

Caregivers'  
Experiences While  
Communicating With  
Autistic Children  
In Nairobi County,  
Kenya

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**ABSTRACT**

Autism is a developmental disorder that is characterized by impairment in verbal and non-verbal communication. Autistic children are not able to effectively communicate verbally and convey meaning to the caregivers as typical children do. Kenya National Bureau of Statistics has no data on autism in Kenya. This shows that autism is yet to get attention it deserves in the country. This study therefore sought to explore the experiences encountered by three Kenyan caregivers while communicating with autistic children. The study adopted a qualitative research design and was conducted in Nairobi County. Semi structured Interviews and observation methods were used to generate data. The findings reveal that caregivers of autistic children face many challenges such as difficulties in communication and lack proper knowledge on communication intervention for autistic children. The study concluded that autistic children can be helped to live a full life like any child with early communication intervention. The study strongly recommends that policy makers should sensitize caregivers on importance of early communication intervention.

**Key Words:** autism, communication challenges, caregivers

**1. INTRODUCTION**

The word autism originates from a Greek word 'autos' meaning self and implies narrow relationships with others Kanner (1943). He considered autistic aloneness as the most fundamental indication of autism with severe limited language and a great obsessive desire that everything remains exactly the same. The insistence on sameness can be frustrating to caregivers especially if the sameness is disruptive to the rest of the family members. Families of autistic children experience enormous struggles on a daily basis that often go unrecognized and untold. The stories of these families can provide vital information to the fight against autism.

Autism is as developmental disorder of the brain that is characterized by impairments in social interaction, communication and repetitive patterns of behavior as per the Diagnostic and Statistical Manual of Mental Disorders (DSM-V, American Psychiatric Association 2013). People with autism may communicate, interact, behave and learn in different ways. It further states that the mentioned impairments must be present in early developmental period. The impairments may not become fully manifested until social demands exceed limited capacities and or can be masked by learning strategies later in life. Signs of autism begin during early childhood and usually last throughout a person's life.

According to Neely et al (2011) autism typically appears during the first three years of a child's life. They further state that autism negatively affects the child's social interactions, communication skills, and pretend or imaginative play. This means that autistic children have difficulties in interacting with family members and the society at large. They also have problems in making their needs and wants known since they are not able to communicate effectively.

## 2. RESEARCH OBJECTIVE

This paper is based on a master's level study conducted between the period 2016 and 2017 to explore communication challenges of caregivers of autistic children in Nairobi County. The study aimed at understanding the lived experiences of the caregivers of autistic children.

The study aimed to respond to the following questions; What communication challenges do the caregivers of autistic children experience? How do communication challenges experienced by caregivers of autistic children affect the family interaction? What adaptive communication strategies do caregivers employ to successfully communicate with the autistic children? What training on communication skills do the caregivers require?

## 3. LITERATURE REVIEW

Powers (1989) notes that autism not only affects the life of the child but also the life of a family as a whole. The prevalence of autism all over the world is alarming and this is evident by the United Nations General Assembly declaring April 2nd as World Autism Awareness Day (WAAD) to draw attention to the unacceptable discrimination, abuse and isolation experienced by people with autism and their families (WHO 2013).

CDC (2016) indicates that 1 in 68 children in America have autism. The prevalence of autism is on the rise as from 2000 & 2002 it was 1 in 150 children, 1 in 125 in 2004, 1 in 110 in 2006, 1 in 88 in 2008 and 1 in 68 in 2010/2012. This marks a 78% increase in prevalence in the past six years. WHO (2013) estimates that the global prevalence of autism is 1 in 160 with many low and middle income countries prevalence so far unknown. In Kenya there are no official records of children with autism or people with autism in general in the Kenya National Bureau of Statistics. Autism Society of Kenya only has records of children who have been taken to them.

According to Landa (2007) early intervention is crucial due to neuro-plasticity of a child's brain. A growing body of literature indicates that intervention is associated with improvements in speech, language and social development. Intervention received by 2 year olds with autism was a significant predictor of language outcome at age 4. Caregivers have an important role in improving the communication of an autistic child by ensuring that the child receives early intervention.

Communication process occurs when the sender who has a message, puts it in a form which can be sent, and sends it in the direction of the receiver. The receiver then receives the message, gets it into their brain, and attributes meaning to it (Coates 2009). In a family set up, communication among the members is essential in the day to day running operations in house and outside the home. Caregivers give instructions to the children on what is expected of them in a day. Siblings also discuss issues amongst themselves. Spouses discuss what they have to do in a day or in the future. In the African set up where we have the extended family communication

to them is also imperative for the well being of the family and the society at large. Communication is basically an engine that runs the family and society in a quality manner.

Landa (2007) states that autism occupies an extreme position among the childhood developmental disabilities. Caregivers are normally the first to observe these characteristics in a child. This makes caregivers an integral part in diagnosis of autism and the implementation of communication interventions. She further claims that early intervention for the communication impairment in autism is important since social communication deficits in autism are a major stressor for caregivers and since gains in communication skills are related to prevention and reduction of maladaptive behaviours.

