



## Autism Spectrum Disorders (ASD) in Kenya: The Diagnostic Experience of Parents of Persons with Autism in Garissa County, and its Policy Implications.

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**ABSTRACT:** Autism spectrum disorder is a diagnosis that includes significant social communication deficits/delays along with restricted patterns of interests and behaviors. While protocols for screening, diagnosis and treatment has increased in recent years in high-income countries (e.g., the United States, and the European Union countries), there is little to no available research in Africa.

In an effort to understand the gap in screening, diagnosis and treatment in Kenya, a country in East Africa. The County Government of Garissa, and Autism Light, Boston/Nairobi commissioned this study in an effort to understand the experience of parents, and other care givers of persons with autism during the diagnostic and treatment process as a whole.

There were 170 participants drawn from Balambala, Daadab, Fafi, Garissa, Lagdera, Masalania and Modogashe sub-counties of Garissa County. Seven major themes emerged as experiences that parents, and care givers encounter as they go about in the diagnosis, and treatment of autism in Kenya. These major themes were; Parents reported developmental concerns as early as 18 months but they were ignored, Dissatisfaction with autism related professionals, the lack of a coherent diagnostic pathway, Incorrect diagnosis, Uncertainty, confusion and despair about the problem and prognosis, Social stigma, Isolation and suffering for mothers and the lack of support services post-diagnosis.

**Keywords:** Autism, diagnosis, experience, treatment, Garissa, Kenya

Received 25Feb., 2020; Accepted 05 Mar., 2020 © The author(s) 2020.

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### I. INTRODUCTION

Autism Spectrum Disorder (ASD) is a disorder of neurobiological origin characterized by impairments in social interaction, communication and repetitive and stereotyped interests or behavior (Fombonne, 2003). Autism typically appears before the age of three years, but varies in the severity of symptoms, age of onset, and the presence of various features, such as mental disability and specific language delays (Center for Disease Control and Prevention, 2012; Faras, Al Ateeqi & Tidmarsh, 2010; National Research Council, 2001). In order for a child to receive an autism diagnosis, specific criteria must be met. Behavioral symptoms are common, and they range from self-injurious behaviors or hyperactivity, to severe tantrums. People with autism may experience uneven development of cognitive skills, eating difficulties, and sleep disorders (American Psychiatric Association, 2013; World Health Organization, 1993). Seizure disorders are also present in approximately 25% of children with the diagnosis (Canitano, 2007).

Autism is one of the fastest-growing developmental disorders in the world. It is more common than childhood cancer, diabetes and AIDS combined (Centers for Disease Control and Prevention, 2009). The United Nations and the World Health Organization has identified autism as a public health concern (United Nations General Assembly, 2007; World Health Organization, 2013).

While the prevalence of autism has increased in recent years in high-income countries (e.g., the United States, and many European Union countries), little is known in Africa about the screening, diagnosis, and effectiveness of autism interventions (Elsabbagh, Divan, Koh, Kim, et al., 2012).

About 1 in 59 children have been identified with autism in the United States according to estimates from the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) (Baio et al., 2018). The same finding was reported earlier in a 2016 National Survey of Children's

Health (Xu, Strathearn, et al., 2018). While studies in Asia, Europe, and North America have identified individuals with autism with an average prevalence of between 1% and 2% (Baio et al., 2018). However, available research, though minimal, presents a similar presentation of autism in Africa as that of high-income countries (Bakare & Munir, 2011).

Receiving a diagnosis of an autism has a huge impact on an individual and their family (Howlin & Moore, 1997). Obtaining a diagnosis is the first step to accessing services and supports for both the person with autism and their family (Mansell & Morris, 2004; Midence & O'Neill, 1999). A positive diagnostic experience is associated with greater levels of acceptance, lower levels of stress, and more effective coping strategies (Woolley, Stein, Forrest & Baum, 1989), while delays in receiving a diagnosis can lead to low levels of parental satisfaction (Howlin & Moore, 1997) and can hinder the implementation of effective supports or intervention strategies (Webb, Jones, Kelly & Dawson, 2014). Furthermore, parents who experience a long diagnostic delay may lose confidence in the healthcare professionals involved, and are more likely to seek alternative treatments for their child that have poor empirical support (Harrington, Patrick, Edwards & Brand, 2006).

This study sought to understand the experiences and opinions of parents and caregivers during the diagnostic process of autism in Garissa, Kenya. The questions for this study were embedded in a larger study conducted by the author for the Garissa County government to inform its initiative to develop autism treatment policies. Findings from the larger study are sequenced in other papers by the same author.

