



Research Paper

Autism Spectrum Disorders (ASD) in Kenya: Barriers Encountered in Diagnosis, Treatment and Management.

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ABSTRACT: Autism is one of five disorders that fall under the umbrella of Pervasive Developmental Disorders (PDD). 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 close the knowledge gap in Kenya, a country in East Africa, this study sought to understand the difficulties that parents, care givers and special needs providers encounter as they experience the diagnosis, and treatment of autism in Kenya. 39 parents, caregivers and 11 special needs providers were participants in this study.

Eight major themes emerged as difficulties that parents, care givers and special needs providers encounter as they go about in the diagnosis, and treatment of autism in Kenya. These major themes were; the lack of awareness, limited research, cultural factors, the lack of treatment protocols, the lack of institutional/government support and the out-of-reach financial price-tag for treatment of children with autism, social stigma, isolation and broken families.

Keywords: Autism, diagnosis, difficulties, treatment, Kenya

I. INTRODUCTION

Autism is one of five disorders that fall under the umbrella of Pervasive Developmental Disorders (PDD). The five sub-categories of PDD are Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder (CDD), Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) and Rett's Disorder (Diagnostic and Statistical Manual of Mental Disorders, 2000). These PDD disorders are all characterized by severe and pervasive deficits in several areas of development including social interactions and communication skills, as well as a presence of unique behaviors that are not typical in a normal child's development. Some of the odd behaviors exhibited by children with autism are repeated body movements including flapping their hands in the air, or rocking back and forth. Children with autism may also develop unusual attachments to objects and resist change in routines. Other than these unique behaviors and the lack of normal language development, children with autism do not manifest any distinct characteristics from typical developing children (Powers, 1989).

Autism 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 retardation and specific language delay (Autism Society of America, n.d.; Center for Disease Control and Prevention, 2012; National Research Council, 2001). In order for a child to receive a diagnosis of autism, specific criteria must be met; but overall, a significant impairment in communication and social interaction must be present, as well as restricted repertoire of activities and interests. Mental retardation is commonly present, as is uneven development of cognitive skills. Behavioral symptoms are common, and they range from self-injurious behaviors to hyperactivity to severe temper tantrums. Some eating difficulties and sleep disorders are also commonly reported. Seizure disorders are also present in approximately 25% of children with the diagnosis (Ginker, 2007).

While prevalence of autism spectrum disorders has increased in recent years in high-income countries (e.g., the United States, and the European Union countries), little is known in Africa about the screening, diagnosis and interventions of autism, and details of clinical presentation remain indescribable for this part of the world (Elsabbagh, Divan, Koh, Kim, et al., 2012). However, available research, though minimal, presents a similar presentation of autism in Africa as that of high-income countries (Bakare & Munir, 2011).

II. METHODOLOGY

In an effort to close the knowledge gap in Kenya, a country in East Africa, this study sought to understand the difficulties that parents, care givers and special needs providers encounter as they experience the diagnosis, and treatment of autism in Kenya.

III. RESEARCH QUESTIONS AND HYOTHESIS

Given the global rising prevalence of autism, and the lack of literature on the challenges, perceptions and treatments in Africa, and the developing countries, this study sought to understand the difficulties that parents, care givers and special needs providers encounter as they go about in the diagnosis, and treatment of autism in Kenya. Two broad questions guided this study:

- (a) What are some of the barriers encountered by parents and care givers of children with autism prior to diagnosis, during treatment and throughout the lifespan?
- (b) What are some of the challenges that providers of autism related services face in the diagnosis, treatment and management of autism?

Towards achieving that goal, the researcher travelled to Kenya where in-depth interviews, and focus groups were utilized in data collection. There were 50 participants for this study. These participants were 39 parents of children with a presumptive diagnosis of autism and 11 professionals who included special needs services teachers, clinicians, social workers, occupational therapists, speech therapists, and religious and lay leaders who work with children with autism. Interviews were a combination of semi-structured and open-ended questions. The interviews were conducted in English, Kiswahili and dialects of Kenya. They were then translated to English for transcription. Data, in the form of transcribed interviews, and field notes, were analyzed using a general inductive approach to create categories and themes. The sample population was drawn from within Kenya's capital, Nairobi, and its outskirt counties including the towns on Kikuyu, Rungiri and Gitaru all in central Kenya. Participants who were interviewed were representative of various cultures and socioeconomic groups.

