

**SOCIAL EFFECTS OF NODDING SYNDROME ON THE LIVES OF  
CHILDREN LIVING IN KITGUM DISTRICT  
NORTHERN UGANDA**

**BY**

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## **DECLARATION**

I declare that this research report is my original work. I also affirm, to the best of my knowledge, that this work has not been presented anywhere else for examination or any other purpose. Where the work of other people has been included, acknowledgement to this has been made in the text and references.

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This research report has been produced under my supervision and submitted with my approval.

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Firstly I thank the Almighty God who has seen me through this research process as well as my academics.

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## **DEDICATION**

This research report is dedicated to my loving sister who has made my academic life a success physically, spiritually, psychologically, emotionally as well as financially.

It's also dedicated to all medical personnel who are interested in neurology and psychiatry.

## **LIST OF ABBREVIATIONS**

BBC – British Broadcasting Corporations.

CDC – Center for Disease Control and Prevention

CNN – Cable News Network

CSF – Cerebrospinal Fluid

EEG – Electro Echocardiogram

IREC - Institutional Research Ethics Committee

IRIN – Integrated Regional Information Networks

KIU-TH – Kampala International University Teaching Hospital

MRI – Magnetic Resonance Imaging

NGO – Non Government Organization

UNCST - Uganda National Council for Science and Technology

WHO – World Health Organization

## LIST OF DEFINITIONS

**Nodding syndrome** – is a neurological condition with unknown etiology.

**Syndrome** – is a group of symptoms that consistently occur together or a condition characterized by a set of associated symptoms.

**River blindness** – is a topical skin disease caused by a parasitic filarial worm, transmitted by the bite of black flies (*Simulium damnosum*) they breed in fast flowing river.

**Onchocerciasis**- is an eye and skin disease caused by a warm filarial known scientifically as *Onchocerca Volvulus*.

**Outbreak** – is an occurrence of cases of disease in excess of what would normally be expected in a defined community.

**Endemic** – is a disease condition regularly found among particular people or in a certain area.

**Seizures** – is a sudden surge of electrical activity in the brain.

**Social** – relating to society or its organization

**Society** – is the gregate of people living together in a more or less ordered community.

**Stigma** – is a mark of disgrace associated with a particular circumstance, quality or person.

**Epilepsy** – is a neurological disorder marked by sudden recurrent episodes of sensory disturbance, loss of consciousness or convulsions, associated with abnormal electrical activity in the brain.

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## ABSTRACT

**Introduction** - The debilitating nature of nodding disease can have a significant socioeconomic impact of the individuals and families affected. A broad understanding of these sociodynamic effects is crucial for an integrated management of the disease.

**Objectives-** General objective was to establish the social effects of Nodding syndrome among the children between the ages of 1-19 years of Kitgum district in Northern Uganda. Specific objectives included; identification of the social effects of nodding syndrome on the lives of children in Kitgum district, identification of how biological and psychological effects of the condition are affecting their social life style, identification of factors related to the symptoms of the syndrome.

**Methodology-** This descriptive cross sectional study interview of 82 affected individuals using questionnaires, focus groups and interviews to study the social effects of nodding syndrome amongst children aged 1 to 19 years in Kitgum (Northern Uganda).

**Research results-** Of the 82, stigma was reported amongst 19.51% (16) at the work places, 25% (4) at home by their siblings, 34.69% (17) by their teachers at school, 61.22% (30) by their fellow students and 24.33% (9) at church and 45.12% (37) by their peers in the neighborhood.

Of the school going age (59.76% that is 49), 40.24% (33) are currently not going to school, Overall, 69.51% of the participants are not happy about their current lives.

63.41% (52) were reported getting seizures during their meals, 54.88% (45) reportedly lost weight and 47.56% (39) were reportedly underperforming in daily activities as compared to their non affected age mates in the neighborhood.

**Conclusion-** The study shows that nodding syndrome victims are stigmatized everywhere which impairs their cognitive, social and developmental milestones.

**Recommendations:** another research to study the physiological impact of nodding syndrome should be conducted; the government should provide special care, the public needs to be educated about this syndrome.

**Key words:** Stigma, Cognitive, descriptive, cross sectional, seizures.

## **-CHAPTER ONE-**

### **1.0 Introduction**

*“By paying attention to the way in which different actors come to terms with mystery and misery, we can catch a glimpse of how people act when faced with uncertainty and affliction”*

Bennell Van K. This report aims to explain one of the most devastating diseases in Kitgum northern Uganda (nodding Syndrome). This chapter gives background information into the syndrome; some of the signs and symptoms as well as explaining its historical origin.

### **1.1 Background information**

Researchers believe that it has a close association with Onchocerciasis volvulus, (a nematode) carried by black fly and causes river blindness (Lucy M, et al 2003). In 2004 most of those who suffered the disease lived close to the Yei River and 93.7% of them were found to harbor the parasite (Lucy M, et al 2003). *Onchocerca volvulus* is unable to travel to its host's brain, so is unlikely to cause the neurological symptoms that's shown by the children with the nodding disease (Kahn, 2012). Nodding syndrome is a neurological condition with unknown etiology (WHO, 2014). Nodding syndrome affects thousands of children in East Africa and is followed by epilepsy, progressive mental deterioration and stunted growth (Kahn, 2014).

There have been findings that the syndrome can also be linked to the chemical exposure of the fire arms from the war times of Joseph Kony as well as malnutrition. (Lucy ,M et al 2003). The Ministry of Health therefore concluded that the disease may have started as early as 2003 when most of the population of Northern Uganda was moved to the Internally Displaced People's camps (Bukuluki et al, 2012). The highest burden of the disease was in Labongo Akwang sub-county in Kitgum district with the prevalence of 1,305 per 100,000 population and Pader district with a prevalence of 519 per 100,000 population (Bukuluki et al, 2012). Most of the populations affected by the nodding syndrome were internally displaced in Uganda and Sudan, the conflict with the Lord's Resistance Army during the 1990s which resulted into dependence on refugee camps and in widespread food shortage during the years preceding nodding syndrome (Scott et al, 2013).

Malnutrition is a condition that results from eating a diet in which nutrients are not enough or are too much such that it causes health problems (New York: United Nations Children's Fund 2010). According to a report by the New York: United Nations Children's Fund 2010, the nutrients include calories, proteins, carbohydrates, Vitamins, or minerals. This situation can result to starvation and may have symptoms which include short height, thin body, very poor energy levels, swollen legs and abdomen (New York: United Nations Children's Fund, 2010. Other causes of malnutrition include anorexia nervosa and bariatric surgery. In 2010, protein energy malnutrition was established to have resulted in 600,000 deaths (New York: United Nations Children's Fund, 2010). Other nutrition deficiencies include iodine deficiencies and iron deficiency anemia resulting in another 84,000deaths (New York: United Nations Children's Fund, 2010. A third of deaths in children are believed to be due to malnutrition (New York: United Nations Children's Fund, 2010. About 165 million children get stunted growth from the condition. Malnutrition is commonly used to define protein-energy malnutrition (New York: United Nations Children's Fund, 2010. This condition other than stunted growth also presents with wasting, and decreased immunity; this commonly leads to kwashiorkor and marasmus(New York: United Nations Children's Fund, 2010).

Wadman reported that, due to the seizures that attack children when they are presented with unfamiliar foods, they fail to eat properly and enough, in the long term they lack most of the nutrients they need and hence start wasting and lead to malnutrition (Wadman M, 2011). The disease first emerged in south Sudan in 1960s and Tanzania in 1962 then latter was discovered in Northern Uganda in 2009 (Wadman M, 2011). More recently the condition has been more prevalent in south Sudan where in 2003 approximately 300 cases were reported in Mudri region (Wadman M, 2011). In 2009 the Ugandan Ministry of Health declared that 2000 children suffered from the disease (Wadman M, 2011). However, in 2011 more than 1000 cases were diagnosed in the last half of the year in Kitgum, Pader and Gulu districts (Wadman M, 2011). In some villages as many as one in six children have the condition and many families have more than one ill child (Kahn, 2014)

Symptoms of the disease include stunted growth, mental handicapping, and nodding seizures while others freeze (Lucy M et al, 2003). The seizures mostly manifest when the individual has been presented with food or when there is change in weather (mostly to cold) but it has also been discovered that when the individual is presented with an unfamiliar food no seizures happen, however, the seizure stops when the child stops eating or when they feel warm again; this condition manifests with some degree of severity. (Lucy M et al, 2003) It was reported by Lucy in 20013, the disease was found to be mentally and physically disabling and only affects children of the age 5-15 (Scott, 2013) mostly though it can stretch from 1 to 19 years of age.

Wadman continues in his report, although the exact diagnosis system of the disease is not yet well advanced, sub-clinical seizures identified in electroencephalograms and MRI scans have shown that there is brain atrophy and damage to the hippocampus and the glial cells of the brain (Wadman M, et al, 2011) as well as evaluation of cerebrospinal fluid, brain imaging and video electro encephalopathy (Scott, 2013). However, at the moment the only way of diagnosis is using a Neurological scan (Wadman M, et al, 2011). There is no known cure for the disease, so currently treatment using anticonvulsants targets the symptoms of the condition, these include; Sodium valproate, Phenobarbital. In most cases it results to death, collapse from the seizures (Wadman M, et al, 2011).

## **1.2 Problem statement**

A report by Lucy et al 2003, states that it has been found the condition has affected in three different countries that is Tanzania, South Sudan and Northern Uganda. Since the war by the Lords Resistance Army led by Joseph Kony in 2009 (Lucy et al, 2003) it was reported that over 1000 children were affected by the condition in Northern Uganda, a new disease as Nodding syndrome has devastated many children in the regions. The last statistic in 2009 it was reported that more than 2000 children had the disease in Kitgum, Pader and Gulu alone (Wadman M, et al, 2011). Many families are torn apart and many parents are wishing death on their children because of the suffering they are experiencing.

In Kitgum district, many children are affected by the condition, but according to statistics, rarely do they survive past the age of 19 year old (Lucy et al, 2003). When children get the condition, it



affects every aspect of their lives such as stunted growth, mental deterioration and disorganization of their social lifestyle. Although parents might not see it as a form of torture rather a protective measure to prevent their children from getting lost or getting into danger or death, many parents continue to tie their children to poles with ropes while leaving them at home. This helps to keep them in a safe corner but to some extent, it affects their emotional development. Most of the affected children lack formal education, cognitive skills as well as social skills. Due to the condition, many of the affected children tend to get disowned by their parents because they see them as of no value. The children cannot do any physical work, they can't think for themselves and get attacked by seizures and in addition, they cannot be left alone due to fear of setting fires, getting lost, getting into accidents.

### **1.3 General objective**

To establish the social effects of Nodding syndrome among the children between the ages of 1-19 years of Kitgum district in Northern Uganda.

### **1.4 Specific objectives**

1. To identify the social effects of nodding syndrome on the lives of children in Kitgum district.
2. To identify how biological and psychological effects of the condition are affecting their social life style.
3. To identify factors related to the symptoms of the syndrome.

### **1.5 Research questions**

1. How is nodding syndrome affecting the social life style of the affected individuals?
2. How are the biological and psychological effects contributing to their social lifestyles?
3. What other factors are related to the symptoms that manifest due to the syndrome?

### **1.6 Null hypothesis**

- Many patients can suffer from the condition and still have a normal life.
- The condition has no effect on their biological development, so they still grow normally.
- The syndrome has no effect on the patient's psychological well being.
- Many patients with the condition still have a normal social life style, that is they go to school and play and study just like any other normal child.

- Patients are not discriminated in society.

### 1.7 Justification of the study

Since 2009 when nodding syndrome was identified in Northern Uganda, over 3000 children have been affected in Pader, Kitgum and Agago district alone (Wadman, 2011). Research has been done by different organizations but until to-date no cause has been fully identified (WHO, 2014), no cure has therefore been identified. Many children continue to suffer in their homes and many end up dying. This study creates awareness into the effects of the syndrome on the physical and mental developments of patients. More understanding in the psychological well being of the patients is addressed and any related/ associated factor. This study brings knowledge to understand how patients with this condition cope on their day to day lives in societies with the normal people. This study also adds knowledge to the general public but more so to the medical discipline and the medicine academics.

### 1.8 Conceptual framework

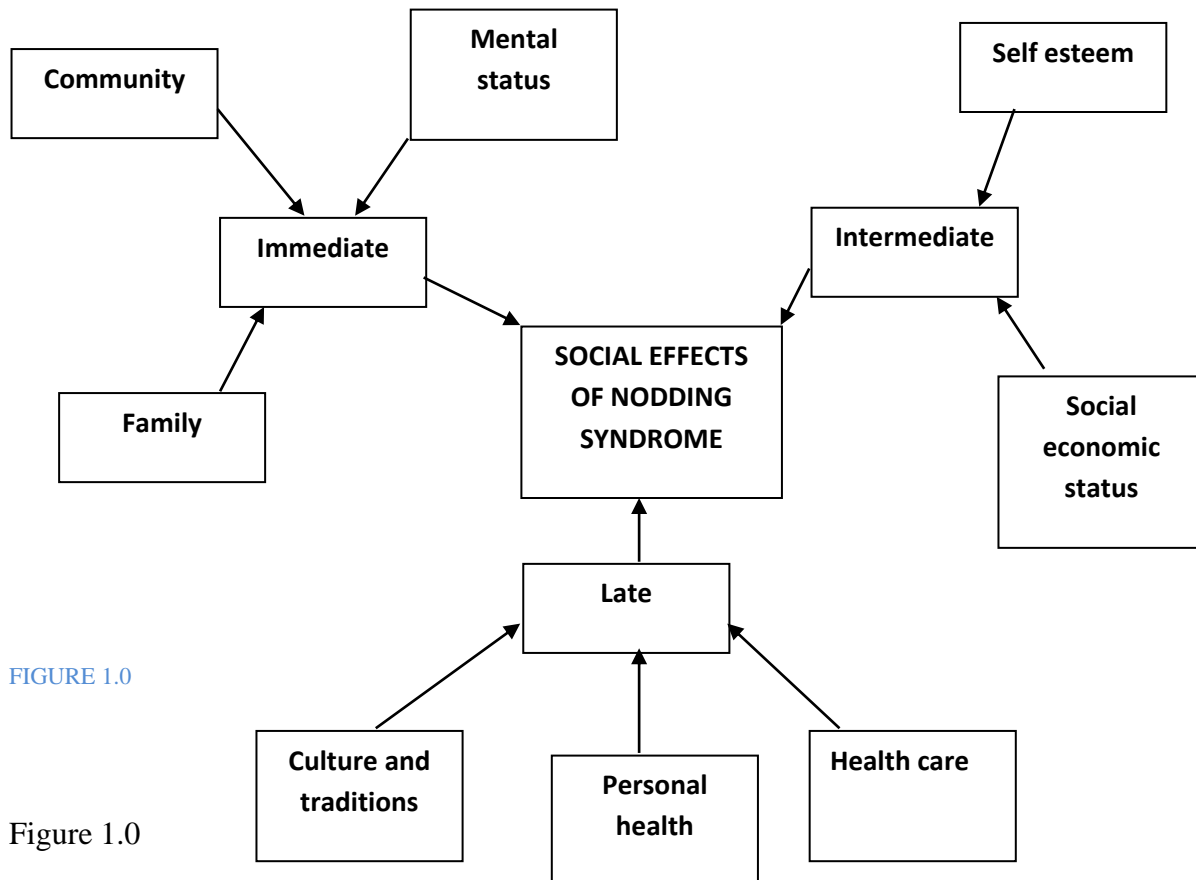


FIGURE 1.0

Figure 1.0

This conceptual framework was divided into three categories according to the length of time taken for the factors to cause the social effects, the variables relate following a time scale.

**Immediate variables:** Mental status/ behavior: Nodding syndrome causes seizures and mental disturbance. Many patients of the condition gained mental instability and therefore they were mentally unstable to socialize with the so called normal people. Community: after the effects of the disease especially on the mental status, the community perceived the individual as “mad” and they immediately refrained from interacting with the patient. Family: because of the instability in life due to the condition, family members started excluding the patient from activities and their relationship/ bond as a family was reduced.

**Intermediate variables:** Education; because of the mental instability, one was no longer able to proceed with their education and therefore if the disease has began at an early age, the individual was be illiterate, want able to read or write hence some aspect in society were not fully met. Self esteem; as a patient, they slowly started having feelings of unworthiness, unappreciated, unloved and lead to reduction in their self esteem. Social economic status; many families in the area of study had a low social economic status. Due to lack of enough funds, many people couldn't afford a standard life style which could help the situation.

**Late variables:** Culture and traditions; with time as the condition progressed, many people around thought that the patient had been bewitched, because of those cultures and beliefs. Health care; nodding syndrome doesn't have any cure at the moment and its ways of spread were not well known by the community. Personal health; many children started getting seizures when they were presented with food, therefore in the long term they became malnourished. This led to immune compromise and hence recurrent infections which could lead to death.

This cross sectional study was focused on how the patient's social lives (82 participants) were affected by the above mentioned variables in all social gatherings. Identification was made on how the participant children were affected especially when out with other people they relate with using questionnaire, interviews as well as focus groups. Observations were made regarding their behavior and response to the environment and the people around.

### **1.9 Scope of the study**

This research looked into the social effects of nodding syndrome on the lives of children of Kitgum district. It is focusing on children of the ages 1-19. In addition to finding out the effects, it has also identified the management projects the non governmental organizations have put into place to care for the patients. Other factors such as biological and psychological contributing to the social effects have also been examined.

## **-CHAPTER TWO-**

### **2.0 Literature Review**

#### **2.1 The social effects of the disease**

An article on nodding syndrome speaks strongly on the people's perception about the transmission of the disease in the community (Katrina B, et al, 2013). Despite associating the appearance of nodding syndrome with the decade of the war, most community members believe that the syndrome is transmitted from one child to another (Katrina B, et al, 2013). Many parents attempt to isolate ill from healthy children (Katrina B, et al, 2013). The village schools indicate similar measures to keep affected children physically separate from others (Katrina B, et al, 2013). One parent expressed that adults are not susceptible to the transmission of the syndrome because 'The blood of elders is stronger' (Katrina B, et al, 2013). Another added 'Adults can resist because they are strong, Adults who are experiencing nodding syndrome may still have the spirits or toxins in them' (Katrina B, et al, 2013)

According to media reports, this devastating condition has created a lot of stigma among the children of Kitgum district northern Uganda, a mother explains to the BBC news reporter in 2012, that her two affected children no longer go to school and the most worrying thing is that the children are not showing any signs of improvement since the start of the medication to control the seizure a year ago, she goes on to explain that the neighbors don't allow their children to interact with them and as a result, the whole family has become isolated from the rest of the society (BBC, 2012). Due to fear of leaving the children unattended to, the father explains to BBC that he has stopped going to the garden to farm as often as he used to in fear that if he leaves, the children will disappear or get into an accident, and this has taken a great impact on their finances so the family is going deeper and deeper into poverty (BBC, 2012).

As the mother of the children explains she adds that she has lost hope for the future, her children are like flowers she has to care for them around the clock because they can't wash themselves nor dress (BBC, 2012). When they get food to eat, they get into epileptic seizures and fall off (BBC, 2012). When the mother goes to the farm, she ties them to a tree so they don't walk off. This has limited their interaction with other people (BBC, 2012). Due to this traumatizing

reaction, from other children, many families like this one have been cut off from society (BBC, 2012). Liberia, Sudan as well as Tanzania has also had outbreaks of the condition but it first came to the attention of authorities in Uganda in 2009 (WHO, 2014). According to a report by the Uganda CDC global health (January 2014), the centre has responded to many requests for assistance from the Uganda ministry of health as well as South Sudan to help in the investigation of the mysterious condition that's affecting many children of the Northern regions of the country (CDC, 2014).

## **2.2 Biological and psychological effects of the condition affecting their social life style.**

This condition; nodding syndrome remains an unexplained neurological condition which is characterized by repetitive dropping of the head forward as well as accompanied by seizure-like episodes (WHO, 2014). This condition has been found to commonly affect children of the ages 5-15 years (WHO, 2014; Kahn 2014) though it also stretched from 1 to 19 years old (WHO, 2014).

A research in Kitgum district northern Uganda discovered that the nodding disease causes seizures and the affected individuals become physically and mentally stunted together with blindness and in some cases death (IRIN, 2009; Bukuluki et al, 2012). Reports that, there is an association between the disease and malnutrition as well as Onchocerciasis remain inconclusive (Wadman, 2011). There has not been a report about the actual cause or even the cure of the nodding syndrome hence it's still in question (Wadman, 2011). Anecdotally, cognitive impairment appears to be progressive; evidence of psychiatric disturbances have included visual and auditory hallucinations along with occasional features such as screaming, shouting, jumping up and running in circles (Scott et al, 2013). Although the actual cause of the condition has not yet been found researchers are associating the disease with Onchocerciasis volvulus, (a nematode) carried by black fly which is known to cause river blindness (Chilton P, 2014). Patients suffer many symptoms like seizures, mental disturbances, behavior changes, but the immediate cause of the symptoms is known to be tonic seizures (CDC global health, 2014).

A medical NGO in the Mundri area of western equatorial South Sudan reported an estimated number of 300 cases in 2003 (IRIN, 2009). It was also reported to IRIN by the local leader

OnonyoYokoyedo (2009) from Kitgum district that 200 children in his village of Okidi had the condition. Janet Oola a Kitgum health officer told IRIN that hundreds had presented with symptoms of the nodding disease in the district in 2008 (IRIN, 2009). She also added that it's an early stage of epilepsy. It has been reported by IRIN that the most likely cause of the disease is a neurological effect of a parasite that causes Onchocerciasis otherwise known as the river blindness (IRIN, 2009). River blindness is a disease transmitted by black flies infected by the filarial worm *Onchocerca volvulus* (IRIN, 2009). In 2009 a study of 8 African countries Uganda included, showed a statistical link between river blindness and epilepsy found that for every 10% increase in the prevalence of Onchocerciasis the epilepsy rate would also increase by 0.4% in the data of over 70,000 patients; a link between the two was found. (IRIN, 2009)

The condition has been discovered as an endemic in 30 African countries (IRIN, 2009). After the health ministry team visited Gulu, Kitgum and Pader, it learnt that the disease was more common among people living near streams and these include: Pader, Lakankodi, Adinga, Lanyalyang and Anyuka (IRIN, 2009). They vary from the briefest lapses of attention or muscle jerks to severe and prolonged convulsions (IRIN, 2009). According to the WHO fact sheet, Grace Lanyero a psychiatrist at Kitgum government hospital reported that food seemed to be one of the triggers of the attacks in many children (IRIN, 2009). The child starts nodding with uncoordinated hand movements that don't reach the mouth (IRIN, 2009). She also told IRIN that the affected children were being treated by anti- convulsants but it has not yet been reported that these medicines can cure the condition all-together nor has any treatment been discovered (IRIN, 2009). Public health investigators classified 1687 children aged 5-18 years in 3 districts of the country as having probable nodding syndrome for a prevalence of 6.8 probable cases per 1000 children in that age group (Lyengar P J et al, 2014). A study in December 2008 by IRIN reports that the seizure disorder had been earlier reported in Tanzania in 1960. Epilepsy affects up to 50 million people worldwide (WHO, 2014).

