

KYAMBOGO UNIVERSITY

THE CULTURAL AND RELIGIOUS CONSTRUCTION OF NODDING DISEASE AMONG THE ACHOLI PEOPLE OF NORTHERN UGANDA

KEDDY OLANYA ACAYO

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SUPERVISORS

This is to confirm that this dissertation entitled, 'The cultural and Religious Construction of Nodding Disease among the Acholi people of Northern Uganda' has been under our supervision and meets the requirements for the award of a Masters of Arts in Religious Studies Degree of Kyambogo University.

1. Dr. Alexander Paul Isiko

Signature.....

Date.....

2. Ass. Prof. Robert Kuloba Wabyanga

Signature.....

Date.....

DECLARATION

I, Acayo Keddy Olanya hereby declare that this dissertation titled 'The Cultural and Religious Construction of Nodding Disease among the Acholi of Northern Uganda', is my own original work and has never been presented to any University or any other institution of higher learning for the award of a degree or any other qualification.

Signed.....

ACAYO KEDDY OLANYA

Date.....

DEDICATION

This dissertation is dedicated to my husband Mwaka Gaspher and my lovely children; Genesis Akena Oryang and Victoria Anena. My dear and respectful parents; Mr. Alphonse Olanya and Hellen Margret Oyella and all my siblings, for the sacrifices they made in order to see me through this undertaking.

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ABBREVIATIONS

ARLPI	Acholi Religious Leaders Peace Initiative
CDO	Community Development Officer
IDP	Internally Displaced Persons
LC3	Local Councilor Three
LRA	Lord's Resistance Army
ND	Nodding Disease
NGOs	Non-Governmental Organizations
NRA	National Resistance Army
NUPI	Northern Uganda Peace Initiative
NUTI	Northern Uganda Transition Initiative
TV	Television
UN	United Nations
UNLA	Uganda National Liberation Army
UPC	Uganda Peoples' Congress
WHO	World Health Organization

ABSTRACT

Since 2009, medical experts and other scientists have tried to make meaning of the nodding disease. Their explanations nevertheless have not been satisfactory to the people of Acholi with no clear explanation on the causes of nodding disease. This has made it difficult to have the right treatment that can cure the nodding disease (ND). With the failure of science to provide a plausible explanation for nodding disease in Northern Uganda, alternative explanations have been sought, with the local people of Acholi finding solace in cultural and religious explanations. This thesis is a result of rigorous attempt to establish and analyse the cultural and religious perception of the people of Acholi about the manifestation, causes, diagnosis and treatment as well as effects of nodding disease among the Acholi of Northern Uganda. The study was qualitative in nature. It entailed use of interviews, observations and document reviews as the data collection methods. Both face to face and phone call interviews were used conveniently. In situations when physical meetings with respondents were not possible due to distance, phone call interviews proved as a convenient substitute to enlist the required information. The snow ball technique was used to identify and reach out to respondents with required information. Both in person and phone call interviews were conducted in Luo language, the language of the Acholi. All interviews were audio recorded, and later translated in English after the transcribing. Using observation method, the researcher observed the physical and social environment in which patients of ND lived as well as the day today interaction between the patient and the family members. Document review and analysis was usefully employed with scholarly resources in form of open access journals from the internet and other such printed articles and books. More relevant information about nodding disease was got through mainstream and social media. The study findings revealed that the manifestation of nodding disease starting by nodding of heads on sights of food. The associated

cause according to cultural leaders, pointed out that evil spirits majorly believed to be as the result of LRA war. Based on this belief, spiritual cleansing of some areas was done to end nodding disease and this showed some response of no new infections of nodding disease in Acholi land. The disease left a huge negative impact in Acholi land especially in affected communities and families. These effects included; poverty in affected families, disability of the affected children and stigma among others. The researcher recommends cleansing of the whole Acholi land by cultural institution to avoid any other calamity unfolding in the land based on unmet cultural obligations

CHAPTER ONE

INTRODUCTION AND BACKGROUND TO THE STUDY

1.0 Introduction

Despite the scientific and specific medical interventions, the nodding disease syndrome (NDS) continues to affect the people of Acholi Sub-region without a plausible explanation to its cause and cure (Kristine, 2014). The disease is continuously a mystery to both the victims and the medics. There also exist several other mysteries concerning nodding disease which require deeper understanding. For example, nodding disease in Uganda has only been reported in Acholi sub region; the disease is new in the region, with no traces of its earlier existence in the country. The disease affects only children between the ages of 5 to 15 years, as adults are free from the disease (Kitara 2013). Science has failed to come up with a satisfactory findings on ND. Therefore, there is needs for a different approach to explain it. Due to such mysteries, the people of Acholi have turned to culture and their religious beliefs to seek for answers about the disease. Whenever Western Science and medicine fail to provide plausible explanations to diseases, many societies find solace in their cultural and religious interpretation. The study is an interrogation of the religious and cultural explanations advanced by the Acholi on the Nodding Disease Syndrome (NDS). The study sought to demystify the mysteries surrounding the emergency and manifestations of Nodding Disease. It sought to answer the following questions; why are only children between 5 to 15 years of age that are infected by the disease? Why are adults not infected with the disease? Why has the disease occurred now and in Acholi sub region of all regions of Uganda? What do the Acholi think of the cause of Nodding Disease? These are questions that this study went out to answer, utilizing people's thinking and their interpretation of the disease.

The study presents the understanding of the NDS from the cultural and mystical religious perspective following an interface with a few selected people of Acholi, as well as prior documented analysis, cultural and religious construction of the disease as the theoretical perspectives. This study analyzed the way the Acholi people visualized, understood and interpreted the Nodding Disease in relation to their cultural and religious beliefs and thinking.

1.1 Background to the Study

The African conception of disease goes beyond the biological explanation of biomedicine. To the African worldview, health is beyond proper functioning of the body organs but, emotional, spiritual physical, and most importantly mental stability of oneself, family and community (White 2015). Good health is looked at as having good relationship with the ancestors, and sickness or ill health is perceived by some, as retribution from the ancestors for neglecting them. When disease strikes, Africans are prone to respond using their time-tested traditional medicine practices. Indeed, some Africans believe that there are some diseases that Western medicine cannot cure but traditional medicine does (White 2015).

Akwasi (1985), provides the Ghanaian example of typical African thinking about disease. He argues that to the people of Ghana, when disease strikes suddenly, or when disease takes away the life of a healthy young person there must be a problem. Worse still, if the disease appears incurable and become chronic, it's probably due to something that the victim or some other agent has done. The Ghanaians never interpret the death of a young person as a natural occurrence. The only death they can consider natural is old age where one can fall sick and die. Despite the many African concepts of diseases, many infectious diseases has hit Africa. Among them are Ebola in West

Africa, (Angeliar, 2015), Smallpox in Benin, (Soumonni, 2010), Nodding syndrome in Liberia, Southern Sudan Tanzania, and currently Northern Uganda (Colebunders et al., 2016)

The nodding syndrome was subsequently reported in Sub-Saharan Africa, in Tanzania in 1960, Liberia in 1983, and in South Sudan in 1990 (Kitara 2013). In the Acholi sub region, it was first reported in Kitgum, and Lamwo districts in August 2009. By that time, of the 30 cases investigated, about 23 of them were confirmed with the Nodding Disease. By 2012, the disease had spread widely in Acholi sub region, which led the government of Uganda to declare the Nodding Disease an epidemic (Kitara, et al. 2017). According to World Health Organization (2012), the government of Uganda's report on the Nodding Disease Syndrome (NDS) in Northern Uganda, indicated that there were about 3,094 cases of children affected in the districts of Kitgum, Lamwo, Pader, and Gulu. The report also highlighted 170 deaths due to the disease, while several other patients' whereabouts were not known because they disappeared under mysterious circumstances (Kristine, 2014). Based on such incidences, parents of Nodding disease patients started keeping their sick children indoor when they were going out of home. Some children were tied on the tree in the compound or on the middle poles inside the huts to avoid their disappearance from home. The report further indicated that many of these children had dropped out of school, neither could they engage in any productive work as others could not feed themselves among other things. This in the long run made them malnourished (Ministry of Health, 2012).

Colebunders et al. (2016), comparing observations from Tanzania, South Sudan and Uganda shows that black flies could have played a role in the spread of an etiological agent that either directly or indirectly causes Nodding syndrome and other forms of epilepsy. According to the first International Scientific Meeting Report (2012), a number of causes of Nodding Disease have been ruled out like genetic predisposition, and infectious environment, while toxicological hypothetical

causes require further investigation (World Health Organization, 2012). The disease is not understood well by medical scientists as it is expected to be in biomedicine. Biomedicine is expected to have a universal understanding and approach to specific diseases, which has not been the case with the nodding disease. Therefore, due to lack of agreement among clinical researchers on the cause and treatment of the nodding disease, the people of Acholi sub region, just like several other African societies, resorted to other means to explain and understand such diseases using their traditional socio-cultural and religious philosophies (Latigo, 2006). To bridge the gap of the unending search for the reality of the nodding disease being the first disease of its kind in Uganda, the local people need more inquiry into their cultural and religious beliefs to gain a nuanced understanding of the Nodding Disease Syndrome and its emergence in Acholi land.

1.1.1 Nodding Disease in Uganda's Context

Nodding syndrome is a neurologic condition which has not been explained. It is characterized by repetitive dropping forward of the head, always followed by other seizure-like activity, such as convulsions or starting spells. The definition of nodding disease remains problematic with no universal acceptance. Scholars like Kitara, et al. (2011), defines Nodding Disease as a neurological disorder whose cause is undefined, and it affects children and adolescents aged between 3-18 years. He states that the disease is caused by simulium (Black fly) commonly found along river basins. This possibly explains why the most affected persons live in Pader and Omoro districts with the Aswa River flowing through them, as well as Kitgum and Lamwo districts with river Pager. These four districts were all highly infested with the black flies before an Aerial spray of the rivers in the year 2012, with an intension to kill the flies (Colebunders et al., 2016). On the other hand, Echodu et al. (2018), describes Nodding disease as a childhood neurological disorder which affects the community in Northern Uganda and it is clustered in the time of Internally Displaced Persons (IDP

Camp stay); -geographically located on both side of Pager and Aswa rivers, affecting children within the age ranges of 5 to 15 years.

Therefore, Kitara et al. (2011) and Echodu et al. (2018) agree to the fact that the nodding disease is only found in Northern Uganda among the people of Acholi sub region. The disease ravages those in river basins of Aswa and Pager, and that it is a purely neurological condition affecting the young. One major issue that separates the two researchers is that Echodu et al. (2018), claims the disease to be prevalent during the time of the people's gestation in the Internally Displaced Camps. Other writers like Colebunders et al. (2016), define nodding disease as a multi-system disorder that affects the central nervous system with key features including nodding of the head, seizures, growth retardation, intellectual disability, and muscle wasting. Whereas Kitara et al. (2011) and Echodu et al. (2018) describe nodding disease based on its causes. Colebunders et al. (2016) focuses on the characteristics of the patients and the effects of the disease on the patient.

Much as Western Science and biomedical studies have made attempts to define and explain the existence of nodding disease, their explanations are not satisfactorily enough. For example, the definition by Kitara et al. (2011), there exist other rivers in several other parts of Uganda with black flies but have never recorded any case of nodding disease. Therefore, relating the cause of nodding disease to black flies along river Aswa and Pager, is not convincing as the cause of nodding disease. A case in point is, River Nile passes through several districts of Uganda, but they have not experienced nodding disease, not even invaded by the black flies that are said to cause nodding disease. The description of nodding disease by Echodu et al. (2018), also brings more questions than answers. Accepting the predisposition of Internally Displaced Persons Camp as the cause of nodding syndrome brings suspicion. Camps were not only created in the fourteen sub-counties of Acholi sub region that have been affected by nodding disease but in more than the

fourteen sub counties. Internally Displaced Camps were created in all the sub counties and districts in Acholi sub region that were affected by the Lord's Resistance Army rebellion. Nonetheless, not all districts of Acholi that had camps have patients of the nodding disease. Moreover, some parts of Teso and Lango sub regions, were affected by the war, with Internally Displaced Peoples' camps created in several of their sub counties, but have not recorded nodding disease victims. There is suspicion by previous scholars that the Lord's Resistance Army war that took place in Northern Uganda is the cause of the nodding disease, but fails to explain why other areas affected by the war are free of nodding disease. Should this be the case, it would be interesting to establish whether the people of Acholi hold any explanation relating the nodding disease to the war situation they experienced. This therefore means that the explanations given by western scholars and biomedicine of the nodding disease goes beyond the confines of their definitions and explanations. This explains the very reason why this study considered taking cultural and religious perspectives as alternatives to the non-satisfactory biomedical.

Since biomedical explanations have been unsatisfactory about providing explanations of the nodding disease to the people of Acholi, this study sought to interrogate cultural and religious meanings that the Acholi attach to the biomedical explanations identified by previous scholars. The study specifically established and analyzed the cultural and religious attachment and meaning that the people of Acholi have in connection with the cause, manifestations, timing, geographical location and age of victims of the nodding disease. The study also analyses the cultural location of the people of Acholi in relation to the disease. Further interest was to establish the cultural and religious relationship that exist between the nodding disease and the rivers in Acholi land. The cultural and religious perceptions of the Acholi people on people's concentration in Internally Displaced People's camps and the phenomenon's relation to the nodding disease was explored too.