IV. RESEARCH DESIGN AND TRADITION

The amount of information that is already known about a topic is a major determinant of the study methodology applied, when little is known about the research topic; exploratory search is called for. In exploratory research, as Lincoln and Guba (1985) suggest, social phenomena are investigated with minimal a priori expectations in order to develop explanations of these phenomena. Exploratory research, as the name states, intends merely to explore the research questions and does not intend to offer final and conclusive solutions to existing problems.

Because autism is a relatively new field in Kenya, and there is little to no research on interventions (Elsabbagh, Divan, Koh, Kim, et al., 2012), this study employed an exploratory research design and utilized a general inductive analysis approach (Thomas, 2006) to analyze the findings.

In-depth, semi-structured and open-ended interviews, and focus groups were employed as data collection methods. The researcher used an interview guide for the interviews and focus group discussions. The use of the interview guide indicated that there was some structure to the interviews, even though they were treated as conversations during which the interviewer drew out detailed information and comments from the respondents. "One way to provide more structure than in the completely unstructured, informal conversational interview, while maintaining a relatively high degree of flexibility, is to use the interview guide strategy" (Patton as cited in Rubin & Babbie, 2001, p. 407). More structure simplifies the researcher's task of organizing and analyzing interview data. It also helps readers of the findings of a study judge the quality of the interviewing methods and instruments used (Johnson, Dunlap, & Benoit, 2010).

For this study, the sample was a pool of participants who included parents of children with autism, special needs services teachers, and other service providers in Kenya. This sample was chosen because it is better placed to provide the "rich details and insights into participants' experiences as they interact with their world" (Merriam, 2002). The interviews and questionnaires were conducted in English, Kiswahili and dialects of Kenya. They were then translated to English for transcription. Data in the form of transcribed interviews, and field notes were analyzed manually using a general inductive approach for analyzing qualitative data to create categories and themes (Merriam, 2009). Manual coding was used because this study did not have a large amount of data.

To derive themes, obtain concepts or make interpretive models from the data from this study, a general inductive analysis (Merriam, 2009) as 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). It was, thus, 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.

V. SITE AND PARTICIPANTS

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 are intentionally chosen to provide information that cannot be collected as well from other selections (Maxwell, 2005). According to Creswell (2007), this strategy is useful for assuring a quality sample. The interviewed participants were parents of children with a presumptive diagnosis of autism and professionals who included special needs services teachers, clinicians, social workers, occupational therapists, speech therapists, and religious and lay leaders who work with children with autism.

A purposive- convenience sampling procedure was considered appropriate for several reasons. First, the study was targeting families with a presumptive diagnosis of autism and professionals who work with children who had a diagnosis of autism in Kenya. Given that this is not a commonly recognized condition and the diagnosis is not routinely made (Gona, Newton, Rimba, et al., 2015), a random selection would not have provided the required sample size. Parents of children with autism were recruited via a series of seminars at a conference on autism conducted in early 2016 in Nairobi, Kenya. Professionals and special needs teachers were recruited from the same conference and from special units and schools that serve children with autism in some form. Since there is no validated screening and diagnostic measure for autism in Kenya, (Gona, Newton, Rimba, et al., 2015), a presumptive diagnosis was used for the sample. There is a likelihood that different methods of autism diagnosis had been used to assess the children in the sample.

VI. DATA COLLECTION METHODS

As part of the interview protocol for this study, the researcher took approximately 20 minutes before each interview, and before the beginning of the focus groups to explain step by step the informed consent form. The informed consent form explained the details of the study. Participants outside the focus groups were interviewed individually; interviews were in-depth, semi-structured and open-ended. Interviews were conducted at a time and place that was suitable and comfortable for each participant. Interviews were audio-recorded digitally and transcribed immediately after each interview by the researcher.

Each interview began with the researcher ensuring the comfort level of the participant by asking questions about the participants and how they were doing. The interview questions were carefully developed based on Butin’s (2010) and Merriam’s (2009) guides to qualitative interviewing. Participants were asked several impartially phrased, open-ended interview questions, each one designed to approach its related research question from a different perspective and stimulate deep, elaborative responses as opposed to “yes” or “no” answers (Butin, 2010). Additional questions and prompts were used as appropriate, depending on participant responses.