Researchers found the nodding to begin when children are fed the local diet of beans and starch, but that candy bar and energy bars do not have any effect (Lacey, 2003). According to CNN (McKenzie D, 2012) reports, doctors are using the drugs for controlling the epilepsy but with limited improvement, it only slows progression of symptoms rather than stop them. The affected

children also require immediate treatment for the Onchocerciasis. A scenario is given by Evelyn Aweko from Pajule village in Pader district who reported to IRIN that her 14 year old son developed the complication in mid 2005 and all treatments failed. “he started presenting unusual behavior, whenever food was brought to him, he nodes and fails to put the food into the mouth, sometimes he appears to have lost his memory, start nodding and eventually fall to the ground”.(McKenzie D, 2012). In addition to failure of proper feeding, these children also suffer from cognitive impairment, delayed puberty and growth retardation; as well as dysmorphic facial features, dwarfism and delayed sexual development have been noted though not consistent (Scott et al, 2013). A medical person at Kitgum General Hospital confirmed that other than the Nodding Syndrome, malnutrition is another serious disease affecting the patients. This affects their body immune system and the potential to absorb treatment (Otim&Odong, 2013)

Studies in Mulago Hospital showed that the cognitive assessment in three children demonstrated profound impairment (BMJ open, 2013). The EEG was abnormal and suggestive symptomatic generalized epilepsy in the majority (BMJ open, 2013). There were different degrees of cortical and cerebella atrophy on brain MRI but no hippocampal changes (BMJ open, 2013)

### **2.3 Other factors related to the symptoms of the syndrome**

CNN (McKenzie D, 2012) reported the following, the seizures start when patients are presented with unfamiliar foods or when the weather changes. Other symptoms like; children wander off by themselves and get lost in the bushes, start fires, appear confused and traumatized, drooling and falling a sleep even when they are not tired, other symptoms like losing cognitive ability and experiencing stunted growth (Hill S,2012). A mother of a patient tells BBC “I’ve lost hope. I’m just taking care of Sarah and Moses like flowers in the home knowing they are no use in the future, when I go off to farm, I tie them to the tree so they don’t get injured (BBC, 2012).. If they walk off they don’t know where they are going they just keep walking and get lost.” (BBC, 2012). This is because of the deterioration in the mental status of the patients, once a child is affected, their cognitive aspect is changed, their understanding of things changes and because the brain is affected, they are not able to understand right from wrong or even carry out an activity (McKenzie D, 2012). Many die of infection because they get weak and malnourished while other die of their reckless behavior (McKenzie D, 2012).



Many children with the condition are born normal but acquire it like any other disease in life (McKenzie D, 2012). According to CNN (McKenzie D, 2012), at the moment there is no real solution to the condition and there is no known cause; however, since many show a deficiency in Vitamin B6 it has been proven that nutrition is associated. The disease has not been found to be as serious as Ebola in terms of outbreaksCNN(McKenzie D, 2012). This outbreak in Uganda is currently confined to the northern region and there is no evidence of it being contagious. CNN (McKenzie D, 2012) also reported that the disease only affects children between 1-19 years old with the worst being 3- 11 years old this results are based on the unreliable evidence gathered by the health workers in the regionCNN(McKenzie D, 2012).

However, it is still unclear of how many fatalities have been caused by the disease itself but its victims are left unable to function in any meaningful way since they are profoundly dependent on others for in all aspects of their lives (McKenzie D, 2012). Therefore parents tie up their children when they have to leave the house in fear of them running away, or getting in accidents which would lead to death (McKenzie D, 2012). Many patients die due to loss of consciousness and the horrific accidents, like falling into a cooking pot, fire or even drowning while others just simply disappear and are never found (Obi W, 2014).

This condition is in a region where many families suffered for many decades from brutality by the Lord's Resistance Army which was lead by Joseph KonyCNN(McKenzie D, 2012). During this time thousands of children were abducted and many civilians ended up in refugee campsCNN(McKenzie D, 2012). Despite the speculations, there are many countries which have river blindness but do not have nodding syndrome (Muhumuza R, 2012). The CDC in Atlanta has been working with the Ugandan government but at the moment, they have come to revelations to identify the cause of the nodding, is it war related chemical exposure, may-be a repose to a local parasite, or vitamin deficiency or genetics (Kielty M. 2013). Many lost their relatives while others had to kill and eat the parts of the individuals they killed. Almost every home in Pader district was affected (Kielty M. 2013).

Simultaneous recordings of 2 episodes of EEG videography, electromyography and electrocardiography documented that the nodding episodes are manifestations of atonic seizures,

in these cases patients head nodding was associated with generalized electrodecrement, followed by generalized sharply contoured rhythmic theta activity, dropping of the chin, and paraspinal electrography abnormalities (Scott et al, 2013). When CSF was assessed, it was grossly clear and all glucose and protein levels were within reference ranges for age (Scott et al, 2013). However, none of the patients show evidence of meningeal or parenchymal inflammation, cystic or other lesions consistent with acute disseminated encephalomyelitis, neurocysticercosis, central nervous system tuberculosis or other focal brain infections (Scott et al, 2013). Pulvinar sign, cortical ribboning or other findings which suggest human prion disease have not been identified (Scott et al, 2013). One magnetic resonance image of a 13 year old boy in Uganda with the condition showed prominent cortical atrophy (Scott et al, 2013)

There is no known cure for nodding syndrome so Uganda's Ministry of Health has begun using anticonvulsants such as sodium valproate to treat its signs and symptoms, meanwhile the disease is continuing to spread says Janet Oola, Pader's health officer and Sam William Oyet the district's medical entomology officer (Abraham, 2011)

Another associated factor to the nodding syndrome is the consumption of monkey meat but investigations have determined no link (Donnelly, 2012). Aside from the potential chemical poisoning the northern Uganda community demonstrates religious and spiritual beliefs about the etiology of nodding syndrome (Katrina B et al, 2013). One parent of an affected child explained 'it's a plan of God, because not all families have it. God is tired of people, and is punishing in many ways (Katrina B et al, 2013). This is for the many sins they have committed, we don't know what the sins are but God does'. The spiritual beliefs are intertwined with the effect of war on their region. Many community members assert that fighting in the war led to the development of nodding syndrome (Katrina B et al, 2013). 'Many people were killed' one parent said. Another added 'if you have a quarrel at home, then you have problems...if you quarrel and then something bad happens, it is the result of the quarrel' (Katrina B et al, 2013)

## **-CHAPTER THREE-**

### **3.0 Research methodology**

#### **3.1 Introduction**

This chapter gives a description of how data was collected; it gives details of the research design, study area, the study population, sampling methods, ethical consideration, study instruments as well as quality control.

#### **3.2 Study design**

For this research, a cross sectional descriptive case study was applied as a means of collecting sufficient data. It was specifically limited at identifying the social effects of nodding disease on the lives of those who are already affected and any other associated factors.

#### **3.3 Study area**

My study area was Kitgum district; located in northern Uganda. It is bordered by south Sudan to the north, Kabong district to the east, Kotido district to the southeast, Agago district to the south, Pader district to the southwest and Lamwo district to the northwest. Kitgum, the largest town in the district is located approximately 108 kilometers (67mi) by road northwest of Gulu the largest city in the sub-region. It's also located 460 kilometers by road north of Uganda's capital, Kampala.

Kitgum is a constituent of Acholi land. The 2002 national census estimated the population of about 41,820. In 2008 the Ugandan bureau of statistics estimated the population of the town to be at 57,300. This has had a rise in 2011 mid-year of about 59,700 and in 2012 it was 247,800. Agriculture is the main economic activity within the district, and some cattle ranching is done although not by many.

#### **3.4 Study population**

The study population included all patients of nodding syndrome who were within the age groups of 1-19 years old. Although the exact number of cases in the district was not known, it was estimated that there are over 3000 cases in the three districts that is Kitgum, Lamwo and Pader. The research was done in Kitgum district where most residents were Acholi a Luo Nilotic ethnic group. Their mother tongue was Acholi and millet bread their staple food.

### 3.5 Sampling methods

For this research used non randomized purposive study method; because I already knew the type of participants I wanted, I therefore didn't need to carry out random selection. This method targeted only people with nodding syndrome between the ages of 1-19 to be part of the study.

### 3.6 Sample size

So as to achieve an accurate value with 5% precision and to be able to attain a 95% confidence level I used fisher's et al 1990 formula

$$N = \frac{Z^2 \times P \times Q}{D^2}$$

N= is the desired sample size

Z= Standard normal deviation which is 1.96 at a confidence level of 95%

P= Proportion of target population estimated to have similar characteristics in my study area.

If there is no measurable estimate, we use 50% (constant) or 0.5. Therefore P=0.5

Therefore Q= is standardized 1.0- P= 0.5

D= is the degree of accuracy desired 0.1 or 10%

$$N = \frac{1.96^2 \times 0.5 \times (1-0.5)}{0.1^2}$$

$$N = \frac{0.9604}{0.01}$$

$$N = 96.04$$

$$N = 96$$

Therefore it was estimated that a sample size of 96 individuals was to be used for the study.

### 3.7 Data collection instruments

The instruments for collecting data were both qualitative and quantitative. Qualitative instruments such as interviews (because some of the patients were not able to understand English or write, therefore could not carry out self administered questionnaire), focus groups and observations.

For quantitative methods I used both open and close ended questions in my questionnaires, document review from hospital. I also moved with the hospital nodding syndrome response team

to health centers to help me with the collection of the correct data as well as translation of the languages as they went to give out mediation. This study focused on only individuals who were affected by the syndrome. These questionnaires were designed to collect social effects of the individuals who were affected by nodding syndrome as well as any other associated factors.

### **3.8 Data quality control**

Data quality control refers to the validity and reliability of the instruments used for data collection. Validity is the degree to which a test measures what it claims or purports to be measuring (Brown, 1996). To ensure validity in this study, the selected data collecting instruments were thoroughly discussed with my supervisor to ensure that they answered the questions correctly. Reliability is the degree to which an assessment tool produces stable and consistent results (Phelan and Wren, 2006). To ensure reliability, the instruments were pre-tested on a small number of patients who were not included in the study.

It was very important to ensure that the data I collected was at its best quality so as to make an accurate conclusion. I ensured quality control by:

- Making sure that the instruments were well equipped and reliable.
- Making sure I got the appropriate participants.
- Ensuring the participants I got were ready to give me all the information I required.
- Asking clear and appropriate questions.
- Ensuring confidentiality and maintain ethics during the interviews and interaction process.
- Use of questions that allowed the participants to express themselves.
- Ensuring that all the information needed from a participant was acquired on the first interaction.
- Making sure that the participants understood the questions being asked and this required an interpreter.
- Reviewing all the instruments/ methods I used to collect data at several stages.

### **3.9 Data processing**

This research was based on social effects which a qualitative finding rather than quantitative. Qualitative research is one that's involved in the development of concepts which help us to understand social phenomena in natural rather than experimental settings, giving due emphasis to the meanings, experiences and views of the participants (Mays et al, 1995). The analysis of such data was based on interpretative philosophy. The idea was to examine the meaningful and symbolic content of the data. Qualitative data analysis involved a range of processes and procedures where by we move from the qualitative data that have been collected into some form of explanation understanding or interpretation of the people and situation we are investigating.

There are five steps that I took during the analysis of my data;

1. Organize the data: This involved data cleaning and recognizing the important data that answered the specific objectives.
2. Identify the framework: it was explanatory, guided by the research question or exploratory guided by the data.
3. Sort data into framework: this involved coding the data into categories such as very good, good, very bad.
4. Used the framework for descriptive analysis: descriptive analysis this involved range of response in categories as well as identifying recurrent themes.
5. Second order analysis: identify recurrent themes, notice patterns in the data, identify respondent clusters, build sequence of events, search data to answer research questions then developed a hypothesis and tested it.

It was important that all the information was categorized and put into table format so as to ease and simplify the analysis. Graphs and pie charts were drawn to represent data in a simplified format.

### **3.10 Statistical methods used**

For proper analysis and inter presentation of the data collected I used the statistical formulae in the Microsoft excel e.g. sum, subtraction

### **3.11 Ethical considerations**

For this study to ensure the practice of ethics and integrity, I ensured the following were carried out with knowledge since my study was on human participants:

After the submission of my research proposal, my supervisor signed it and granted me permission to go ahead and carry out the research. Ethical approval for the conduction of the study was obtained from Kampala International University Institutional Research Ethics Committee (IREC), Mbarara University of sciences and technology and Uganda National Council for Science and Technology (UNCST). This permission was be obtained by acquiring an introductory letter into the district through the office of the dean of clinical medicine and dentistry. With this letter I went to the office of the in charge of Kitgum General Hospital (Dr. Okello Geoffrey). Through him the responsible person on nodding syndrome research in the district granted me permission to go a head with my study. With the permission from the hospital in charge, I was then referred to the nodding syndrome hospital ward where I met the head of the department and with him I worked both in the ward and in the community.

All patients of nodding syndrome in this study were with in the ages of 1-19; are considered to be minors and therefore cannot give consent. However in addition to the age, they were also unable to speak and understand the questions that were asked. Therefore all the information gathered was collateral from the care takers. Before starting the data collection process, I ensured that the questionnaire was fully validated by pre-testing. With feedback, I then made changes to the questions that needed to be changed. On the questionnaire, there was be a space for the participant such that before I asked them questions, the aims, the process and the importance of the study was fully explained to them before they consented. After consenting to the study, they signed as a proof of permission granted. When explaining the study to the participants I was very open and honest so they knew exactly what they were required to do and anything they did not wish to do or answer they could reject.

Autonomy was practiced such that no individual was bribed into answering questions so the response to the participation was entirely voluntary and they had the right to withdraw at any time. I maintained the respect that was due to the participants in such a way that I did not afflict

any form of physical, spiritual or psychological stress on them. All the information that was provided by the participants was respected and treated with confidentiality. I did not include names of the participants to avoid any identification incase the information got to the public.

### **3.12 Work plan**

According to the work plan in appendix VII, my plan with the authorities started on the 21<sup>th</sup> November. This helped me to have made a connection with the people of the area prior to my travel. As soon as I arrived, the following day I went and met the person I had spoken to (the hospital in charge) and gave him my introductory letter. This quickened the process. After collecting all my data for two days, I started traveling back to KIU-TH on the 30<sup>th</sup> of November.

### **3.13 Budget**

Appendix VIII is the budget giving the outline of all the items that were required and the money both per unit and the total sum.

### **3.14 Study limitations**

There are a number of challenges that faced during this process of collecting data such as;

- Language barrier: therefore I had a translator to help me with communicating to the patients. However, the translator needed to be facilitated as well as trained about the questionnaires that took some time though not a lot.
- Locating the correct places to find the participants: on the day I arrived at the hospital, the nodding syndrome repose team was going for an outreach I was therefore asked to join them for that day and the next.
- Participants not understanding the questions very well: the translator had to explain the questions to the participating patients.
- Not enough time: due to limited time, I did my best to collect as much information as possible within two days.
- Due to not having enough time as well as resources I stayed for only two days and with in those days I only managed to reach 82 patients and therefore did not meet my sample size target, because the villages are very big and all homesteads are scattered and far apart.



**3.15 Inclusion criteria**

All patients with nodding syndrome living in Kitgum district were valid to take part in the research process on the basis of first contact so as to limit the study to my sample size.

**3.16 Exclusion criteria**

This research was only focusing on nodding syndrome patients with in the age group of 1-19 years old. Anyone outside this age group was not considered. It also excluded all patients who refused to take part in the study process.

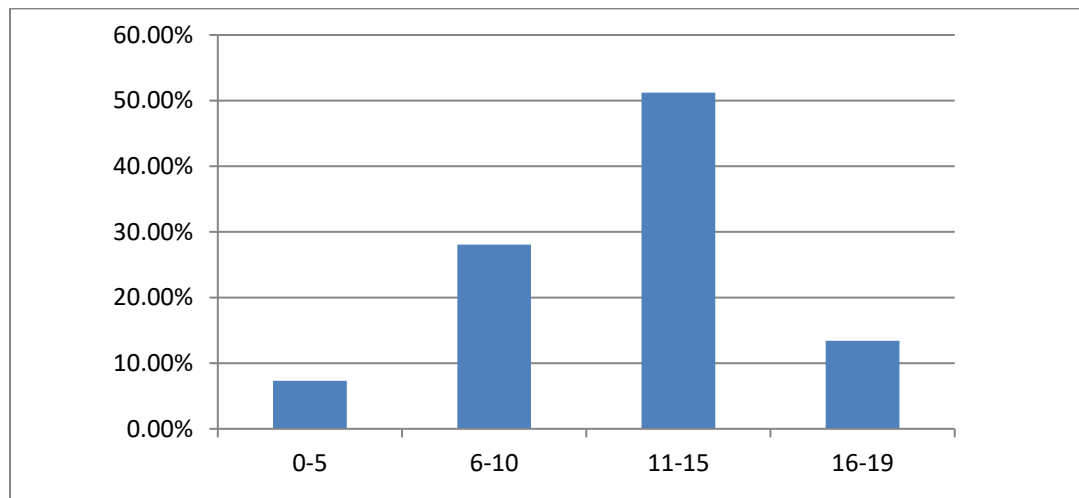
## **-CHAPTER FOUR –**

### **4.0 Results finding**

#### **4.1 Introduction**

This research was conducted in Kitgum District General Hospital as well as the community around. According to the calculations, my sample size was initially 96 individuals. However, due to insufficient time as well as funds, 82 participants were involved in this research. Many patients of the syndrome were not mentally stable and since most of them were below the age of 18, according to Ugandan law persons under the age of 18 years old were not fit to give informed consent. Therefore all questions were directed to the patient's parent who was present at the time of the interview. This information is collateral and therefore might not give a full picture of how the patients feel themselves. Although some families had more than two patient individuals, every patient was interviewed independently of the sibling.

#### **4.2 Demographic data**



**Figure 1: % number of participants in age groups**

This graph shows the number of participants in every age group. 7.32% (6) were in 0-5 years old which was the minority, 28.05% (23) were between 6-11 year old, 51.22% (42) were between 11-15 years the great majority and 13.41% (11) were between 16-19 year old.

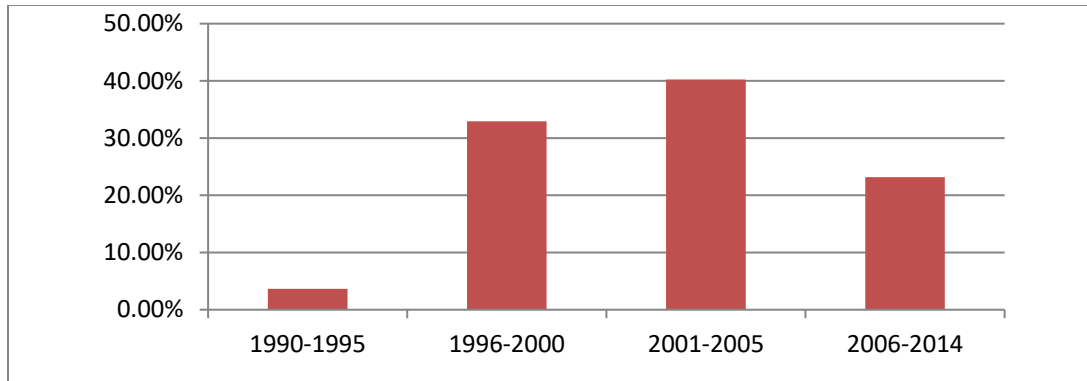


Figure 2: Years of birth of participants

The great number of participants which was 40.24% (42) were born between 2001-2005, and the least number 3.66% (3) were born between 1990-1995, 32.93% (27) were born between 1996-2000 and 23.17% (19) were born between 2006 and 2014.