Problems in communication are considered to be the key symptoms of autism (Noens & Van Berckelaer-Onnes 2005). This justifies for intensive research into the complex problems in autism. First, the absence or loss of language is usually one of first problems that worry parents of autistic children. Second is the impaired communication.

Rapin (2006) states that there is often delay in language development in autistic children and the language that does develop is deficient for conversational use especially non-verbal language. Gillberg & Coleman (2002) adds that autistic children fail to grasp the meaning of communication and have difficulty comprehending gestures and speech. Autistic children make little use of communication skills and have a deficit in use of social imitation. Coupled with this difficulty is the children's misinterpretation of facial expression. Children with autism usually have a delayed development of speech or have normal development until the age of two years when it ceases. The speech that autistic children do develop tends to have an oddity in vocal volume and pitch.

According to Trevarthen, Aitken, Papoudi, & Robarts (1996) most of the children diagnosed with autism never develop language. Approximately 30% of children who are diagnosed with autism have no language at all. Those who do have some language produce odd vocalizations that are not considered speech or babble. When they do develop language they are incapable of using correct pronunciation and reproducing grammatical constructions. Autistic children are therefore unable to engage in a meaningful communication with others and inform them of their needs, wants or pain. Caregivers therefore have a challenge in addressing the problems and various needs of their children for instance knowing when the child is sick. Tager-Flusberg, Paul, & Lord (2005) estimates that 20% to 50% of autistic people never develop functional communication at all.

NIDCD Fact Sheet (2012) states that children with autism are self absorbed and often seem to exist in a private world where they are unable to successfully communicate and interact with others. Autistic children may have difficulty developing language skills and understanding what others say to them. They may also have difficulty communicating nonverbally for instance through hand gestures, eye contact and facial expressions. It however notes that not every autistic child will have a language problem. A child's ability to communicate will vary depending on his or her intellectual and social development. Some autistic children may be unable to speak,

others will have rich vocabulary and be able to talk about specific subjects in great detail. Most autistic children have little or no problem pronouncing words. Majority however have difficulty using language effectively especially when talking to people. They have problems with meaning and rhythm of words and sentences. They also may be unable to understand body language and nuances of vocal tones.

Nolen-Hoeksema et al (2009) posits that children with autism show a number of difficulties in communication and speech. Children with autism who can speak may say things that have no meaning or that seem out of context in conversations with others. For instance, a child may count from one to five repeatedly. Further, instead of gathering his own words, an autistic child may echo what he has just heard, a phenomenon called echolalia. The child may have patterns of repeating a word or phrases out of context. For example, he may hear a phrase on TV and then hours later repeat it.

### **3.1 THEORETICAL FRAMEWORK**

This study was informed by the Interactional View theory propounded by the Palo Alto Group (Griffin et al 2014). This theory was focuses on the interactions of family units and miscommunications that arise from varying situations. According to this theory, human relationships are considered as systems. The relationships within a family system are interconnected and highly resistant to change. Communication among members has a content component and a relationship component that centers on issues of control. The systems can be transformed only when members receive outside help to reframe their meta-communication. The interaction process keeps the systems in balance and maintains the status quo.

This theory has five axioms; one cannot not communicate; human beings communicate both digitally and analogically; Communication has content and a relationship; the nature of a relationship depends on how both parties punctuate the communication sequence and lastly all communication is either symmetrical or complementary. This study employed only three axioms; one cannot not communicate, Every communication has a content and relationship aspect such that the latter classifies the former and is therefore a meta-communication and Human communication involves both digital and analogic modalities.

### **4. DATA ANALYSIS AND FINDINGS**

In order to achieve the set objectives, the study used the social constructivist world view which is which Creswell (2009) considers ideal for qualitative research. Individuals seek understanding of the world in which they live and work. They develop subjective meanings of their experiences where meanings are directed towards certain objects or things. This study sought to understand the experiences of caregivers while communicating with autistic children.

The study adopted a case study approach. Case studies are a strategy of inquiry in which a researcher explores in depth a program, event, activity, process or one or more individuals. Cases are bound by time and activity

and researchers collect information using a variety of data collection procedures (Creswell 2009). This study focused on caregivers with autistic children in Nairobi County as the basis of the study. The study was conducted in the homes of the caregivers.

The participants of the study were drawn from Caregivers of autistic children that sought services from Autism Society of Kenya in 2015. A sample of 3 families was selected using purposive sampling technique. This technique was used because the researcher intended to describe the experiences of caregivers in communicating with autistic children which is a specific type of experience.

The study employed semi-structured interviews and focused participant observation to obtain data from the caregivers. The data was obtained from the interviews schedules and observation field notes. The analysis of data gathered from the interviews involved developing a coding system based on relevant themes identified. The coded information was then analyzed thematically based on the research questions of the study. All coded information under the major themes identified were put together for summarization of the study. Key insights or quotations from the study were also highlighted and presented verbatim. The data collected from field notes were coded and inculcated into the themes already derived from the interview schedules data.