All cultural societies, whether Western or African try to understand disease/sickness by looking at issues like: naming of the disease according to their specific cultural circumstances; description of the disease and all forms of its manifestations; causes of the disease according to their cultural environment; characterizations of the disease; diagnosing and treatment of the disease and the impact of the disease upon society.

1.2 The Context of Acholi Sub region

This study was conducted in the Acholi sub-region of Northern Uganda. The Acholi sub-region is bordered by the Republic of South Sudan to the North, West Nile sub-region in the West, Karamoja sub-region to the East and Lango sub-regions in the South. The Acholi are Luo speaking group that came from Barh el Ghazel in Southern Sudan. Some of them settled in Northern Uganda and others in Kenya. The Acholi people are found in South Sudan and Northern Uganda. This study is specific to the Acholi sub region in Northern Uganda. The population for Acholi people in Northern Uganda is approximately 1.47 million people, representing about 4.4% of the national population (UBOS, 2014). The sub-region has eight districts; Agago, Amuru, Gulu, Kitgum, Lamwo, Nwoya, Pader and Omoro. Cases of nodding disease is only reported in four of these districts. The four districts are Lamwo, Kitgum, Omoro, and Pader as reported in the Ministry of Health press statement on Nodding Disease in Northern Uganda (Aceng, 2018).

Acholi sub-region became known to the world because of the long civil war against the legitimate government of Uganda. The war led by Joseph Kony; an Acholi from Omoro district was called the Lord's Resistance Army (LRA). To fight the LRA rebels better, the Uganda government in a scorch-earth policy, decided to forcefully move thousands of people away from their often-self-sufficient homesteads into squalid Internally Displaced Persons (IDP) Camps across the sub-

region. This was to protect the people against the rebels who were abducting indiscriminately (Latigo, 2006). The conditions in IDP camps were inhuman, and it was reported at one time that 1,000 people, mostly children were dying every week in the camps (Latigo, 2006). The IDP camps became a place for the production of an after-war disease; the nodding syndrome (Kristine 2015) and (Colebunders et al. 2016). Therefore, these IDP camps are critical in the understanding of the Acholi sub region in relation to the nodding disease because of their setting and social construction.

1.2.1 The Cultural and Religious Setting of the Acholi people

Acholi are part of a Nilotic group of people. The word Acholi is used to describe both a person/tribe (people and society) and the language. This study is looking at the Acholi; both as the people and society because it is the people that makes society. Traditionalists, Christians and Moslems and both the traditional and contemporary Acholi are all considered in the study. The name Acholi was transformed from the calling 'Shooli' by the Arabic speaking traders from the North during the 2nd half of 19th century (Kwekudee, 2013) and (Atkinson 1990). Another scholar said the name 'Acholi' is English version of 'Acoli'. The could have been derived from an Acholi word 'col' meaning 'dark' or 'black' (Ocaya, 2020). This could be basically because of the physical appearance of the Acholi people, most of them are extremely dark skinned. The name Acholi can be traced hundred years back mainly on the basis of oral tradition (Atkinson, 1999). According to history, the Acholi is of many groups of people, they migrated, inter-divided and mixed with others. They split after migration leading to formation of Luo speaking groups known today as Acholi, Jophadhola, Alur and Luo of Kenya with common legendary kingdom of Bunyoro-Kitara (Odhiambo et al., 2003).

History states that the Acholi people came to Northern Uganda from Bahr el Gazel in South Sudan. They developed new socio-political orders by forming chiefdoms headed by Rwodi (rulers). By mid-19th century, about 60 small chiefdoms existed in Eastern Acholi land (Amone, 2015) and (Atkinson, 1989). The numerous chiefdoms have affected the operation of the Acholi cultural institution. There is a lot of disunity in the various chiefdoms based on power struggle. This is partly because of the hereditary nature of the chiefdom. The size of the chiefdom was small because of the non-violent approach. Whenever there was discontent, one would just move and settle in another place (Amone & Okulu, 2014).

The Acholi people are known internationally, most especially because of the war by the Lord's Resistance Army (LRA) led by Joseph Kony; an Acholi from Odek sub-county in Omoro district. The war took about 20 years with a lot of atrocities within the Acholi land and some neighboring districts. This made the government to force the people of Acholi into Internally Displaced Persons camps for easy protection against LRA atrocities (Atkinson, 2011). The aftermath of the war greatly impacted negatively on the Acholi.

It is against this background that the LRA wars lead to the development of IDP camps and the massive killings of innocent people and the eventually emergence of the nodding disease as noted by many scholars. These scholars include Latigo (2006), Kristine (2015) and Colebunders et al (2016) along others. The researcher also agrees with the scholars based on the information with regards to the community pointing at the LRA war and its various problems. These problems include among others development of IDP camps and its impact, and massive blood shed that soiled the land. The aforementioned is what is believed by the local people to have given birth to nodding disease.

The Acholi are pluralistic, they have many religious beliefs and practices. The current Acholi believe in both Christianity and traditional religion. The traditional religious belief of the Acholi is mainly based on spirits and gods (jogi). The spirits are of the ancestors and relatives kept in shrines (abila) that were turned to for fertility, blessings, good health and thanks giving for good harvest (Malandra, 1939). There were some spirits which were not sent to 'abila' (shrine) especially spirits of strangers. They moved wildly, were hostile and they referred to use different names based on their level of atrocities. Some are called 'cen' (ghost); they fight in any style and direction, and they also kill people. These can be sent off by diviner priests (ajwaka) (Grove, 1919). These type of 'cen which can be chased off are called 'cen aywaya', but there are some evil spirits that have gone beyond 'cen'. They become 'lapiny' (rejected spirits) and are the worse type of evil spirits. The major aims of the 'lapiny' (rejected spirits) are cursing and killing people because they were neglected and rejected. When strange sickness strikes, spirits were consulted through diviner priests and solutions were sought. What the spirits demanded to end the problem or sickness was done as demanded by elders and 'rwodi' (chiefs).

The Acholi were also engaged in the ceremonies of 'jogi' (gods) especially child birth, marriage, planting and harvest with offertory ranging from birds, animals, food and drinks. Almost each clan had their own 'jok' which was responsible for the people's welfare. This welfare ranged from guidance, dependence and protection of the people in a particular clan. These gods include among others; Lagoro in Pader but mainly consulted as general 'jok' for the whole Acholi, Baka for Patiko, Loka for Koch, Olalteng for Puranga, Nyilak for Atiak, Kalawinya for Ogom, Labeja twol for Alero, and Kilegaber for Koro. However, Christianity was introduced in Acholi land in the 2nd decade of the 20th century and attracted many followers, this did not end the traditional beliefs of the people of Acholi. The tradition still persisted and mixed with the Christian doctrine made the

Acholi tradition weak and complicated. This is because many people now pay less attention to the 'jogi'. This has weakened the Acholi in combating any strange sickness in the land; a case in point is the Holy Spirit Movement of Alice Lakwena and the Lord's Resistance Army of Joseph Kony who were believed to be led by Holy Spirits in their wars (Finnstrom, 2006).

A very important practice among the Acholi is 'Mato oput' (reconciliation) which is done in case of misunderstanding that led to death. The clan or family elders of the deceased and the murderer come together for reconciliation and compensation of the deceased by the killer's (offender) clan/family. This is to put the two families at peace (Atkinson 2011). The significance of this ritual is to reunite the two communities who were previously estranged due to violent/conflict but reconciliation did not take place. Adibo (2017) states that when reconciliation is not made, the spirits will haunt the offender. "Mato oput" is a cultural ritual well-known among the Acholi. It essentially entails drinking a bitter herb prepared from the root of a tree known as "oput". The ritual is always performed during the peak of a conflict-resolution process by a person/s of the community who has killed another. According to Latigo (2008) and Baines (2005), the ritual is practiced to suppress hate and resentment. Redemption is only possible if there is a voluntary admission of wrong doing, the acceptance of responsibility, and the seeking of forgiveness. "Mato oput" is conducted after "culukwor" (reparation). The two clan elders of the offenders and the victims agree on the compensation there after, mato oput is performed (Ker Kwaro Acholi, 2001).

However, given the various views on the causes of nodding disease as a result of LRA war and the significance of "mato oput" where killing has occurred, the rituals has not been performed on the LRA victims who have been killed or those who had killed. This could be because none of the killer's families or clans are known and none of them sought for forgiveness and reconciliation from the victim's families because they either don't know the victim's families, lack of willingness

or the offender also died in the bush, thus making reconciliation impossible. With regards to this impossibility, one would conclude that the nodding syndrome came as a result of the spirit of the dead hunting the people. Spirits leads to moral norms that all the people of Acholi are expected to follow and the spirit is expected to revenge in response to violations of the moral code (JRP, 2012). The religion of Acholi forbids the killing of human beings based on the sanctity of human life. This is because killing one another in the Acholi community provokes the anger of the deities and ancestral spirits of the victim(s) making the evil spirits to invade the homesteads and causing harm to its inhabitants (Tom, 2006). This can make one link the nodding disease which is more spiritual to the absence of reconciliation among the victims and the offenders' families or clans.

The Acholi people have experienced so many strange sicknesses from generation to generation. These included Atipa, jok kulu (spirits from river banks) among others. Rituals were done and these people got cured. A deadly disease that led to many losses of life was 'odye' (small pork). It mainly killed the people of the payira clan who were staying along Murchison falls. As a result of this, they had to vacate the place. Other diseases were 'two anino' (sleeping sickness), 'two dobo' (leprosy), 'two anyoo' (measles) and Cholera which also claimed many lives but were treated locally using traditional herbs mainly leaves and roots from plants. 'Two odero' (epilepsy) is one of the sickness that has ever affected the Acholi people to date though it is no longer a common sickness like many years back. Cultural rituals were performed for the cure of Epilepsy and indeed the patient would recover and gain good health. There was also Ebola which was brought from Congo to the Acholi land in the year 2000; rituals were performed in Aruu falls where a goat was slaughtered, prayer said and other ritual ceremonies performed that led to the end of Ebola (A. Lacambel, personal interview, Aug. 29. 2020). All the above sicknesses were treated and cured. Currently we have nodding disease which seems to have taken quite long for the solution/

treatment and cure to be found. Nodding disease is similar to epilepsy according to its manifestation on the attack. The only difference is that epilepsy is traditionally curable while the nodding syndrome has yet failed to respond to any treatment both traditionally and scientifically. However, not all hopes are lost since there seems to be no newer infections.

1.3 Statement of the Problem

Medics and scientists have tried to make meaning of the nodding disease; attempting to explain its nature, causes and possible remedies. Biomedical scientific explanations have yielded more contradictions than convergence of ideologies about the nature and etiology of the nodding disease (Isiko & Acayo, 2021). Amidst these contradictions, are the mysteries that surround the nodding disease among the Acholi. It is mysterious that the nodding disease is restricted to the Acholi sub-region; affecting children and adolescents of 5 to 15 years and that there is no previous history of the disease in the area among others. The Acholi's quest to understand the mystery of the disease in their area (a place that has previously been hit by a rebel insurgency for over twenty years) at this particular time in their history of existence remain unsatisfied through attempts of modern science. Dismissing scientific explanation of nodding disease, the people of Acholi have attempted to interpret the disease beyond science. They have resorted to their cultural and religious cosmologies in search of meaning. This study therefore attempted to establish, understand and analyze the way the Acholi people conceive and interpreted nodding disease using their cultural and religious lenses.

1.4 General Objective

The general objective of the study is to analyze the cultural and religious construction of nodding disease among the Acholi of Northern Uganda.

1.4.1 Objectives of the Study

The study was guided by the following specific objectives

- a. To explore the cultural and religious beliefs about the nature and manifestation of the nodding disease.
- b. To explore the religious and cultural interpretations of the causes of the nodding disease.
- c. To explore the cultural and religious perceptions on diagnosis, treatment and rehabilitation of patients with the nodding disease.
- d. To examine the effect of the Acholi traditional cultural and religious perception of the nodding disease upon the society.

1.5. Research Questions

The study was guided by the following research questions.

- a. What are the cultural and religious beliefs about the nature and manifestation of the nodding disease?
- b. What are the religious and cultural interpretations of the causes of the nodding disease?
- c. What are the cultural and religious perceptions on diagnosis, treatment and rehabilitation of patients with the nodding disease?
- d. What are effects of the Acholi cultural and religious perceptions of the nodding disease upon their society?

1.6 Scope of the Study

This section considered the study scope at three levels. These were the geographical scope, content scope and time scope. Geographically, the study was conducted in Acholi sub region. Acholi sub

region is bordered by West Nile Sub region to the West, Karamoja Sub region to the East, Lango Sub region to the South and The Republic of South Sudan to the North. The size of the Acholi sub region is 28,009 square kilometers of Uganda's land (Ocaya 2020). The Acholi sub-region was selected because the nodding disease has been experienced only in this part of Uganda (Kitara et al 2013), despite sharing a historical experience of rebel activities with some other parts of the country (Isiko and Acayo 2021). The content scope was limited to the study of the cultural and religious beliefs and interpretation held by the Acholi on the nodding disease. Specifically, the following core issues were studied; cultural and religious beliefs about the nature and manifestation of the nodding disease, cultural and religious interpretations on the causes of the nodding disease, cultural and religious perceptions on the treatment and rehabilitation of the nodding disease patients, effect of the Acholi traditional/cultural and religious perceptions of the nodding disease upon patients and their care givers and the alternative explanation of the nodding disease. This alternative came because of the failure of the biomedical scientific explanation of the nodding disease. On the other hand, the time scope was between 2009 to date. The year 2009 is important to the study because it was at the time that the nodding disease phenomena was first reported in the sub region (Kitara and Amone, 2012). The disease continues to affect and ravage several families in Acholi land to date.