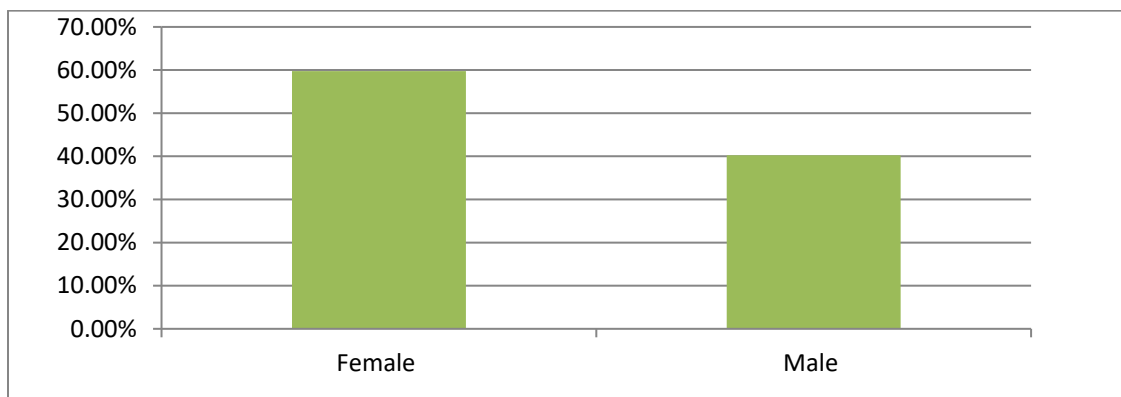


Figure 3: Gender of participants

There were more female participants that took part in this research compared to males as evidenced by the following figures; females 59.76% (49) while the males 40.24% (33)

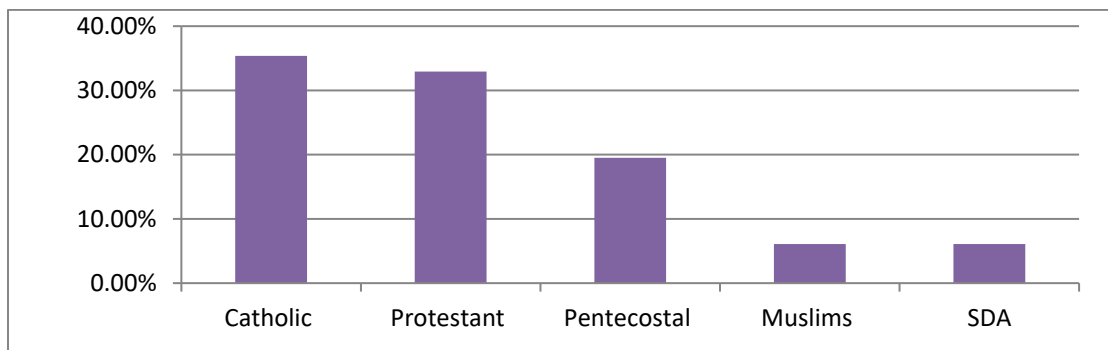


Figure 4: Religious groups of participants

This graph represents the different categories of religious groups of participants as follows; catholic were 35.37% (29), Protestants were 32.93% (27), Pentecostal were 19.50% (16), Muslims were 6.10% (5) while Seventh Day Adventists were 6.10% (5)

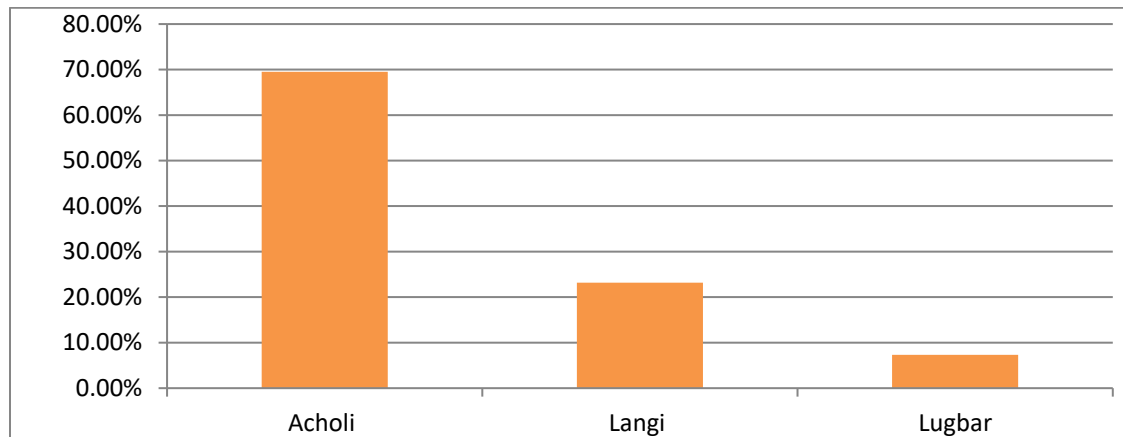


Figure 5: Tribal groups of participants

This graph shows the various tribal groups involved in the research with Acholi being the dominant tribe with 69.52% (57) followed by Langi with 23.17% (19) while the Lugbar were the least 7.32% (6).

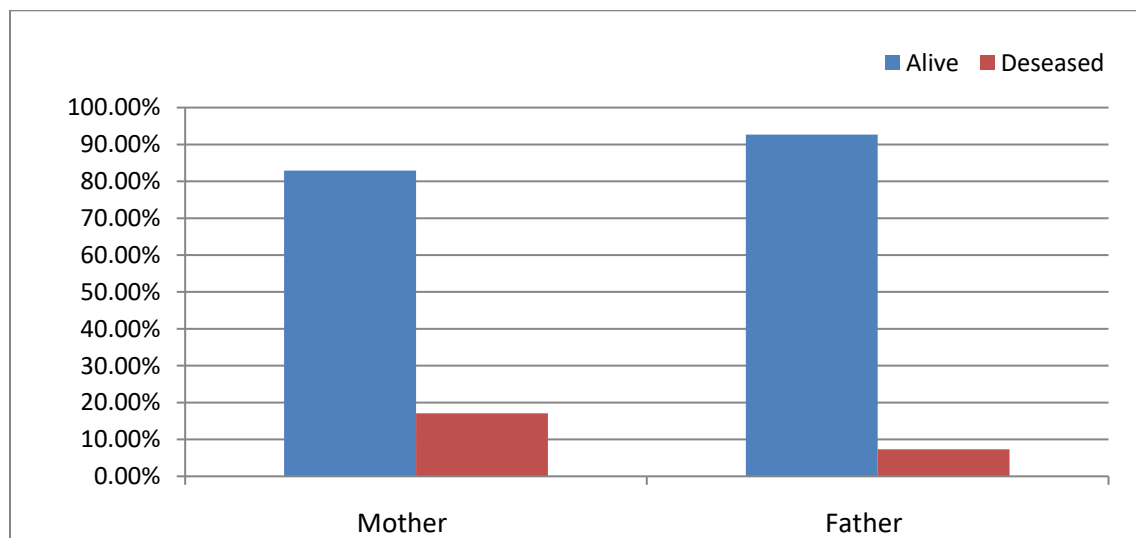
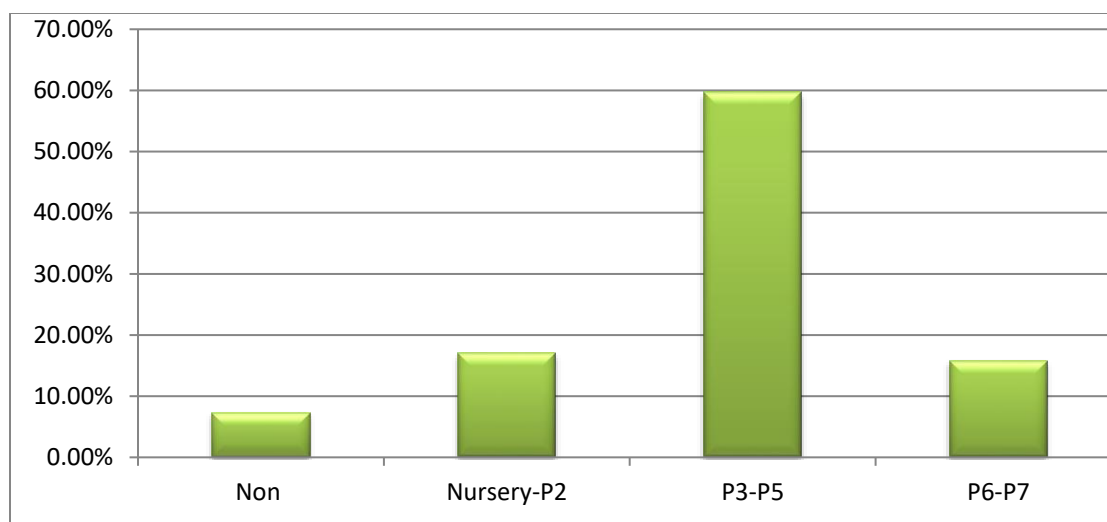


Figure 6: Status of participants whether orphaned or not

This graph gives information on the status of the participants' parents whether alive or diseased with percentages of 82.93% (68) mother alive and 17.07% (14) diseased. As well as 92.68% (76) of the fathers alive and 7.32% (6) diseased.



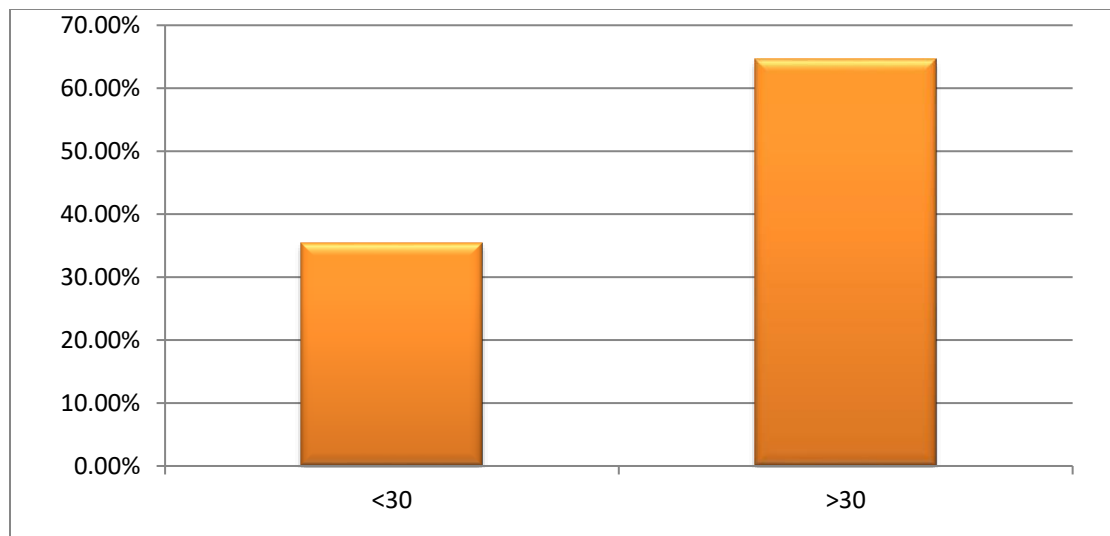
**Figure 7: Academic status of participants**

All participants were either in primary or not in school; 7.32% (6) not in any formal education, 17.07% (14) were between nursery and primary 2, 59.76% (49) were between primary 3 and primary 5, where as 15.85% (13) were between primary six and primary seven.

**Table 1: Frequency of residents in the villages**

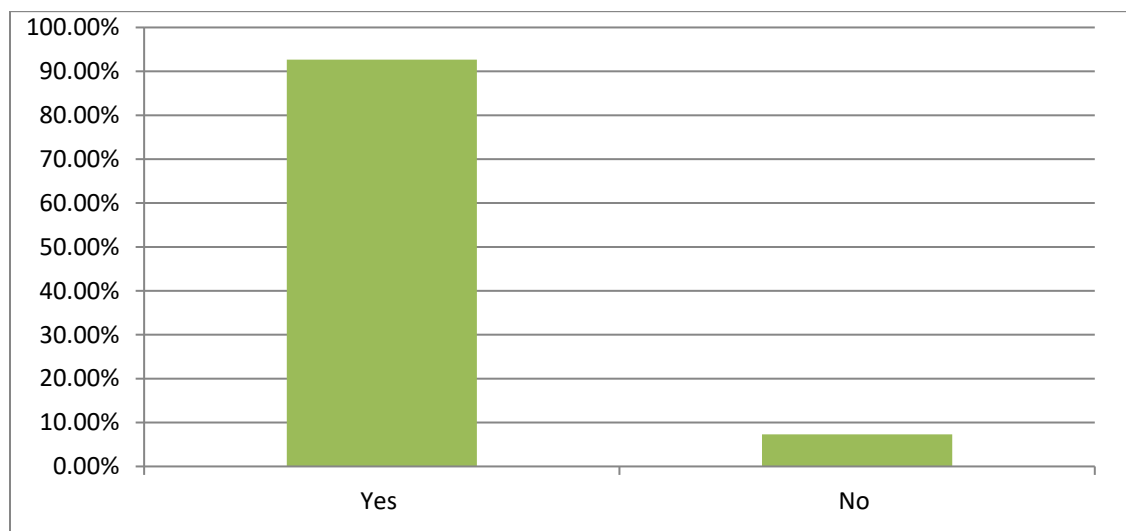
Village	Frequency of residence
Lamach south	5
Awere	6
Lapoqui	4
Hibon	7
Bobi- Kitgummatidi HC III	19
Tumango	23
Okidi – Okidi HC III	18

The great majority (23) reside in Tumango village while the least ( 4) in Lapoqui village.



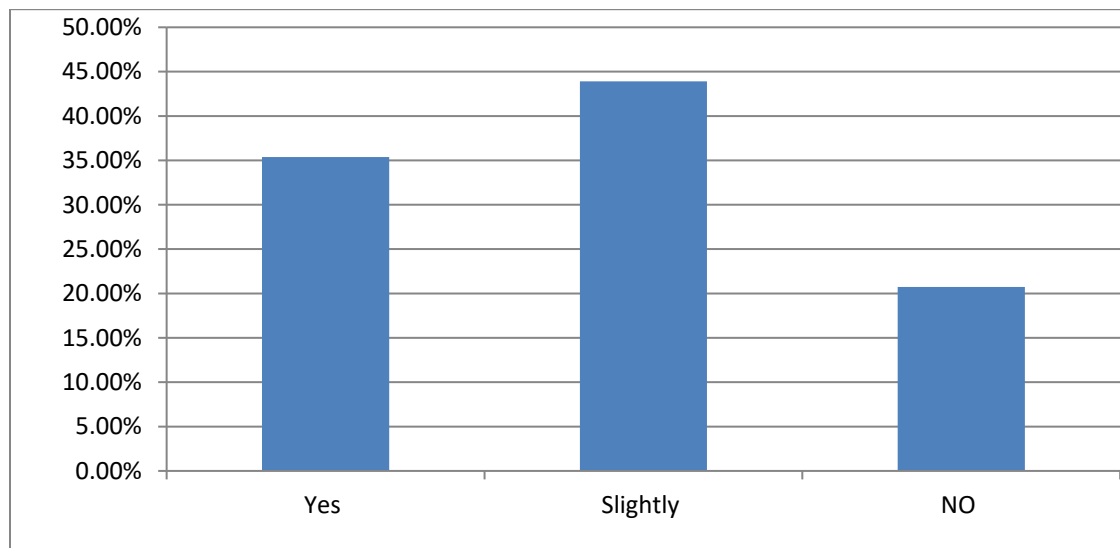
**Figure 8: Period the family has resided in the current village in years**

This graph shows the amount of time participants' families had lived in their villages of residents; 35.37% (29) had less than 30 years while 64.63% (53) had lived in the villages for more than 30 years.



**Figure 9: Participants on medication**

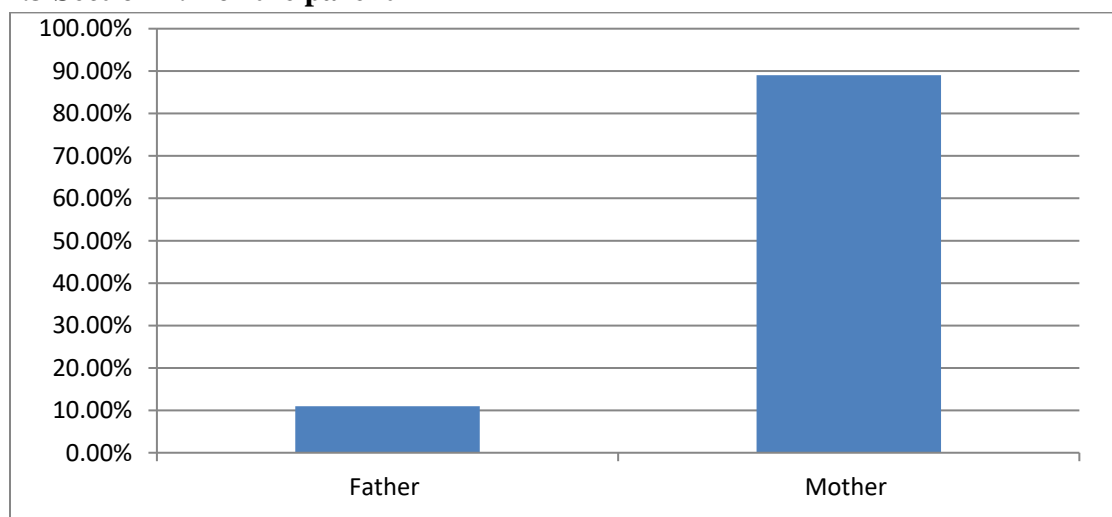
The graph above shows that 92.68% (76) of the participants were on medication and 7.32% (6) were not yet on medication.



**Figure 10: Improvement with or without medication**

The above shows the level of improvement with or without medication; 35.37% (29) showed great improvement, 43.90% (36) had shown slight improvement and 20.73% (17) had shown no improvement at all.

#### 4.3 Section 2: For the parent



**Figure 11: Parent who was present at time of interview**

At the time of interview, it was mostly mothers who were available to give us the collateral information where by there were 89.02% (73) and only 10.98% (9) fathers.

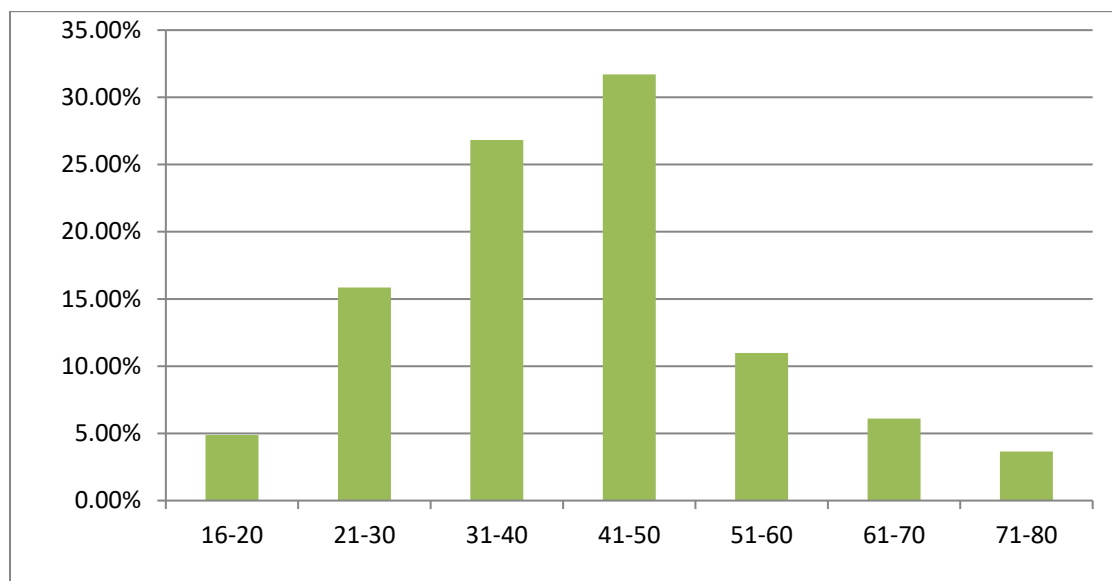


Figure 12: Age of the parent interviewed

The graph above shows the different age groups of the parents with their frequency; 4.88% (4) between 16-20 years old, 15.85% (13) between 21-30 year old, 26.83% (22) between 31-40 year old, 31.71% (26) between 41-50 years old, 10.98% (9) between 51-60 years old, 6.10% (5) between 61- 70 years old and 3.65% (3) between 71-80 years old.

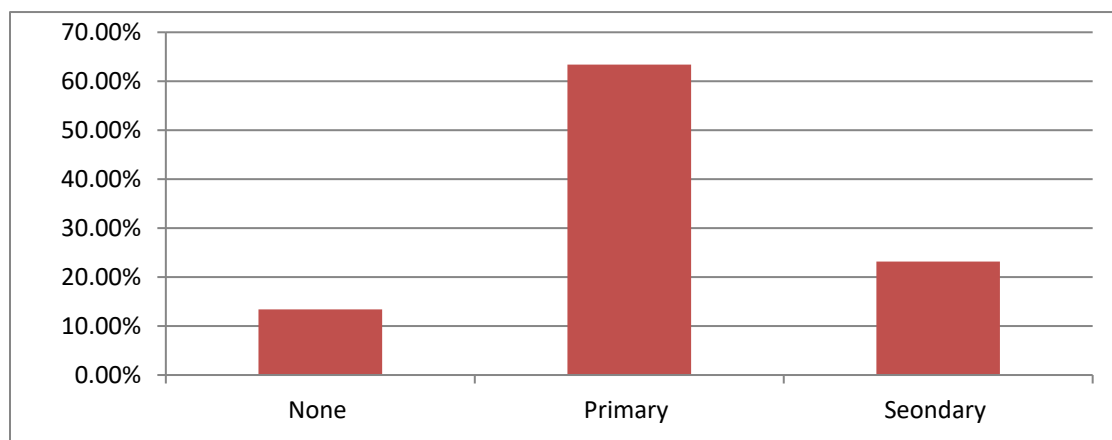


Figure 13: Education level of the interviewed parent

The great majority 63.42% (52) went to primary school, only 23.18% (19) attended some level of secondary education while 13.41% (11) did not receive any formal education.



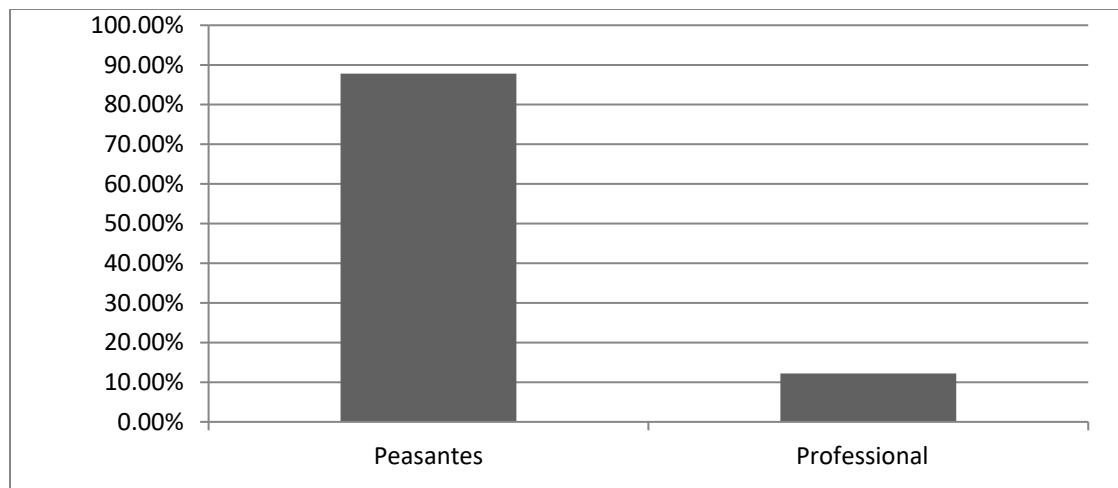


Figure 14: Occupation category of the parent interviewed

A large number of the participants 87.80% (72) were peasants while 12.20% (10) were in professional jobs.