During the interviews, the researcher took extensive notes. This process was carefully and thoughtfully explained to the participants at the onset of the interview. Notes taken during interviews recorded observable behaviors not communicable via transcriptions (e.g., facial expressions, gestures, visible emotions). Reflective memos were also written after each interview to document the researcher’s overall thoughts and impressions; these memos included an audit trail (Lincoln & Guba, 1985). An audit trail is a journal or series of memos noting the research process as it is happening; such audit trails include reflections, questions, and conclusions the researcher makes in response to ideas or issues in the course of the study (Merriam, 2009). The eventual goal of these interview sessions was to have “meaningful and ‘deep’ responses that take the shape of narratives... [and] data ‘thick’ enough to scrutinize” (Butin, 2010, p. 97).

The participants were also informed that they have a right to decide to stop and continue with the interview at a later date, discontinue at a later date or to discontinue the process altogether. The researcher facilitated the focus groups and an interview schedule was developed in the same manner as that for the personal interview questions.

The concept of interpretivism (Lincoln & Guba, 1985) played a significant role in this naturalistic qualitative study. According to Golafshani (2003), “An open-ended perspective in interpretivism adheres with the notion of data triangulation by allowing participants in a research study to assist the researcher in the research question as well as with the data collection” (p. 604). This study engagement of personal interviews and focus groups lead to more valid, reliable and diverse construction of realities. It was anticipated that by

using in-depth, semi-structured and open-ended questions, the researcher would enable participants to go beyond the questions posed in the semi-structured interviews and all their contributions add to the depth of data gained.

VII. DATA STORAGE

A flash drive containing recordings of interviews and focus groups audio recording and raw transcribed data was stored in a lockable file cabinet until transcripts were verified for accuracy; data was also stored on a password-protected computer that was only accessible by the researcher.

VIII. DATA ANALYSIS

Data, in the form of transcribed interviews, field notes, and important documents was analyzed by hand using a general inductive approach for analyzing qualitative data (Merriam, 2009). The result of the analysis was the development of categories based on themes that the researcher sought to identify as the most significant based on the researcher's interpretation (Merriam, 2002).

According to Thomas (2006), the procedure for inductive analysis of data 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 often 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. It is worth noting that in inductive coding, categories are usually created from actual phrases or meanings in specific text segments. Several procedures for creating categories may be used, e.g., manual or qualitative analysis software can be used to speed up the coding process when there are large amounts of text data (Durkin, 1997).

Because this study did not have a large amount of data, manual coding was used for data analysis. Data analysis is a process of examining, analyzing, and interpreting data in order to draw meaning, increase understanding, and develop knowledge (Strauss & Corbin, 1998). Data analysis is an iterative procedure in qualitative research (Creswell, 2007; Hatch, 2002; Merriam, 2009; Saldaña, 2009; Thomas, 2006). Using the general inductive analysis approach (Merriam, 2009; Thomas, 2006; Saldaña, 2009; Strauss & Corbin, 1998), the researcher engages into the details of the data to look for patterns, develop codes to assign to categories, and places emphasis on the outcome of themes identified as most significant based on the researcher's interpretations and their alignment with the research questions and conceptual framework (Merriam, 2009; Thomas, 2006; Saldaña, 2009). Table 1 illustrates the iterative process of data analysis employed for this study.

Table 1 Inductive Analysis Coding Process

Initial closely read the raw transcripts multiple times until I am familiar with its contents Multiple pages of transcribed data from interviews	Break the raw transcribed data into discrete individual parts or segments/units Constant Open Coding Multiple of segments/units	Assign codes to each individual segment/unit; re-examined to stabilize codes to create categories and codebook Comparison Numerous categories +20	Re-examine coded categories to reduce overlapping and to synthesize categories Axial Coding 15 – 20 categories	Produce themes that are most important and beneficial to study 5 - 6 themes
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Note. This table adapted from Corbin and Strauss (1998), Merriam (2009) and Thomas (2006) illustrates the Inductive Analysis Coding Process used in this study.