## **II. METHODOLOGY**

### **Setting and Participants**

There were 170 participants in the study. The participants were drawn from the 7 sub-counties in the larger Garissa County; Balambala, Daadab, Fafi, Garissa, Lagdera, Masalania and Modogashe sub-counties. The pool of participants included parents of children with autism, medical personnel at Daadab sub-county hospital, special needs services teachers, and other services providers in Garissa County. Purposeful selection, also referred to as purposeful sampling (Creswell, 2007; Maxwell, 2005; Merriam, 2009), was employed to secure participants for this study. In this sampling strategy, people and settings were intentionally chosen to provide information that could not be collected as well from other selections (Maxwell, 2005). According to Creswell (2007), this strategy is useful for assuring a quality sample; additionally, the sample chosen here was better placed to provide the “rich details and insights into participants’ experiences as they interact with their world” (Merriam, 2002).

### **Measurement**

Data were collected from August 6<sup>th</sup>, 2019 to August 26<sup>th</sup>, 2019. The interviews and questionnaires were conducted in English, Kiswahili, and the native languages of the area depending on the participant preference. Interviews were comprised of both semi-structured and open-ended questions, and were performed at the participant’s home or place of work. All participants gave their informed consent prior to their participation.

Since there are no validated screening or diagnostic measures for autism in Kenya, (Gona et al., 2015), the participants’ assertion that their child met the diagnostic criteria for autism provided by a medical facility personnel was taken as presumptive diagnosis of autism.

Data in the form of transcribed interviews (all translated to English for coding), field notes, and important documents were analyzed by hand using a general inductive approach (Merriam, 2009). In the inductive analysis of data, the researcher begins with the preparation of raw data files. During this process, also known as data cleaning, the researcher formats the raw data in a common format (for example, font size, margins, questions or interviewer comments are highlighted). The researcher then makes a back-up of each raw data file at this stage. This stage is then followed by the close reading of the data text in detail until the researcher is conversant with its content and gains an understanding of the events and themes emergent in the text. Once the evaluator identifies and defines the categories or themes, coding can begin (Thomas, 2006). Given that this study did not have a large amount of data, manual coding was used for data analysis (Creswell, 2007; Hatch, 2002; Merriam, 2009; Saldaña, 2009; Thomas, 2006). Table 1 illustrates the iterative process of data analysis employed.

To derive themes, obtain concepts, or make interpretive models from the data, a general inductive analysis (Merriam, 2009) was employed. Thomas (2006) refers to this design as a “general inductive approach” (p. 237), while Merriam (2002) refers to this form of research as a basic interpretive study (p. 4). According to Thomas (2006), “the general inductive approach [is] easy to use, does not require an in-depth understanding of an expert approach, and produces findings that justifiably address evaluation objectives and questions...[this

approach] provides a suitable and efficient way of analyzing qualitative data for these purposes” (p. 246). Thus, it was an ideal approach for this study. Furthermore, Merriam (2002) notes that an interpretive qualitative approach is also appropriate when researchers are interested in knowing how people interact with and experience their social worlds and the meaning these interactions and experiences have for them.

**Table 1.** Inductive Analysis Coding Process

Initial closely read the raw transcripts multiple times until I am familiar with its contents	Break the raw transcribed data into discrete individual parts or segments/units	Assign codes to each individual segment/unit; re-examined to stabilize codes to create categories and codebook	Re-examine coded categories to reduce overlapping and to synthesize categories	Produce themes that are most important and beneficial to study
Multiple pages of transcribed data from interviews	Constant Open Coding	Comparison of Numerous categories +20	Axial Coding	5 - 6 themes
	Multiple of segments/units		15 – 20 categories	

Note. This table was adapted from Adapted from Creswell, 2002, Figure 9.4, p. 266 and illustrates the Inductive Analysis Coding Process used in this study.

### III. RESULTS

Seven major themes emerged as challenges that parents and care givers of person with autism experience as they go about in the diagnosis, and treatment of autism in Garissa, Kenya. These themes were:

1. Parents reported developmental concerns as early as 18 months: Results of the study indicated that as early as one and a half years, parents of children who later received the diagnosis of autism noted concerns with their child’s development. These early concerns were related to impairments in social and/or emotional delays (e.g., many parents mentioned their child’s lack of interest in others), the presence of restricted or atypical interests or routines, the present of behavioral challenges (e.g., severe tantrums) and delays in physical and/or motor milestones as compared to other children. Some of the parent participants discussed these concerns with their medical providers during regular screening but their concerns were not adequately addressed. The responses received were mixed; for example, some were told their children would outgrow those concerns, while others were completely ignored. For those who were provided with some information it was inadequate and unsatisfactory.