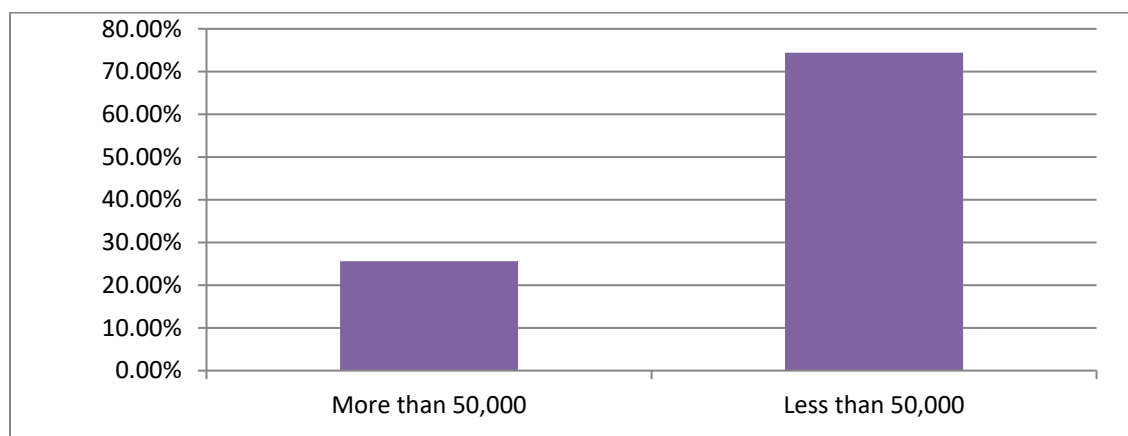
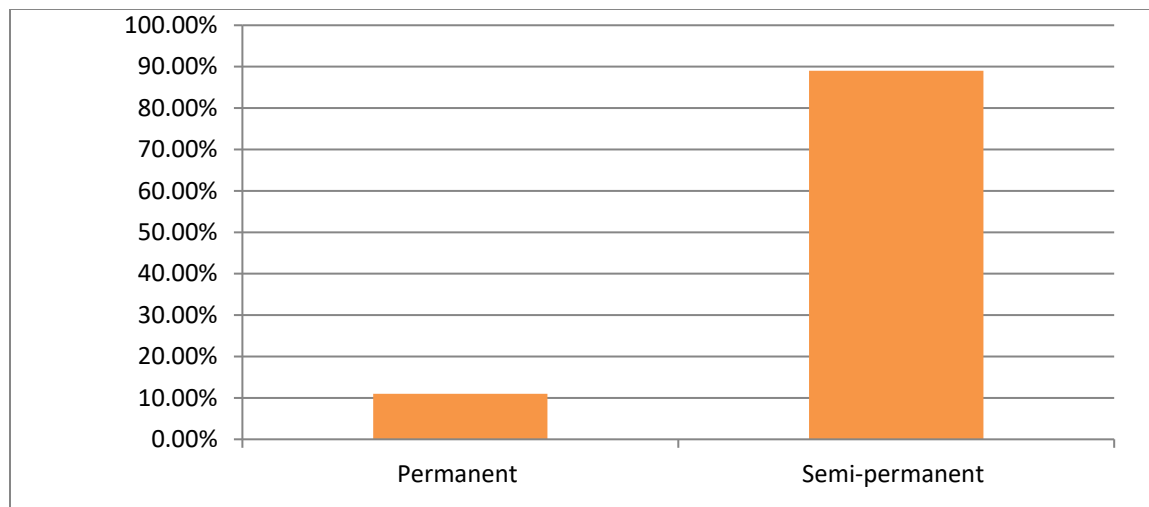


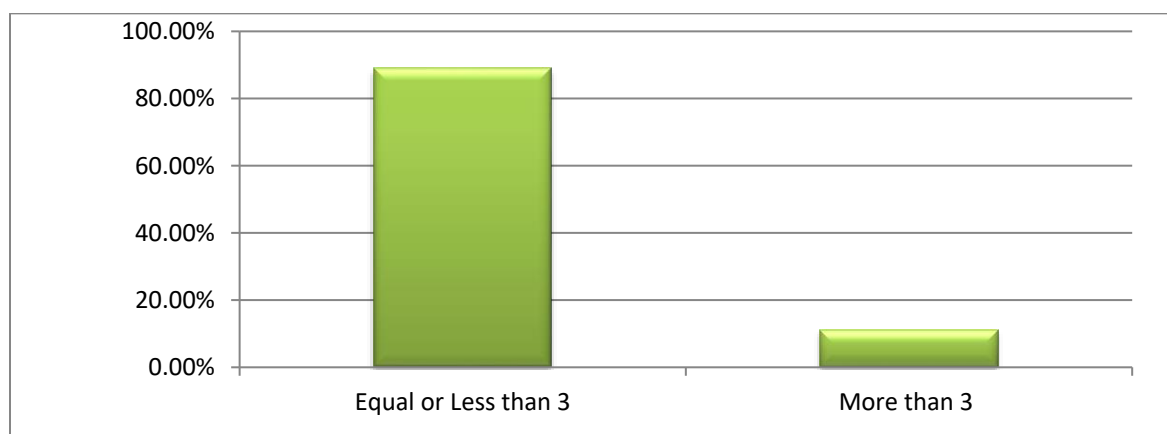
Figure 15: Household income per month

Only 25.61% (21) participants' parents are able to run more than 50,000 Ugandan shilling but not more than 150,000 Ugandan shilling and a big portion 74.39% (61) are less than 50,000 Ugandan shillings.



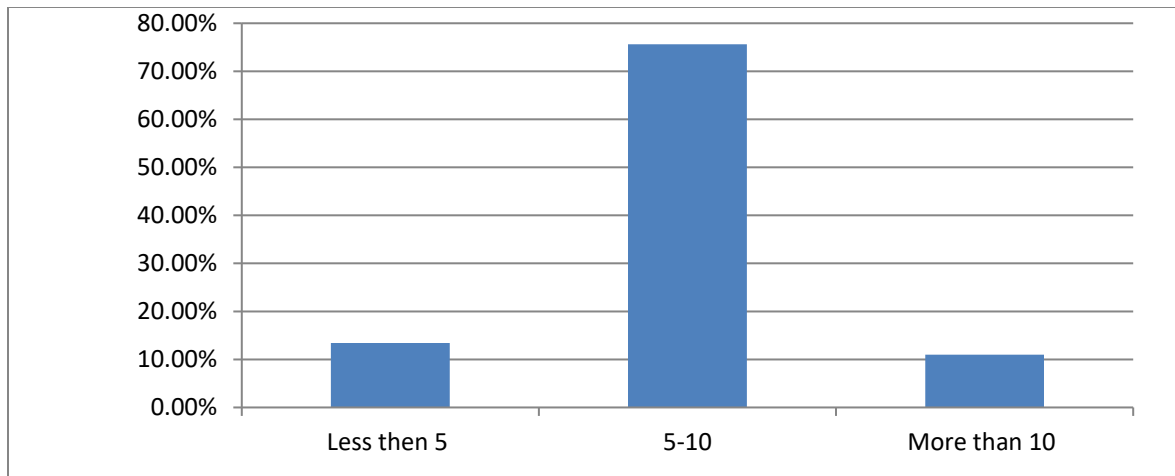
**Figure 16: Type of housing**

The majority 89.02% (73) of the participants lived in semi-permanent houses while only 10.98% (9) lived in permanent houses.



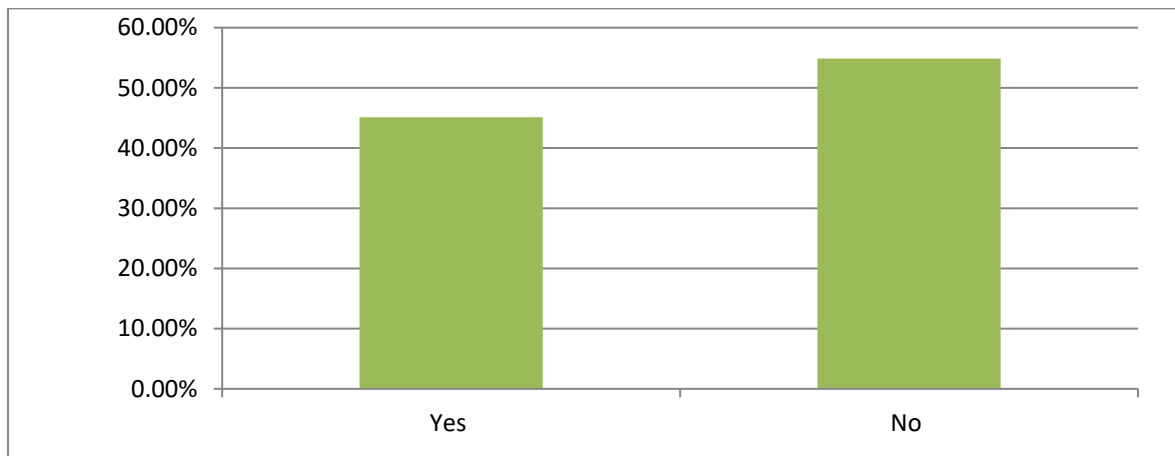
**Figure 17: Number of bedrooms in the house**

In their houses the majority 89.02% (73) had three bed rooms or less and the minority 10.98% had more than three but less than five bed rooms.



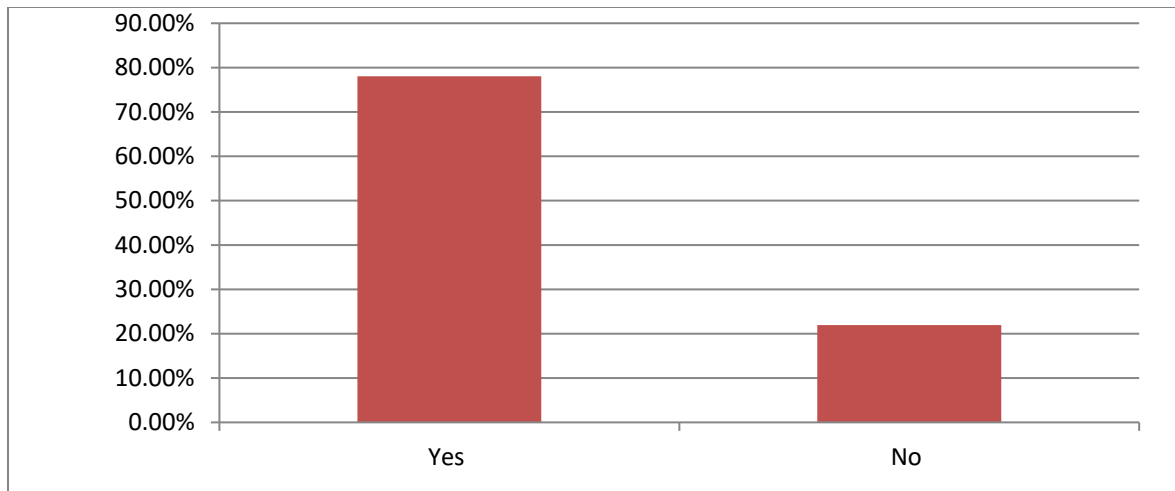
**Figure 18: Number of people residing in the house**

Most homes 75.61% (62) had between 5 to 10 people residing in the same house. 13.41% (11) had less than five people residing in the house while the minorities 10.98% (9) had more than 10 people in the same house.



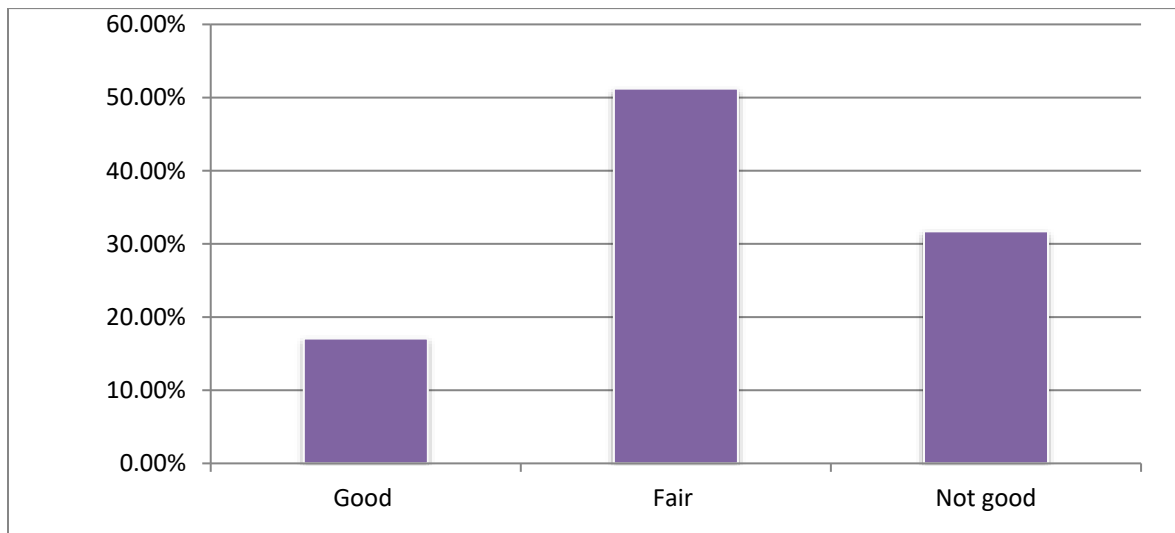
**Figure 19: Number of participants with a mobile phone at home**

To assess their level of income, I found out that most 54.88% (45) didn't have a mobile phone while only 45.12% (37) had a mobile phone in their homes.



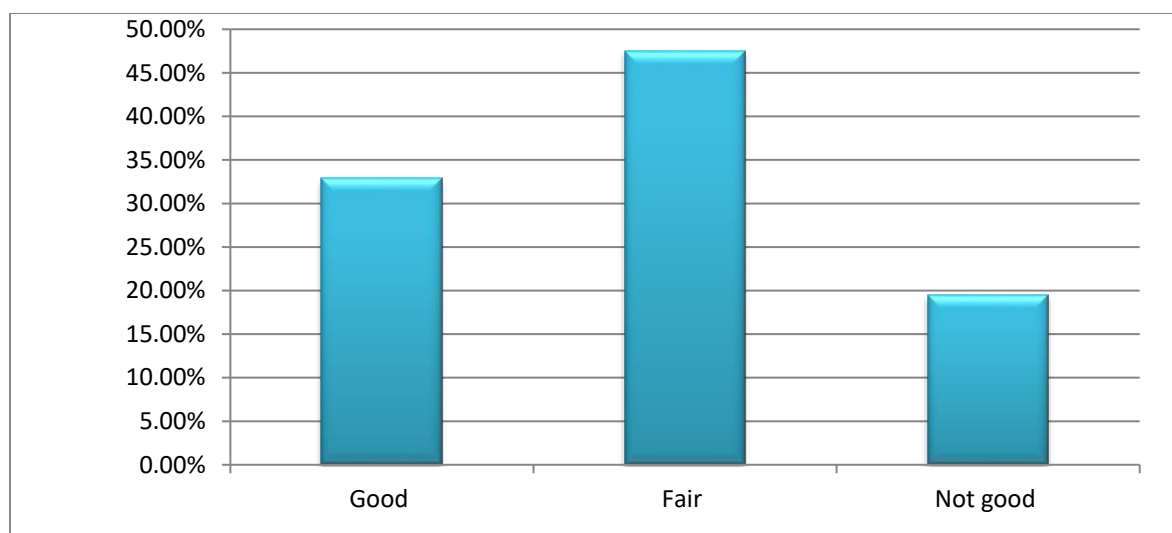
**Figure 20: Number of participants with radio at home**

I further went on to ask if they had a radio at home and 78.05% (64) responded yes while 21.95% (18) responded no.



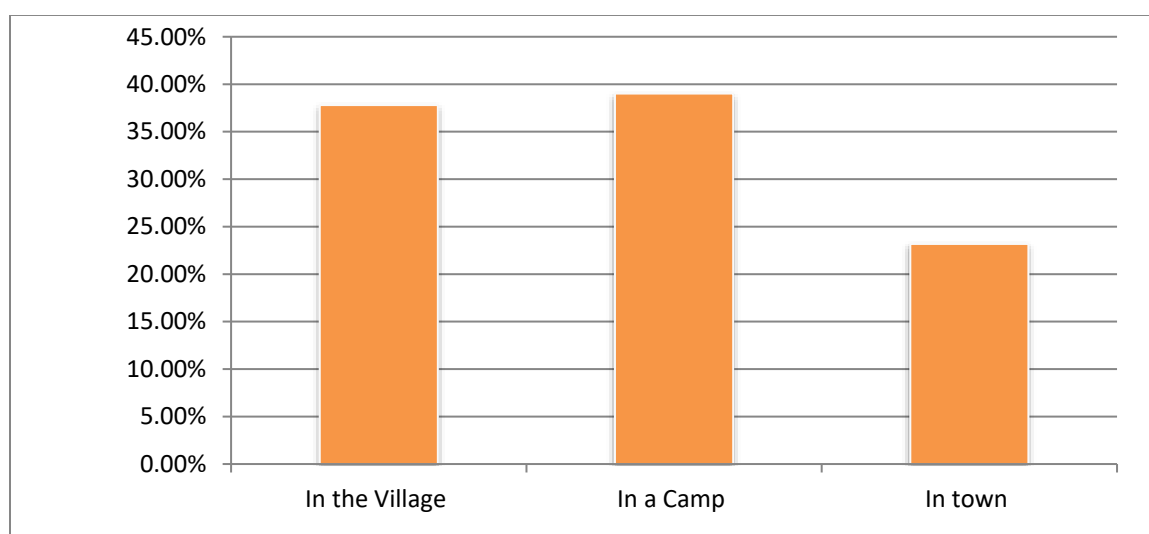
**Figure 21: Relationship with their neighbors**

Concerning the disease of the participants I asked how is the family's relationship with the neighbors and 17.07% (14) said it was good, 51.22% (42) said it was fair while 31.71% (26) said is not good.



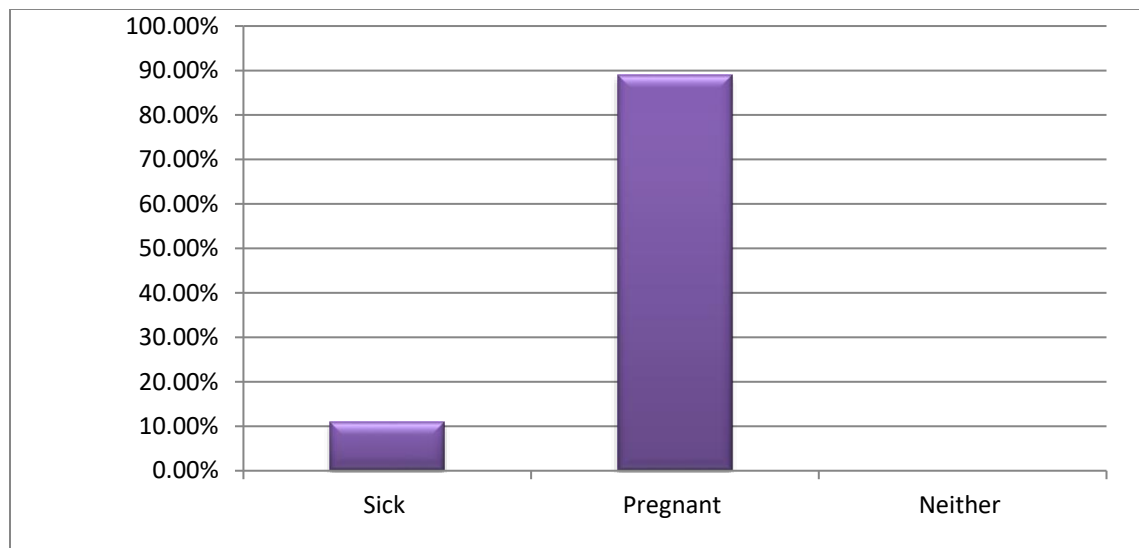
**Figure 22: Relationship of the parents with their co-workers**

Relationship of the parent with his/her co-workers 32.93% (27) said that their relationship was good, 47.56% (39) said that their relationship was fair and 19.51% (16) said it was not good.



**Figure 23: Participant's parent's location between 1987-2008**

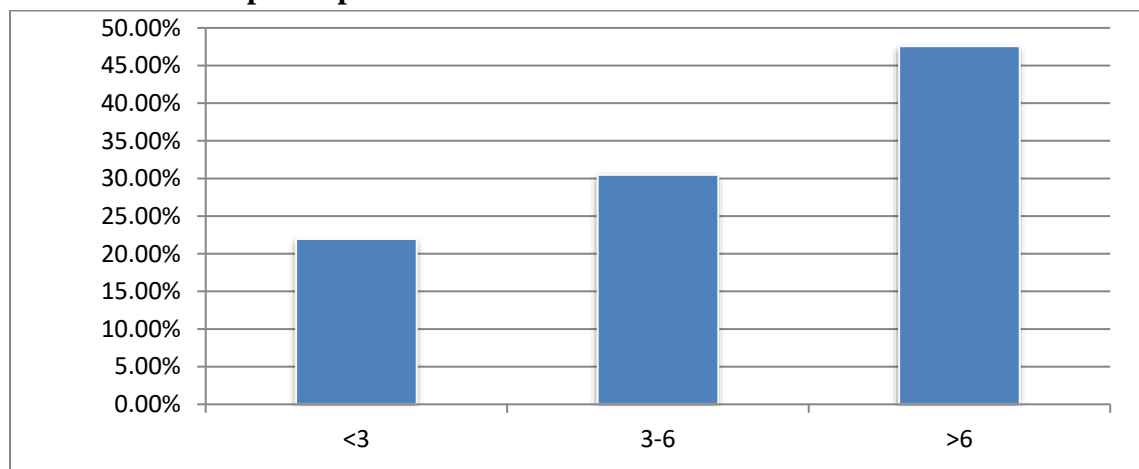
During 1987-2008 was the time when the Lord's Resistance Army was having a war in Northern Uganda the majority 39.02% (3) of the residences in this district were in camps, 37.81% (31) were in their villages, while the minority 23.17% (19) went to town.