Strauss and Corbin (1998) and Saldaña (2009) suggest a two-cycle methodology to coding; open and axial coding. The first cycle of coding, known as open-coding or initial coding, involves breaking down the raw transcribed data into distinct parts or splitting data into individual units for closer examination (Maxwell, 2005; Merriam, 2009; Saldaña, 2012; Strauss & Corbin, 1998). Data are broken down into meaningful units by identifying crucial phrases, short phrases and paragraphs (Hatch, 2002; Merriam, 2009; Saldaña, 2009). Codes are then assigned to the units; codes are stabilized and are recorded in a codebook in order to index and standardize their meanings. The second cycle (and subsequent cycles) of coding is known as axial coding (Saldaña, 2012; Strauss & Corbin, 1998), which ultimately leads to categories of thematic and theoretical findings of the study. It is more interpretative than the open coding (Hatch, 2002) and creates synthesized categories (Saldaña, 2009; Strauss & Corbin, 1998).

In this study, the researcher began by closely reading the raw transcripts numerous times until becoming completely acquainted with the contents (Hatch, 2002). In these readings the researcher looked for and noted meaningful words, paragraphs, and phrases through a line-by-line analysis (Saldaña, 2009). Using a line-by-line analysis, data was split into individual segments and parts (Merriam, 2009; Saldaña, 2009; Strauss

& Corbin, 1998). Codes were then assigned to the individual units identified using in vivo and descriptive coding. These meaningful individual units became categories (Maxwell, 2005) through the continuous analysis.

In vivo and descriptive coding was used to establish substantive categories (Maxwell, 2005) as opposed to organizational categories. Some groupings may be more general in nature and others more specific (Maxwell, 2005). Organizational categories are broad areas or issues that researchers establish prior to their interviews or observations and are easily anticipated (Maxwell, 2005). In contrast, substantive categories are often inductively developed through the open coding of the data (Maxwell, 2005). Inductively developed means researchers gather data and build concepts and theories, rather than testing hypotheses, as in deductive analysis (Merriam, 2009). They are descriptive in that they are “descriptions of participants’ concepts and beliefs, and stay close to the data categorized and do not imply an abstract theory” (Maxwell, 2005, p. 97). In vivo coding, using interviewees’ pseudonyms, honor respondents’ voices by using their words or short phrases and quotes verbatim, and to enhance and deepen the understanding of their culture and worldviews, which are often marginalized (Saldaña, 2009). The researcher quotes the participants as necessary for the audience to understand the difficulties that parents, care givers and special needs providers encounter as they go about in the diagnosis, and treatment of autism in Kenya.

Additionally, descriptive coding was used to summarize in words and short phrases the individual parts in which the researcher was not directly quoting the respondents (Saldaña, 2009). The goal of descriptive coding is to assist the intended audience in seeing what the researcher sees or hears in the data collected (Saldaña, 2009).

Understanding that the initial cycle of coding often results in fragmented codes and conceptual connections, thus, coded units were reexamined and recoded to stabilize the codes (Saldaña, 2009). Throughout data analysis, there was a constant evaluation of data (Merriam, 2009) looking for patterns; those that are similar or different. This was followed by recoding along the way and putting group patterns together based on those similarities and differences to make them substantive categories. Codes were recorded in a codebook to index and standardize their meanings (Strauss & Corbin, 1998). This led to a categorized inventory of the content of data and grounds for the next cycle of coding to further the data analysis to findings (Saldaña, 2009).

A reflective memo on what the researcher learned along the way was also kept at each cycle of the data analysis. The goal of these reflective memos was to assist the researcher with capturing ideas and patterns that may have emerged along the way. This reflective memo also created an audit trail that was useful in the findings (Merriam, 2009).

In the second cycle of coding, codes from the first cycle were analyzed to create theoretical categories by looking for recurring regularities in the data that had common properties (Merriam, 2009). Coded data was regrouped and reanalyzed by constantly comparing, reorganizing, or refocusing the codes into categories to prioritize, integrate, synthesize, abstract and conceptualize the categories to thematic/theoretical findings (Saldaña, 2012). This coding was used to establish explanatory or inferential codes that identify emergent themes or assertions by condensing the coded data into a more meaningful unit of analysis as specific categories or subcategories using a few words that explain the study (Saldaña, 2009; Strauss & Corbin, 1998). Using the iterative process, the researcher read the transcripts closely and coded them. They were continually compared throughout the data analysis process. Thus, the data was frequently compared and analyzed from the initial cycle to the second cycle until themes emerged. The result of the coding was the creation of a small number of summary categories, which captured the key aspects of the themes identified in the coded raw data as important and beneficial to this study (Strauss & Corbin, 1998; Lincoln & Guba, 1985; Merriam, 2009; Thomas, 2006; Saldaña, 2009). Of course, even with the most intensive data collection and analysis, the findings of a study will serve no purpose if it is lacking in validity/trustworthiness.