This study dealt with people; caregivers of autistic children as the participants hence the need to consider ethical issues. For this study consent was obtained from the caregivers to participate voluntarily for the study. A permit was also obtained from the National Council for Science and Technology Innovation after which permission was also sought from Nairobi County Commissioner and Nairobi County Education Officer. Pseudo names were also used for the participants to protect their identity.

#### **4.1 DESCRIPTION OF CASES**

The study used multiple case studies of three families with autistic children. The caregivers responded well to the interviews and cooperated during observation exercise. The experience of talking to caregivers of autistic children and spending time with them was an eye opener to the insurmountable challenges that they face communicating with the autistic children.

##### *Case 1*

This family consisted of a divorced mother who lived in Starehe District with her 12 year old son, 10 year old autistic son, 7 year old daughter and a house help. This lady was married after having her first born son out of wedlock. She moved into her new family with her first born son. She was then blessed with a second son and daughter. However, after realizing that the second son was autistic, they had marital conflicts that led to separation and finally divorce. For the purpose of this study the pseudo name for the autistic child in this family will be Jeremy.

### *Case 2*

This family consisted of a father, mother, 9 year old autistic son, a nephew and a house help. The father worked outside Nairobi and he is home over the weekends. The family lives in Embakasi District in one of the school compounds where the mother teaches. The extended family has autistic tendencies where the paternal grandfather had what seems to be autism. The pseudo name for the autistic child of this family will be Kiptoo.

### *Case 3*

This family consisted of a father, mother, paternal grandmother, a 12 year old son, a 9 year old autistic daughter and a house help. The mother had secured a job in Malawi and visits the family in Kenya thrice or twice a year. The grandmother was in charge of the household in absence of his son. This family lived in Langata District. The autistic child's pseudo name will be Farida.

#### **4.1.1 KEY FINDINGS**

The findings revealed that communicating with autistic children is a big challenge since the language development was impaired. The children lacked the necessary communication skills which other children attain at a similar age.

**Mum Jeremy:** communication is a big problem with Jeremy. You know, I cannot talk to him the way I am talking to you. It is basically impossible.....his speech is limited and with limited speech he cannot engage in a conversation..... I cannot really say he is verbal....he cannot reply to you when you talk to him.

The autistic children use echolalia which is the repeating of sounds and words which is quite common in children with autism. The autistic children were also not able to neither initiate nor sustain a conversation. Some kind of initiation was observed when the children wanted something. However, the conversation could not be maintained.

The children said words which indicated something. Jeremy said 'Lion Lion' he calls his elder brother 'Lion' and at that instance he wanted sitting space where 'Lion' was sitting so that he could watch cartoon. Kiptoo on the other hand said 'Kiptoo *akule*' (Kiptoo eat) using the third person though referring to himself. When he said this, the mother gave him food. This shows that the use of two words in the third person meant that he wanted to eat or he was hungry. Farida on the other hand said 'pancake', 'banana' indicating what she wanted to eat though using one word.

The three autistic children utilized non-verbal communication as a means of conveying messages. The children were seen physical picking whatever they wanted and in one case one autistic child (Farida) looked at an item she wanted suggestively. She stood near the water dispenser and looked at it suggestively, when she was given a glass of water she moved away from the dispenser. Jeremy physically took the remote from his brother, Kiptoo

went to the fridge and took a packet of juice and served himself and Farida went and took her plate. These children use manual gestures to communicate to others.

The autistic children portrayed a kind of repetitive behavior such as swinging a thread, rolling a tape measure over and over, choosing specific dresses, playing with specific toys among others. Jeremy swung a thread continuously; Kiptoo collected and held the sticks tightly and tapped them on the floor whereas Farida played with specific toys and arranged them in a certain order. These behaviours can be used as a means of communication by the autistic children to their caregivers. The like of specific toys by Farida can be an indication of the games she likes or the kind of colour she likes which is purple. For Jeremy the swinging of thread appears to be a way he soothes his anger as he relaxed from a tantrum when her sister gave the thread.

It was also evident that autism does affect communication between family members. With the presence of an autistic child who cannot communicate like typical children the interaction of the family members is affected.

**Dad Farida:** it is hard to share a topic as a family since she would not participate. She may prefer to stay in isolation and this leads to other members of the family abandoning the topic altogether... she is less interested in other children unless they have something she is interested in.

It was observed that the autistic children were interested in interacting with their siblings or other children if those children are playing a game that they like or if they had something that they wanted otherwise they preferred to be alone. These children seem to prefer to be alone most of the time.

Despite the limited interaction between the autistic children and their caregivers, all the participants in the study expressed a close relationship with their autistic children. The caregivers cherish the moments they spend with their children and the expression of affection they receive no matter how little it is.

**Mum Kiptoo:** my relationship with my son is good. I have taught him to hug me which he does ... he also greets me but shortly

The caregivers also give first priority to the autistic children and worry more about them. Only caregiver had one autistic child hence there was no competition for attention unlike the other two caregivers.

It is notable that one participant in the study cited strained family relations and eventually divorce due to the presence of an autistic child in the family. Autism affects how a family as a unit operates and relates to the society.