1.7 Significance of the study

The research shows the importance of combination of science, religion and culture working hand in hand in the fight of any persistent strange and infectious sicknesses or diseases that strikes the community. This is because science, religion and tradition play different roles in one's life. Science helps in treating the body, culture helps in treating the mindset and religion handles the belief and soul. Such perfect combinations help in the rapid therapy and psychological healing, as the

treatment of the mind is the greatest treatment a patient requires for the body to respond to the physical treatment. This relationship brings hope to the people of Acholi in the fight and ending of the nodding disease.

The research findings will benefit quite a number of stake holders among them are; the Acholi traditional cultural leaders, Acholi Religious leaders and the medical fraternity in the fight against strange sicknesses. This is because the disease will be looked at in a wider perception not only in the medical line but also along the line of culture and religion. This study is important because it helps in the understanding of the society's cultural perspective in analyzing some diseases. This is because some diseases seem to be more of cultural than medical and can be handled well culturally than medically. There is need to embrace culture in the fight against strange sicknesses especially where science seems to be failing in controlling the disease. This would help curb the disease before it affects many people.

1.8. Conclusion

It's important to always look at the background of a particular society where diseases strike. The nature of the disease as well as the mode of transmission, especially for non-commutable diseases. The cultural and religious leaders of the area can be of more help than the medical team in the fight against some of such diseases. Other than side lining and restricting them from handling the disease as it was in the case of the nodding disease; where the government was too strict for other interventions but only the medical teams were to handle the disease. Some policies need to be flexible especially when it comes to issues of humanity that affect a particular community; allow them to give in their input as it might be a faster and cheaper option.

CHAPTER TWO

LITERATURE REVIEW

2.1. Theoretical framework: Cultural Construction of Disease

The Cultural Construction Theory is derived from the theoretical domain of the cultural construction of reality (Henderson and Henderson, 2002). Within this theoretical body, cultural constructs exist as cognitive domains subsumed within the realm of total existence. The cultural construction of health and illness is viewed as a device for categorizing or systematizing symptoms. Illness constructs are organizing frameworks for imposing structure upon the continuum of experience. Illness constructs reflect core cultural values in that they express normative understandings about the nature and causes of anomaly and dysfunction. The meaningfulness of any cultural construction for any particular group is necessarily a function of that group's cultural values. Cultural construction of health emphasizes the symbolic dimension of the understanding of health and includes the knowledge, perceptions and cognitions used to define, classify, perceive and explain disease. Each and all cultures possess concepts of what it is to be sick or healthy. There are classifications of disease, arranged according to severity, criteria of symptoms, etc. The classification and the concepts of illness, and health rarely reflect the biomedical definitions meaning they are not universal (Langdon & Wiik, 2010). Sociologists and Anthropologists are main proposers of the theory on Cultural Construction of Disease. The anthropologists include, Karl Mannheim, Emile Durkheim and William Isaac Thomas (Conrad and Baker, 2010).

Some illnesses are attached to cultural meanings which is not derived from the condition but from the society giving it a social dimension of the disease as said by Conrad and Baker, (2010). Some

of these diseases are stigmatizing because they have social and cultural impacts on the patients and health care. The theory is therefore called Cultural Construction because it is the traditional or cultural society that make it the way it is. This is best explained through their interpretation, belief, perception, attitudes, care and treatment which is culturally done as well as the naming of the disease.

The concepts of illness and disease have been explained by different scholars. According to Langdon and Wiik (2010), illness is a person's experiences of loss in his or her health. Langdon says, illness and health are universal in human life and present in all societies. While diseases are always socially constructed by their cause. Disease is referred to a physical or mental disorder involving symptoms, dysfunction or tissue damage. Not all causes of diseases are biological. In the society, culture constructs the way its members think and feel about a sickness and their names. Sickness is a more subjective concept related to a personal experience of a disease. Similar sicknesses have different social construction depending on the cultural belief in a given society (Langdon and Wiik, 2010). Illness is a condition characterized by a deviation from a normal health state manifested with a physical and psychological symptom. On the one hand, disease is a physical or mental disturbance involving symptoms, dysfunction or tissue damage. There are many diseases that can affect the human body ranging from cold; which is considered as a minor illness to a complicated disease. Illness is culturally determined, explaining health and illness is the work of culture (Ayodele, 2002).

Eisenberg (1977) posits that social construction of illness gives important understanding of social dimension of illnesses which clearly differentiate the concept of disease as a biological condition and illness as a social meaning of the condition. The medical people take diseases as universal to

time or place while social constructionists emphasize how the meaning and experience of illness is shaped by cultural and social system.

Disease is not thought to strike randomly but rather as a consequence of a disruption in the social or moral order, which has to be repaired (Buchman, 2014). This belief associate most of the sicknesses to come from within the society not from anywhere else, this explains why most of the illnesses are linked to society or culture but not nature.

Illnesses have both experiential and biomedical dimensions. Some illnesses have particular cultural or social meanings referred to them which may have its own impact on the patients and health care, which may significantly impact on those afflicted (Sontag, 1978). On the one hand, the sociologists examine the result of other cultural meanings involved in illness. According to this sociologist, that assert that not all illnesses are the same. Some are stigmatizing and considered disability while others are not. However, these illnesses all exist for social and not purely biological reasons. The sociologists are therefore more interested in the difference. Cultural meanings have impacts on the way illnesses are experienced. The theory demonstrates exactly the cultural perception of illnesses, care treatment and cure among the traditional Africans. Therefore, both cultural and social construction of illnesses are important in the study, since some illnesses have both social and cultural meaning (Conrad and Baker, 2010).

It is worth mentioning that the nodding disease associated with many culturally and socially related issues. There are quite a number of important issues to borrow which are applicable to the research topic at hand, i.e. a sickness which has been culturally constructed by the society based on the nature of the sickness; how it affects the patients and the community's perception around the sickness. They have failed to identify a name for the illness but just describe it based on the behavior of the patients. Just as Conrad and Baker (2010) put it, there is a lot of stigma surrounding

nodding disease which does not come from anywhere but from the society where these patients live. This affects the healing process because some patients would shy away from going for treatment due to fear of stigma.

The researcher used the theoretical perspective to establish and understand meanings that the Acholi as a cultural society place on the nodding disease, given the challenges that have surrounded biomedical scientists on the same. This theoretical perspective has been of value in answering the research questions on this study. The study established and analyzed the Acholi society experiential dimension with the nodding disease, taking into consideration that disease have both experiential and biomedical dimensions. The researcher aimed at analysing the often taken for granted particular cultural and social meanings that the Acholi attach to nodding syndrome. These meanings are sometimes embedded with metaphorical connotations. Secondly, using the theory's pragmatic underpinning of constructionism, the researcher analyzed how the Acholi socially constructed nodding disease basing on their experience with the disease, well knowing that reality created by individuals who act in and toward their world but not just waiting to be discovered, but rather is This analysis will reveal the Acholi's every day and subjective experience of the nodding disease, based on their unique circumstances. These findings demonstrate that diseases and illnesses are as much social products as medical-scientific. It doesn't invalidate scientific and medical perspectives, (Conrad & Barker, 2010).

2.2 Cultural and Religious beliefs about the nature and manifestation of disease

Various scholars mainly characterized culture as something that is widely shared by members of a social group by virtue of belonging to that group. Among the many scholars are; Tylor (1871), defines culture as that complex whole which includes knowledge, belief, art, law, morals, customs;

any other capability and habits acquired by man as a member of society. Another scholar Geertz (1973), defines culture as a historically transmitted pattern of meaning embodied in symbols interpretation of cultures. Religion on the other hand has so many definitions advanced by many scholars. For instance, Durkheim (1955), defines religion as the conservation of values. It belief that individual present themselves in the society they live. Society existed before and have values and norms. Religion came as a way to control values.

A psychologist Sigmund (1953), defines religion as seeking comfort in a world which is desperately considered, i.e. the more the problem the more religious the person become and the less problems the less a person seek for God. With these definitions of culture and religion, the two-move hand in hand. Culture and religion give similar explanation on the construction of disease. Culturally and religiously, diseases do not strike randomly but there are factors that lead to sickness especially on the way the disease manifest itself. The nature and manifestation of disease shows how the disease appears or signs of attack and how the patient behaves or conducts him/herself. Diseases always appears in various dimensions. For the case of the nodding disease, it is mainly cultural because the disease seems more spiritual according to the way the patients behaves and what they say of attack.

A number of authors have written about Religion, Culture and disease. These include Conrad & Baker (2010), Langdon & Wiik (2010), and Eisenberg (1997) among others. Soumonni (1968), believes that disease is not a medical condition but a punishment from the gods. Diseases were seen as god sent punishment that can only be cured by the specific god empowered to inflict such punishment or by the priest devoted to its worship. According to some people, diseases are primarily interpreted as punishment by the gods for the wrong doing, the nature and weight of the punishment vary from the offence committed. Akwasi (1985), states that people who have belief

in unclean diseases, are a disgrace to the patient and the family or relatives. This makes the relatives keep the patient indoor, thus worsening the condition.

Conrad and Baker (2010), says illnesses are socially constructed but it is not a natural phenomenon. We have cultural meaning of illnesses which is not directly derived from the nature of the condition that shapes how society responds to those afflicted and experienced all that illness. An illness is socially constructed at experiential level based on how individuals come to understand and live with the illness.

Conrad and Baker (2010), points towards a general agreement that there is cultural interpretation of disease. Across the various cultures, they believe that disease is not a natural condition but it is something that is generated socially by society and they give it a cultural meaning as emphasized by Conrad and Baker (2010). Most societies believe in illnesses as socially generated that is why some sicknesses are termed as unclean as noted by Akwasi (1985). However, unclean is not a medical term but a term constructed by the society for some illnesses. This could explain why in their search for cure, their first priority is the traditional herbalist since they belief in illnesses immerging from within the community, and thus the solution should be sought within rather than outside.

To the Acholi who are now Christians, the traditional belief about the nodding disease doesn't hold water in this era of the 21st century. They disagree with traditional beliefs and agree with the explanation of modern science. The children with low immunity is usually associated with manifestation of the nodding syndrome. This explains the fact that not all families in the same area(s) or children from the same families are affected with the nodding disease. This makes the disease even more complicated, this makes the Christianized Acholi belief that the nodding disease

is a punishment from God. However, complicated the issue of the nodding disease is, traditional culture and modern religion has a role to play in ending the disease in Acholi land.

2.3 Religious and Cultural interpretation of the causes of disease

From a cultural perspective, diseases are at times believed to be triggered by an event that leads to other conditions which are considered the causes of particular disease or ailment. In this case, the researcher is using a cultural theory in an attempt to interpret the events that led to the nodding disease syndrome in the Acholi land. The theory on the cultural construction of disease is in agreement with both culture and religion because they both have a role to play in ending the nodding disease in Acholi. Religion and culture move hand in hand. Among the Acholi people, rituals are performed for traditional healing and prayer is involve in performing the rituals either symbolically or verbally and sometimes for the rituals to be effective, the name of almighty God, “jok ma malo” is invoked. This clearly shows that Religion and culture believe that diseases do not just strike randomly but are caused by either spirits, God’s punishment or curse. Several authors are in support of this view on the cultural and religious believe on the causes of diseases.

Akwasi (1985) states that, there are some diseases caused by God as a punishment to the people due to their misconducts especially for the leaders like Tribal Chiefs when they persistently offend the gods. The gods then send punishments on the peoples’ leader through disease. This makes the whole tribe or community come around the leader, they make sacrifices to God to appease Him for healing. In this case they believe modern medicine is inadequate for the cure, spiritually caused disease should be spiritually handled.

Akwasi (1985) further notes that, some diseases are caused by Ancestral spirits. The living people are to observe traditional laws, customs and taboos of a traditional community such as performing

proper funeral rites for a dead relative. If this is not properly done, the ancestors are said to become annoyed and punish the living with disease. On a similar note on taboos, (Gyekye, 1995) notably said, violation of taboos may also lead to sickness. Taboo is an important part of the African Traditional Religion as a way of life. There are a lot of taboos, among which are food taboo; where communities are to observe food and meat related taboos. Disobeying the taboo leads to severe illness of the person or community involved. Taboos have some moral and ethical connotations, even if violated secretly a person cannot go unpunished.

Witchcraft and spell-casting is another cause of sickness. People with evil powers cause those they don't like or those disrespectful to them to become sick as a punishment to them (Olupon, 2004). Many traditional Africans think that certain illness have unforeseen forces which cannot be treated scientifically but treated with witchcraft (Obina, 2012). However, Akpenpuun (2014), on the other hand disagree with Obina arguing that recovery from illness is basically influenced by people's religious beliefs and behaviors towards health care but not witchcraft. Their religious believe help medics for effective health care needs of patients of the different religions. This is true for psychological healing however, there are some religions with negative influence that jeopardize patients healing process. The findings of the above researchers give wider views of religious and cultural belief of the causes of diseases. The Traditional Africans mainly look at most illnesses as punishment from either God or the gods, spirits both evil spirits and Ancestral spirits for the peoples' misconducts or failure to observe the societal norms.