**Figure 24: Health status of the participant's parent between 1987-2008**

During that period the graph above shows the health status of the interviewed parent, where by 10.98% (9) were sick, 89.02% (73) all women were pregnant at some point and 0% were neither sick nor pregnant.

#### **4.4 Section 3 The participants – Social effects**



**Figure 25: Number of the participant's siblings**

The graph above shows the number of siblings the participant patient had, 21.95% (18) had less than 3 siblings, 30.49% (25) had between 3-6 siblings and 47.56% (36) had more than 6 siblings.

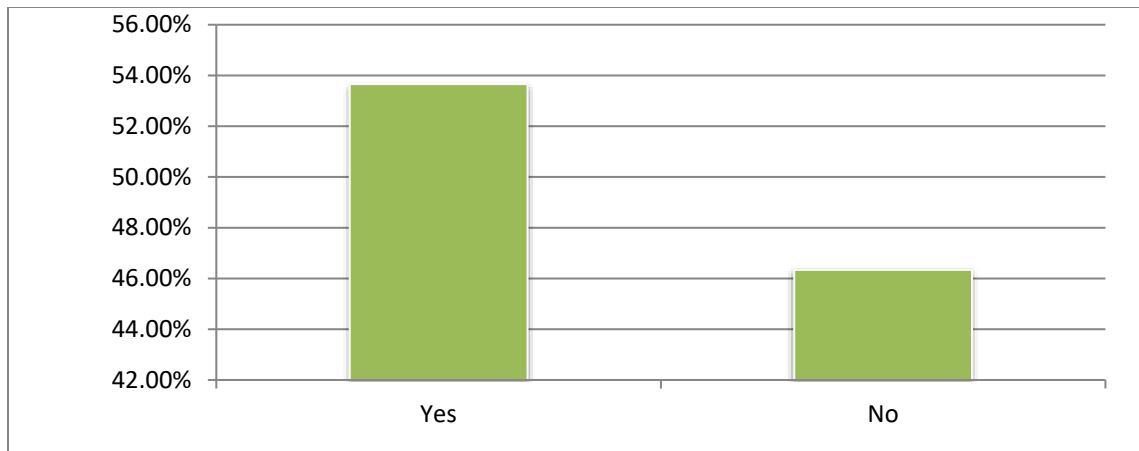


Figure 26: Participants with siblings who had the same syndrome

This graph shows the number of participants with sibling who had the same condition; 53.66% (44) said yes they did while 46.34% (38) said they didn't.

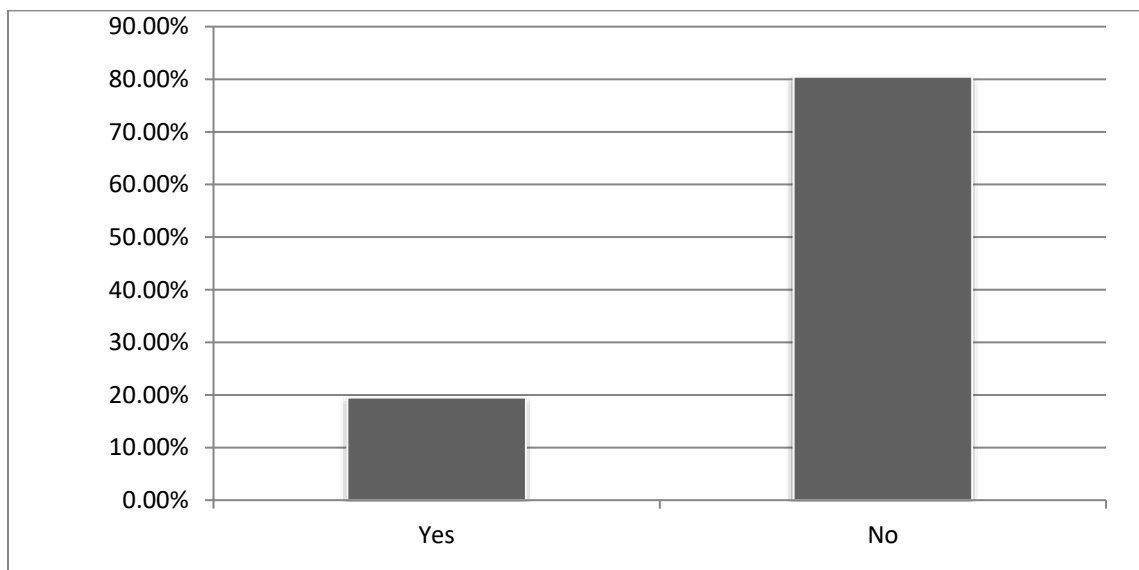


Figure 27: Participants sharing a bed with sibling

I then asked about how many participant patients shared a bed with their other sibling; 19.51% (16) said yes they did while 80.49% (66) said they didn't share a bed.

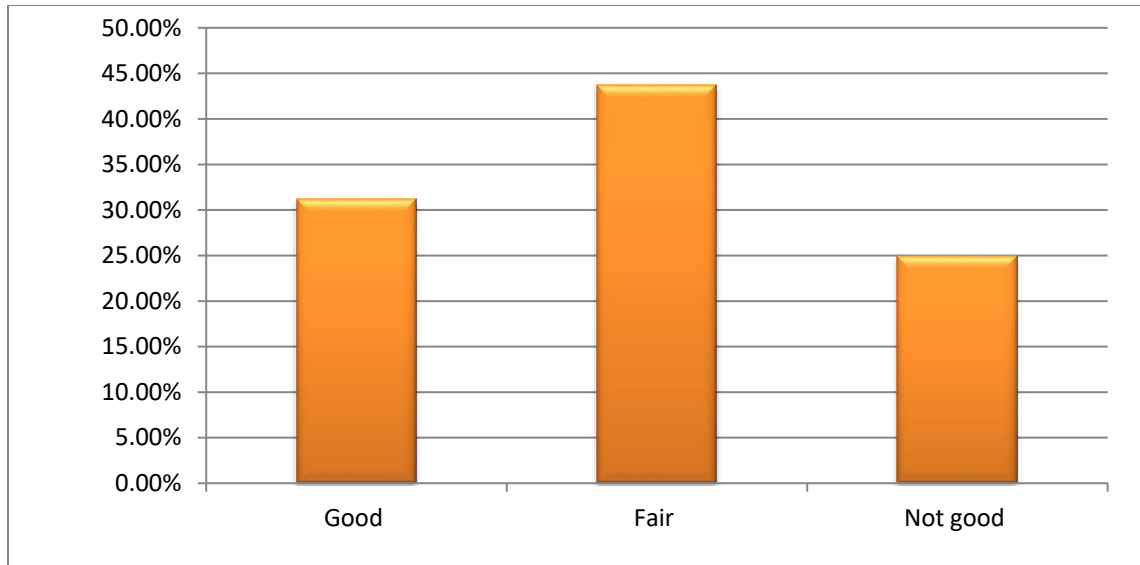


Figure 28: Reaction of other sibling when sharing a bed with participant

I then asked the participants who shared a bed what were the reactions of the other people who shared the bed; 31.25% (5) said the reaction was good, 43.75% (7) said it was fair and not very bad it was just good whereas 25% (4) said their reactions were not good.

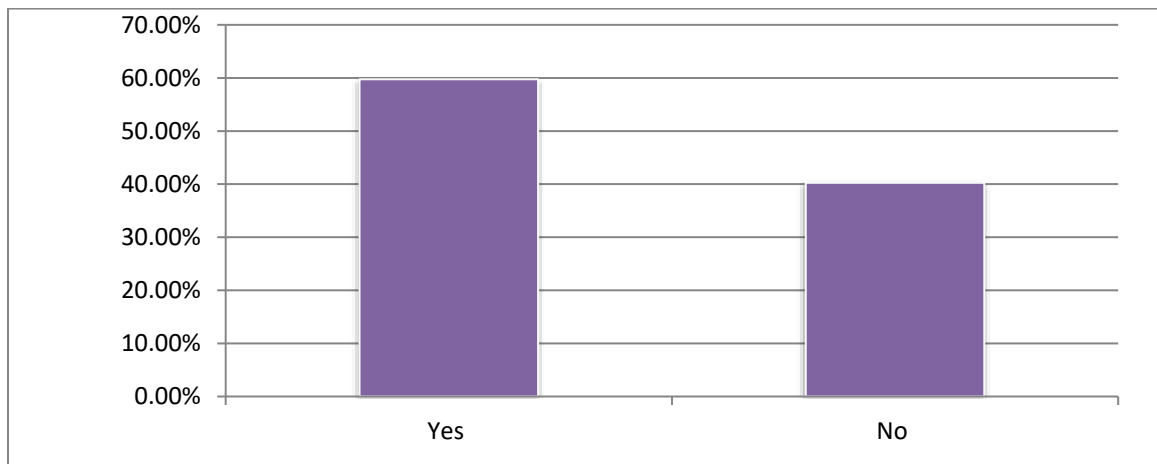


Figure 29: Number of participants who go to school

The graph above shows the number of participants who were attending school; 59.76% (49) still attended school while 40.24% (33) no longer attended school.



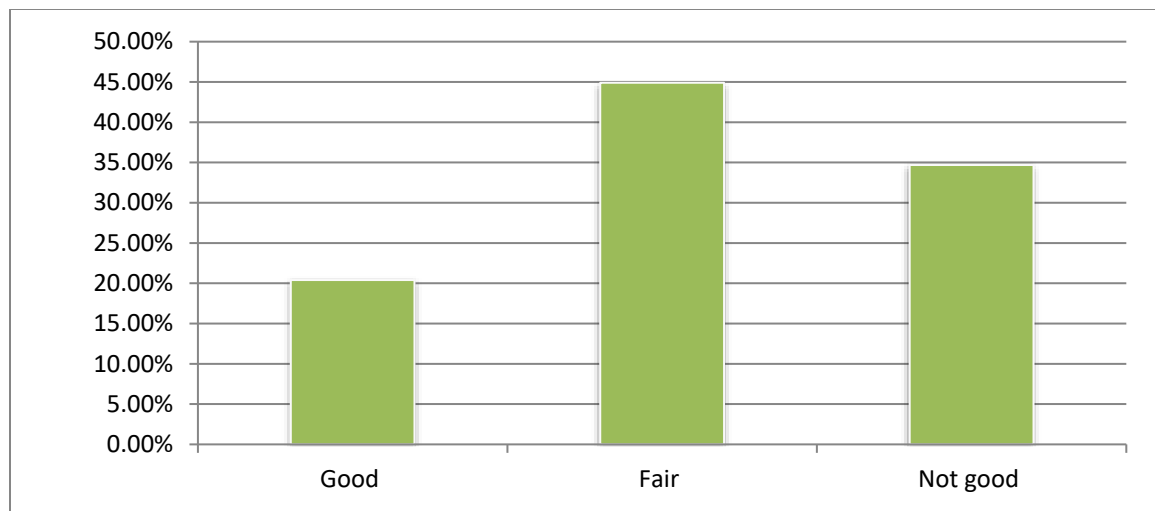


Figure 30: Relationship between the 49 participants who attended school and their teachers

The graph above shows that 20.41% (10) had a good relationship with their teacher, 44.90% (22) have just a fair relationship while 34.69% (17) hadnot good relationships with their teachers.

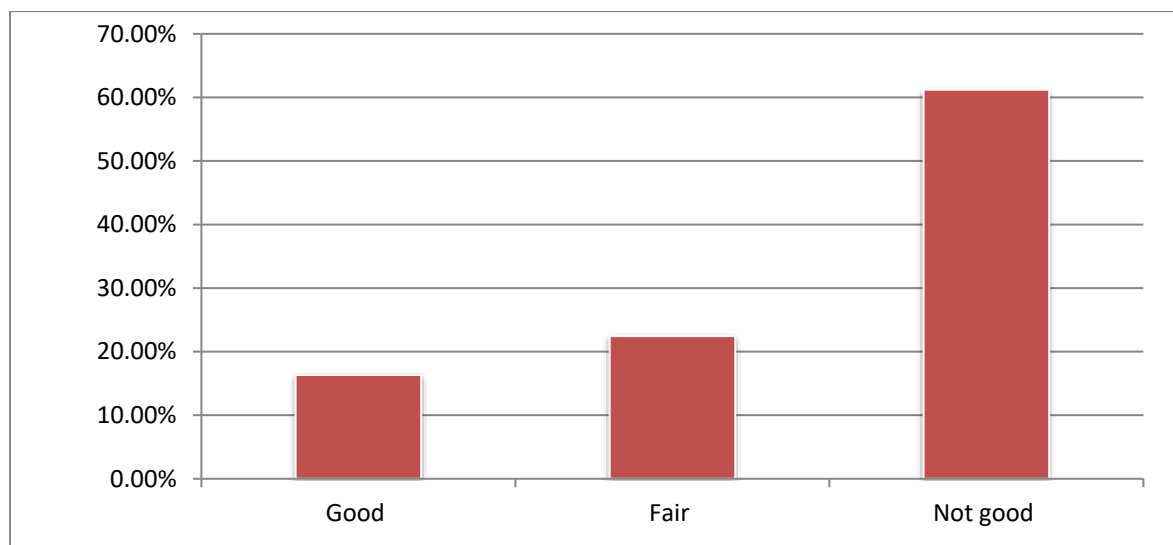


Figure 31: Relationship between the 49 participants who attended school and their fellow students

The graph above measured the relationship between the participants and their fellow students, 16.33% (8) said the relationship/ reactions good, 22.45% (11) said reactions were fair while 61.22% (30) said that the reactions were not good towards them.

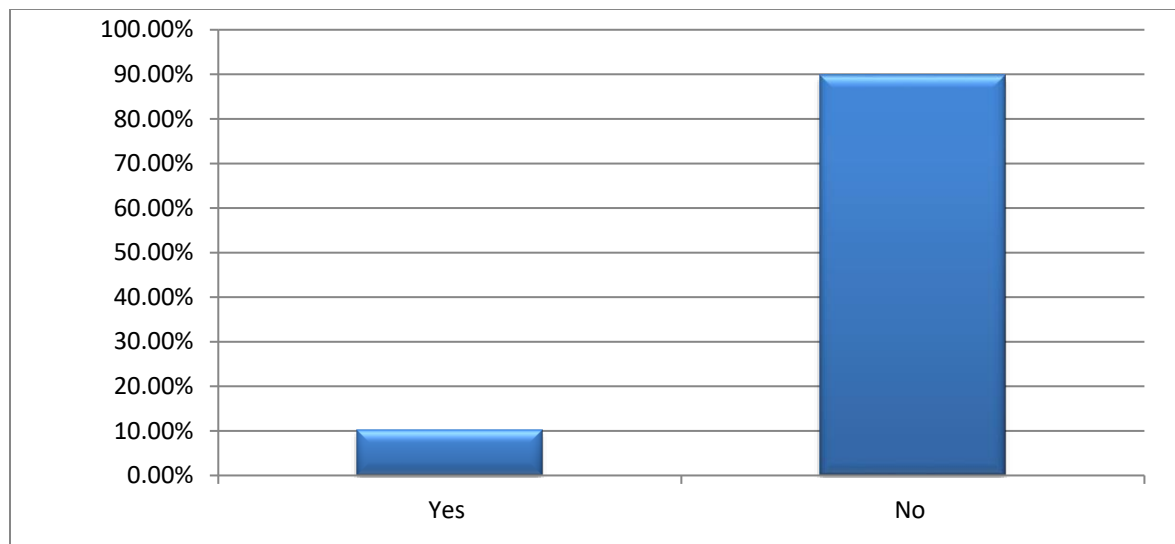


Figure 32: Participants of the 49 who studied well like other students

The graph above showed that only 10.20% (5) participants studied well like other students while 89.80% (44) participants didn't study well like other students.

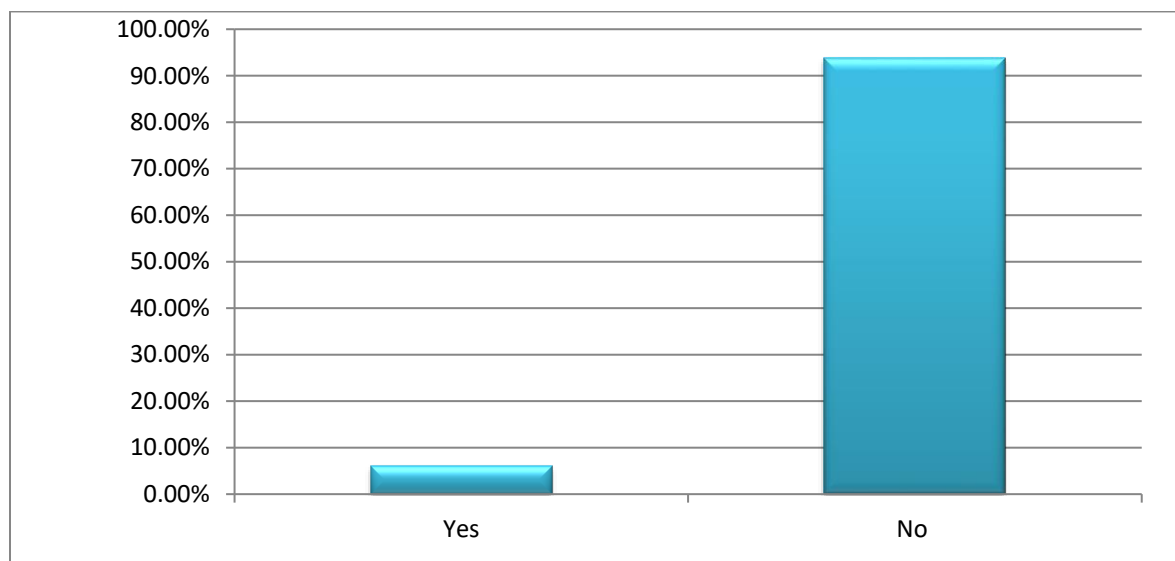
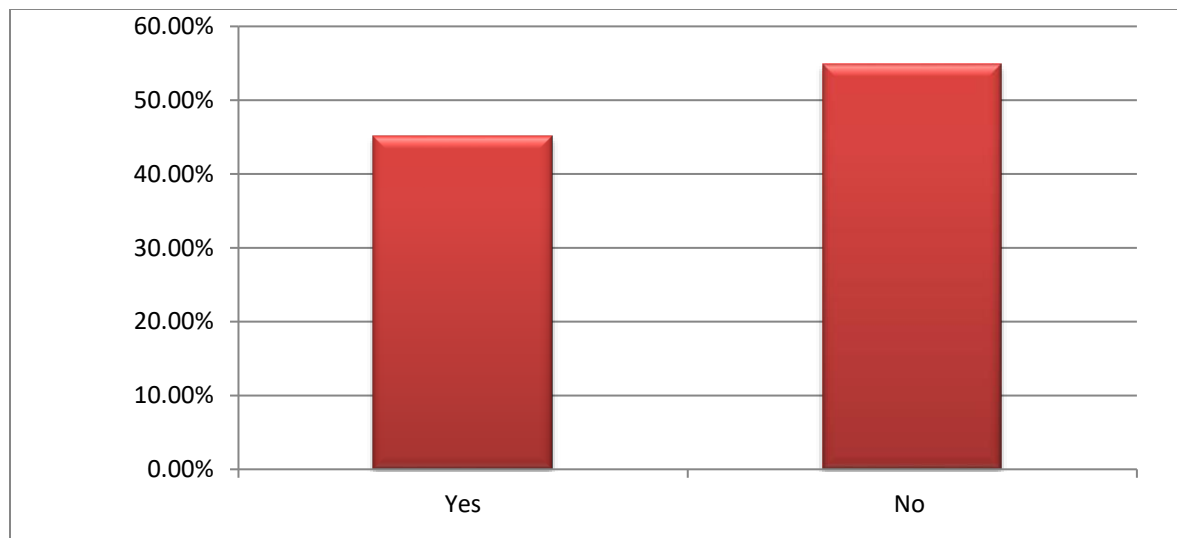


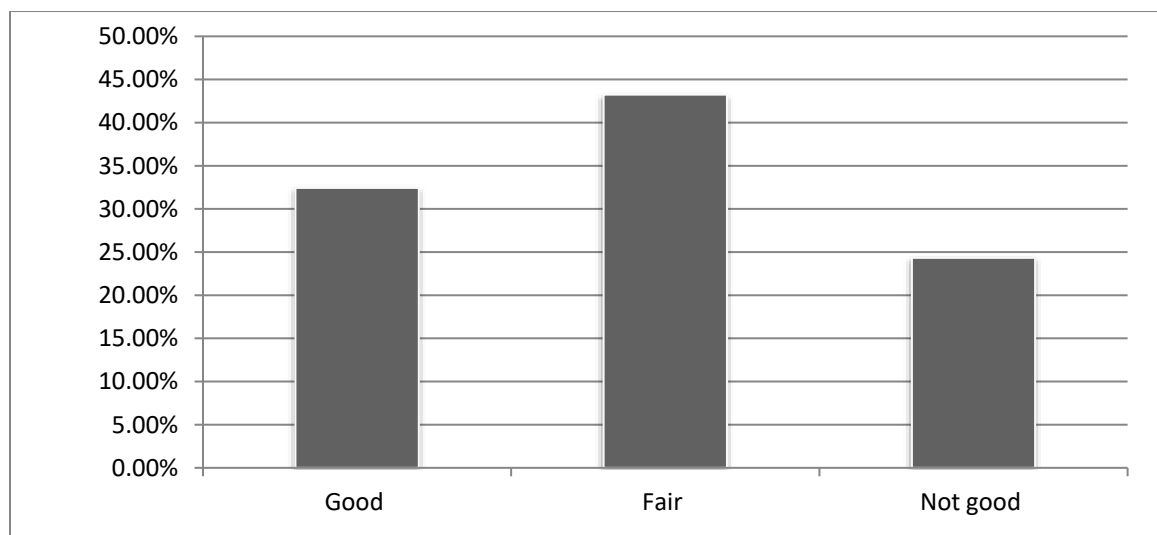
Figure 33: Participants of the 29 who received special care at school

Only a few 6.12% (3) participants received special care at school due to their condition while the remaining 93% (46) didn't receive special care at school.