**Mum Jeremy:** After realizing that the child was not verbal he started being problematic saying I was mistreating the child. He left us ... My own family members ...since they realised my child had a problem they have never visited my house that is like 8 to 9 years. We just meet in the streets. They said I got a bad child because I married a *kisii mara urogi ya wakisii* blah blah blah, so many stories.

Data from the interview schedules revealed that caregivers in the study employed various methods of communicating with the child ranging from use of gestures, expressions and behaviour. This was necessitated



by the fact that the caregivers realized that their children were not able to communicate in the normal way like other children hence they had to figure out a way of reaching out to these special children.

**Mum Kiptoo:** I bribe him for him to respond. I have taught him to ask or demand for things ...when something does not work, I try a new technique, if it works okay. If it does not I try something else until I find something workable... Another thing is that he cannot tell you what his name is, if you ask him 'what is your name?' he will just keep quite but if you say 'my name is ...' he will complete the sentence for you saying '...Kiptoo.'

One participant taught the child various means of communication such as use of picture books, picture cards and even sought services of a speech therapist. The other two caregivers made no efforts of training the autistic children how to improve their communication abilities.

Two participants felt that they needed help in the use of sign language/gestures and speech therapy to be able to assist their children communicate to others. One participant felt that she did not require any communication training since she has learnt her child's way of communication and was able to understand her child her well.

**Mum Kiptoo:** i don't think i need any training on communication because from my experience you just have to learn your child ways and behaviours of reaching out to you

#### ***4.1.1.1 Discussion of Findings***

In relation to the first axiom informing this study 'one cannot not communicate' where every human behaviour is a kind of communication, the autistic children use a different style of communication than that used by typical children. By doing so, the autistic children communicate and the caregivers need to try and understand the message being passed to them. The axiom means that any perceivable behaviour including the absence of action has the potential to be interpreted by other people as having some meaning.

In a study conducted by Trevarthen, Aitken, Papoudi, & Robarts (1996) they found out that most of the children diagnosed with autism never develop language. Approximately 30% of children who are diagnosed with autism have no language at all. Those who do have some language produce odd vocalizations that are not considered speech or babble. When they do develop language they are incapable of using correct pronunciation and reproducing grammatical constructions. The results of the present study is similar to that of Trevarthen, Aitken, Papoudi, & Robarts (1996) as all the three autistic children had impaired language and produced some intelligible sounds that made no sense. With this kind of language difficulties autistic children are unable to engage in a meaningful conversation with others and inform them of their needs, wants or pain. Caregivers therefore have a challenge in addressing the problems and various needs of their children.

According to Nolen-Hoeksema et al (2009) children with autism do not gather their own words. These children can speak things that have no meaning or that seem or that seem out of context in conversations with others. In the present study all the three autistic children employed the use of echolalia. Schneider (2004) states immediate echolalia can serve a communicative purpose to initiate or maintain an interaction. When asked if the child

wants a cookie, the child may request the cookie by repeating the last word produced that is “cookie.” It can also be non interactive and serve as an aid to process the information to facilitate understanding or to help the children move through an activity. The key to understanding the purpose of delayed echolalia lies in the listener’s familiarity with the child’s idiosyncratic use of verbalizations and past experience with the child’s language patterns. In the present study all the children used immediate and delayed echolalia at various points in their day to day life. All the caregivers in the study did not view echolalia as a way that could help them in communicating with the autistic children as stated by Schneider.

The use of echolalia by autistic children in the study denotes Watzlawick fourth axiom that states that human communication involves both digital and analogic modalities. In this instance the children are making use of the digital modality which is the use of defined elements of communication usually words. However, in this case the autistic children disrupts the normal way of using words by repeating what they are told either immediately or later by the caregivers or what they watch in the television.

Farmer (2003) concurs that initiation of a conversation or topics and turn taking is commonly absent in autistic children. They will often show a deficit in comprehension, will not express original ideas, and show lack of verbal reasoning and lack of rapid word retrieval. Bloom (2000) further reiterates that autistic children are also incapable of attending to and comprehending the conversation of others. Trevarthen et al (1996) further states that when speech is present in children with autism, it is not usually used spontaneously and functionally in a conversation. These support the findings of the current study that autistic children are unable to initiate conversations. This means that the children cannot participate in a communication setting as expected hence making conveyance of a message difficult.

According to Watzlawick second axiom ‘Every communication has a content and relationship aspect such that the latter classifies the former and is therefore a meta-communication’ the caregivers responds to the content of the communication in the context of the relationship between them. That is an autistic child who cannot communicate well as a typical child and the caregiver understands this. The caregiver therefore responds as per the context at that particular time even though the child cannot initiate a conversation nor respond to what the caregiver tells him to.

Gupta (2004) maintains that autistic individuals may use unconventional forms of non-verbal communication. They may grab, pull, or reach to gain desired objects as their ability to point to a desired object is delayed, if present at all. Simple gestures noted in children under the age of 18 months including nodding and shaking the head may or may not develop in children with autism. In this study, Jeremy takes sodas forcefully from other people in functions and took the remote from his siblings. Kiptoo as young as he is makes it his responsibility to close doors, switch off lights and went to the fridge and served himself juice. Farida took her plate so that she was given food. Autistic children therefore use any other means possible to communicate their feelings or

needs which appears unconventional as it is not according to the standard norm of communication used by other children but they pass across a message which the caregivers should take note of.