2.4 Perception on Diagnosis, Treatment and Rehabilitation of Patients

Diagnosis, treatment and rehabilitation in the context of disease, illness and sickness can be understood in various ways. For example, Merriam (2002) defines Diagnosis as the identification

of an illness or disease by examining the symptoms. Treatment is the care for or how we deal with a disease or sickness and Rehabilitation is the process of helping a person who has suffered an illness or injury restore lost skills or hope and regain maximum self-sufficiency. In summary therefore, diagnosis, treatment and rehabilitation are the processes of finding out what exactly the disease is all about, dealing with it (the disease) through care and medication and eventually restoring the person who was sick into his/her normal life.

In the African context, diagnosis of disease is to find out if the cause of the illness is either physical or mystical (Dime, 1995). This involves examining the patient and consulting the spirits by medicine men. They always consult the spirits to identify the cause of the sickness if in any case it was a violation of order by the sick, or any other cause. They use cowry shells and bones in their examination of the illness.

Culturally, there are some diseases that strike and the society will automatically look for cultural interventions because of the way they manifest themselves (Akwasi, 1985). A case in point is a person possessed by evil spirit who cannot be taken to the hospital but to a traditional healer to intervene. In most cases, if the person is not position to talk then a chicken is slaughtered to diagnosis the disease from inside the chicken. This will display some clue of the sickness and solution generated. This can only be done by a special person who is gifted in that work. Other than cultural interventions, some sicknesses need religious intervention especially those that are believed to be cursed or punished by God/gods for their evil.

Besides other causes of diseases as mentioned about evil spirits, some sicknesses are natural. It is normal to fall sick but the disease should be treatable without difficulties. There are some sicknesses or complications that are diagnosed and traditional medicines/ herbs are used to treat such ailments better than the modern/western medicine. Traditional medicine applies to both

spiritual and physical remedies. If the person fails to respond to the treatment then the disease is considered a special or unique illness that needs a more and serious investigation to find out the cause and the right treatment for the disease (Akwas, 1985). This is the main reason why this study is conducted for the case of the nodding disease in Acholi land, i.e. to find out why the disease is being treated but cannot get cured.

However much a sickness is unique that the diagnosis and treatment is challenging, a traditional African would do what it takes for holistic healing. The healer deals with the complete person and provides treatment for physical, psychological, spiritual and social symptoms without separating the natural from the spiritual or the physical from the super natural (Thorpe, 1993). For diseases from spiritual attacks, they use charms, amulets and spiritual birth among others to drive away the evil spirits. Some diseases require offering sacrifices of animals or birds depending on the request of the spirits. Some of these offertories of birds and animals are either buried alive or slaughtered for the blood to provide cleansing/healing (Olupona, 2004).

Soumonni, (1968) also notes that traditional medicine men play a leading role in the diagnosis and prescription of medicine mostly based on medicinal plants. He further states that not all traditional doctors can treat all diseases nor do they prescribe the same treatment to different types of diseases. In the 19th century, traditional priests were the doctors of the various diseases in the area. To date even when there is good progress in modern medicine, majority of people strongly believe in the effectiveness of traditional medicine mainly based on the medicinal plants that are as well used in making some modern medicines. A common belief among people in the rural areas is that some sicknesses may not be treated with modern medicine, but rather belief that local medicines or remedies are better in such instances. This is evidenced for instance in treating cough, fresh leaves of mangoes, avocado and eucalyptus trees are chewed or boiled and taken after cooling. However,

for any of these to be effective the disease or ailment must first be diagnosed or specifically identified. The respective remedies are then mixed to treat the identified disease / ailment for the patients' health to be fully restored coupled with other community process of recuperation.

Angellar et al (2015) explains that it is important to recognize the impact of traditional and religious practices which can be helpful on health promotion. For instance, based on the case of Ebola in West Africa, purely scientific method was not enough to control the transmission of the infectious Ebola disease. Yet, some of the methods of combating the transmission of the infectious disease were not culturally and religiously accepted. It was high time they explored traditional and religious practices effectively in combating the spread of the disease. Dealing with cultural and religious issues negatively affects the spread of infectious disease. As custodians of the day-to-day cultural values, traditional and religious leaders command more respects and authority in their community than trained health workers. This explains the need to widely consult and collaborate with traditional and religious leaders (Angellar, 2015). The argument of Angellar (2015) is similar to the situation of the nodding disease in Acholi land where cultural and religious leaders were kept away from the fight against the nodding disease. This was done even when science failed to provide cure for the disease. This should be a lesson that there are some diseases that need combined efforts especially with culture and religion.

Subsequently, it is important to have culture and religion on the forefront in the fight of some strange sickness. Some of the sicknesses have spiritual connotations which needs practitioners who can handle metaphysical matters to deal with. Some sicknesses could not be resolved by scientifically known means. Thus, cultural-spiritual means may not be far-fetched alternatives. The narratives around these issues inspired the researcher to dwell deeper into carrying out her

study on the religious and cultural perception on disease focusing on the nodding disease syndrome in the Acholi land as a case study.

2.5 Effect of Cultural and Religious Perceptions of Disease on Society

Disease in the African context is considered as a bad omen. It is always associated with punishment due to evil act. This makes the victims and their relatives live with shame in the community. Some tend to hide the patient to avoid shame and laughter from the community since they are looked at as a disgrace to the community (Akwasi, 1998). To the Africans, one is punished with a disease due to their misconduct and this has no medical treatment (Soumonni, 1968).

Some cultural perceptions of a particular disease affects relationships (Gramam, 1989). There are some sicknesses that do not strike anyhow, but as a result of witchcraft. This leads to jealousy and aggression among people who are to live in peace and protect each other from external enemies (Isiko, 2018). A case in point are sicknesses which are as a result of witch hunting or transferred from one person/family to another. Such practices are more common among relatives or people from the same area who are to co-exist peacefully. However, this peaceful relationship is contradicted by the witchcraft practiced. This is also worsened by diseases which are stigmatizing. There are some diseases that make one stay in isolation to keep away from shame. Some conditions are worsened without solutions; it cannot be reversed. This makes a person feel more punished and hated. This include some conditions like barrenness; once a person is given her own menstrual or birth blood in food and the person eats it. This marks the end of the person's fertility and the beginning of barrenness; a condition that is irreversible. Such act creates permanent enmity between the person who did the work and the person who is affected. At times close relatives are also involved in the enmity (Conrad et al, 2010).

Kristine (2014), asserts that the cultural perception of diseases gives the community sleepless night with the mind that your child is the next to fall sick. The cultural perception of the disease leads to stigma, isolation and sense of hopelessness. The stigma itself makes the affected people more traumatized; you can't smile in public but ever isolated and sad. Some of the children with the disease are also called with disgusting names such as useless, a disgrace to the community, a dead person moving among others. All these come about based on how people culturally perceive sickness as it strikes due to some gaps that do not conform to societal norms.

The way culture treats some sicknesses makes people also attend to the patient with a lot of laxity. Culturally, some illnesses are socially considered as disability (Conrad et al, 2010). To the Africans, when a person does not live according to the societal norms, that person is liable to suffer from diseases that is believed to be a curse due to his/her evil act. The perception of evil causes leads to shunning of the sick, no treatment given leading to disability, isolation and loss of economic prosperity. On the hand, those with leprosy especially are unable to do constructive economic activity while some patients need full time attention. However, there are also some death cases which are caused by poor ways of burial as noted by Angellar et al (2015).

The way a disease is perceived and interpreted culturally and religiously, affects the patients' education. These children are considered a burden to the family/teachers and a waste of resources to educate as they are helpless. Those who are able to go to school are stigmatized and others isolated from the rest of the learners. Most of them tend to drop out of school due to a number of factors ranging from personal- the sickness, the community perspective about them and the hostile school environment (Kristine 2014). All these come as a result of interpretation and perception of cultural norms and practices in response to some of the diseases. On the one hand, the mode of

response to some diseases and ailments discourages the victims from freely mixing with others to prevent and evade transmission; others do not require such restrictions.

Thus, the effects of cultural and religious perceptions relating to diseases and ailments ranges from social, economic, psychological, and financial impacts. A lot was mentioned by many scholars and a lot was also left out. Therefore, the researcher had to go on and come out with more of the effects of cultural and religious perceptions of disease on the society. The researcher is in agreement with the findings of other authors however, the effect was not exhaustive enough. Thus, made the researcher go on with the study and come up with more findings on the effects of cultural and religious perception on disease.

2.6. Conclusion

According to the work of various authors, a lot has been written in illness and disease and nodding disease in particular. The researcher appreciate the work of other authors on illness and disease and the cultural views on disease and illness. A lot has been written about nodding disease especially on medical ground and a lot has also been left out especially on the culture and religion. The researcher is in agreement with the various authors on cultural construct of nodding disease. However, a lot was missing in their work in regards to cultural and religious perception on nodding disease. It's against this background that made the reasecher motivated to find out more about the cultural and religious perception of the Acholi people on nodding disease.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. Research design

The researcher selected interpretive qualitative approach for this study. This approach was used because the interviews were conducted in the Acholi language. The data collected in the Acholi language was later translated to the English language.

According to Merriam (2002), “basic interpretive qualitative approach is an interpretive and descriptive qualitative study. It exemplifies all the characteristics in which the researcher is interested in understanding how participants make meaning of the situations under investigation using inductive approach and then the study outcomes are descriptive”.

The basic interpretive qualitative approach allowed the researcher to collect data through interviews, observations, and document analysis to bring to glaring light the issues within the families or among the nodding disease patients being investigated. Characteristically, descriptive design is abundantly descriptive and mainly use words to convey what have been learnt about the nodding disease. The quotes from field notes, documents and interviews mainly form the depth of the matter which the qualitative researcher comprehensively reports to the outside world.

Using the basic interpretive qualitative approach as a sole research design in this study, allowed the researcher collect data which helped in the description and explanation of the cultural and religious beliefs in the nature and manifestation of the nodding disease; religious and cultural interpretation of the causes of nodding disease; cultural and religious perception on diagnosis; treatment and rehabilitation of patients with nodding disease; major effects of the Acholi

traditional, cultural and religious perceptions of the nodding disease on patients and their care givers in Acholi sub-region in Northern Uganda.

3.2. Area of study

The study was carried out in Acholi Sub-Region, Northern Uganda. The choice of the Acholi sub region was because it is the only region in Uganda that has been hit by the nodding disease. The Acholi Sub-Region comprised 8 districts namely; Gulu, Kitgum, Amuru, Nwoya, Pader, Omoro, Lamwo and Agago. The study was done purposively in two of the eight districts. These were the districts of Omoro and Pader. In Omoro district, Odek Sub-County was selected, while in Pader district, the study was conducted in the sub counties of Atanga, Angagura, and Awere. The researcher selected these particular districts and their sub-counties because they reported more cases of the nodding disease than the other districts of the Acholi Sub-region (Aceng, 2018). These very areas were reported to have much of the black flies' infestations which caused Onchocerciasis and suspected to be the root cause of the nodding syndrome (Hermann et al., 2014).

3.3 Study population

The study population included both male and female, cultural and religious leaders, parents and caregivers of the nodding disease patients, elders, traditionalists (those who believe only in traditional religion) and health workers. Religious leaders were interviewed to find out the religious perception on the causes of the nodding disease based on its manifestation as well as any effort made on the treatment and rehabilitation of the patient. Traditional/cultural leaders such as traditional chiefs and their prime ministers were another target of the researcher. This aided investigation on cultural perception of the Acholi people in response to the nodding disease since science had failed to treat and cure the disease. The cultural and religious responses were

paramount to the researcher in regards to the research goals. Parents/caregivers of patients with the nodding disease were chosen because they were always with the nodding disease patients. They have personal experiences on the manifestation of the disease when the children got attacked. They also tried various treatments and they experienced direct effects of the disease as a family. Another category were the healthcare givers. This included in-charges, nurses and village health team in public health facilities. Health workers were chosen because they are the ones treating the nodding disease patients and were responsible for some of the improvements on the health of the patients. Although, these patients were not cured. It was as well necessary to find out their perception of the nodding disease based on their interactions with the patients, observing the patients' behavior, manifestation of the disease and its possible cause, the outcome of the treatment administered to the patients and the possible solution. Besides, the health workers were the ones directly involved in the rehabilitation centers. Additionally, were the Acholi elders and the traditionalists- (the Acholi who have failed to embrace modernity but sticks to traditional believes and religion of the Acholi).

3.4. Sample size for the study

The data was collected from 26 participants which comprised: 4 cultural leaders; 7 religious' leaders, i.e. Catholics, Anglican, Pentecostal and Muslim; 2 staff from religious affiliated institutions, i.e. Acholi Religious Leaders Peace Initiative (ARLPI) and Kitgum Diocese Development Program; 4 elders, 2 traditionalists, 4 primary healthcare providers working in public health facilities and 5 parents/caregivers. This sample size was considered appropriate for a qualitative study based on recommendations by Creswell (2020) and Morse (2000). Each of these authors recommended at least 20 to 30 respondents for qualitative studies. In addition, Denzin and Lincoln (2005) recommended 30 to 50 interviews for qualitative studies. Furthermore, Yin (2014) recommended at least 6 sources of evidence and Creswell recommended not more than 4 or 5 cases (Marshall, Cardon, Poddar & Fontenot, 2013; Trotter, 2012). However, to justify the selection of the sample size, the researcher had planned to interview at least 50 participants but the researcher reached saturation point after interviewing 26 participants who covered all the concepts in the study. This because the other participants provided similar responses as the 26 participants.