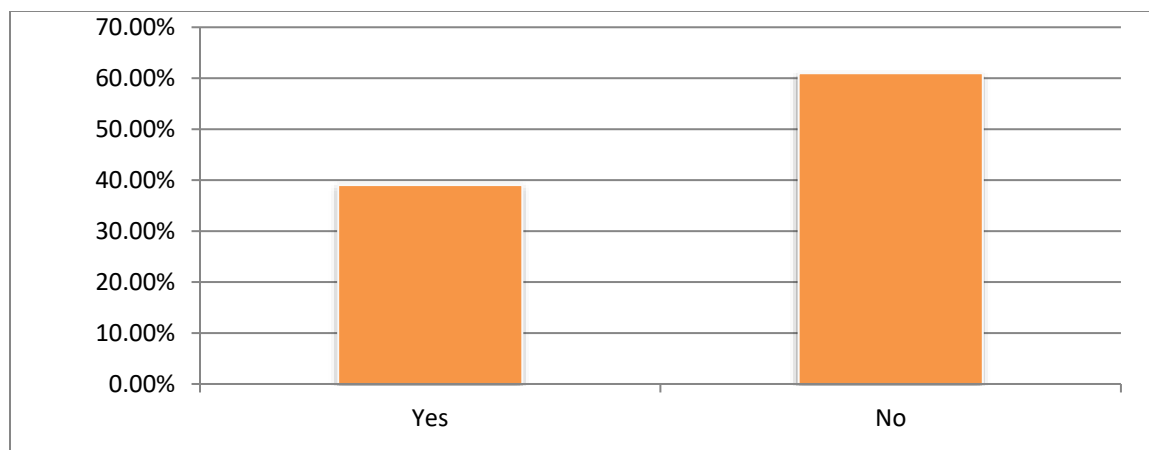
**Figure 34: Participants' religious group attendance**

From the graph above, only 45.12% (37) of the participants attended their religious gatherings, while the majority 54.88% (45) no longer attended these gatherings.



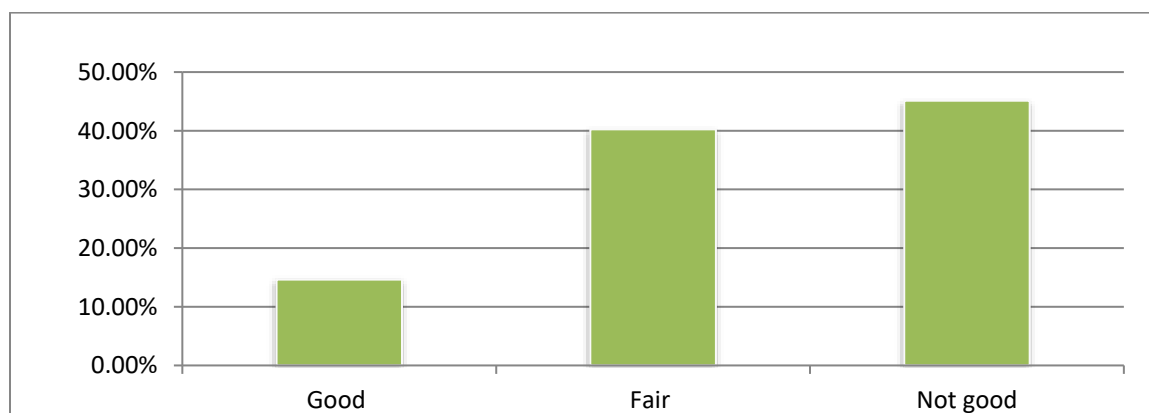
**Figure 35: Relationship with other people at church/ Mosque**

Concerning the relationship with other people at their religious gatherings, 32.43% (12) said their relationships were good, 43.24% (16) said it was fair while 24.33% (9) said it was not good.



**Figure 36: Participants who played with other children**

A small number 39.02% (32) of participants got the opportunity to play with their fellow friends however, the majority 60.98% (50) didn't play with their fellow children/ age mates.



**Figure 37: Reactions from other children**

14.64% (12) said it was good, 40.24% (33) said it was fair while 45.12% (37) said it was not good.



Figure 38: Participants currently employed

None (100% that is 82) of the participants were currently employed.

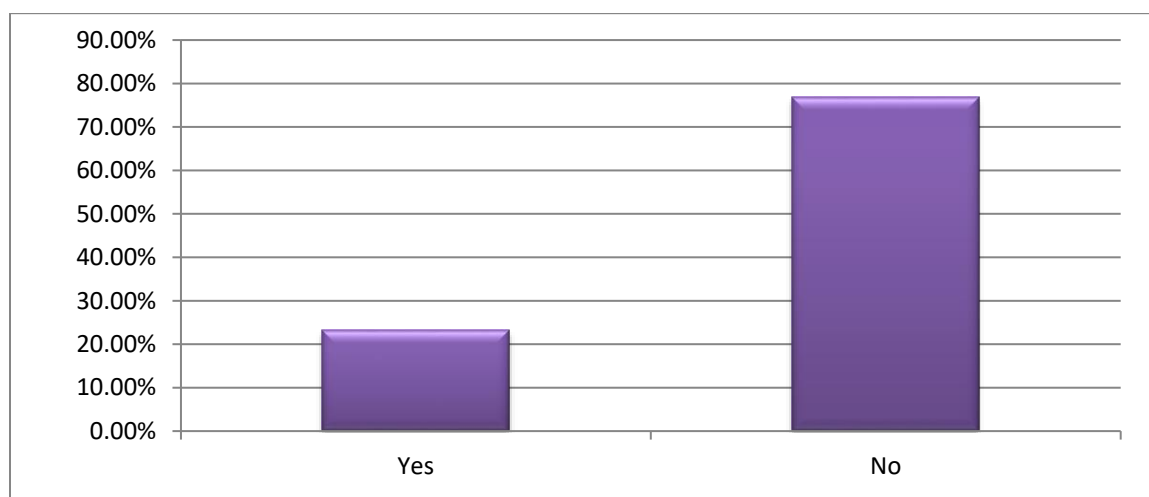


Figure 39: Participants who tried looking for work

From the study, 23.17% (19) tries to look for a job while 76.83% (63) have never tried looking for jobs.

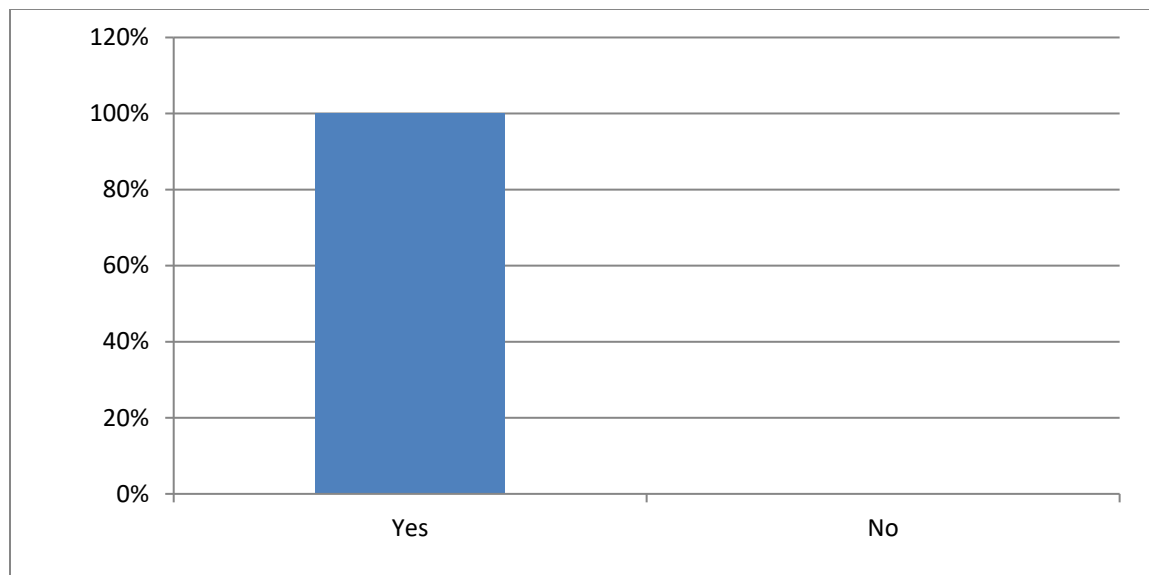


Figure 40: Participants who got seizures

The graph above shows that 100% that is 82, all the participants got seizure.

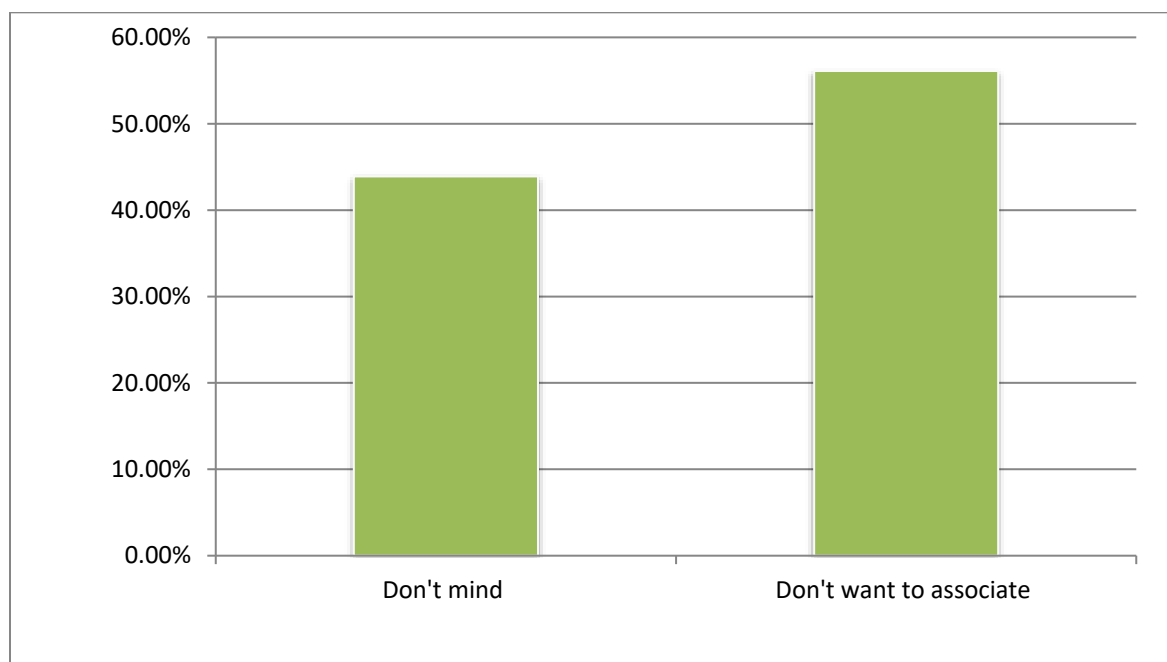
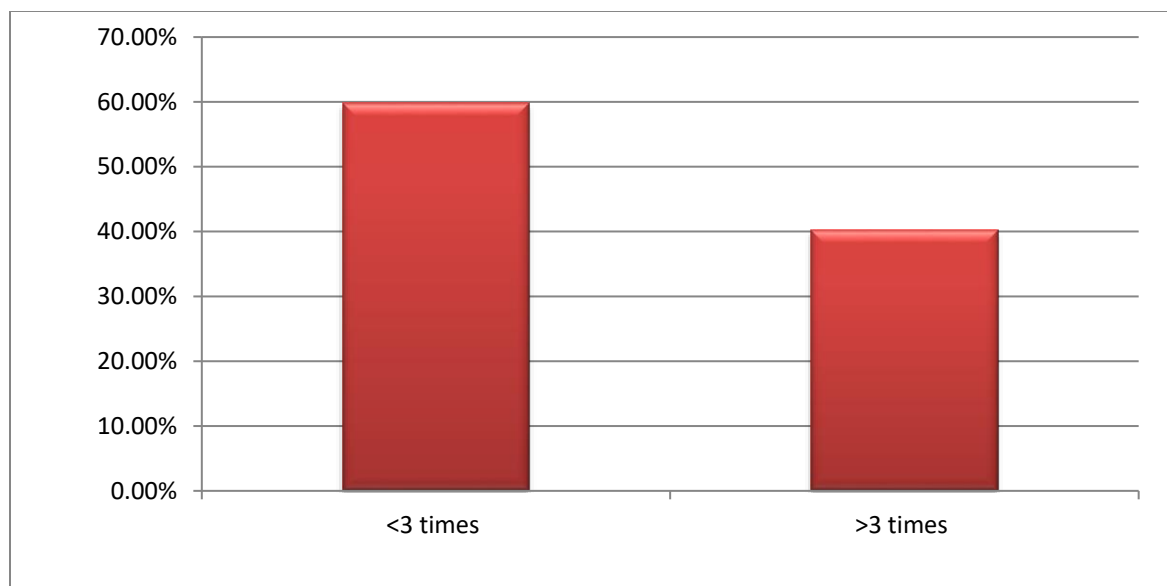


Figure 41: Reaction of other people towards the participants' seizures

From the graph above, 43.90% (36) said that the people round them didn't mind about them having seizures while 56.20% (46) said that the people around them actually didn't want to associate with them.



**Figure 42: Occurrence of seizures in a day**

From the graph above, 59.76% (49) of the participants got seizures less than three times in a day while 40.24% (33) got seizures more than three times in a day.

**Table 2: Memory level of participants**

Level	Percentage
Very good	0%
Good	10.98%
Very bad	89.02.%

The bale above show that the majority 89.02% (73) of the participants had very bad memory while only 10.98% ( 9)had good memory but 0% had very good memory.

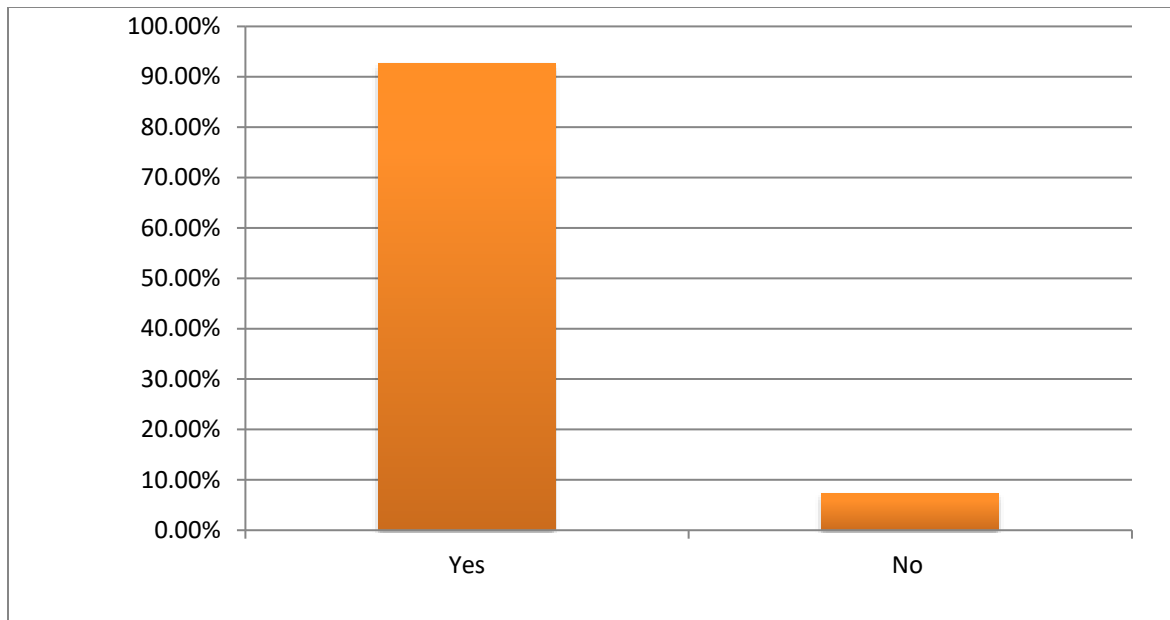


Figure 43: Behavior changes when participants got the syndrome

Since the start of the manifestation of the symptoms, 92.68% (76) of the participants had behavior changes, while only 7.32% (6) had no change in behavior.

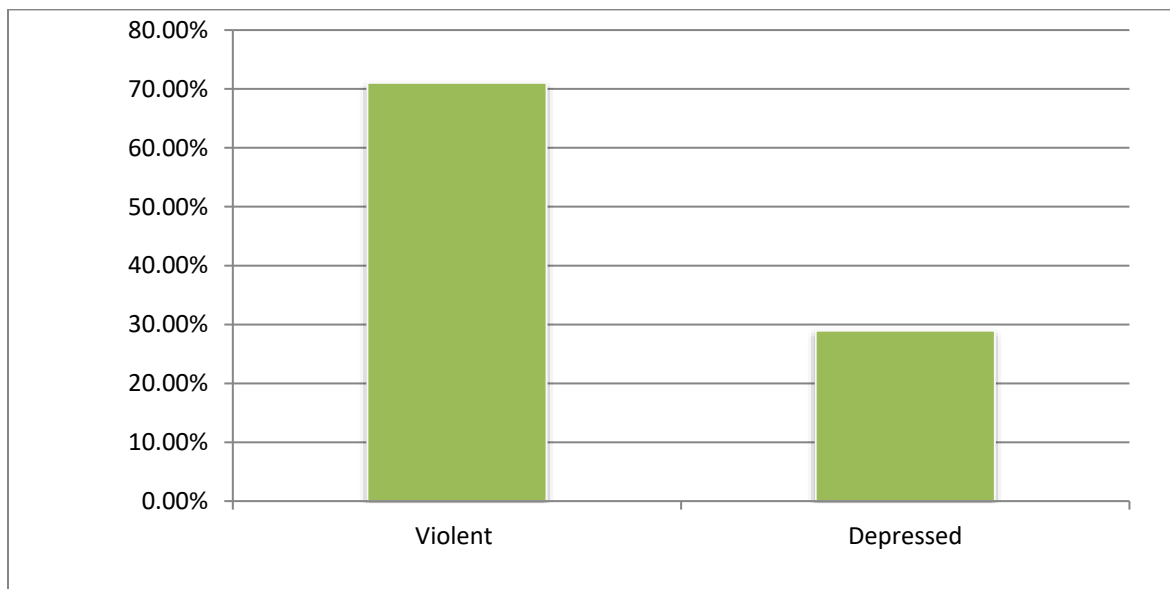


Figure 44: How behavior changed

The graph above show changes in behavior of the participants since they acquired the condition; 71.05% (54) of the participants had become more violent while 28.95% (22) seem to be depressed.



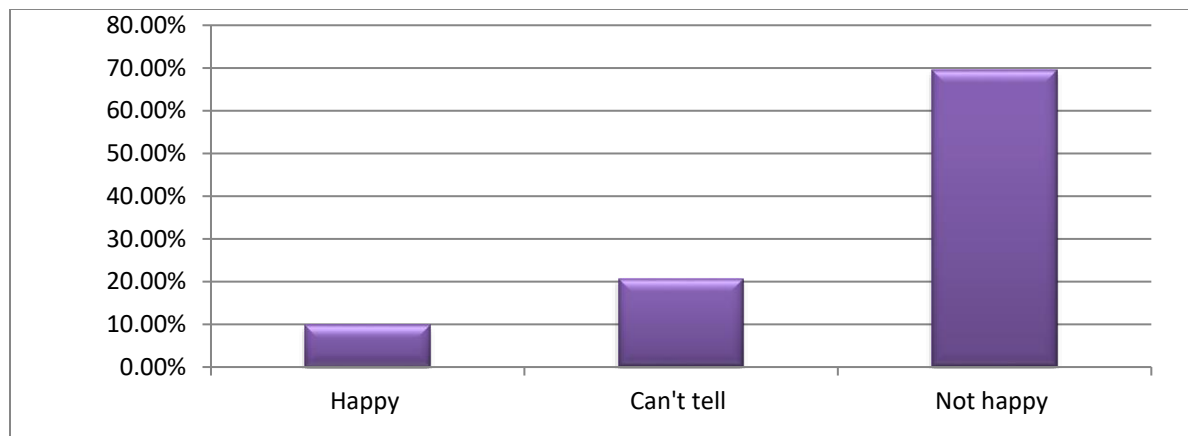


Figure 45: How participants felt about themselves

I then asked the parent how the patient participant feel about themselves; 9.76% (8) said they were happy, 20.73% (17) they can't tell mood kept changing and 69.51% (57) said they were not happy most of the time.

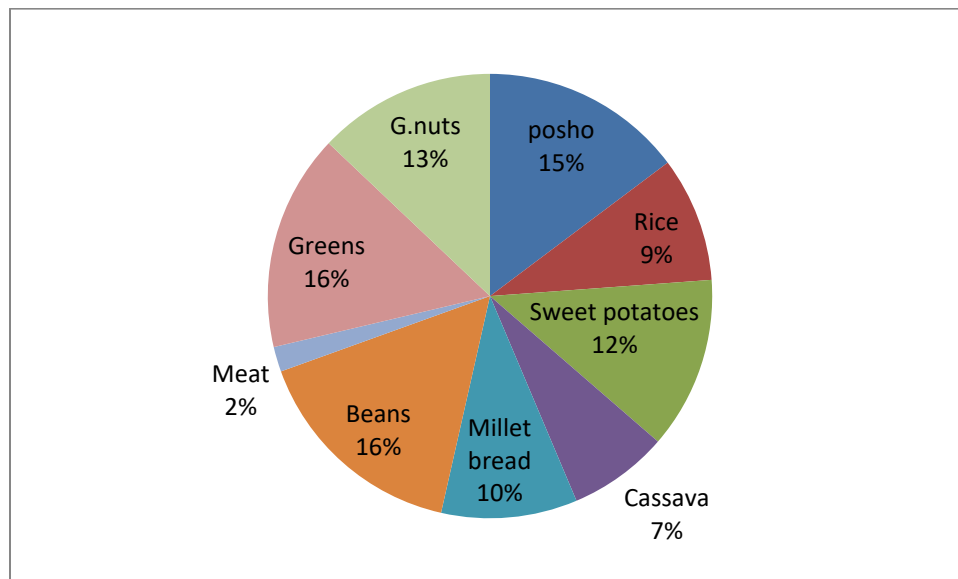


Figure 46: Common foods eaten by the participant

The pie chart above gives the different foods that were commonly eaten by the participants with their percentages of quantity.