Howlin (1997) states that impairment in communication is a significant cause of behavioural disturbance in autism. He brings to attention accounts of individuals with autism such as Dr. Temple Grandin who is unable to neither communicate effectively nor make sense of what others are saying and this causes her enormous distress and anxiety leading to aggression, disruptive behaviour or withdrawal into ritualistic obsession activities. He observes that such behaviour may be extremely adaptive and effective if an individual is unable to express his needs, feelings and emotions in any other way. It is easier for autistic children to get attention or avoid something by throwing a tantrum than by trying to explain verbally what the matter is. All the caregivers during the interviews reported that the autistic children throw tantrums that are not interesting. During the observation exercise, Jeremy threw a tantrum because the house girl lifted him up from carpet where he was playing with threads. This shows that inappropriate behaviours have a communicative function for children with autism and should not be seen as an aggression from the children.

Communication between family members is important for the relation and interaction within the unit and when there is hampered communication conflicts will arise. In the present study, autism related family conflicts emerged as one of the themes. It was observed that the autistic children appeared interested in interacting with other children if those children were playing a game that they like or if they had something that they wanted. It is not easy for the caregivers when their autistic children operate like lone rangers in this world. This makes them look queer to the society.

Two caregivers in the present study who had other children apart from the autistic child gave more attention to the autistic children at the expense of the other typical children. One caregiver had only the autistic child hence there was no competition for attention. Amanda (2008) found out that the mothers concentrated more on the autistic children at the expense of the other siblings. Some expected the normal children to help in taking care of the autistic child. In this present study, the typical siblings were always concerned about the autistic children and gave up what they would enjoy for the comfort of the autistic sibling.

All the participants in the study expressed a close relationship with their autistic children. The caregivers cherish the moments they spend with their children and the expression of affection they receive no matter how little it is. The autistic children have low levels of showing affection. This can be attributed to the fact that autistic children's communication skills are poor hence the children cannot express themselves well. Some studies have shown that majority of mothers with autistic children consider their children's sign of attachment to be insufficient and they rate their emotional reciprocity as low compared to mothers of children with other disabilities (Abbeduto et al. 2004; Hoppes & Harris, 1990).

The close relationship that all the caregivers in this study stated to have with their autistic children can be viewed to have an impact on the level of communication process. Watzlawick second axiom states that there are both content and relationship levels of communication. The relationship level impacts on how two communicators view one another and how they convey it and how the communication is to be taken. The caregivers have a close relationship with the children and they view them as special children who cannot communicate like typical children. The communication between them is skewed but they try to understand each other.

One participant in the study cited strained family relations leading to divorce due to the presence of an autistic child in the family. Hall (2000) similarly states that in more severe cases, parental disagreement on subjective aspects, such as the fairness of each parent's share of parenting and how much each parent should do, could result in irreparable breakdown of the marital relationship and eventual divorce. Amanda (2008) in her study found out that there was loss of marital and family relationships as four out of ten participants had undergone divorce citing autism as the cause of their marriage breakdowns.

Boyd (2002) further claims that Primary caregivers of autistic children are one of the most stressed parental groups, who are in need of effective and efficient professional services to be better able to meet the needs of the family and help them cope with taking care of their autistic children at home and within the community. The life that the caregivers of autistic children live in, is difficult as they try to juggle between working to provide for the family, taking care of the autistic child and their special needs and the other siblings. Finding a balance in all these is a challenge and at the end of the day the caregiver may neglect himself and have total burnout. In Kenya, with the little resources a caregiver has getting something extra for professional help may not be possible.

Schopler, Van Bourgondien, & Bristol (1993) puts forward that though most children with autism do have a predictable way of expressing their emotions vocally, these means must be learned by others to be able to interpret it as communication. Non verbal communication means should always be considered for all autistic children between 2½ - 3 years who are not naturally developing speech. However, if the intervention causes excessive levels of frustration, it should be stopped. The participants in the study employed various methods of communicating with the child ranging from use of gestures, expressions and behaviour. This was necessitated by the fact that the caregivers realized that their children were not able to communicate in the normal way like typical children hence they had to figure out a way of reaching out to these special children.

Speech therapy is recommended for speech improvement, use of language and broadening of vocabulary. The therapy may involve teaching gestural communication, working with electronic talking devices or using visual communication aids when a child is largely nonverbal. For a child who speaks, the therapy often deals with using language and engaging in two-way conversation (Rimland et al 2004). Two Caregivers, Mum Jeremy

and Dad Farida took their autistic children for speech therapies but Mum Jeremy gave up as the services were expensive and she could not afford it. Dad Farida had a speech therapist going to his house and working with the autistic child to improve her communication abilities.

Picture Exchange Communication System (PECS) has also been used to assist autistic children communicate. PECS uses a system of picture cards as a means of communication. The PECS approach can teach a non-verbal child to understand and use language in order to communicate and learn effectively. Children are taught to exchange a single picture for a desired item and eventually to construct picture-based sentences (Landa 2007). In the current study only Dad Farida used this approach though the autistic child was yet to apply this concept. He also informed the researcher that he has read widely on autism. Farida's brother assisted her sister to learn about the picture cards. This caregiver should broaden their teaching to assist the child to construct sentences using the picture cards.