3.5. Sampling method

The researcher used purposive sampling to select participants for the study. The choice of the participants was based on the topic which is on culture, religion and disease. This explains why religious leaders, the Acholi cultural leaders, the Acholi elders, and Acholi traditionalist were selected. Parents/caregivers of the affected children were chosen because they had more information about the patients since they were always together in the family. The health workers on the other hand, operated within the affected areas where children suffering from the nodding disease received treatment (they were the ones who treated the patients in health facilities).

Purposive sampling was used because it provided information from participants who were directly involved with the nodding disease at various levels to have reliable and valid data for the study (Tongco, 2007). Furthermore, the researcher used snow ball technique to reach the sampled respondents. The researcher was referred from one participant after interview to another for more reliable information. The researcher was able to gather important information especially on cultural perception of the Acholi on ND. This was a very interesting and fruitful method the researcher unexpectedly used.

3.6. Source of data

The researcher used both primary and secondary sources of data. The primary sources of data included data collected through interviews and observations. The data got from personal interviews and observation was very important. The respondents were very honest and open minded in telling their plight. The researcher was able to gather a lot of information based on the participants' responses. Some responses gave clue to other questions which produced more rich information on cultural and religious perception of the nodding disease. The researcher was also able to observe the non-verbal communication and how some participants were emotional in expressing themselves on the plight of the children and families affected by the nodding disease. Primary data also confirmed what had been written which is used as secondary data. The manifestations and likely causes of the nodding disease according to the interview responses agreed that the disease started at the sight of food; mainly caused as a result of the LRA war and black flies around river Aswa. In addition, secondary data sources included published literature on the nodding syndrome and other relevant documents from the internet to help build on the study concepts.

3.7. Data collection methods and instruments

3.7.1. Interview

The researcher used one-on-one interviews using interview guide. This was possible because the researcher went through the sub county offices and was assigned local leaders to move with her to the respondents of the researcher's interest. The researcher introduced herself and explained the intention of the interview to the respondent as purely academic. This was to build confidence and openness by the respondents to avoid withholding important information due to fear of exposure and arrest. Rapport was built between the researcher and the respondents before beginning the interviews. The respondents also introduced themselves and the researcher sought for their consent to carry out the interviews and also take some photos. The interviews involved asking questions generally face-to-face contact. Use of one-on-one interviews proved important for the study because the researcher collected good amount of data and also was able to get reliable information from participants. The interviews were both tape-recorded in Luo with permission from the respondents and hand written in a book in English. Some photos of the patients and the environment they live in were taken with the consent of the parents/caregivers. To supplement face-to-face and one-on-one interviews, the researcher also conducted telephone interviews with participants who were hard-to-reach physically during the study time. The researcher started by introducing herself to the respondents she called, explained how she got their contacts and the people who referred her to the respondents. This was to make the respondents feel free to interact as regards the intention of the interviewer. The researcher voice-recorded the interviews using the phone (voice recording) and also wrote down the responses in a notebook. Use of telephone interviews also allowed the researcher to easily contact inaccessible individuals who were out of

reach physically during the study time. The researcher used the same interview guide for both one on one/face to face interview and phone calls interviews. See appendix B.

3.7.2. Observation

The researcher used observation as a complementary method for collecting data during the study. The researcher was able to directly see the situations on the ground surrounding homes and patients with the nodding disease and the neighborhood using the observation checklist. She only observed some situations without asking questions on them. The researcher also observed and noted some of the non-verbal communications like facial expression, behaviors among other things of both the respondents and the patients. The method was advantageous because the researcher was able to observe the families where the nodding syndrome children live (environment), their lifestyle and how they interact with other family members. Further, using observation, the researcher was able to observe facilities where they got treated and the plight of affected children who are child mothers. Patients in confinement and those with multiple disability as a result of suffering from the nodding disease were also observed. The researcher used this method to help get some of the information that the respondents might have kept secret, like the children in confinement, the general cleanliness of the patients, the relationship between the patients and the family; the relationship between the affected families and the healthy families in the neighborhood among others. The researcher was guided by observation checklist. See appendix A

3.7.3. Document review

With regards to secondary sources, the researcher reviewed and analyze some documents which contained relevant information to the study. This information originated from organizations, TVs, Radios and internet sources. Some of the documents reviewed using data checklist of records were

published reports from the Ministry of Health on the nodding disease; registers and treatment books at the health center as reflected in appendix C; published medical journals on the internet; articles on the New Vision on 'ryemo gemo'- nodding disease and reconciliation. These sources of information were all related to the nodding disease. This method was appropriate because most documents were accessible in the public domains, less costly, more accurate and covered long span of time, especially those accessed from internet sources.

3.8. Validity and reliability of study

The researcher ensured trustworthiness to enhance validity and reliability of the study. The researcher paid attention to the non-verbal communications expressed by the respondents which were more reliable than the verbal communications. A case in point was when a respondent admitted that she was okay with the suffering of the children, as tears flowed down her cheeks. To ensure validity of the information, the researcher further engaged the respondents in off-record chats after the interview on related issues to confirm some of the responses from the interview. The researcher also compared some of the responses on similar questions asked from the same community on a particular item on the interview guide. This was achieved without mentioning names to ensure the factuality in the information. A lot of probing questions were asked to ensure validity of the information.

The reliability of the study was also tested based on the secondary data/information. Some questions were asked based on what was already in circulation from the previous researches conducted. Similar responses confirmed the facts about the study. Some of the references were also made on previous interviews to compare the responses, so as to achieve validity and reliability of the many information acquired from the field of study. Honesty was emphasized so that any

similar research that would be conducted should not deviate much from this current study. This was made possible to ensure consistency and accuracy over a period of time as noted by Golafshani (2003); Noble and Smith (2015).

3.9. Data analysis and presentation

After tape recording the interview, the researcher later listened to the audio; transcribed the audio in a notebook; translated the transcribed data into the Acholi language in word document for easy analysis; noted the new concepts from the recordings. Afterwards, she manually made a thorough analysis and presentation of the data. The researcher carefully read through the interview transcripts, observation data and documentary data several times. The data was categorized according to manifestation of the nodding disease; interpretation of causes of nodding disease, diagnosis; treatment and rehabilitation of nodding disease; effect of cultural and religious perception of nodding disease on patients; families/caregivers and society. The researcher then put each specific objective as a sub-chapter on its own presenting findings, analyzing data and discussing it under the same sub-chapter. Data analysis and presentations were put in four different sub-chapters based on the four different objectives. The researcher finally typed the data in word documents which provided meaning and interpretations for the study's objectives and questions.

3.10. Ethical considerations

Before the study began, the researcher sought an introductory letter from the School of Graduate Studies, Kyambogo University to help her access study sites and participants. The researcher also sought administrative clearances from the Sub-County Chiefs of the areas of study to allow access to participants. The researcher explained the purpose of the study to the participants and all the participants gave verbal consents, expressing willingness to be included in the study. The

researcher informed participants that participation is voluntary and they could decide to leave participation at will without any reprimand. The researcher further sought the participants' consent to use their identification in her report. The researcher also assured the respondents that data collected will be stored in secured places accessed only by the researcher. Some participants voluntarily gave the researcher a go ahead to openly use their names in her quotes because there was nothing to hide about the information since they were facts.

3.11. Limitations

The researcher faced several challenges, which included the following among others; there was a challenge of seeking permission from the offices of the Sub County Chiefs due to absenteeism from office either on official commitment elsewhere or personal commitment. However, in some Sub-counties, the Community Development Officer or LC3 attended to researcher, while in some Sub-counties it was only the Sub County Chief who was able to give authority. This made the researcher to move more than once to be authorized to carry out the study in the area.

Other than absenteeism, there were challenges of late coming where the researcher reached the Sub-county offices by 11am but found no one to attend to her since only the office attendants were present in the office at that time. The researcher had to wait for the respective officers to attend to her. In some cases, she made phone calls to confirm if the officer will be coming or if someone could be delegated to attend to her. Such scenarios made the researcher to start making prior appointments with the respective officers she was to meet. The researcher achieved this by searching for phone contacts of the respective officers in the areas to be visited from their colleagues from the areas visited.

Another challenge was holding of information by some participants especially those who were formally employed (government employees). They claimed that the ND has a lot of political concerns behind. This partly explains why a lot of research has also been conducted on ND but the findings are not released or availed to people to read. This made the researcher to contact the people she knew to link her up with the respective personnel to be interviewed. She assured them that the research is purely academic. Getting some participants were not easy due to their tight schedules as the researcher needed to make appointments with them. Besides, some of them had emergencies that made them to be out of office even after making appointments with them. Another day was scheduled for such cases.

Some of the situation on the ground made the researcher emotional because some of the stories and situations/living conditions of the patients were touching. Therefore, the researcher defied the odd and provided some material things like soaps, biscuits and sweets to some of the patients visited. What the caregivers/parents were going through in taking care of the patients was another painful situation all together.

3.12. Conclusion.

The methods used by the researcher were simple reliable and realistic that was achievable, this made it easy for the data collection. The intended target respondents were interacted with through interviews and observations were made to confirm most of the information given. With this the researcher believe that the research will stand the taste of time. Snow ball played a great role in the data collection of important information because most of the respondents interviewed as a result of snowball were people with great information about nodding disease since they were either directly or indirectly engaged in the fight against nodding disease.

CHAPTER FOUR

BELIEFS ABOUT NATURE AND MANIFESTATION OF NODDING DISEASE

4.0. Introduction

The participants interviewed agreed that nodding disease affects mainly children between 5-18 years. The disease manifests starting by children nodding their heads on sights of food. However, other common manifestations were frequently falling down, convulsion, being aggressive, flows of saliva from affected children mouths, deformation and disorientation in daily activities. These findings collaborate what other researchers have found. Olum et al., (2020) indicated that manifestation of nodding occurring as psychiatric and psychological manifestations, including major depression, aggressive outbursts, mood changes, sleep disturbances, and episodes of wandering. It is similar to Iyenger et al., (2014) who said manifestation of a syndrome that includes cognitive impairment, neurologic deterioration, and additional seizure types. Idro et al., (2013) also elaborated the manifestation of nodding syndrome as head nodding precipitated by food, associated with cold weather

4.1. Naming the disease

The patients were called names because of their behavior. Some were called 'lapoya' (mad) because when they were possessed some of them behaved like mad people. Some became aggressive, as noted as well by Olum et al., (2020), others talked to themselves while others could run away from home. Others were called 'lagoro' (disable) because they could not help themselves fully without the help of another person. Those who were severely affected had multiple

disabilities. There were those who were deaf and dumb; lame and some had paralyzed hands, whereas some were completely crippled.

4.2. Physical and Social manifestation

The children's behaviors showed someone possessed by evil spirits. Among the Acholi, a person possessed by evil spirits (gemo) at times ran away from home when the spirit was being cast out to the well, where cleansing rituals were done and the person became normal. But for the case of the nodding disease, such cleansing rituals were not conducted due to the abandoning of culture, i.e. the 'jogi' (the gods) were no longer taken good care of as it was before by offering sacrifices to evoke blessings, neither were they consulted in case of such strange sickness like the nodding disease due to mixed believes between the Christians (especially the born again) and the Traditionalist. This had left people divided and no longer spoke one language. This had been worsened by the government's restrictions of treating the nodding disease, i.e. treated medically without cultural or religious intervention and political interests. The affected children were instead tied up in one place to avoid running away from home. The environment where they were tied was always dirty. Most of the Acholi community have embraced Christianity and the Christians were against most of the traditional/cultural practices and rather prayed. However, to some people prayers didn't provide all solutions to cultural problems. According to a participant, Kitgum diocese had banned all radio stations in Kitgum from hosting any traditionalist on air to talk about cultural practices which was against the Christian doctrines (E. Luk, personal interview, Kitgum, September. 9th 2020).

Among the Acholi, traditionally if 'gemo' (evil spirits) strikes, fact finding 'moyo cere' was done so as to find out the problem and the solution to the problem. Cleansing was done by the elders in

charge of cleansing rituals who did what was called 'agat' (intercession prayer). It was not done by everyone but there were people with the special gifts of making 'agat' (A, Oloo, personal interview, Gulu, February 19th 2020). On the one hand, those who performed the cleansing ritual slaughtered birds and animals, sprinkled the blood on those who were to be cleansed. The blood was to wash away the problem from these people and the community. The slaughtered animals and birds were only eaten by the male elders who were responsible for the cleansing rituals. This was mainly done by clan/area traditional leaders to end the suffering in the community. It was mainly done very early in the morning between 3-6am at the river banks/wells which was believed to be dwelling places of the spirits; these was the time when spirits were at work.

Some respondents explained that, some families were able to carry out death rituals of their departed relatives. Although the body was not recovered, this was done with the help of witchdoctors. They had been able to bring home the spirits of their departed relatives from wondering in the wilderness which if not brought back home brought curses, sickness, suffering and death as is the case of the nodding disease. On the one hand, some families that were able to detect danger at the start went to the shrines, offered sacrifices to the gods/spirits (jok) seeking for protection of their homes. This can explain why some parts of the Acholi land was more affected than the others. Some part of the Acholi land still practiced death and burial rituals while some ignored such cultural believes and practices. Those who ignored such practices, followed the modern way of only conducting prayers and finishing everything at once. In the former, the last funeral rites to send the spirits of the departed to the spirit world, organized peaceful feasting almost for 3-5 days (E. Luk, personal interview, Kitgum, September 09 2020).