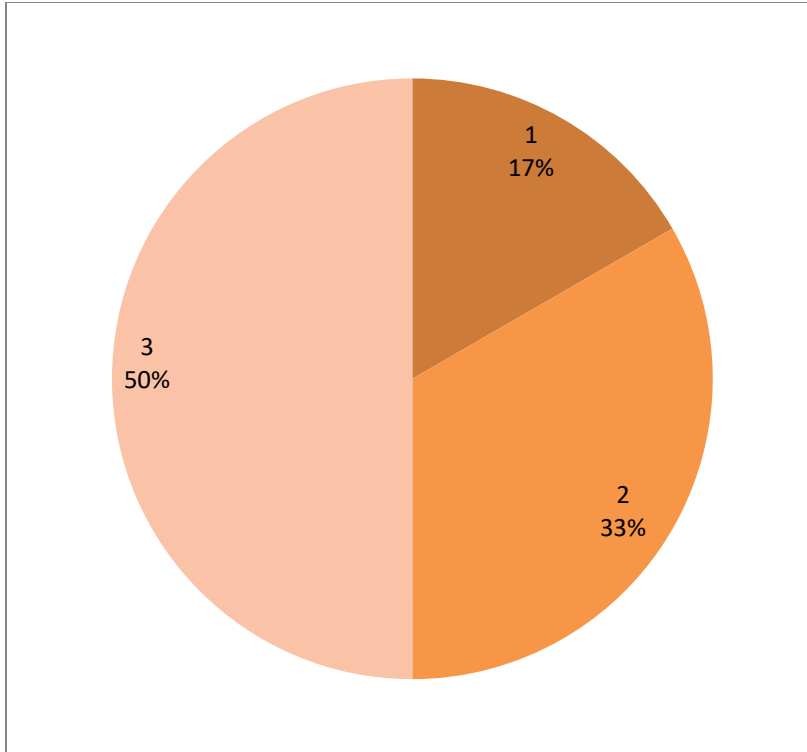


Figure 47: Number of meals per day

The pie chart above shows the percentages of participants with the different number of meals that were eaten in a day.

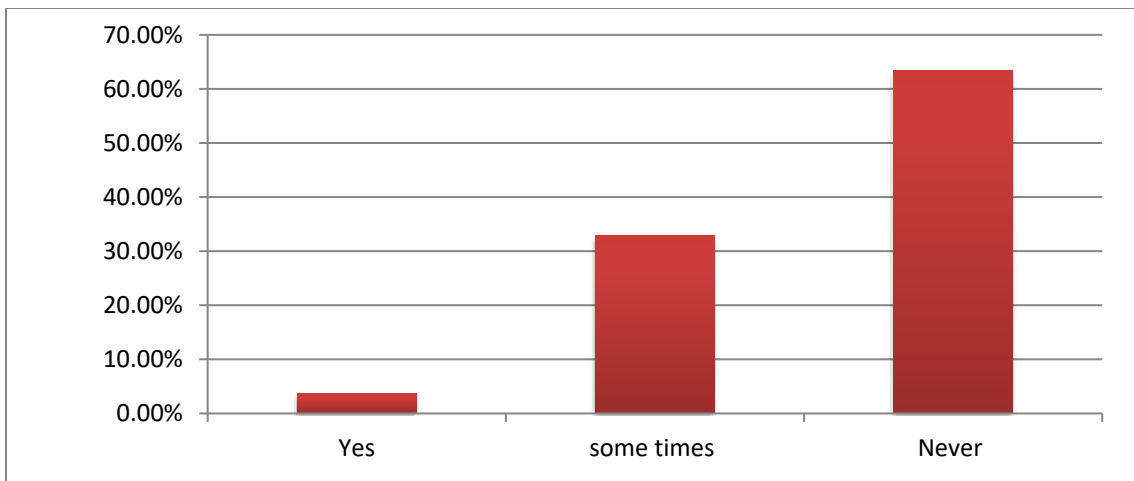


Figure 48: Can finish a meal without having seizures

In the graph above, it shows that only 3.66% (3) of the participants could finish a meal without seizure attacks, 32.93% (27) sometimes could finish a meal while the majority 63.41% (52) could never finish a meal without have seizure attacks.

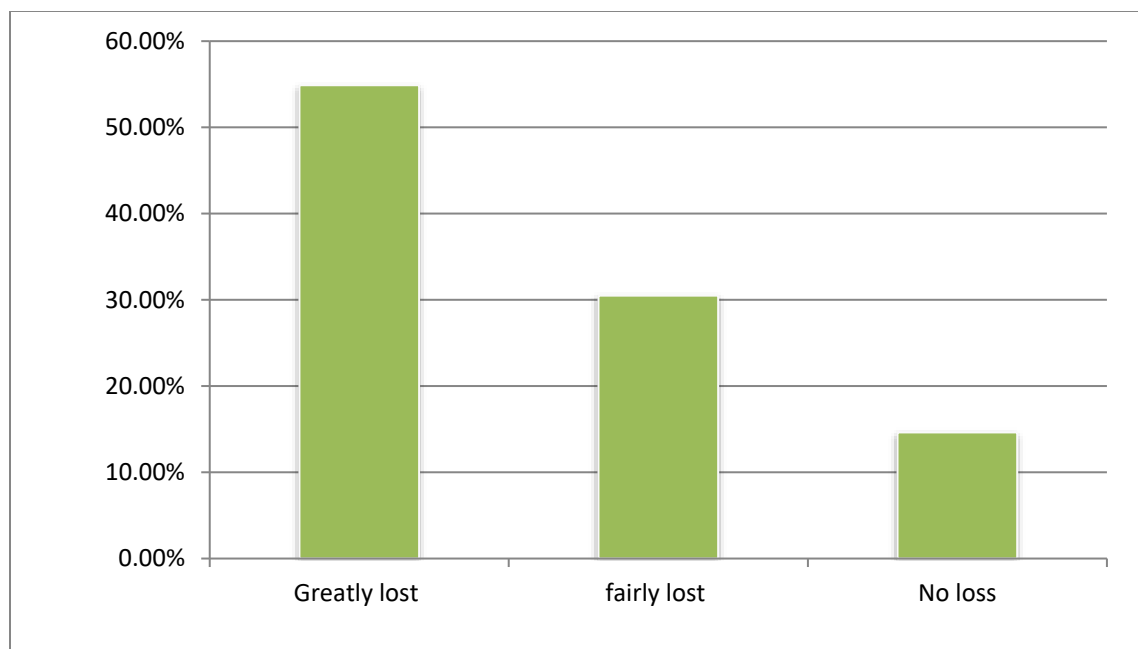


Figure 49: Loss in weight since the disease started

From the graph above, 54.88% (45) of the participants had greatly lost since the onset of the syndrome, 30.49% (25) had fairly lost while 14.63% (12) had not lost any weight.

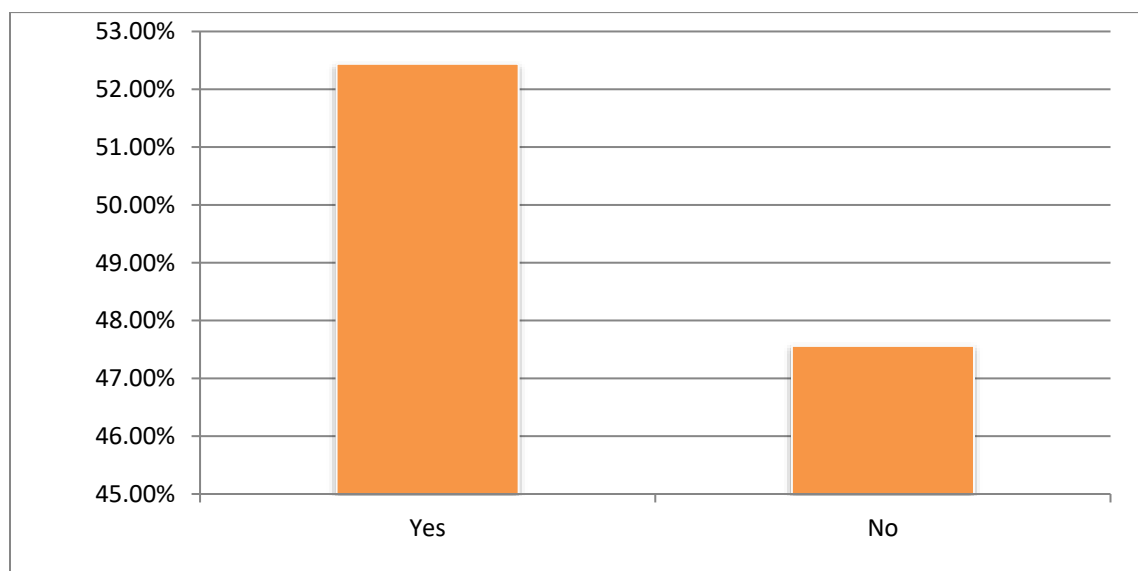


Figure 50: Participants growing well

From the graph above, 52.44% (43) participants were growing compared to other children in the neighborhood and 47.56% (39) are not growing well.

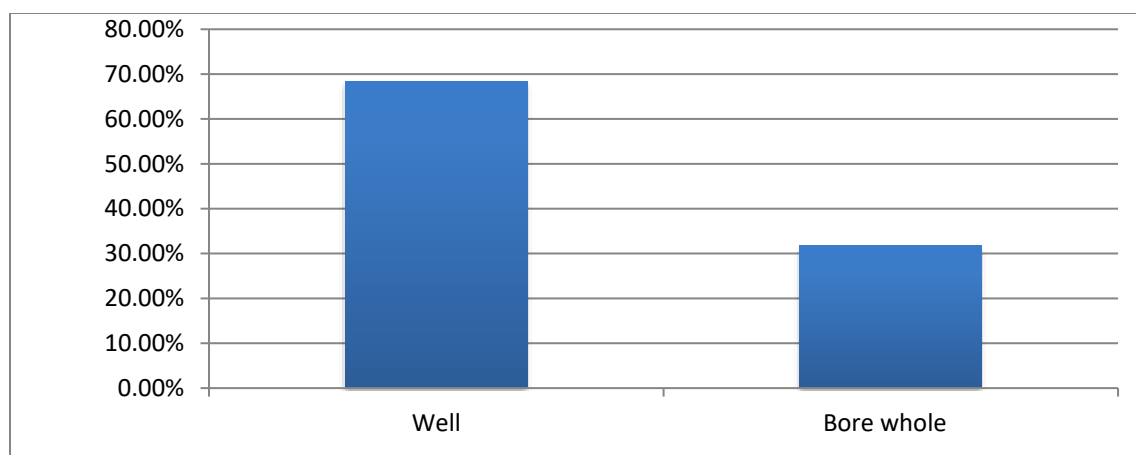


Figure 51: Source of domestic water

In the graph above, 68.29% (56) got their water for domestic use from a well while 31.71% (26) got their water from a bore whole.

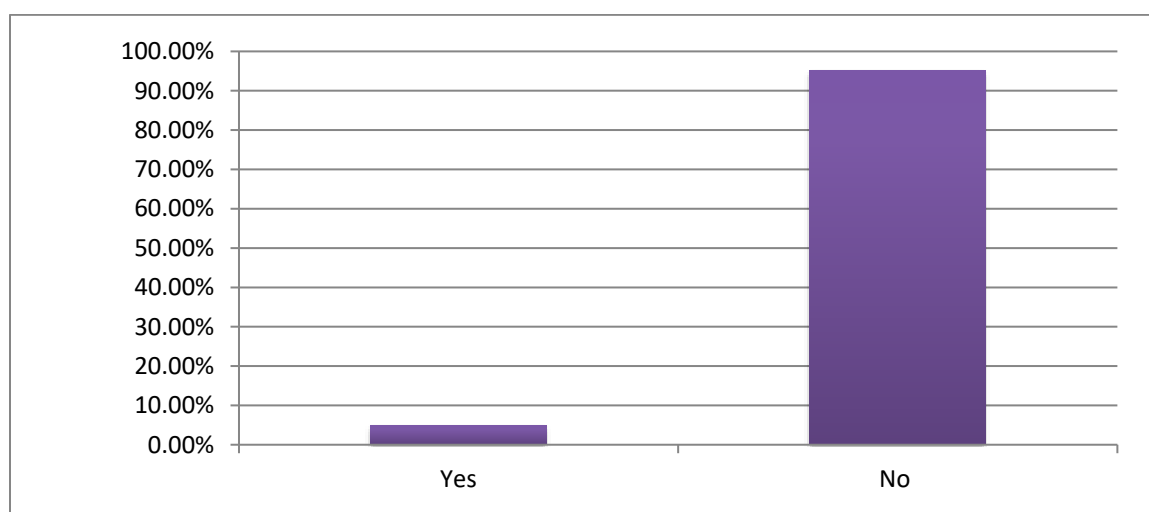


Figure 52: Participants who drink boiled water

From the graph above, only 4.88% (4) boiled their water for drinking while 95.12% (78) did not boil their drinking water.

Table 3: Frequency of those who live a long a river

Live a long a river	Frequency
Yes	17
No	65

The highest number of participants (65) do not live close to any river.

## **-CHAPTER FIVE-**

### **5.0 Discussion**

#### **5.1 Introduction**

This chapter will be discussing the results that were obtained from the research in comparison with the literature review. This chapter gives more details into the answers that were given on the questionnaire.

#### **5.2 Discussion**

This discussion is based on data that was collected from 82 participants who are suffering from nodding syndrome. This data was collateral due to the age of the participants being low for informed consent and their inability to understand the questions and give a productive answer.

Of the 82 participants; 51.22% of the children were between the ages of 11 and 15 years old. 7.32% were between 0 and 5 years old being the least number with only 6 individuals, 28.05% being between the ages of 6-10 years old that is 23 children and 13.41% being between the ages of 16-19 years old and that is 11 children. This proved the point that; This condition has been found to commonly affect children of the ages 5-15 years (WHO, 2014; Kahn 2014) though it also stretched from 1 to 19 years old (WHO, 2014). 40.24% of the participants that is 33 children were born within 2001-2005 with the least number of 3 that is 3.66% being born between 1990 to 1995. 19 children 23.17% of the total were born between 2006 to 2014 whereas 27 individuals 32.93% of the participants were born with in 1996 – 2000.

There were more females 49 that is 59.76% who participated in this research as compared to the males who were only 33 that is 40.24%. In Kitgum district among the interviewed participants, a great majority belonged to catholic religion that is 29 which is 35.37% followed by the Protestants with 27 individuals that is 32.93% of the total. This was then followed by the Pentecostals with 16 individuals that is 19.50%. The least being the Muslims and the Seventh Day Adventists with only 5 individuals per group with a percentage of 6.10% of the total size. A great majority 69.51% that is 57 of the participants living in Kitgum district were Acholi and the least being Lugbar with only 6 individuals of the total interviewed that is 7.32%. The second

biggest tribal group who participated in this research was the Langi with a percentage of 23.17% that is 19 individuals.

This condition was found to be in a region where many families suffered for many decades from brutality by the Lord's Resistance Army which was lead by Joseph Kony CNN (McKenzie D, 2012). From the 82 individuals who were interviewed, it was discovered that 82.93% (68) of their mothers were alive and 17.07% (14) were diseased. Where as 92.68% (76) of their father were alive and only 7.32% (6) had their fathers diseased. Most of the diseased parents died due to: The Joseph Kony war – murdered, Illness. A large number 59.76% that is 29 of the participants were found to be currently of have stopped between primary 3 and primary 5. This is followed by 17.07% that is 14 of the participants being between Nursery and primary 2. 15.85% that is 13 of the total participants were found to be between primary 6 and primary 7. The minority of 7.32% (6) were currently not in any formal education. Results show that 100% of the participants were single. The largest number of participants 32 came from the Tumango village while the least (4) came from Lapoqui village.

Of the 82 participants, 76 that is 92.68% were on medication and the remaining 6 that is 7.32% were not on medication. The medication that is being used was: Diazepam, Folic acid, Phentoin, sodium Valproate, Vitamin B complex, Phenobarbital, Chlorpromazine, Stellazine, Artenel, Promethazine and Carbamazepine. Most of the individuals that is 43.90% (36) on medication showed slight improvement in the symptom of the syndrome, 35.37% (29) showed improvement in such away that the frequency of seizures had reduced incredibly. However, despite being on treatment, 20.73% (17) showed no improvement.

At the time of interview, from results more mothers were present than fathers. With 89.02% (73) being mothers and 10.98% (9) fathers. This low number of fathers being at home at the time of the interview was due to the fact that the interview was carried out during the week days while they were at work. For the parent interviewed the great majority 31.71% (26) were within the age group of 40-50 years. Followed by 26.83% (22) who were between the ages of 30 and 40, then 15.85% (13) were between 20-30 years old, 10.98% (9) being between 50-60 year old.

6.10% (5) were between the ages of 60-70years old. Only 4.88% (4) parent's participants were between 16-20 years old, with the least group of 70-80 years old being 3.65% (3)

Many (63.42%) that is 52 of the parents who were giving the information during the interviews did not complete primary while few finished primary 7. Only 23.18% (19) of the parents went to secondary school but none completed senior four. The least category of 13.42% (11) had no any formal education during their life time. As a result of not having enough skill required to do career jobs, a large number of them 87.80 % ( 72) were peasants farmers, and street venders. Only 12.20% (10) of the parents interviewed had professional jobs like teaching, administration and cooks. Due to a great number of parents working as peasants, this has reflected on their income levels per house hold such that 74.39% (61) earning less than 50,000 Ugandan shilling a month while only 25.62% (21) parents earned more than 50,000 Ugandan shillings. However, there were no reports of any one earning more that 150,000 Ugandan shillings.

A great number of participants lived in semi-permanent grass thatched houses. That is 89.02% (73) while only a small percentage of 10.98% leaved in permanent houses. These houses were found to hold less than three bedrooms that is 89.02% (73) and only a small percentage had more than three rooms but not more than 5 this took up only 10.98% (9) individuals. This was mainly due to the small household income earned per month. There would not be enough money to cater for many partitions of the house. However, when a child grows beyond the age of 19 they were married off if they were girls or they had to build their own house with in the compound so this reduced on the congestion in the house if they were boys.

It was learnt that many families have big numbers and this could be associated with poor health planning methods or education. From the research, a great number of participants 75.61% (62) reside 5-10 individuals in one house. Only 10.98% had less than 5 people residing in one hat. However, there were also homes with more than ten individuals living in the same house. Although many people earn less than 50,000 a month, a good number of families 45.12% (37) had at least one mobile phone on either MTN or airtel. However, they were not smart phones but they could afford to communicate with other people over phone by calling or texting. However, the majority 54.88% (45) still don't own mobiles phones in their homes due to maintenance

costs. However, 78.05% (64) of the participants at least had a radio that uses dry cells at home and only 21.95% (18) still lacked radios in their homes. No individual owned a television because most of the homes didn't have electricity.

This syndrome has created a lot of stigma within the community and it has created some division on how families relate to each other. 17.07% (14) participants' parents said they had a good relationship with their neighbors despite the illness, they didn't mind about their children interacting with their neighbors. 51.22% (42) said that their relationship was fair there were good days and there were bad days. While 31.71% (26) of the participants didn't relate with their neighbor very well, they didn't interact and they didn't allow their children to play with them either they believed that the disease was contagious and it would spread to their children and kill them.

Despite associating the appearance of nodding syndrome with the decade of the war, most community members believe that the syndrome is transmitted from one child to another (Katrina B, et al, 2013). This stigma has also extended to their work places and has affected the relationship with their co-workers. 32.93% (27) said that their co-workers had a good relationship they help each other and advise each other. 47.56% (39) said they have a fair relationship sometimes their co-workers are fine with them other days they are not very associative with them. Although they are in a fair relationship, they are not very close to the extent of helping them personally. 19.51% (16) said there is a lot of stigma with their co-workers, they are isolated and when their boss find out about their children's condition, they get fired because their boss believe that they might bring their evil spirits in to the business and cause them to fail. One parent expressed that adults are not susceptible to the transmission of the syndrome because 'The blood of elders is stronger' (Katrina B, et al, 2013). Another added 'Adults can resist because they are strong, Adults who are experiencing nodding syndrome may still have the spirits or toxins in them' (Katrina B, et al, 2013)

29.02% (32) of the participants' parents were displaced into camps due to the Lord's Resistance Army led by Joseph Kony war. Most places in northern Uganda were not safe for individuals to stay so many people were displaced into camps for protection and food. However, 37.81% (31)



of the parents remained in their villages but in hiding with minimum security, and 23.17% (19) of the participants' parents moved to towns where more security was available. During this period, all the mothers 89.02% (73) who were interviewed were pregnant at least more than once with or without any other illness. 10.98% (9) of the participants' parents were sick at least once during this period of time. Many people got wounds and musculoskeletal diseases. 0% of the participants' parents were not affected in any other way. 47.56% (39) of the participants had more than 6 siblings all alive and living together, 30.49% (25) of the participants had between 3-6 siblings; where as only 21.95% (18) of the participants had less than 3 siblings. There was no participant who was recorded to be the only child in the family. In addition, 53.66% (44) of the participants had at least one more of their siblings also affected with the nodding syndrome, while 46.34% (38) had no any other sibling with the syndrome.

Due to the great capacity of individuals living in a small house with not more than 5 bed rooms the majority having 3 bedrooms (89.02%), some of the participants had to share bed with their siblings and that was 19.51% (16). While the remaining 80.49% (66) didn't share beds with their siblings and this was because they each had their own beds, or due to stigma from their siblings, some of them didn't want to share beds because the patients get seizures during the night and other participants were put in separate rooms by their parents so they didn't disturb in the middle of the night. Some slept tied up in stores so they don't start wondering around in the night. Many parents attempted to isolate ill from healthy children (Katrina B, et al, 2013) Although some sibling (31.25% (5)) didn't mind and treat their ill sibling good others that is 43.75% (7) just had to tolerate them and be fair to them because they are their siblings and can't help it. However, 25% (4) of those who shared a bed with their other siblings were treated badly with cruelty and hatred. They say that "these siblings with this illness have evil spirits within them and they may spread to the others in the family".