Trevarthen (1999;Wigram 2002) recommends music therapy as an effective means of facilitating communication. This is because music as a medium of communication involves a complex range of expressive qualities, dynamic form and alternative communication which can be established to help achieve engagement, interaction and relationship. In the present study none of the caregivers used music therapy and they seemed to be unaware that music could be used as a strategy of improving communication.

Laird (1997) conducted a study to test the effectiveness of music on cognitive and communication skills in children with autism. The material that was paired with music was achieved sooner than the material paired with only verbal instruction. Wylie (1971) conducted a study to determine if music paired with speech therapy would increase spontaneous speech. Although the results were not statically significant they did show that the music group was more successful than the control group in producing spontaneous speech. Trevarthen, Aitken, Papoudi, & Robarts (1996) put forward that music improvisation has been the most successful activity in modifying behavior of the autistic population. It has been used to motivate and promote pleasurable companionship. Improvisation can also encourage efforts to reach meaningful communication. The spontaneity of improvisation directly engages and activates the rhythmic and sympathetic impulses from which all human communication comes from. Further, music has been used to support communication and to encourage and bring out body expression and gesture in interaction and limitation.

There are various strategies that caregivers in Kenya are yet to utilise to improve the communication abilities of autistic children. Caregivers of autistic children need to read widely on communication interventions used in other countries especially United States of America where several interventions have been tested and try to domesticate these interventions to suit the autistic child. All the caregivers should put in more effort in ensuring that the autistic children are assisted to improve their way of communication so that they can integrate freely with the rest of the society even in the absence of the caregivers.

The participants felt that they needed help in some areas for them to be able to assist their children live comfortably. Two of the participants felt that they needed training in use of sign language/gestures and speech therapy. One participant felt that she did not require any communication training since she has learnt her child's way of communication. This caregiver should however learn other ways of helping the child improve his communication skills. The caregiver may understand the child but the teachers and other people that interact with the autistic child may not understand how the child is communicating. We can therefore agree with previous studies that early intervention is necessary and speech therapy should be given more focus since all the children have delayed speech.

Landa (2007) recommends that early intervention is crucial due to the neuro-plasticity of a child's brain. Intervention received by 2 year olds with autism was a significant predictor of language outcome at age 4. A growing body of literature indicates that early intervention is associated with improvements in speech, language and social development. Many studies have recommended early intervention as a way of helping autistic children live a better life as teenagers and adults. Caregivers are an integral part of this process especially during the early life of the children.

Chua (2015) in a study in Singapore focused on a triple-E model that is Enablement, Engagement and Empowerment of the caregivers of autistic children. In Enablement, the caregivers of autistic children are provided with necessary means and opportunities to accept the reality of autism diagnosis in terms of provision of relevant information, education and support. In Engagement, there is a shared and continuous responsibility between the caregivers, schools and other community agencies to support and improve the child's learning, development and health. In Empowerment, the effectiveness of parent training programs to increase the child's motivation to participate in social-communicative and play interactions. This shows that caregivers of autistic children need support in training as in the case of Singapore. In Kenya however, caregivers feel neglected by the stakeholders as they get no assistance in terms of assessment, treatment, education or therapies. Kenya considers the vulnerable group which most of the time includes visible disabilities like blindness, handicap and the monetary help provided is so minimal.

Two of the caregivers in the study expressed interest in receiving what Chua (2015) terms as empowerment. Autism affects each child differently hence what may work for one child may not work for another one but when the caregiver is empowered he can try various techniques until he finds the appropriate one for the child. Chua (2015) further states that caregivers need to be aware that there is no one size fit all approach to intervention and treatment of autistic children.

According to Rimland et al (2004) Applied Behavioural Analysis (ABA) has been effective in children with autism. Children are taught skills by therapists in a simple step-by-step manner. For instance teaching colours only at one time, that is learning to point to a colour when its name is given. After some time, there is a shift

towards generalizing skills to other situations and environment. Play is also important in teaching language and social skills. This therapy can be extended by the family members and friends throughout the day. Fortunato (2007) adds that Applied Behaviour Analysis or ABA therapy is a treatment with an impressive record of its effectiveness with its unique ability to break down a social skill that the therapist would like the child to learn and teach that skill one step at a time until it is mastered. This concept was not used by the caregivers in the present study and probably if put in practice, the autistic children social and communication skills would improve.