2. Dissatisfaction with the medical and/or associated professionals when it came to autism: When parents raised concerns to their medical personnel, majority of parent participants reported that their medical professional did not respond appropriately and that their concerns were not taken seriously. For example, some parents felt their medical professionals were unprepared to conduct any screening or assessments. Others reported that their medical professionals addressed them like they (parents) did not know what they were talking about. More than 10 parents reported that they had to make more than three visits to their medical professionals before they could be convinced there was something wrong with their child. These additional three or more visits took between four to five months. For a parent with concerns, this was a long time. There was not a specific autism diagnosing profession identified in the study. Parents raised their concerns with available medical personnel from nurses, Occupational Therapists, Physical Therapists, Speech and Language pathologists, Physician assistants and Pediatricians.

3. The lack of a coherent diagnostic pathway: Parents expressed that the diagnostic process was incoherent. They reported that the diagnostic process typically involved daunting visits with multiple professionals, and involved waiting for lengthy periods between 3-12 months before obtaining an appointment with a professional who could make the autism diagnosis. It was not uncommon for parents to wait for 3 months to get an MRI, another 3 months to get a hearing test, and another 6 months to get a developmental pediatrician to look at the results. Most of these diagnostic professionals were located hundreds of miles away from parent participants, which created resource burdens for many families.

4. Incorrect diagnosis: The majority of parent participants reported receiving an incorrect diagnosis for their child (e.g., deafness, fragile X syndrome, speech impairments, and psychosis among others). One parent, who happened to be a medical doctor reported, “It was a nightmare.” Despite his medical background and training, he struggled to obtain a conclusive diagnosis for his son.

5. Uncertainty, confusion and despair about the problem and prognosis: The process from the moment a parent noticed atypical behaviors, to reporting their concerns to medical professionals was reported to be grueling. Additionally, some parents reported feeling uncertain, confused, anxious, stressed and sad. While the majority of parent participants reported feeling relieved, angry, and shocked after receiving the diagnosis.

6. Social stigma, isolation, and suffering for mothers: after the diagnosis and as symptoms for autism progresses, this study found that many parents retreat and suffer in silence. Parents reported the reason being conflicting claims on causes of autism in addition to the lack of awareness for community members. Children with autism often exhibit challenging behaviors such as shouting, head banging, or self-injury. There is a general lack of understanding in the community regarding autism and its' related symptoms. Mothers report their children being referred to as *mwenda wazimu* [that is the Kiswahili term for crazy person] when they displayed such behaviors in the community.

Furthermore, there were reports of fathers leaving or abandoning their children when learning that their child had autism. Parents reported that this issue was related to family pride. It was also reported that fathers in this community often see sons as the bearer of the family line, and daughters likely to bring wealth in bride price when they get married. Of course, such isolation and rejection puts a strain on families and especially on mothers serve as the primary caretakers for children in Kenya.

7. Lack of support post-diagnosis: Parents reported that having access to support services post-diagnosis was very important. Unfortunately, educational and therapeutic support services for individuals with autism in Kenya is highly limited. Parents reported that there are currently no hospitals in Kenya offering coherent interventions for autism. In almost every hospital and/or mental health facility these parents visited to get care, primary care doctors and mental health providers were reported as unprepared to treat children. Garissa county government, like both the national government and other county government, does not have a solid position on diagnosis, treatment, and management of autism. Additionally, they lack mental health service options that would be beneficial to persons with autism.

#### **IV. DISCUSSION**

The findings of this study provide insight regarding the experience and challenges of parents and other caregivers of persons with autism in Garissa, a northern region of Kenya. Its findings could provide variable pointers to parties responsible for autism treatment in Kenya and serve as a guide for important policy makers.

It is clear from the findings that there are no coherent guidelines on diagnosis, treatment and management of autism, or delivery of any allayment of mental and medical health service that would be beneficial to persons with autism in Kenya. There are currently no hospitals in Kenya offering evidence-based interventions for autism. This study established that the center at Kenyatta National hospital, which is one of the largest referral centers in Kenya, is ill-equipped and lacks credentialed professionals.

In almost every hospital and mental health facility in Kenya that the parents in this study visited, participants reported that primary care doctors and mental health providers were often unprepared to treat this population. Individuals with autism who may engage in challenging behaviors are often turned away from hospitals or other mental health facilities.

Due to the lack of expert opinion on autism, this study confirmed reports from previous literature (i.e., Bakare & Munir, 2011) regarding the use of spiritual or superstitious explanations. For example, families, and service providers of this population may turn to pseudoscientific treatments that often include the involvement of religious and traditional healers, "medical tourism packages," and other non-evident therapies some of which are harmful.