Due to their illness, many children were being denied the opportunity to be children like any other and go to school to attain a formal education. This is mainly due to the constant seizures as well as the slight mental retardation, the poor memory, the bad behavior and the lack of understanding of what is being taught in class so parents feel like they are wasting money. As a result only 59.76% (49) of the participants went to school and the remaining 40.24%

(33) dropped out due to the above mentioned reasons. For the 49 student who were still attending school though not regularly, not all teachers have come to terms with this illness therefore many (34.69% that is 17 reported) were still being mistreated by their teachers and abused because they don't understand what was being taught. In some schools however, the government made an effort to educate teachers on how to deal with these cases just like any other student and 20.41% (10) were being treated with care and given more time to understand what was being taught and 44.90% (22) were being treated just like any other child with no discrimination and no special care being given.

These affected children have been left vulnerable by the illness and open to mistreatment by their fellow students, like bullying, physical miss-treatment and emotions distress. During this research, it was found that the majority (61.22% that is 30 students) of the participants were treated very badly because just by their looks they appeared different, they behaved differently and they didn't fit into the society just like any other children did. As children it's in their nature to play together, to share food and even have a best friend they just like to be with all the time. These children most of the times, other children didn't like to share food with them, they didn't like to sit next to them because some times they took off their clothes without really understanding, and when they got into convulsions, their friends thought that they were being attacked by evil spirits. A median percentage of 22.45% (11) was neither mistreated nor treated specially by their fellow students. Only a few 16.33% (8) had some friends who looked after them and were nice to them. For these being treated nicely were in the youngest age category and their seizures were not as intense as those in other age groups.

When the parents/ caretakers were asked about the performance of their sick children in academics, only 10% (5) were reported to be studying well and moving with their academics, because they were reported to be on medication since the symptoms started manifesting and as a results the frequency of seizures was not as bad as those who started their medication late so they were able to sit in class and get through a lesson and be able to do heir homework well and pas exams although not very excellently. A large number of students 89.80% (44) out of the 49 were not studying well like other students, they had repeated classes a number of times and still

not progressing to pass primary seven. The great risk was that parents were spending money on uniforms and books and were soon giving up on their academics.

This disease has only been officially identified in 2009 in Kitgum district and has therefore been made aware to the public for 6 years. Not all teachers have come to terms with this disease and having some of their students being affected by this condition; it is therefore a struggle for the teachers to understand what these students are going through in all aspect of health. However, in some schools, the government has started educating teachers about this condition and giving them instruction on how they should be handling the affected. At the time of this research, only 6.12% (3) were being given special care like extra couching and having more of teacher-student time. Unfortunately a great majority of 93.88% (46) out of the 49 students were not getting any special help from the school so they had to struggle on their own for their success.

All the 82 participants who took part in this research had a religious affiliation to one group or another as follows; Catholics (35.37% that is 29), Protestants (32.93% that is 27), Pentecostal (19.50% that is 16), Muslims (6.10% that is 5) and seventh day Adventists (6.10% that is 5). However there was a larger number 54.88% (45) of the participants who did not attend their religious groups for their spiritual growth this is due to stigma that has been created within the society. As one parent was telling me that when they go to church ‘no one wants to sit with them on the same bench because many believe that these children have evil spirits in them, and can therefore pass on to other children’. As a result unfortunately only 45.12% (37) attend these groups. From the 37 participants who attend their religious groups, only 32.43% (12) were treated with respect and compassion by other religious members, 43.24% (16) were neither discriminated nor given any special kind of love or care. One father told me “church is meant to be one of the most peaceful and loving places in all our life but when we go and they treat us like we are a devil, it make me feel like I want to just kill myself and the whole family and rest from the mistreatment, its not fair”. 24.33 % (9) of the participants reported cruel behavior from their fellow religious members one mother told me “one day we went to church and my child was refused to attend Sunday school” this kind of treatment discriminates these patients from having a health social life style.

According to media reports, this devastating condition has created a lot of stigma among the children of Kitgum district northern Uganda, a mother explains to the BBC news reporter in 2012, that her two affected children no longer go to school and the most worrying thing is that the children are not showing any signs of improvement since the start of the medication to control the seizure a year ago, she goes on to explain that the neighbors don't allow their children to interact with them and as a result, the whole family has become isolated from the rest of the society (BBC, 2012). A large number of children 60.98% (50) did not play with their fellow children as they should like any other child. Their major problem was having seizure randomly at any time, getting into accidents and wondering off if left to play in the neighbors' complex without an adult's watch. When parents are going away, these children are most of the time left tied up on a tree or in the house to avoid unnecessary accident. Only 39.02% (32) of the participants got to play with their fellow children and that was because they played while their parent's watched, they were not isolated by their parents or others, and they were on medication so their seizure attacks were not very violent like others. When they got to interact with their fellow age mates, only 14.64% (12) were treated well by their friends they cared for them and kept an eye on them. 40.24% (33) were neither mistreated nor loved by their fellow age mates. However, 45.12% (37) of the participants were treated badly by their friends and therefore tend to keep to themselves and avoid going to play with the other children so to avoid the emotional and physical stress.

There were no participants who took part in this research that had a job, 100% of the participants did not have jobs this was due to stigma and inability to perform on the work they had to do. However, of the 82 participants only 23.17% (19) had tried looking for work because they were above 13 year old. And the remaining 76.83% (63) had not tried to look for work because they were still very young and did not have the necessary skills required. Nodding syndrome remains an unexplained neurological condition which is characterized by repetitive dropping of the head forward as well as accompanied by seizure like episodes (WHO, 2014). This syndrome is mainly characterized by seizures and according to my research 100% of the participants get seizures though the intensity and severity varies. Only 43.90% (36) of the participants said that the people around them didn't mind being around them despite their condition. However, 56.10% (46) of the participants said that those around them didn't want to associate with them most of the time.

For some people, with or without medication the occurrence of seizure was not greatly affected, 40.24% (33) of the participants got seizure attacks more than 3 times in a day and 59.76% (49) of the participants experienced seizures less than 3 times in a day. This was regardless of time and without any specific triggers. Since these individuals started showing symptoms of the syndrome, 92.68% (76) of the children's behavior had changed while in 7.32% (6) no change in behavior had been noticed by the parents. Of the 76 participants whose behavior had changed, it was reported that 71.05% (54) of the participants had become more violent both at home and with their friends this was mainly physical violence while 28.95% (22) of the participants had become depressed. They were dull and didn't want to do anything, sometimes they just slept throughout the day even when they were not tired.

Following the change in behavior the participants' parents were asked how their children felt about themselves, their self esteem. 9.76% (8) said they were happy with their lives, 20.73% (17) said they can't really tell if they are happy or sad they were just there emotionless and a great majority 69.51% (57) said that they "think their children are not happy because they are very sad and dull, they don't like to go out to play with their fellow friends". When asked about diet a great majority of participants commonly ate sweet potatoes as their main food with 12% while cassava was eaten the least with only 7%. Greens were the most commonly eaten sauce with 16% of the participants and meat was least eaten with only 2%. Although commonly the children participants would desire to eat more of meat than greens and rice rather than sweet potatoes or cassava the families didn't have enough finances to be able to cater for these expensive food.

50% of the participants ate 3 meals in a day that is breakfast where they ate food from the previous night; they also ate lunch as well as dinner. 33% of the participants ate only 2 meals in a day this was due to the fact that there was not enough food at home to cater for all the three meals. A minority 17% of the participants had only one meal in a day this was because there was insufficient food at home and some families had a large number. However, another reason why they didn't have all the three meals for some of the participants was because they can't finish a meal without getting seizure attacks. During this research, it was found out that only 3.44% (3) individuals finished their food without any seizure attacks, 32.93% (27) sometimes got seizures

but sometimes they were able to finish their meals while the majority 63.41% (52) of the participants couldn't finish a meal without getting seizure attacks which means that they wouldn't be able to have all the three meals properly. This has led to a number of health problems which include loss of weight.

Parents reported that 54.88% (45) of the participants had greatly lost weight, 30.49% (25) had fairly lost weight and 14.63% (12) reported no loss of weight since the start of the disease onset. This loss of weight has brought upon many negative changes on the development lives of the children. 52.44% (43) of the participants were reported to be developing well when compared to their age mates however 47.56% (39) of the participants were reported not to be growing well when compared to other children who were not affected by the condition. This is partly due to the loss of weight, due to lack of some nutrients needed for proper development, some children have become retarded in their development such that an 18 year old individual looks like a 10 year old. From the 82 participants it was reported that 68.29% (56) get their domestic water from a well or a stream most of which are not protected and the water is not filtered and 31.71% (26) get their domestic water from a bore hole which is a well protected pump that gives limited chances of water contamination. Of those who use the above mentioned sources of water only 4.88% (4) boil their water before drinking and the remaining 95.12% (78) drink unboiled water and they are hence more susceptible to water borne diseases. In 2004 most of those who suffered the disease lived close to the Yei River and 93.7% of them were found to harbor the parasite (Lucy M, et al 2003). From this study, majority (65) of the participants didn't live close to rivers however; there was no participants who reported to be living along Yei River.

## **-CHAPTER SIX-**

### **6.0 Conclusion and recommendations**

#### **6.1 Conclusion**

Based on the results of the present study, children affected by nodding are stigmatized at home, school and social gatherings which severely affect their cognitive and socio-developmental milestones culminating into low self-esteem and weight loss attributable to seizures occurring between meals.

#### **6.2 Recommendations**

These recommendations are directed to Kitgum General Hospital, the government of Uganda as well as the public.

- A research about the physiological impact of nodding syndrome should be conducted to expand knowledge and identify relationship to social effects.
- The government or non-governmental organizations should setup schools for nodding syndrome children and provide special care to cater for their psychological and social well-being.
- The hospital should find means on how to provide balanced diet meals for the patients during their stay at the hospital.
- All teachers within the district should be fully educated about the syndrome and counseled on how to deal with the affected children in their classes.
- Religious leaders should be educated about the syndrome and they should provide a warm and comfortable place for these patients to feel welcomed and not stigmatized.
- The general public should be fully educated about this syndrome to avoid stigmatization of the patients.

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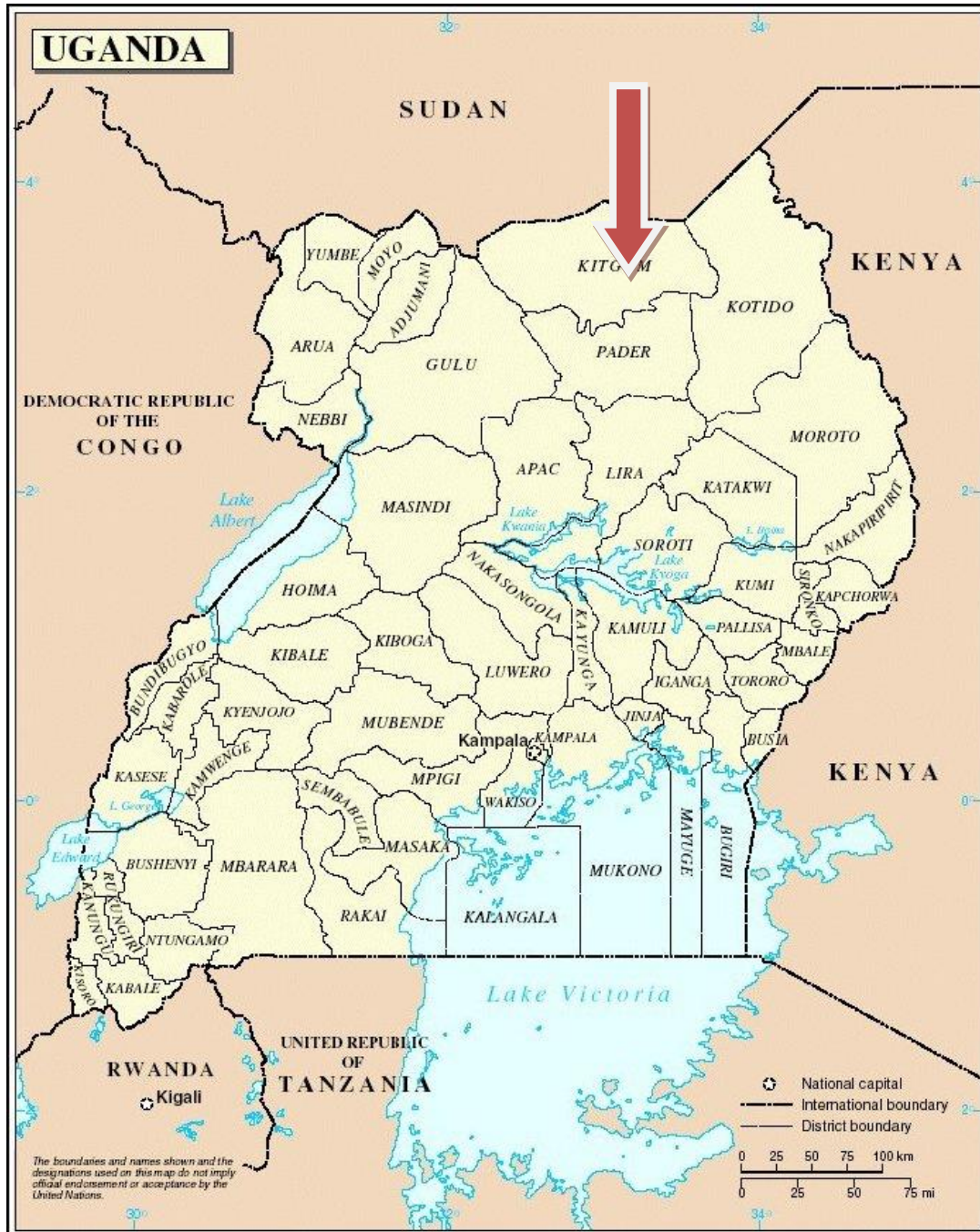
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## APPENDIX

APPENDIX I: Map of Uganda showing the location of Kitgum district



## APPENDIX II: Map of Kitgum district



### APPENDIX III: Questionnaire

#### SOCIAL EFFECTS OF NODDING SYNDROME ON THE LIVES OF CHILDREN LIVING IN KITGUM DISTRICT NORTHERN UGANDA- QUESTIONNAIRE

This is a study on Nodding syndrome a neurological disease which has devastated many people of Kitgum district. This study is aimed at identifying the social effects of the syndrome on the lives of the children between the ages of 1-19 years. As a participant you have the right to reject this participation. I can assure you that this study will not include you giving samples nor will it include you undergoing any kind of surgical procedure. However, it might involve physical examination s of the affected parts of the body. All information provided will be kept in confidentiality and will not be publicized. This is collateral data.

#### Granting permission

I .....have read/ heard and understood the above and hereby give permission to.....to continue with the questionnaire. Sign .....Date .....

#### Section 1: The patient participant -demographic data

1. Age     0-5 ☐     6-10 ☐     11-15 ☐     16-19 ☐
2. Date of birth .....
3. Gender     M ☐     F ☐
4. Religion .....
5. Tribe.....Mother .....Father .....
6. Parents/ next of keen: mother - Alive ☐     Diseases ☐     Cause of death .....  
Father - Alive ☐     Diseases ☐     Cause of death.....
7. Academic level .....
8. Marital status: Single ☐     Married ☐

9. Village of residence .....
10. How long has the family lived in this village for?.....
11. When did he/she acquire the condition and at what age? .....
12. Is he/she you currently on any medication? YES ☐ NO ☐ If NO, why not? .....
13. If YES what is it? .....
14. When did he/she start taking the medication? .....
15. Is there any improvement since the start of the medication and how?.....

## **Section 2 For the parents:**

16. Father ..... Mother .....
17. Age .....
18. Level of education .....
19. What is your occupation?.....
20. On average how much do you earn a month? .....
21. Type of housing?.....How many rooms does the house have?.....
22. How many people live in the house?.....
23. Do you have mobile phones, how many?.....
24. Do you have a TV or radio?.....
25. How is the family affected by this condition?.....
26. How does your family relate with the neighbor?.....
27. How do you relate with the people you work with? .....
28. Where were you between 1987 and 2008.....
29. Do you remember any events that happened during that time?.....
30. Were you pregnant or sick during that time?.....

### **Section 3 the patient participant: Social effects**

31. How many siblings does he/she have? ..... Which number is he/she?.....
32. How many people are in the family? .....
33. Is there anyone else in the family with the same condition?.....
34. Is there any one you have lost in the family? YES ☐ NO ☐ Cause of death .....
35. Does he/she share a bed room with any one?.....
36. If Yes how do they react to wards him/her?.....
37. If no, why? .....
38. Does he/she go to school? YES ☐ NO ☐ If No, why?.....
39. If YES, How do the teachers treat him/her? .....
40. How do the fellow students treat him/her? .....
41. Does he/she study well like other children? YES ☐ NO ☐ If NO Why .....
42. Is there any special care that is given to him/her? YES ☐ NO ☐ If YES,.....
43. Does he/she feel like you are like any other children? YES ☐ NO ☐ If NO Why.....
44. Does he/she go to church or mosque? YES ☐ NO ☐ If NO, Why
45. If YES, how do people react towards his/her condition? .....
- .....
46. Does he/she play with other children? YES ☐ NO ☐ In NO, Why .....
47. If YES, how do they react towards his/her condition? .....
48. Is he/she currently employed?.....
49. If NO has he/she ever tried looking for employment?.....
50. If Yes has the condition affected his/her work in any way and how? .....

51. Does he/she get seizures YES ☐ NO ☐ If YES what triggers them .....
52. How do people react to wards that? .....
53. How often does he/she get seizures?.....
54. When mostly do they attack? .....
55. How is his/her memory? .....
56. Has his/her behavior changed since the condition started? .....
57. If YES, in what way has it changed? .....
58. How does he/she feel about her/himself?.....
59. What foods does he/she mostly eat?.....
60. How many meals does he/she take in a day?.....
61. How are his/her feeding habits? (can he/she eat a meal and finish without any seizures or not  
.....
62. Has there been any lose or gain of weight since the condition? If yes what are the associated  
factors?.....
63. Is she/he growing well?.....
64. The water used for domestic use where is it from?.....
65. Does he/she take boiled water? YES ☐ NO ☐
66. Is there any river or lake around your area? YES ☐ NO ☐ If YES what is it?
67. Any other comments about the condition?  
.....

**THANK YOU FOR YOUR PATICIPATION**



## APPENDIX IV: Introductory letter



KAMPALA  
INTERNATIONAL  
UNIVERSITY

Ishaka Bushenyi \* PO BOX 71 Ishaka, Uganda  
Tel: +256 (0)771696711/0703817216 Fax: +256 (0) 41 - 501 974  
E-mail: admin@kiu.ac.ug \* Website: <http://www.kiu.ac.ug>

OFFICE OF THE DEAN,  
FACULTY OF CLINICAL MEDICINE & DENTISTRY

25/11/2014

### TO WHOM IT MAY CONCERN

**RE: JANET KANYANGE (BMS/0004/113/DU)**

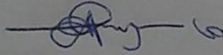
The above named is a student of fourth year at Kampala International University pursuing a Bachelor of Medicine, Bachelor of Surgery (MBChB) programme.

She wishes to conduct her research project in your hospital and the community around.

**Topic:** Social effects of nodding syndrome on the lives of children living in Kitgum district Northern Uganda.

Any assistance given will be appreciated.

Thank you

  
**Benjamin Oonge**  
Dean, FCM &D



*"Exploring the Heights"*

## APPENDIX V: Permission letter

Kampala International University  
Western Campus  
P.O. Box 71, Bushenyi

25<sup>th</sup> November 2014

The medical superintendent

Kitgum General Hospital

Dr. Geoffrey Okello

Dear Sir,

My name is Janet Kanyange a fourth year medical student in Kampala International University pursuing a degree in medicine and dentistry. I would wish to carry out a research on the "Social effects of nodding syndrome on the lives of children living in Kitgum District" as a requirement of my academic progress in Kitgum General Hospital and the community around.

When permission granted, this research will last no longer than two days. All information provided will be kept confidential and only used for academic purposes.

I truly appreciate your assistance.

Yours sincerely

Janet Kanyange

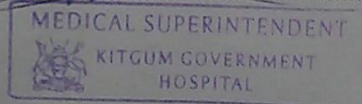


Permission granted

Name Dr. Geoffrey Okello

Sign [Signature]

Date 28/11/2014



## APPENDIX VI: Pictures during research



**Permanent house**



**At the nodding syndrome**

**centre – Kitgum General Hospital**







**Semi-permanent houses**

## APPENDIX VII: Work plan

Activity			Dates in November – December 2014									
	August	1 <sup>st</sup> - 30 <sup>th</sup> Oct	1 <sup>st</sup> - 20 <sup>th</sup>	21 <sup>st</sup> - 24 <sup>th</sup>	24 <sup>th</sup> - 25 <sup>th</sup>	26 <sup>th</sup>	27 <sup>th</sup>	28 <sup>th</sup>	29 <sup>th</sup>	30 <sup>th</sup>	1 <sup>st</sup> – 9 <sup>th</sup> Dec	10- 11 <sup>th</sup> Dec
Topic identification												
Proposal writing and editing												
Final proposal submission and approval												
Contact the authorities												
Print the questionnaires												
Travel to Kitgum district												
Meet the authorities and present introductory letter												
Start research process												
Complete research process												
Travel back to KIU												

Report writing and editing.												
Report approval and submission												

## APPENDIX VIII: Budget

Item	Quantity	Per unit Ugx	Total cost Ugx
Questionnaires	96 (four pages each)	100	38,400
Pens	2	700	1,400
Transport	2 (to and from)	60,000	120,000
Accommodation	4 nights	20,000	80,000
Food	4 days	15,000	60,000
Facilitation to translator	4 days	80,000	80,000
Printing proposal and report		50,000	50,000
Binding		3000	3000
Compact Disc		1500	1500
Miscellaneous			50,000
<b>Total</b>			<b>484,300</b>