In relation to the nodding disease, 'moyo cere' and cleansing were done in Palabek which yielded some good results. However, it was not done in all the Acholi sub region because some areas had

disunity among the leaders which made it impossible. For any ritual cleansing to be effective, the concerned people had to speak one language (E. Luk, personal interview, Kitgum, September 9th 2020). Families that had carried out ritual cleansings and offering of sacrifices in the right way had their children free from the nodding disease. Still on spirits, another parent said;

“Kal-okwera (not real name)-one of the sick children, started manifesting when he started saying he saw a big snake that his dad killed by cutting into pieces and took the pieces to his house... the children were normally presented with red eyes. The children sometimes refused food when given. The disease struck hard when it was cold.... The nodding disease is different from epilepsy. The children with the nodding disease sometimes turned violent and uncontrollable”. (Parent 4)

Based on this parent’s explanation of what happened to one of her sick children, the child was able to see objects inform of the dad killing a snake. Among the Acholi, snakes were either taken as evil or spiritual (jok). This was related to spirits of a dead person, sometimes revelation came in form of visions. The spirits were revealed how some of the people were brutally killed during the LRA war. The LRA army were said to have done a lot of atrocities to the people; some people were cut into pieces, others cooked in big saucepans and others were forced to kill their own dear ones; on refusal to kill, the person becomes the victim of murders as the relative looked on. This was a tormenting and barbaric way of killing which was traumatizing to those who witnessed it. This could be the reason why some of the children suffering from the nodding disease were so aggressive with red eyes when attacked by the nodding disease. This portrayed the behavior and appearance of an evil person and a murderer. Spirits also didn’t strike randomly. They attacked where there was connection. It was possible that it was either the spirit of the dead relatives attacking the children; - demanding for something to be done inform of cleansing or sacrifices to

be made. Akwasi, (1985), as well gave a similar explanation of a disease that strikes suddenly without cure as being due to something that either the victim or someone have done. Another school of thought lamented that the spirit of the person might have attacked the family of the killer for killing him/her in cold blood. This also explained why some families were affected while others were not. With regards to why it was only the Acholi people suffering while the Lango and the Teso were free from the nodding disease, it was simply because it was an Acholi top-commander who ordered the atrocities; so the innocent blood cried out (A. Lacambel, personal interview, Gulu, Aug 29 2020).

Some of the patients muted as in the case of the first parent on attack while some talked to themselves. Both were signs of someone being possessed by 'gemo' according to the Acholi. In Acholi, 'gemo' was a sign of calamities. Gemo struck when something was not right and something needed to be done. 'Gemo' has no treatment, the only solution was to go back to tradition (L. P'Layeng, phone calls interview, Omoro, February. 15th. 2020). Based on this participant's narration and those of the other participants, one can believe that the nodding disease was more of spiritual issues which needs to be handled either culturally or religiously other than medically. It was cultural because the Acholi people seemed to have answers to the problems but what was lacking was the willingness and how to begin executing the remedies. Everyone seemed fearful of the belling the cat. Meaning there is fear because everyone fear leading the ritual cleansing due to the government restriction on issues of nodding disease. I say so because it was fruitful in a small community according to a participant who participated physically in the ritual. Therefore, why not do it in all the land? Religiously we believe in cleansing for purity in case of evil or uncleanness but no step was taken yet to admit that the problem of the nodding disease was

spiritual. This could be the reason why the medical treatment that the patients were receiving was not curing them.

The children were anemic because they were not eating well since once food was brought, they got attacked, thus unable to eat. They stayed hungry and ended up with lack of food in the body. According to some few respondents out of the many asked why the children got attacked at the sight of food, it was a sign that the spirits of the departed relatives were hungry and were not being fed with food. The Acholi used to feed the spirits of the departed relatives by offering sacrifices and taking food to the shrines ('abila'). If not done, the spirits caught the attention and intervention of the living by interfering with their normal life of the living, thus rescuing the situation.

The way nodding disease manifested itself was similar to epilepsy which the Acholi call 'two odero'. However, it was treatable and curable unlike the nodding disease which has so far defeated both traditional medicine and modern medicine. At the start of the nodding disease, they thought it was epilepsy and tried treating it the way they traditionally treated epilepsy. This was why the herbs were used until it failed. The disease persisted and many children died. It was at this period that the modern medicine was fully relied on. However, this treatment was not even effective in curing the nodding disease. This made the Acholi believe that the disease was spiritual and needed traditionally measures like cleansing where the cultural leaders and herbalists were involved. With regard to this, one participant stated that,

"This disease attacked children below 18 years. It threw them down with foam coming from their mouths. In Acholi such strange happening was associated to 'yamo marac' (bad wind/evil) which was normally cursed out by cleansing. The disease was similar to the one which was in Acholi called 'two odero' (epilepsy) but it was treated and got cured, unlike this new one (the nodding disease)". (Cultural leader 1)

In Acholi when sickness struck seriously like the nodding disease without a clear cause and solution, it was referred to as 'yamo marac' or 'gemo' (evil spirits). This called for elders and custodians of 'jok' to swing into action of 'moyo cere' (cleansing the hills) in consultation with the 'jok' (the god), i.e. mostly Lagoro on what could the problem could be and the way forward. In most cases ritual cleansing was done where animal and birds sacrifices were made so that their blood washed away the evils causing the problems in the land. The nodding disease had also been considered as 'yamo marac' which needed cleansing, but the only problem was lack of unity.

The Acholi people admitted that other options failed and the disease was spiritual, therefore there was needs to address the matter culturally through cleansing rituals. There was need to handle the nodding disease with one strong voice and action as it was with Ebola and Kony (the LRA leader). This had been the appeal of the cultural leaders, religious leaders and elders interviewed who admitted that nothing much had been done on the nodding disease as a group. However, a lot had been done in small groups and individually. The disease needed the Acholi as a whole to unite together and act together to have impact on the disease.

The nodding disease had divided the people of Acholi and it had made the Acholi to wash their dirty linens in public. This had been shown by the level of disunity portrayed in the fight against the nodding disease. Most people were divided along religious lines; the modern religion especially Anglican Church was against culture in favor of their Christian doctrine to fight the nodding disease. Economically, some people looked at the nodding disease in terms of economic gains, thus strategizing on how they could benefit out of the disease. As a result, the treatment center in Odek Sub-county in Omoro district was closed due to mismanagement and embezzlement of the funds meant to run the center. Politically, most politicians turned the nodding disease into tools of milking money from the government and gaining political capital. They made noise but

once they were elected or given money, they pocketed it and kept quiet. Therefore, the nodding disease couldn't be handled culturally when people were divided. For cultural activities like cleansing rituals or offering sacrifices to be effective, it needed unity because everyone was to give their blessings (A. Oloo, personal interview, Gulu, February. 19. 2020). He further lamented that 'the nodding syndrome was a new disease and people didn't have deep knowledge about it. It came like 'gemo' (bad spirit) in case of sin or some happening in life leading to attack. All the bad things came to attack us, we needed to be prepared to fight them'.

The people of Acholi were worried of the nodding disease because it was among the diseases they treat as 'gemo' (bad/evil spirits) which was not easy to solve. It struck painfully that you really saw your dear one suffering. In most cases led to death when you were helpless to support the victim, especially when not treated as an emergency by the elders and cultural leaders. Such sicknesses regarded as 'gemo' were handled best by religion and culture. Once they handle that, the spirit went for good and never returned. Such bad spirits were believed to be resulting from the sins committed and reconciliation or cleansing rituals not performed. For the case of the nodding disease, the atrocities committed on the innocent souls during the LRA war by the LRA rebels (who were Acholi predominantly) through abduction, killing, raping of young girls and women, looting people's property, burning people's huts sometimes with people inside and to mention but a few were believed to be the causes of the disease. This served like a punishment for their evil acts during the war. This could explain why it was after the LRA war and only the Acholi sub region was affected in Uganda since LRA rebels were mainly Acholi. This was similar to South Sudan that had been in war for long and they were affected too by the nodding disease.

4.3. The Time of attack

According to some participants, the children got more attacks on the sight of food and in the morning when it was cold, this finding is in collaboration to Idro et al., (2013). Children affected also frequently fell down because they had become unconscious. They could not take control of themselves at that time, Iyenger et al., (2014) described this stage as neurologic deterioration and cognitive impairment. Children at this stage loose balance, they can't take control of their stability especially those at advanced stages (after suffering for many years of frequent attack). Some of the patients who frequently nodded eventually become epileptic according to most participants.

The participants believed that the children who were affected by the nodding disease start showing signs by nodding their heads especially on the site of food. This finding is in agreement to what Idro et al., (2013) came up with of head nodding of the patients. This explained how the disease came to be known as the nodding disease; just a description of the signs and behavior portrayed by the patients on attack.

A participant had this to say;

“Nodding disease started from IDP camp but it was not yet noticed. She started nodding when I gave her food, she kept on nodding and she rarely talked, in most cases she muted. At times, she told me she saw something like a big human being during day, sometimes she saw the same during night time (...Spirit...). I can sincerely tell you that the children remained dull and some people considered them as mad people from our village ... the sickness always threw this girl down frequently and it was serious.” (Parent 1)

The children who were attacked during food time could not eat. Some participants associated it to spirits demanding to be fed through sacrifices. They stated that the spirits of the dead were as well

hungry and they needed to eat but they had been ignored this made them send signals to elders by attacking the children. However, as the participants associate the spirit attacks to hungry spirits, some scholars associate spirit attack to be initiated by God because of his anger on the people upon their misconduct, (Akwasi, 1985). In the African society, to make the elders act so fast, you attacked the children who are the future generation and the helpers of elders at their old age. For the case of this child, the spirit appeared to her which made it easy to know that the problem was spiritual. Unfortunately, it prevented her from talking. In addition, in some cases, the spirits talked through the possessed person making it easy to know their intentions and demands.

According to some participants, families that had been able to offer sacrifices to the spirits in the shrines had their children healed. While those who either lack the means/resources, the person to help lead them carry out the sacrifices or families that disagree on cultural practices in preference to prayers had their children suffering. What is not clear is why fail to compromise at the expense of suffering and death of the children, could it be due to religious differences? According to the few respondents interviewed on this, to them there were some families that felt happy seeing another family suffer; or it could be that the evil spirits were sent from another family. Therefore, relieving the suffering family would either mean it would go to another family or it even got back to you.

Given the timing which was immediately after the LRA war and when people had just started returning back home from the IDP Camps in the Acholi sub region; -where the war was intense, the behavior of the children during the attack made people link the nodding disease a lot to the LRA war. The Nodding disease was linked to the spirits of the dead people who might have been brutally killed during the LRA war but were not properly buried. Some bodies were not recovered

but only bones of unknown dead bodies discovered when people started going back from IDP camps to their homes.

4.4. Geographical location

However, the LRA war was in the whole of the Acholi sub region even worse in West Acholi, i.e. in the districts of Nwoya, Amuru, Gulu and Omoro where many people were more killed than in the East Acholi, i.e. in the districts of Agago, Pader, Kitgum and Lamwo. On the contrary, the Nodding disease had worst hit East Acholi than West Acholi. This made the above sentiment/belief wanting. Some Acholi people thought that the nodding disease was brought in Acholi land from elsewhere for the purpose of finishing the Acholi (J. Latigo, personal interview, Gulu, October 1st 2020) and (A. Lacambel, personal interview, Gulu, August. 29. 2020). According to Latigo, the government of Uganda had shown too much interest in Acholi land and they were trying all possible means to weaken the occupants so as to acquire the land easily. Just like Ebola which was brought to the Acholi land from Congo, it killed people until rituals were done in Aruu falls which ended the further spread of Ebola in Acholi land (A. Lacambel, personal interview, Gulu, Aug 29 2020) an Acholi elder and (A. Olaa, personal interview, Gulu, February. 19. 2020). The argument of Latigo and Lacambel pointed that the ND was political because of the love for the Acholi land which is so fertile.

There were also occurrences in life leading to attacks. The Acholi people were believed to have started indulging in evil acts that they copied from other societies during the war; where they were confined in camps and from where they fled across Karuma Bridge on River Nile due to diverse cultures. They started some practices of idolatry, witch-hunting, selfishness, rivalry over land, rivalry over leadership, hatreds within the same clan and so many other evil practices which was

minimum before the war. Possibly these had annoyed 'jogi' (the gods) who were the custodians of all types of spirits and compelled them to relax on the bad spirits which had struck the land.

4.5. Age of the victims

The findings reveals that, the age group most affected are children between 5-18 years and is the most productive age. According to one of the known traditionalists (E. Luk, personal interview, Kitgum, September. 09. 2020), between the age of 5-18 was when the young generation was trained for future responsibilities and it was a productive age that adults mainly relied on. Whenever this age bracket was affected, it was like one eye was affected, hence reduced one's efficiency, productivity and a person felt more touched. Therefore, the attack on the 5-18 years was a hard bite on the people of Acholi; where it pained the most, thus immediate response was paramount ending. Thus, ending the curses, sicknesses, diseases, death and misery and evoking blessings and good health for the children and the Acholi land as a whole.