IX. INTERNAL VALIDITY

Internal validity is the process in which the researcher ensure that findings are congruent with reality and what the researcher intended to research (Gay et al., 2009; Lincoln & Guba, 1985). Creswell (2008) further notes that in qualitative research, the researcher determines the accuracy or credibility of his or her findings through strategies such as member checking and triangulation.

To maintain credibility, member checking, which Lincoln and Guba point to as “the most critical technique for establishing credibility” (p. 314), was utilized in the study to solicit participants’ views of the researcher’s findings and interpretations. Member checking involves the process of the researcher asking one or more participants in the study to check the accuracy of the data collected from the participants (Creswell, 2009).

Additionally, an executive summary of the research findings was shared with participants to corroborate the study conclusions. Comments received from the member checking process were reviewed and incorporated into the study results.

X. EXTERNAL VALIDITY

Another element in the establishment of a study's trustworthiness is a study's external validity. External validity is concerned with the degree to which the study's findings can be generalized or applied to other institutions' situations (Gay et al., 2009; Lincoln & Guba, 1985). While generalizability is not intended in qualitative research, it does occur (Gay et al., 2009). The aim of qualitative research is not the application of research findings to settings and contexts different from the ones in which they were obtained, nor generalization of the findings among various populations. It is to present unique interpretations of events (Gay et al., 2009; Merriam, 2009).

External validity can be achieved through transferability (Merriam, 2009). Although no tests were administered in this study, generalizability employed the term transferability as noted by Locke, Silverman and Spirduso (2010) and Golafshani (2003). The researcher anticipates that the information revealed from the study would benefit parents, care givers, special needs providers like social workers, medical personnel, occupation therapists, speech and occupational therapists, and dieticians. This information could also guide public policy entities faced with the challenges of autism in Kenya. External validity can also be achieved through contributions, because each study is unique. Something can be learned through accumulation of knowledge from all studies (Merriam, 2009).

Additionally, in an effort to certify trustworthiness in internal and external validity, the researcher discloses any bias brought to the study, through open and honest self-reflection. This should resonate with the audience because it lets them know that the researcher's experience in the study's area and in qualitative research is shaped by his own gender, culture, history, and socioeconomic origin as well as the researchers training in Applied Behavior Analysis (ABA) (Creswell, 2009).

XI. POSITIONALITY STATEMENT

It is worth noting that the researcher's beliefs may play a significant role in how the study progresses, and how the researcher interprets the data. This notion that the conclusions reached by a researcher can be influenced by their culture, customs, perspectives, social standing, occupation, race, gender and background is referred to as positionality (Briscoe, 2005; Calton Parsons, 2008).

The qualitative researcher in this study was the main instrument in the study; that is, the researcher interacted with participants, and documented, construed, analyzed, and described the subject matter (Creswell, 2007; Merriam, 2009; Seidman, 2006). Because the researcher is a human instrument, researcher bias, personal thoughts, feelings, opinions, and tastes are realities that may present a concern. The researcher is a Doctoral-level, Board Certified Behavior Analyst (BCBA-D) © and a Licensed Applied Behavior Analyst (LBA). BCBA's© and LBAs are responsible for adopting and operating effective quality in ABA-based programs for children with autism. While the majority of the researcher's work has been in clinical settings, in the United States of America, the researcher has been an active member of the Kenya autism treatment community. The researcher is therefore emotionally invested in the study. In order to minimize researcher bias, the researcher phrased study questions as neutrally as possible and was mindful of his own body language, tone, and facial expressions during interviews and focus group discussion so as not to lead participants. The use of the inductive approach for data analysis also allowed themes to emerge from data using the participants' words as opposed to testing themes created by the researcher beforehand.

The participants in this study, both professionals and parents, had not consulted with the researcher previously. Additionally, the researcher made it clear that his role in this study was that of a researcher. The researcher is also Kenyan.

XII. PROTECTION OF HUMAN SUBJECTS

In order to protect the human subjects involved in this research study, proper precautions were taken to protect the identity of the participants. Through written informed consents, participants were told that participating in the study was voluntary and there were no subsequent consequences for refusal or withdrawal.