Additionally in the absence of a national policy on autism in Kenya, there is not a single medical insurance policy, not even the National Hospital Insurance Fund (NHIF) which is a largely tax-funded medical insurance that cover services for autism even when parents want to seek out services. Neither of the other emerging user-funded insurance schemes in Kenya cover the services either. The full onus of treatment falls on the parents, even for those in paid employment. This is an expensive enterprise, when you factor in both medical and associated nonmedical costs (Ganz, 2007).

Put together the aforementioned factors coupled with the uncertainty and emotional toil expressed by parents of persons with autism, the isolation and associated social stigma, and having a child with autism becomes like a parent put it "a living nightmare."

Autism intervention specialists both in Kenya and abroad, the Kenya government's respective ministries of education, and health and other stakeholders have a responsibility to raise awareness, develop screening tools, and increase service capacity for persons with autism in Kenya. This author wishes to make the following recommendations on autism treatment in Kenya:

**Development of a National Policy on Autism.** There needs to be a national policy on autism. The Kenya government, through the ministries of health, and the department of Human Services, must formulate and/or endorse policy initiatives that will raise awareness, screening, treatment, training and service for autism in Kenya.

**Capacity Building.** The Kenya government needs to investment in workforce development to increase the number of trained professionals (i.e., nurses, pediatric and specialty physicians, psychiatrists, Social workers, psychologist, etc.) who can assess, diagnose and treat autism across the country.

Additionally, both public and private universities and colleges ought to adopt training curriculums for autism intervention. Such programs could also foster research, create public awareness and professional attention on autism. They could also provide accurate information to parents and other caregivers of children with autism in Kenya on what early signs to look for, where to seek help, and what treatment could be more beneficial for the child to achieve greater outcomes from an early age.

**Monitoring system.** Autism is on the increase, yet even the Ministry of Health does not have epidemiological data in Kenya. There out to be a strategic surveillance/ monitoring and report system that will report on the current numbers of autism in the country, and on the future state of autism. This monitoring system should also assess and quantify needs of children and youth with autism and other comorbid mental challenges so that solutions can be brought forth.

**Early Screening and Diagnosis.** For over a decade now, several developed countries (e.g., the United States, Canada and the United Kingdom) have advocated for early and regular screening for autism (American Academy of Pediatrics Committee on Children with Disabilities, 2001; Filipek et al., 1999; Filipek et al., 2000). As of 2007 in the United States, many pediatricians provide surveillance at every well-child visit and an autism specific screening for all children at 18 and 24 months of age (Arunyanart et al., 2012; Johnson & Myers, 2007). When identified early and evidence-based interventions put in place, for example, behavioral programs that are implemented as early as possible and in an intensive manner [often referred as early intensive behavioral interventions (EIBI)], persons with autism show cognitive, adaptive, and social-communicative gains (Reinchow et al., 2012; Wallace & Rogers, 2011).

Emerging research is confirming a critical window of time for certain children, dubbed the “optimal outcome” window, meaning that when identified early enough, a subset of children with autism outgrow their diagnoses (Turner & Stone, 2007; Wiggins et al., 2012; Zwaigenbaum, et al., 2015). Research suggests that those people who lost their autism diagnoses were diagnosed younger, before 31 months of age (Turner & Stone, 2007; Wiggins et al., 2012).

Early screening, diagnosis and treatment also presents with sizeable financial incentive. A study by Jacobson, et al. (1998) in the United States estimates that the savings for children who receive intensive early intervention could be in the range of \$1 million to \$2 million taxpayer dollars per individual over their lifespan. This is such a substantial saving, and a reason why policy makers in Kenya should provide intervention now and save on future costs of individuals who do not get interventions for both the families of these children, and the tax payers who will foot the ever increasing the bill over these person’s lifetime (Ganz, 2007).

**Family support.** Families are suffering. Both the national government and county governments ought to facilitate centers at county headquarters or at the Ministries of health to assist the families of persons with autism access information, training, emotional support, resources and supports around advocacy, assessments and treatment of their children with autism. Persons with autism and their families, deserve respite for their challenging experience. This study highlights some first steps.

#### **ACKNOWLEDGMENT**

The author would like to thank Autism Lights Inc., Boston, USA and Nairobi, Kenya. Ms. Mary Kimani, Honorable Wamaratu Chege, the Director of Policy and Special Projects at Autism Lights, Waberi MCA Hussein Dagane, the entire Garissa County Assembly and Jessi Heller, the most able clinical assistant for their assistance in the recruitment process and other stages of the study. Most importantly the author would like to express appreciation to all participants who took part in the study.

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