On the other hand, with regards to age variation of specific age groups, there were many myths and beliefs among the people of Acholi in relation to the timing and the age group to the time of the war. This was a period when pregnant women and breast-feeding mothers were sleeping in coldness in the bush, running away from homes, fearing the attack and abduction by the LRA rebels. This was before the people were taken to IDP camps. Since these mothers encountered bad spirits, dead bodies or others were killed near them from the bush, these explained why this specific age bracket was affected by the nodding disease. Culturally, when a person encountered such bad omens, there were rituals that were performed to avoid the spirits taking possession of the person. Some pregnant women had bites from black flies or the bad weather they experienced while in the

bush affected the unborn or the young child, leading to low body immunity making them volatile to attack by strange diseases (Kristine, 2014).

4.6. Conclusion

The belief about the nature and manifestation of nodding disease among the Acholi people is embedded in Acholi cultural religious methodologies which is specifically their belief in Ancestral spirits. The major nature and manifestation of nodding disease as per the findings are the disease affect children between the ages of 5 to 18 years. The children starts nodding their heads at the sight of food and its more frequent during coldness, they fall down, some have convulsion and flow of saliva from the mouth. The Acholi are more convinced that this is the manifestation of evil spirit because the behavior of nodding disease patients are more of someone possessed by the evil spirit.

CHAPTER FIVE

INTERPRETATION OF THE CAUSES OF NODDING DISEASE

5.0. Introduction

The participants also agreed that nodding disease had been in existence in other countries that were involved in wars like South Sudan and Liberia before Northern Uganda according to report from WHO, (2019). Similarly, this is in line with what some authors have published in regards to the countries affected by nodding disease before it hits Northern Uganda, Colebunders et al., (2016). The nodding disease in Uganda was only in the Acholi land where there was the LRA war. This was a signal and a confirmation that the nodding syndrome might be associated with war places like in Acholi land where the LRA war took place. We were in a transitional period after the war. Some of the respondents said it might be spirits of the dead possessing the children. However, there were mixed opinions on the causes of the nodding disease. Culturally, people believed it was caused by evil spirits from the dead relatives that had not been properly buried. Many participants associated the causes to many things like black flies from the fast-flowing rivers, overcrowding in the IDP camps, food poisoning from the food distributed from the IDP camps, poison from bombs during the LRA war and God's punishment. The most outstanding cause according to participants was the neglect of shrines and the serious bloodshed in Acholi land which began in 1971 during Amin's regime to the recent LRA war. This was because cleansing rituals had not been performed according to some participants. Studies conducted earlier shows that the causes of nodding disease are not confirmed but its speculation (Olum et al., 2020). The causes of the nodding disease had been categorized where similar causes fell in certain categories. The categories included; spiritually related causes, cultural and contemporary mythologies and contemporary religious

views. This therefore formed the basis of analyzing and explaining the causes raised by the various participants/ respondents.

5.1. Spiritual related causes

5.1.1. Evil spirits of the dead

The most outstanding cause of nodding disease according to the respondents was the evil spirits of the dead. There were so many people who died in Acholi land or in the hands of the Acholi during the LRA insurgency. Most of them were killed by the LRA rebels while others died of diseases. Other factors were due to hard life during the war or in camps but their death was not treated as expected/rightly. Death rituals of either a person who was murdered or someone who died of sickness were not followed. Other researchers as well are in harmony with the findings of evil spirits attack as the cause of disease among them are, Colebunders et al., (2016) and Peter, (2015). Both Peter and Colebunders believes that its evil spirits that causes disease just like any African would think and the Acholi too given the situations they went through during the LRA war and the massive killing of innocent civilians that took place in Northern Uganda. This seems to be a wider cultural perception on the causes of diseases in many communities. With this therefore, it was possible that the spirits of the dead tormented the children as mentioned by one of the parents;

“When my child was attacked, she kept on asking for goats that she wanted to keep. This was evil spirit. The girl prayed but prayers did not help, we were praying but we thought the spirits of those killed by Kony (Lord Resistance Army) were entering our children...”
(Parent 4).

Just like this parent, many parents believed that what their children were going through were just attacks from the evil spirits of either a dead relative or the spirit of someone killed by their relatives whose burial had not been handled well. The Acholi believed that spirits do not strike randomly but they strike where they were provoked or attacked the relatives of the person who caused their death. When such attacks were realized, reconciliation for a person murdered was made between the family of the killer and the family of the deceased, mediated by Acholi elders. On the other hand, for other the deaths, they carried out sacrifices for cleansing but most of these things had not been done. This is a common perception among African society of evil spirits as a cause for disease. Akwasi, (1985), is not any different but in agreement with the finding of evil spirits as the cause of disease.

Given the location where the nodding disease was more common, i.e. along river Aswa and Agago; and the evil spirit liked behavior of patients when attacked, one could easily say that the nodding disease was caused by evil spirits. In Acholi, rivers or big water bodies were known as habitat for bad spirits and in most cases cleansing rituals were done at river banks. This also explains why river banks were referred to as dwelling places for spirits and considered special places not to be tampered with. There were as well a lot of people who got drowned in rivers during the war in Acholi land; either when running away from attacks and captivities of rebels or were thrown by the rebels to sink and die in water- for those who could not swim. Others who jumped into the water were as well shot dead leading to many dead bodies floating on rivers. Others were eaten by fish and some ended at the edge of the river as they were swept by water waves to the river banks. Most of these dead bodies ended up not being buried and their spirits were not taken home and they keep lingering in the wilderness or at the river banks where their bodies got rotten. This explains why areas along the rivers in Acholi sub-region were more affected and some parts of

Lango sub-region which bordered Omoro district at Aromo-wanglobo near river Aswa were also affected by the nodding disease. This explained the relationship between the nodding disease and rivers or why areas along rivers were more affected with the nodding disease than other areas as narrated by some participants

5.1.2. Bloodshed and lack of cleansing rituals

Some respondents said there were so many things that had not been done right in Acholi land that led to the suffering and death of the people. Culturally in Acholi, any bad thing that happened in the community or in the land was followed by ritual cleansing to wash away the bad thing from causing atrocities in the land. In relation to this, a lot of killing was done in Acholi land by the Acholi themselves but the land was not cleansed of the innocent blood that was poured in the land. In Acholi, blood was sacred. When it was shed, it was considered harmful and cultural rituals needed to be performed. Unfortunately, this had not been done for a long time (J. Latigo, personal interview, Gulu, October. 1st.2020). Some parents who lost their children could have made curses when their children were murdered while some of those murdered died crying. This could call for ritual cleansing of the land by the Acholi cultural leaders and Acholi elders. However, this was not done and no one thought of it until when the nodding disease invaded the land then the elders started thinking right. A traditionalist painfully explained;

“A lot is being said by many people on the causes of the nodding disease but the bottom line of the cause is the blood shed of the people killed in Acholi land. However, nothing like cleansing of the land has been performed. Wise families were able to offer sacrifices after sensing danger in the land to appease the spirits of their dead relatives hence making them less affected than others. Some parts of Acholi still practiced tradition of death rituals like among those in Gulu unlike their counter parts in Kitgum. This was why the West

Acholi was less hit by the nodding disease than the East Acholi. Similarly, Palabek where the disease started had cleansing rituals performed and eventually there was no new infection and the sick got healed in one week” (Traditionalist)

According to the respondents, after identifying the problem, a solution was generated but it was done partially; this meant cleansing of the whole land would have led to the end and cure of the nodding disease in the whole of Acholi land. However, this was not done due to multiple factors. The most outstanding was disunity among many groups of people. This was why one of the cultural leaders said ‘leave issues of culture to the cultural leaders’ (A. Oloo, personal interview, Gulu, February. 19. 2020). There had been a lot of interference with the work of the cultural leaders in ending the nodding disease after the failure of science. To the cultural institution, they were not given the opportunity to carry out cleansing rituals by the government instead the whole thing was politicized. So as cultural institutions, they didn’t work where there was tension because for their work to be effective, it needs blessings from everyone. This was why some places were cleansed by the cultural leaders and elders of that particular places while some areas were not. This also explained why some wise families with strong elders went out and offered sacrifices as a family and all was well with their families. Spirits don’t strike randomly, (Akwasi, 1985) but it strikes where there are loopholes in life, if Acholi were to carry out cleansing of the whole land the nodding disease wouldn’t have spread to the whole land and caused a lot of death as it did.

Pertaining death rituals among the Acholi; death, burial, and funeral rites were highly observed among the traditional Acholi. The dead were buried side way to rest peacefully but not upside down where spirits left the body and wandered around. In case of a male, in the early morning of the third day, elderly women picked up branches of leave called ‘oboke olwedo’ with a small calabash (awal) with some water in it, moved to the nearby bush near the grave site and would

start calling the name of the dead while sprinkling water from the calabash using the ‘oboke olwedo’. Further still they came backward towards home until they enter the house backward to bring the spirits of the dead home to live peacefully with the family. This spirit would never think that they had been neglected. For a female, it was done after four days (E, Luk, personal interview, Kitgum, September. 9. 2020). However, this practice was only being maintained mainly in the East Acholi but not in the West Acholi in the name of Christianity as emphasized by the Kitgum diocese while the Northern diocese was relaxed on traditional cultural practices. This practice had also not been done to the spirits of those who died during the LRA war. Most people were buried hurriedly for those who were buried and no more going back after burial due to fear of abduction and killing by LRA rebels. Worse of all very many bodies were not recovered and accorded decent burials. These were some of the things that needed ritual cleansing of the Acholi land to wash away any problem that would come due to such gaps.

5.1.3 Neglect of shrines

The neglect of ‘abila’ (shrines) and ‘jogi’ (spirits) had been recorded by quite a number of participants. Among the Acholi, ‘abila’ (shrine) was a place accorded great importance because they were temples of ‘jogi’ (spirits). Shrines in Acholi served very many purposes among them was, a place for offering sacrifices to the spirits to seek blessings when planting crops, going for war or hunting. Seeds and spears to be blessed were placed in ‘abila’ over night before they were used, hence success was registered after using them because it had been blessed. Abila was the shield of the people of Acholi, protecting them from any misfortunes that was to befall the land. A lot of sacrifices were offered to the abila ranging from grains after successful harvest to birds and animals in form of food prepared and served in ‘atabo lobo’ (a bowl made out of clay burnt

brown in color) and placed in the shrine for 'jok/jogi' (spirits) to eat. Such practices were believed to make life successful for the Acholi.

Unfortunately, the modern Acholi had turned their backs to the 'abila' (shrine) as an elder was quoted saying "we are no longer handling 'abila' (shrine) the way it should be handled as instructed by 'Lagoro'. The custodians of 'abila' had mismanaged the rules for handling the spears they had been put in charge. This annoyed 'Lagoro' and can be a contributing factor to the calamities faced in Acholi which was leading to so many problems in the land" (A. Latigo, personal interview Gulu October. 1st. 2020). The participant said this with a lot of bitterness based on the act of Rwot Lugai who was one of the custodians of the spear. He went with the spear to his home and instead of leaving it outside in front of the hut, he entered with it inside the house contrary to the conditions of being in custody of the spear.

In addition to what Latigo explained, Luk had this to say in a personal interview;

"Acholi have neglected 'jogi'(gods/spirits) and 'abila' (shrines) that we have been serving since generations and generations as the major shield of protection against any calamity that would befall the land like strange sickness, suffering or death because of the wide coming of modernity in the land. So, what do you expect from 'jogi', apart from showing their disappointment with us through sickness, suffering and death? (Traditionalist)

Abila (shrine) was the shield for protection and guidance of the Acholi land and people that never failed them. Almost every home had its own 'abila' either in the center of the court yard or at the extreme end of the court yard under a planted tree called 'okango.' They didn't use firewood from 'okango' for cooking because it was regarded as a sacred object. When used, it caused wounds on the head of the children in that family. It was regarded as a special tree. It was unfortunate that

Acholi today have neglected such an important thing in their lives. With the coming of modernity, shrines had been condemned as barbaric and the few Acholi who still have 'abila' in their homes had been banned from openly talking about abila. Renowned Acholi traditionalists in Gulu and Kitgum had been banned from radio programs by the Bishops of Northern Uganda and Kitgum Dioceses respectively accusing them of confusing Christians, said P'layeng and Luk. This was one of the confusions bringing the Acholi down. Acholi tradition was a very strong one that would sort a lot of Acholi problems without affecting them much to the point of massive death as the nodding disease had done. However, as a result of Christian and Islamic religion, the Acholi are getting lost. This was the major reason for the neglect of the 'abila' that has eventually led to suffering and death in terms of sicknesses in this case the nodding disease. The presence of modern religions has over shadowed traditional religion and culture has led to the suffering of the people of Acholi

5.1.4. 'Gemo' (bad spirit)

Among the Acholi, strange sicknesses are associated with evil spirit also called 'gemo' in Luo language. The Acholi have so many types of bad spirits that range from the less harmful to the most harmful ones. The former was easy to cast out while the latter needed serious casting. Some could be worked on by traditional herbalist while the dangerous ones needed a strong traditional doctor. Among the bad spirits we had ranged from their level of harm were 'jok' (spirits). This spirit was easy to cast out as a herbalist or a priest could cast out this spirit. Spirits like 'gemo, cen, lapiny, ayweya and kulu' (volatile spirits) were noted as dangerous categories. These categories of spirits were dangerous species and fought in any style and directions. They attacked and led to calamities if not properly handled and they were all considered as gemo (A. Lacambel, personal interview, Gulu, August 29th 2020).

