in Brazil. Instrument was useful as an initial screener but should not be used for formal diagnosis [8]. Wong et al. 2004 investigated the applicability of a modified version of the Checklist for Autism in Toddlers with 23 variables (CHAT-23). Among a population of 212 children with mental ages of 18 to 24 months the measure was both sensitive and specific for Chinese children [9]. Wakabayashi et al. 2007 compared the child version of the Autism-Spectrum Quotient (AQ) in Japanese and British children and found that the instrument distinguishes the children who have autistic traits at a clinical level from typically developing children equally well in both countries [10].

A systematic search of electronic database and other sources for original studies which evaluated the use of CHAT-23 and M-CHAT in screening for autism in children younger than 5 years of age to evaluate the sensitivity and/or specificity of CHAT or M-CHAT, and to describe the best age to administer these instruments indicated that M-CHAT had a high specificity and sensitivity and was best used between 18-36 months where the regression and manifestation of the signs are most evident. [7]

Similarly, in a selected sample with suspicion of autism, 82 children were screened using the Autism Diagnostic Observation Schedule – Toddler Module (ADOS-T) at two time points around 18 months and 36 months. Short-term stability was documented for children diagnosed at 19 months on average, although a minority of children initially showed unclear diagnostic presentations. Findings highlight utility of the ADOS-T in making early diagnoses and predicting follow-up diagnoses. Children with ASD demonstrated improvement in social communication behaviors and unfolding of repetitive behaviors, suggesting that certain early patterns of change in symptoms may be characteristic of ASD [6-11].

Early this year the introduction of the DSM-V criteria for enhanced detection on screening for autism has increased the confusion, because of over-simplification of the criteria [12]. Limited research exists regarding the role of teachers in screening for ASD. In a study in Houston, USA, the use of the Social Communication Questionnaire (SCQ) and Social Responsiveness Scale (SRS) as completed by parents and teachers about school-age children from the Simons Simplex Collection revealed low specificity and sensitivity [13,14].

Due to increased prevalence of ASDs as well as emerging evidence of the efficacy of early intervention, there is a need to focus attention on the need for early identification of young children suspected of having an ASD. Several studies have suggested that while parents report concerns early in development, it may be months before children can be evaluated and services provided, and these delays may be even more marked in underserved populations. The American Academy of Pediatrics recently recommended universal screening for autism spectrum disorders at the 18 and 24 month well-child pediatric visit [15,16]. In order to improve rates of detection, it is also important that training of such conditions be integrated in the academic detailing as well as clinical practice. In a study which compared 5 pediatrics' unit which received training compared to similar number where such training did not happen, showed a significant awareness and early diagnosis of ASD [16].

b. Reports from other African countries

The reports on prevalence of ASD in Africa is still in the grey zone and its occurrence as a universal condition is still queried, although Lotter described its occurrence in four African countries over 4 decades ago [17,18]. He concluded that the prevalence rates in Africa are much less common than in Britain, while early studies by Sanua et al. concluded that infantile autism (as it used to be termed earlier) appears to be an illness of western civilization, and appears in countries of high technology, where the nuclear family dominates and called for research into socio-cultural aspects of the illness. We do not know whether children who use social services in Africa are drawn disproportionately from the elite [19]. Over the last decade, knowledge about ASD and its prevalence has been documented as being on the rise in different regions of the world, with most literature coming from

the western world, the situation in Africa on aspects of ASD remain unclear [19]. Few studies in North Africa and even fewer in Southern Africa have reported some dynamics on autism including the associated co-morbidity such as intellectual disability, epilepsy and oculo-cutaneous albinism. Etiological factors postulated included post-encephalitic infection, genetic and auto-immune factors and vitamin D deficiency. There is a need for epidemiological studies in Africa to define the magnitude of the problem of ASD and the characteristics of children affected by ASD in this region. This would help in planning and might be helpful in answering the question of etiology of ASD. Policy making needs to be directed at issues of childhood developmental disorders in Africa [20-30].

Likewise the knowledge about ASD in Africa is still low. In a study in Enugu State, Nigeria, among medical undergraduates, pediatricians, nurses and even psychologists, the level of knowledge was very shallow to identify with confidence a development disorder such as ASD [27-31]. In Libya, a selective population of 180 children with history of delayed speech and language as well as behavioral difficulties 128 were found to have ASD (4% prevalence in the selected population), therefore emphasizing that physicians should consider autistic spectrum in the differential diagnosis of any child presenting with a speech and language disorder and/or behavioral difficulties [32-33].