Since there was no coding of participants' personal information, complete anonymity is to be ascertained. Additionally, the researcher ensured that the participants were fully aware of the steps of the study before they become involved. Interviews provided for the comfort of the participants and if they were not comfortable answering any particular question, they did not have to answer it. There were no immediate, direct benefits for participation in the study.

XIII. RESULTS

The findings here present the views of 39 parents, caregivers and 11 special needs providers who were participants in this study. Eight major themes emerged as difficulties that parents, care givers and special needs providers encounter as they go about in the diagnosis, and treatment of autism in Kenya. These major themes were; the lack of awareness, limited research, cultural factors, the lack of treatment protocols, the lack of

institutional/government support and the out-of-reach financial price-tag for treatment of children with autism, social stigma, isolation and broken families.

Lack of awareness

There is a lack of awareness coupled with many misconceptions on autism, both with parents and professionals. Many aspects of autism, this study found out, remain poorly understood with contradicting and sometimes absurd claims on the causes even among professionals. Participants of this study largely reported autism to be a mental illness often with spiritual underpinnings. While parents did not attribute their child's autism on curses or angered spirits, almost often, most other participants did.

Limited research, Cultural factors and the lack of treatment protocols

When professional cannot explain autism, this study found, cultural and spiritual explanations stepped in. This finding is similar to a survey that asked pediatricians and psychiatrists in West Africa about the causes of autism. Many of the professionals surveyed regarded autism to have supernatural causes precipitated by angered ancestral spirits, sinful wrong doing, predominantly by the mother, or the actions of some evil (Bakare & Munir (2011)). Similarly, this study found the same. Additionally, this study found out that misconceptions, such as those aforementioned, informed by Kenyan cultural practices and void of empirical research guide treatment for autism. For example a common way for autism intervention that came up repeatedly as a theme was the involvement of religious and traditional healers. After diagnosis a common pathway this study found involves a child going to see a religious leader or traditional healer, before parents seeks other interventions. While this could be explained via cultural factors, it can also be attributed to the fact that there is also a lack of research on interventions and treatment protocols for autism management in Kenya. This study was able to identify only 8 schools that serve children with autism in Kenya. These were City Primary School in Ngara, Oshwal Academy Primary in Westlands, Kestrel Manor School in Parklands, Gibson's School in Karen, Kaizora School in Karen, Barut School in Nakuru, Embu School for Special Needs and Muguini Primary School in Thika. Of these 8, four of them were in Nairobi.

To put things into perspective, there are an estimated 800,000 children with autism in Kenya (Autism Society of Kenya, n.d.), and about 25,000 of them are in Nairobi (Riccio, 2011). Of these 8 schools reported by the study only one center seemed to ascribe to a version of empirical based interventions, albeit mostly western based tools and methodologies of interventions (e.g., VB-MAPP, PECS's protocols). The author does not wish to discredit this use of western-based intervention protocols used at the mentioned school. This is meant to highlight the lack of any treatment protocols in Kenya, and indicate that what is available is only imported.

The most common used methods of intervention in Kenya this research found are diet-based interventions, sensory integration and expensive drug therapies that promise to calm hyperactivity, reduce repetitive behaviors and improve social interaction. Diet-based interventions often comprised of removing gluten (mostly wheat based products), Casein (milk products) and avoiding sugary foods. Sensory integration included hydrotherapy, vestibular stimulation and spiritual development. The use of drugs this study found out was based along the reasoning that autism can be treated similarly to other childhood disorders that present the same, for example Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD).

For the reason that there is a lack of awareness, diagnostic, and treatment avenues for autism in Kenya, even when diagnosed, the age of diagnosis is relatively late compared to that of the United States, and Canada where the author is familiar. The age of first diagnosis ranges from 9-10 years old through adolescence in comparison to North America where it is done at about age 3- 5 years old. Of course this late diagnosis may contribute to worse overall life outcomes for individuals with autism.

Lack of institutional/government support

This study found that because autism is a relatively new field in Kenya, and there is little to no research on interventions, there is also a lack of institutional support. Both the national government, through the ministry of Education, Health, Science and Technology nor county governments have solid positions on diagnosis, treatment and management of autism, or delivery of any allays of service options that would be beneficial to individuals with autism.

"The government is doing very little, and we do not expect anything from the government." Were common themes in this study. Even in Nairobi, which is urban, participants could not name any government run center for children with autism.