Sign language has also been proposed as another important intervention to improve the communicative ability of autistic children by many researchers. Trevarthen, Aitken, Papoudi, & Robarts (1996) suggest that teaching sign language to autistic children supports all other aspects of interpersonal communication. It can assist in overcoming sensory and motor handicaps. However, when children with autism use sign language they do not always use it to gain social contact or to share ideas. It has also helped to decrease echolalia and other non communicative expressions and improved socialization and resulted in fewer tantrums or self destructive behavior. Daniels (2001) adds that when signs are used as visual cues it can make it easier for autistic children to follow directions and make connections between words and concepts that may lead them to speak. The use of signs and gestures should be used within the context of a specific activity for instance when a child echoes a question to indicate they want something, the caregiver should make a gesture using the object the child wants and interrupt them saying 'yes' (Maurice, Green & Luce 1996). In the present study Mum Jeremy wanted training on the use of gestures and sign language whereas Dad Farida mentioned speech therapy and related training where sign language can fit in. These caregivers if assisted in the areas they mentioned they will be able to understand how autistic children communicate and also aid their children to improve and communicate better.

The caregivers of autistic children in this study learnt the autistic children way of communication and reached out to them. However, this is a new thing for them and they need assistance to learn other strategies that they can use to enhance their understanding of autism and communication and assist their children to communicate better. By doing this, they will be able to understand one another hence fulfilling the axiom 'one cannot not communicate'.

There are several intervention methods that caregivers of autistic children can use to improve the communication skills of their children. In Kenya such services are not freely provided to this special group of children, the caregiver has to go an extra mile to learn about autism and the latest intervention to use. After learning the caregiver should implement these interventions and find what best suits her child. In this study, the caregivers have learnt and devised ways to communicate with their children and this is laudable. There is a challenge however on how the child communicates to the rest of the society in the absence of the caregiver.

These children will soon be adolescents then adults and the caregiver may not always be there for them hence the need to improve the communication abilities of the children. The caregivers can also form a support group where they can help each other and learn new strategies from the group and walk together in the journey of raising autistic children.

A lot should be done by all stakeholders when the child is young so that improvements can be achieved be it in terms of communication, behavior and basic skills. These will help autistic children live comfortable lives as adolescents and adults and they can survive well with other members of the society who may not understand their situation at first. With the growing research being conducted and awareness campaigns being carried out worldwide, autism will certainly receive the much needed attention in Kenya. Caregivers can access materials on autism and learn how to assist their children as stated by Dad Farida who reads a lot on autism. There is certainly light at the end of the tunnel for children with autism in Kenya.

## 5. CONCLUSION

This study provided a glimpse into the lives of caregivers of autistic children with each caregiver having unique experience though all are interrelated. This study has revealed that caregivers of autistic children have enormous difficulties communicating with the autistic since the language development of autistic children is delayed. These communication challenges spills over to the rest of the family members and the way they interact. Autism was cited as the cause of bad family relation and at worst marital divorce. The relation between the autistic child and their siblings is also a challenge as most siblings are yet to grasp how to communicate to their autistic sibling.

Caregivers in the study realized that their autistic children could not communicate like typical children and they developed ways of reaching out to their children. They have learnt to be familiar and keen on the facial expression, behavior and any kind of sound produced by the child in order to fulfill the needs and wants of their child. In a way they have their own unique communication style. Despite caregivers devising their own way of communicating to their autistic children, they need assistance in learning communication skills that is appropriate for autistic children such as use of picture cards, music and sign language. All said and done no caregiver wishes to have an autistic child and marital conflicts relating to autism. All caregivers would want to interact with their autistic child in a typical way and feel the joy of being a parent.

## 6. REFERENCES

- Abbeduto, L., Seltzer, M.M., Shattuck, P, et al. (2004). Stress and Coping in mothers of youths with Down Syndrome, Autism and Fragile X Syndrome. *American Journal of Mental Retardation*, 109, 237-254.
- Amanda, L.G. (2008). Mothers' Experiences of Having a Child Diagnosed with an Autism Spectrum Disorder. Massachusetts 01063.



- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* ( 5<sup>th</sup> Ed.). American Psychiatric Association, Arlington, VA
- Autism Spectrum Disorder and Other Developmental Disorders: *From raising awareness to building capacity*. Meeting Report 16 – 18 September 2013 World Health Organization, Geneva Switzerland
- Bloom, P.(2000). *How Children Learn the Meanings of Words*. Cambridge, MA:MIT Press
- Boyd, B.A. (2002). Examining the Relationship between Stress and Lack of Social Support in Mothers of Children with Autism. *Focus on Autism and other Developmental Disabilities*, 17 (4), 208-215.
- CDC Report 2016 retrieved on April 26, 2017 from <https://www.cdc.gov/ncbddd/autism/data.html>
- Centre for Disease Control. (2016). *Prevalence and Characteristics of Autism Spectrum Disorder among Children Aged 8 Years – Autism and Developmental Disabilities Monitoring Network*, 11 sites, United States, 2012. Morbidity and Mortality Weekly Report Surveillance Summary, 65(3);1-23
- Chua, K.C.A. (2015). A Triple E Framework on Parental Involvement of Children with Autism Spectrum Disorder in Early Intervention. *International Journal of Multidisciplinary Research and Development*. 2( 9), 579-586
- Coates, G.T. (2009) *Notes on Communication*. Retrieved from Wanterfall eBooks.<http://www.wanterfall.com/Communication-Contents-page.htm>
- Constitution of Kenya (2010). Government of Kenya. Nairobi: Government Printer.
- Creswell, J.W. (Ed). (2009). *Research Design*. London: Sage Publication.
- Claassen, M., Naude, H., Pretorius, E., & Bosman. M. C. (2008). *The Contribution of Prenatal Stress to the Pathogenesis of Autism as a Neurobiological Developmental Disorder: a Dizygotic Twin Study*. *Early Child Development and Care* 178(5), 487-511.
- Donaldson, O.S., Elder, H.J., Self, H.E. & Christie, B.M. (2011). Fathers' Perception of their roles during In-Home Training for Children with Autism. *Journal of Child and Adolescent Psychiatric Nursing*. 24, 200-207
- Farmer, K.J. (2003). *The Effects of Music vs Non music paired with Gestures on Spontaneous verbal and non-verbal communication skills of children with autism between the ages of 1-5*. Florida University.
- Fortunato, J. A., Sigafos, J., & Morsillo-Searls, L.S. (2007). A Communication Plan for Autism and Its Applied Behavior Analysis Treatment: A Framing Strategy. *Child and Youth Care Forum* 36(2-3), 87-97.
- Gillberg, C. & Coleman, M. (2000). *The Biology of the Autistic Syndrome*.(3<sup>rd</sup> Ed) London: Mac Keith Press
- Gupta, B.V. (Ed) (2004). *Autism Spectrum Disorders in Children*. Marcel Dekker Inc. New York.
- Griffin, E., Ledbetter, A., & Sparks, G.(Ed) (2014). *A First Look at Communication Theory*. MacGraw Hill. New York.
- Hall, T. (2000). Never say never – Keep on keeping on. *Focus on Autism & Other Developmental Disabilities*, 15 (4), 208-210.
- Howlin, P. (1997) Interventions for People with Autism: Recent Advance. *Journal of Continuing Professional Development*. 3, 94-102.
- Kanner, L. (1943). Autistic disturbance of affective contact. *Nervous Child* 2; 217-250
- Landa, R. (2007). Early Communication Development and Intervention for Children with Autism. *Mental Retardation and Developmental Disabilities Research Reviews*. 13: 16-25. DOI 10.1002
- Laird, P.D. (1997). *The Effects of Music on Cognitive Communication Skills with Students Diagnosed with Autism, Autistic like characteristics and other related pervasive developmental Disorders*. 'Unpublished Masters Thesis' The Florida State University, Tallahassee
- Maurice, C., Green, G., & Luce, C.S. (Eds) (1996). *Behavioural Intervention for Young Children with Autism; A Manual for Caregivers and Professionals*. Austin, TX: PP 400
- Neely, J., Amatea, S., Echevarria-Doan, S. & Tannen, T. (2011). Working with Families Living with Autism: Potential Contributions of Marriage and Family Therapists. *Journal of Marital and Family Therapy*. Doi:10.1111/j1752-0606.2011.00265.x1-16
- Nolen-Hoeksema, S., Fredrickson, L.B., Loftus, R.G. & Wagenaar, A.W. (Ed.) (2009). *Atkinson & Hilgard's Introduction to Psychology*. United Kingdom: Wadsworth.

- Noens, I. & Van Berckelaer-Onnes, I.A. (2005). Captured by details. Sense-making, Language and Communication in Autism. *Journal of Communication Disorders*, 38, 123-141
- National Institute on Deafness and other Communication Disorders Fact Sheet (2010). *Communication Problems in Children with Autism*. Publication No. 10-4315
- Powers, M.D. (1989) *Children with Autism: A Caregivers' Guide*. Woodbine House: U.S.A Rapin, I. (2006). *Language and Communication: Clinical Assessment and Different Diagnosis*, 51-67
- Rimland, B., Grandin, T., Edelson, M.S., & Adams, B.J. (2004). *Advice for Caregivers of Young Autistic Children: Working Paper*
- Schneider, D.E. (2004). *Communication Disorders in Children with Autism: Characteristics, Assessment, Treatment*. In Gupta, V.B. (Ed.). *Autism Spectrum Disorders in Children*. (pp 193-208). New York: Marcel Dekker Inc.
- Schopler, E., Van Bourgondien, M., & Bristol, M.M. (Eds) (1993). *Preschool Issues in Autism*. New York: Plenum
- Tager-Flusberg, H., Paul, R., & Lord, C. (2005). *Language and communication in autism*. In F. Volkmer, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders*(pp. 355-364). Hoboken, NJ: JohnWiley and Sons.
- Trevarthen, C., Aitken, K., Papoudi, D., & Robarts, J. (Ed.). (1996). *Children with Autism*. London: Jessica Kinglsey Publishers.
- Vision 2030 (2007). Government of the Republic of Kenya.
- Wigram, T.(2002). *Indications in Music Therapy: Evidence from Assessment that can Identify the expectations of Music Therapy as a Treatment for Autistic Spectrum Disorder (AUTISM); Meeting the challenge of evidence based practice*. *British Journal of Music Therapy*; 16(1) 11-28.
- World Health Organisation (WHO). (2013). *Autism Spectrum Disorders & Other Developmental Disorders*. From Raising Awareness to Building Capacity. Geneva, Switzerland