The prevalence of ASD among sub-Saharan African children with intellectual disability are about 0.7% more than three decades ago [19]. In a study in Nigeria 44 children with intellectual disability were assessed for diagnosis of childhood autism based on criteria specified in International Classification of Diseases, Tenth Edition (ICD-10) Diagnostic Criteria for Research [27]. Five (11.4%) of the children studied met the diagnostic criteria for childhood autism. This indicates that there is need to clearly define the inter-relationship between ASD and intellectual disability in this population and to help in health care policy formulation [34].

C. Report from Tanzania

The clinical presentation of ASD in Tanzania is still elusive. The only published study available from Tanzania is a case series of 14 children with ASD. This study used the ADI-R translated into Kiswahili to examine 20 children previously diagnosed with autism in a school in Dar es Salaam, Tanzania (14 met criteria for autism). This tool helps to distinguish the verbal versus the non-verbal cases of ASD and has been in place since early 90s. The proportion of nonverbal cases was found to be higher than in developed countries. Seven of the cases had suffered from malaria and three out of the 14 cases had entirely normal development through the first two years of life acquired autism immediately after having severe malaria. Thus, considering a possible infectious etiology, although the numbers of patients studied are too small to give a meaningful indication on etiology [35-36].

2. Epidemiological findings from the survey and interviews

There have been several schools to cater for children with special needs such as autism and developmental delays in Tanzania, but most of these are either faith based or privately sponsored. The exact number of children with ASD is not clear and these schools cater for all types of mental and developmental disabilities.

In a private clinic in urban setting, one Pediatrician recorded 18 children who fulfilled criteria for autism in a span of 3 years from 2010-2013 using the clinical guidelines and the DSM IV criteria [37]. All the children were boys aged between 3-9 years with major learning difficulties, speech delay and abnormal behavior. Out of the 18 children, 9 of them had co-morbid conditions. Four had a history of birth asphyxia, neonatal sepsis in one, convulsion in three, one had cerebral malaria and one had a brain tumor after the diagnosis of autism, and was referred abroad for treatment. All the 18 children belong to high socio-economic strata, although this maybe a selection bias due to the nature of the private clinic. One of the major challenges is the lack of awareness of the population and caretakers about autism. In one instance, the care-taker has been to various faith-healers in vain, while in another instance, she has been divorced for not being able to raise an obedient child [38].

Similarly, in one of the centre which caters for educating children with developmental disorders and mental retardation, out of the 28 children ranging 4-18 years, 14 had a clinical diagnosis of autism confirmed by experts from various reliable institutions using the various diagnostic checklists, while others were cerebral palsy (2), Down's syndrome (4), Pervasive developmental Disorders Not Otherwise Specified

(PDDNOS- 2), mental retardation (4) and so on. Of the 14 children with ASD there was a co-morbid condition (deafness) in one of them and all of these belonged to high socio-economic strata. The trustee of the centre mentioned "Today as many as 1 out of every 166 children will be born autistic. Accurate diagnosis and early intervention can provide for building an effective and appropriate education and treatment program". In resource-constrained countries, the facilities to treat children with autism are poor and very expensive. Children with autism and other disabling conditions are discriminated and considered to be useless. These groups of children are deprived of any treatment or therapy and end up in institutions enduring terrible suffering for the rest of their lives. Though it is very difficult to find specific data on the number of children affected by autism in Africa, the number of diagnoses is rising, and is now higher than it has ever been before. Only recently in the "Lancet" the U.K. reported approximately 2% of boys have ASD, and that is truly catastrophic. Third world nations in Africa or in Asia don't have that kind of collecting power, to go out into the community and really get good statistics for us, and the little bit that we do know would indicate that it's every bit as bad if not worse than in those nations" [39].

A centre and organization which is working diligently to connect autism in Tanzania with the rest of the world is working very hard to empower the various centers, about 10-15 in and around Northern Tanzania. This organization conducts workshops and onsite training as well as provides services of teachers specialized in Autism in one of the main centers with which it collaborates. Four workshops are conducted annually , there is a sponsored outreach program to the rural villages and have developed simple tools for primary care-takers and teachers as well as for public so as to raise awareness among the community [40].