The only one center that parents of kids with autism were referred to constantly referred to was Kenyatta National Hospital, but even here, medical doctors treated autism as a disease. One parent who travelled from Northeastern Kenya to Kenyatta National Hospital a distant of over 100 miles for monthly clinics after her son was diagnosed with autism reported that doctors told her, her son would outgrow the condition, but it did not happen.

This study also found that there were only a handful of government schools that had integrated special needs education programs and of those only few had any special education teachers.

The out-of-reach financial price-tag for treatment

The national health insurance fund network (NHIF), which is a largely tax-funded medical insurance entity in Kenya does not have autism as one of the diagnosis it could cover even for parents who want to seek out services, neither do other emerging user-funded insurance schemes. This study found that this could be attributed to the fact that autism is not a life-threatening condition, and there is limited recognition and acceptance on autism even by health insurance administrators. Of course the lack of state or private insurance to cover the costs of autism treatment has put any chance of autism treatment out of reach for most children in Kenya. The average autism professional in Kenya, most of them expatriate practitioners go for about 6,000 - 10,000 Kenya shillings, per hour (approximately \$60-100 per hour). The average worker in Kenya earns about \$0.34/ hour (Kenya Gazette, 2016). These expert professionals are largely available within the confines of big cities and those in rural areas this study found have no access to resources either in experts or information.

Social stigma, Isolation and broken families

This study found out that a lot of parents mostly mothers of children with autism retreat and suffer in silence. Because of the claims mentioned earlier on the beliefs and causes of autism even among professionals (e.g., spiritual causes, or a curse), in addition to the lack of awareness for parents, family members and community members, Parents reported repeatedly how their children with autism have been shunned by peers and other community members. One mother drew a lot of sympathy at a focus group when she stood to speak

“...as a mother of a child with autism [she said], I meet many challenges. I have few friends. There is a lot of rejection from both friends and family especially the in-laws. It has become a life where it's me and me only with my son. Most of the time I find myself in tears without knowing. When my son is outside the house alone, I am not comfortable. I want him to be where I can see him because of the bullying by other kids who call him *mwenda wazimu* [that is the Kiswahili term for crazy person]. I have been insulted by my neighbors and they do not like my son near their kids. It breaks my heart. I pray to God every day for power and strength...”

Such isolation and rejection were common themes in this study. Additionally, there were reports of fathers leaving after finding their sons had autism. This is largely because of the pressure fathers have to bear sons to carry the family line. Of course such isolation and rejection puts strains on families and most of them break down, subsequently the children and single mothers suffer even more.

XIV. DISCUSSION

Increased recognition, understanding, and public awareness of autism, could undoubtedly create more social acceptability and widespread services for individuals with autism in Kenya. This could also lead to a growth in research. Such research could make contributions towards the development of screening, diagnostic and intervention tools for the Kenyan clinical setting. Such tools are currently absent.

Such research could also bend the arm of the Kenyan government and policy experts. There are about 800,000 individuals with autism in Kenya (Autism Society of Kenya, n.d.). Without any resources and/or appropriate tools for screening, diagnosis and intervention in place going forward, the consequences look grim by any interpretation.

Autism intervention specialists both in Kenya and abroad have a responsibility to spearhead a collaborated effort to develop culturally sensitive, context based intervention methodologies. While interventions such as Applied Behavior Analysis (ABA) have empirical research in high-income countries, such interventions require intensive therapy sessions, large upfront investments are often insurance funded. Such approaches are unlikely to be of practical application in Kenya, especially in low-resource settings. This author wishes to place a call for culturally, and linguistically sensitive, less intensive, more flexible, ABA based intervention methodologies for Kenya, and rural Africa in general. Such a methodology would likely be more practical if it laid emphasis on parent, caregivers and extended family members as these are at the core of child care in Kenya.

The Kenya government, with its respective ministries of education and health cannot just watch and wait. It needs to endorse policy initiatives that raise awareness, develop screening tools, training and service for autism in Kenya. The Kenya government can also facilitate the adoption of training curriculums for autism intervention in public Universities and colleges. Program at such universities and colleges could 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.

Public universities in collaborations with the respective government ministries could also create an array of services that can be provided for children with autism both at home and at school.

Children with autism, all the 800,000 (Autism Society of Kenya, n.d.) of them in Kenya, deserve to be given a chance to live to their fullest potential despite their limitations.

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