At the Muhimbili National Hospital (a tertiary care centre in the country) interviews with psychologists and psychiatrists revealed that they had seen many children with suspicion of autism, but were not fully engaged in their follow-up or in their therapy at any appreciable level. An attempt at having a database and following these children closely is being done but severe lack of human resources in the department including speech and behavioral therapists make it even more difficult with huge burden on the existing staff to handle psychiatry patients, those with substance abuse and even those with organic disorders such as epilepsy. A research to determine the phenotype as well as genetic mapping as proposed by a PhD student revealed that there are several centers for special needs and these children are clustered together with those of mentally challenged and cerebral palsy [41].

Data from the Directorate of Mental Health at the Ministry of Health and Social Welfare indicate that Childhood Mental health is not yet given much importance and seeking care for children with mental disabilities is still not much sought. In the available information, the data indicated MR, CP and other disorders. In the other disorders, Autism featured as one of the conditions, thus indicating that we maybe actually missing many other children in the community and/or mislabeling several others [42].

Information from the Ministry of Education and Vocational Training showed that there are 8 public schools registered for educating children with autism and there are further 15-20 privately owned Faith Based Organizations and unregistered centers which cater for these children. Some of the good schools and resource centers have relatively and understandably high fees whereby an average Tanzanian family may not be able to afford. Some of these schools have visiting scholars and teachers and volunteers who come for short periods of time to train and volunteer during the summer holidays in the care of these children. This highly appreciated activity is however not sustained due to various reasons and due to lack of a sustainable long-term program in the country. The total number of children in the 8 public schools is 105 (male 75 and female 30). One of the public run centers at Patandi, Arumeru district, Arusha region has a teachers' training centre for special education needs at certificate and diploma levels. There is also a degree course offered at St. Sebastian College in Lushoto district, Tanga region. In the efforts to improve diagnosis and raise awareness the MEVT is planning to establish Education Support Resource and Assessment Centers (ESRAC) in all the Districts in the country, which will start as a national base from the BRAIL press at Uhuru Primary School in Dar es Salaam subject to availability of funds. One of the challenges mentioned by all the stakeholders referred above is that there is a great need to have more qualified persons in Special Needs Education and that the availability of experts to provide a fairly accurate diagnosis and its

ramifications. One senior official is quoted "Autism is poorly recognized, and clumped together with other children who have cerebral palsy, mentally challenged or other disorders" [43].

Interviews with 4 renowned Pediatricians in Dar-es-Salaam, two each from private and public centers, echoed the same feelings that this condition is probably increasing, but is still unrecognized and facilities or centers to cater for them are lacking.[38]

Semi-quantitative results from the school/facilities

Fifteen different centers in Dar-es-Salaam, Moshi and Arusha were contacted by email, phone or in person and general information sought for the following questions with their results below:-

Table 1: Information derived from various schools which handle autism

1. What is the prevalence of autism in Tanzania? In your centre?	The prevalence is high, various centers reported variable numbers. therefore total number reported were 437 (65, 1, 10, 200, 0, 10, 28, 35, 20, 17, 15, 8, 32, 6)
2. What are the challenges in diagnosis of Autism in Tanzania?	Lack of awareness of primary health care workers, care takers, teachers and the community.
3. What are the possible resources available in Tanzania?	Several public and private centers exist but are not well geared to cater for the needs of autistic children. List of schools available in table 2.
4. Is there any training you attend or conduct for the parents, teachers, health workers and caretakers?	The responses were none in most centers except 3. Of which in one there is one workshop annually, in other 2 the training, workshop and seminars were more than 4, with experts from inside and outside the country and both were private.
5. How can one access your centre?	Information by word of mouth. Access on website only three centers all of which are private.
6. What is the cost of training a Child with autism in your centre?	Range from 50,000-450,000 TSh. per month excluding the economic burden of travel to and fro.
7. Do you have a specific training guideline or curriculum for these children?	Only 3 centers had a training module or guideline. One used the UK- Early childhood learning curriculum. Others did not have a specific module. Many did not have any organized training schedule.
8. What are the challenges in the management of Autism in Tanzania?	Lack of Awareness in mental health filed, poor involvement of Government, lack of teachers, community awareness and financial constraints for the centers as well as the parents/caretakers

NB: The list of the centers where this information was derived is listed in table 2 below, except for Mbugani Primary School-Geita, Kiwanja Cha Ndege Morogoro where interviews were not conducted.

Table 2: List of schools which handle children with Autism

A. Ministry of Education and Vocational Training (MEVT) registered schools
Patandi Primary School – Arusha
Leganga Primary School – Arusha
Uhuru Primary School – Arusha
Kaloleni Primary School – Arusha
Msimbazi Mseto – Dar es Salaam
Mbuyuni Primary School – Dar-es-Salaam
Mbugani Primary School – Geita
Uhuru Kiwanja Cha Ndege – Morogoro
B. Not registered yet by MEVT
Arusha region
Sibuiso Foundation centre
Naurei Primary School
Moshi Region
Shauri Moyo
Shirima Tunda
Korongola Primary
Gabriella Rehabilitation centre
Dar es Salaam
Al-Muntazir Autistic centre
Star Rise Child Centre

NB: i. About 155 schools for mentally challenged children are registered with MEVT. Possible has many children with autism, but unrecognized. ii. There may be several other schools in Tanzania, but the author has limited to these, and therefore the list is not exhaustive. iii. The detailed contact of school/resource persons in these centre is available with the author and may be contacted for the same

Discussion

It is evident that there is a serious deficiency in the awareness, facilities and human resources for children with autism in Tanzania. There have been good attempts by parents to come together and form an association of parents with children with autism and this needs support and encouragement.

There is a serious lack of human resources and ongoing capacity building of caretakers among the schools surveyed and authorities of the schools interviewed.

In view of the scarce report, it is worthwhile quoting Tomilson and Swartz who in 2003 found that out of a total of 764 journals about infant health surveyed 78% were from North America and 16% from Europe, only 4% were found to come from the rest of the world. However, 90% of the world's children are born in countries which are termed "low income" or developing. It is clear that there is an imbalance of knowledge about infancy worldwide: most infants are born in poor countries, and most of what we know about infant mental health comes from wealthier countries [44]. In terms of mental health services for children over the world; there is only one psychiatrist for every hundred thousand population in South East Asia, and less than one psychiatrist per million populations in sub-Saharan Africa. Traditional healers continue to hold the keys to healthcare until modern services become more accessible. Steps to improving service provision in these countries includes: focus should be on healthy development of children, work to demystify mental illness and gain support of elders in the community (senior professionals, administrators, policy makers and the like) [45].

Some of the schools visited had no facilities for any meaningful training with very limited resources and staff. Conditions in other schools were relatively better, but highly donor dependent and individual efforts by teachers and parents. A National Association of Parents with Autism in Tanzania (NAPAT) has been recently formed and these parents are self-motivated to improve the condition of their children and are based at the Msimbazi Mseto Primary School, Dar-es-Salaam [38]. From a National perspective, there is still much left to be desired even for mainstream schooling, let alone the attention on special needs. A review of special needs education by Hippensteel draw attention on the situation of education in relation to special need in Tanzania [46].

The average cost of educating a student with disabilities is 2.3 times more than the cost of educating a student without disabilities, so the attitudes of the Government and the general public tend to favor spending the already limited funds on general education. The majority of special schools and programs for students with special needs in Tanzania are supported by external non-governmental organizations and thus "achieving Western models of inclusion remains unrealistic" [47].

In a newspaper article, it was reported that "In many areas vulnerable children have been isolated by their societies as they lack crucial social services like access to better education, health care and psychosocial support. It is time that the Government shoud do something about the needy children" as said by Lillian Badi of the World Education Program [48].

Conclusion

Autism is a recognized developmental disorder in Tanzania. Research on the prevalence, epidemiology and determinants is seriously lacking. Awareness at various levels and facilities for addressing the needs of such children is also dismal. There is need to raise awareness at all levels, advocacy and improve the situation for these children in Tanzania. Studies which will include knowledge, attitude, practices, phenotyping, possible therapies, determinants, associations with co-morbidities, early diagnosis are all required as a matter of priority for the benefit of the children with ASD and their families.

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