One of the outstanding causes of the nodding disease mentioned by some participants was ‘gemo’ (bad wind or bad spirit). Gemo always struck as a result of something bad happening in the community. The spirits showed their disappointment by sending in strange sickness that would have no treatment other than going the traditional way. Whoever failed to follow the traditional mode of healing would die. One of the cultural leaders said gemo was the cause of the nodding disease;

As cultural leaders, we believe nodding disease is an evil spirit (gemo), because little is known about the disease and it came very suddenly. Anything which is not well understood, especially disease is suspected to be gemo. This is “bad wind” which comes when atrocities have been committed in Acholi land or when the ‘door of life’ is left open allowing bad things to enter in. We need to get prepared to chase this ‘gemo’ away by doing ritual and sacrifice which we have not been doing for such a long time. This should include giving offertory to god (tum) and cleansing (moyo piny) (Cultural leader 3).

Among the Acholi, strange sicknesses were associated to ‘gemo’ (evil spirits) that requires cleansing to purify the person or community. The way the nodding disease came to the Acholi land was quite strange because it had never been reported anywhere in Uganda. It was the first of its kind in the country and it was worsened by the fact that there was no cure for the disease. This put the people of Acholi to a state of panic without answers based on the manifestation. It was said to be ‘gemo’ (evil spirits). Gemo was defined as the evil spirits of the dead that had not been handled in the right way following death rituals. Therefore, instead of blessing the people, they brought calamities to the people. Spirits among the Acholi were kept in ‘abila’ (shrines) by the specialist concern and they were constantly fed through sacrifices. According to some participants, ‘abila’ had not been catered for, hence annoying the spirits. They had moved out of ‘abila’ into the

community thus causing disasters. According to an Acholi traditionalist, spirits were not treated in the hospitals as with the nodding disease, but traditionally through cultural rituals like cleansing (O. P'Layeng, phone call interview, February 15th 2020). "It was unfortunate that the nodding disease attacked us at a time that we lacked the spirit of oneness due to different reasons which were; political, social, economic and religious". This was evidenced in Kitgum district where the Church leaders stopped any form of ritual cleansing in the fight against the nodding disease by putting the situation into prayers. In her own words she said 'the Bishop of the Diocese of Kitgum himself stopped all the radio stations from hosting me with my program on culture and tradition of Acholi', said Luk of Okidi parish in Amida Sub County in Kitgum district. This portrayed a missing link between Christianity and tradition. This district had the highest infection rate. It also had so many Born Again churches that were completely against cultural rituals as revealed by one of the participants in an interview, yet they had as well failed to provide cure for the nodding disease patients (E. Luk, personal interview, Kitgum, Sept. 9. 2020).

Traditionally, the Acholi conducted cleansing rituals in an area that had some strange happening before it spread to other parts of the land. This was done instantly to appease the spirits or to cast out the bad spirits causing problem. It was done by a small group of concerned people among them were custodians of 'jok', the elders, cultural leaders and a few selected people. There was also general cleansing of the land by sending away evils New Year's Eve by the whole community carrying out exorcism (ryemo gemo). This was done by banging whatever can cause noise to scare away the bad spirits to leave the community or the land.

Ryemo gemo was a cultural practice of the Acholi done yearly on the eve of every 31st December to chase away any evil spirit of that year from entering the New Year. It was an annual communal event among the Acholi although the practice was drastically reducing due to modernization.

However as stated before, 'ryemo gemo' could be done at any time of the year in case of any strange happening. A case in point was 'ryemo gemo' in Acholi land which took place on the evening of 30th and early morning/dawn of 31st March 2022; where banging of Jerrycans, saucepans, doors or anything that could cause noise took place in the name of sending off the bad spirits of Covid-19 (Isiko 2020) and the locust from reaching and causing destruction in Acholi land. This was done following consultation of 'jok' Lagoro by the Acholi elders and cultural leaders at Lagoro hill. However, it didn't work, Covid-19 still ravaged the land with its negative impacts. This 'ryemo gemo' on the other hand caused a lot of queries by people from different parts of Uganda and the president of the Republic of Uganda himself had to send a delegation led by the prime minister from Kampala to come to Acholi land to meet the Acholi cultural leaders and elders for the relevance of their 'ryemo gemo' in relation to Covid-19.

The Acholi probably understood the cause of the nodding disease but they lacked unity to come together, speak one voice and carry out cleansing for the whole land, except for some parts of the land. If it was done in Palabek and it yielded positive results, they would have done it in the whole of the Acholi land. The nodding disease should have been a unifying factor for the people of Acholi if at all they had some differences.

Misunderstanding was one of the loopholes that evil spirits always used to do havoc to a person or society. Therefore, the persistent effect of the nodding disease could have been also attributed to the individual differences or disunity among the Acholi leaders or elders as noted by the aforementioned participant

These are evil spirits (gemo) coming as result of people leaving their cultural practices for so long. People are not fulfilling rituals and offering sacrifices to "Jogi". These have

resulted into calamities; it is like “Jok ma malo” (God) is giving punishment to us because we are not following cultural rituals strictly” (Cultural leader 4).

The Acholi used to perform all forms of rituals be it cleansing, blessings, send off of spirits among others including burial rituals of a relative whose body wasn't discovered. They also conduct rituals in reburying remains of a person. They collect the remains in a white piece of cloth and perform some rituals in the grave before reburying the person. This is done to maintain peace among the dead and the living (Kagumire, 2009). Unfortunately, this is far from happening today among the Acholi people because of the different understanding between the cultural and religious leaders in Acholi land, (E. Luk, personal interview, Kitgum, Sept. 9. 2020).

5.2. Contemporary Cultural Mythologies on the Cause of Nodding Disease

There were quite a number of reasons given by the participants which were more of myths than realities given the distribution/spotting of the nodding disease in Acholi land. The people of Acholi were in real despair to understand deeply the cause or causes of the nodding disease. This made them relate anything as the cause of the nodding disease.

5.2.1. Black flies

Given the location where the nodding disease was more common along river Aswa and river Agago, some people associated the cause of the nodding disease to ‘olwango otong tong’ (black flies). The acceptance of black flies as the cause of nodding disease is as well a common believe among different scientists (Abbo et al., 2019). This had been a common conviction among the respondents interviewed. However, so many researches were conducted on the flies along river Aswa according to a participant but there had been no confirmation, of black flies as the cause of nodding disease. Notably a participant was quoted saying;

“The cause of the nodding disease is not yet known, they suspected the black flies because most of the cases were along river Aswa and river Agago. However, despite the fact that different researchers visited river Aswa, to trap the black flies for research, to date they haven’t yet come up with their findings to confirm the black flies as the cause of the nodding syndrome” (Health worker 1).

The participants who believed that the cause of the nodding disease was the black flies disagreed with the view that it was caused by evil spirits. To them if it were the evil spirits that caused the disease, by now the cultural leaders would have worked on it through cleansing and the disease would have been no more. While those who say ND is caused by evil spirits base their argument on the behavior of the ND patients which is more of a possessed person. They further added that many researches have been conducted on the black flies but no evidence up to now to show that black flies is responsible for the cause of nodding disease. Given the behavior of the nodding disease patients, one could easily tell that the cause was more than the black flies (W. Obong, personal interview, Pader, Feb. 10. 2020).

The reason for the black flies being associated with the cause of the nodding disease was because most of the heavily affected areas were around fast flowing rivers, i.e. Aswa and Agago; infested with the black flies. At the same time these were places culturally known as dwelling places of evil spirits. Similarly, river banks were used for cleansing rituals, and this implied that all the bad spirits cast out of a person resided in river banks. However, the scientist associated the cause of the nodding disease to the black flies. This was because the majority of the patients lived along the rivers and the black flies were believed to be common in river Aswa. This explained why the government sprayed it using the Aerial spraying in 2003. But what remains unanswered by

scientists was, why only the Acholi sub region that was affected as other parts of Uganda had bigger water bodies.

There is the myth of the black flies. The association of black flies to nodding disease is based on the fact that most of the heavily affected areas are around fast flowing rivers, mainly River Aswa and River Agago. Black flies which cause Onchocerciasis, seem to have gained more acceptance among scientists as the most likely cause of nodding disease (Abbo et al., 2019). Some scientists dispute the relationship between nodding disease and black flies on account that despite the numerous studies done about them, no clear findings have confirmed black flies as the cause of nodding disease. To the Acholi, given the behavior of the nodding disease patients, one can easily tell that the cause is more than black flies, (W. Obong, Personal Interview, Pader, February 10, 2020). The Acholi believe that rivers and other such big water bodies are known habitats of bad spirits. Secondly, in most cases cleansing rituals are performed at river banks. This might make people living near these water bodies susceptible to attack by evil spirits. It is very common for people who live near such water bodies to encroach on their banks, also the dwelling places of the spirits, provoking their anger against encroachers.

After the LRA war, the Acholi engaged in aggressive farming for both cash and food production. Some of the known fertile soils are on river banks, destroying the spirits' habitats. They also engaged in fishing for food as well as cutting of trees for both construction and burning of charcoal for sale to raise money. All these human activities deprived the spirits of their habitats, making them to move from place to place, hence attacking humanity. To some other respondents, there were a lot of people who drowned in rivers during wars in Acholi land, either in the process of running away from attack and captivities of rebels or were thrown into the rivers by the rebels. Some were simply shot dead, making many dead bodies float on rivers, eaten by fish and some

ended at the edge of the river as they were swept by wind to the river banks. Most of these dead bodies ended up not being buried as their spirits kept lingering in the wilderness or at the river banks where their bodies got rotten.

The findings of dead bodies unburied explains the big effect of nodding disease among people living along the rivers, including those living in some parts of Lango sub region, like Aromowanglobo near river Aswa. West Acholi witnessed a few cases in families that resided along River Aswa in the area of Odek, home to Joseph Kony, the overall LRA commander. Other areas in western Acholi affected were Omoro and Lapuda in Gulu, which coincidentally share settlements near River Aswa, with locals, whose domestic livelihood depends on this river water.

5.2.2. Confinement in Internally Displaced Persons Camps

The Acholi people were so proud of their homes and they felt more comfortable in their large courtyard surrounded with banana plantations or fruits like mangoes, oranges, and jack fruit trees among others. They proudly said 'arwot ki oda' which means 'am a king in my house'. However, this became short lived in the mid-1990s when the LRA wars became intensive in the region and the government forcefully confined people to IDP camps in almost every sub county. The people couldn't move out of the camps to their homes to look for food or other basic needs. They were as well fed on beans, posho and cooking oil supplied by world food programs. It was from the camps that the people of Acholi started suffering seriously. They were hit by famine because the food was distributed once a month, different types of diseases attacked them due to poor hygiene which came as a result of overcrowding/congestion of the people, and poor feeding. One of the participants (religious leader) said, "Also many of this sickness such as cholera, hepatitis B and

others came as a result of poor hygiene. People were crowded together during the period of the camps”.

The argument that the nodding disease was caused by the life in the camp was further supported by another participant who said a lot of nasty things that transpired when the Acholi were in the camps. To him due to the congestion, some people came along with the disease but what he didn't clarify was who those people were and why the nodding disease did not also affect the areas they came from. This made it more of a myth than a reality and a baseless argument. He was quoted saying;

“In my opinion, this disease was brought to us...I also believe it was because of changes in environment and current development. Why? In the past we only knew of epilepsy (two odero) which was curable. The nodding syndrome was not there but now almost every household is affected and the sickness affected only children (Cultural leader 2).

5.2.3. Food poison

The Acholi have developed mythologies of nodding disease around contemporary occurrences in their society. These arise due to their mistrust in the government of the day. In addition to the view that the nodding syndrome was caused by confinement in the camp, there was another group of people who believed that the disease was caused by food poisoning. The food that was distributed by the World Food Program to people in the camps was believed to have been poisonous. This reason was evidenced in this quotation;

“The nodding disease can be as a result of eating distributed food from camps which could have poison. For example, the same World Food that distributed food in Acholi during the LRA war also distributed food in Karamoja some few years back. This killed some

Karamojong and they said the food was poisoned. I believe ours also had poison. However, ours was slow poison which brought sickness and not eventual death” (health worker 2)

As per the belief that food distributed by the government of Uganda and the World food program had food poison, many participants raised it as the possible cause of the nodding disease. To them, they believed that the government was against the people of Acholi for the reason best known to them. Some said the government hate the Acholi because they are rebellious people while others cited cases of government interest in the Acholi land to serve as animal ranches because the land was good for grazing. In support of food poisoning, a scholar agreed that it can be possible that the people of Acholi could have eaten poisoned food while in camp. His argument differs with the way Acholi believe. To him, the people of Acholi might have eaten the seeds distributed for planting that were mixed with chemicals due to poverty (Bemmel, et al., 20014), but not intentionally put in the food of world food as the people of Acholi say it.

The research findings shows that this was a myth that people said out of frustration with the nodding disease that had failed treatment. The researcher considered it a myth because food was distributed in all parts of the Acholi, Lango and Teso, i.e. those who were in IDP camps. However, such areas were not affected, only some sub counties in Acholi not even the whole of the Acholi were affected. The East Acholi was worse affected while the West Acholi had only few areas along R. Aswa in the area of Odek where Joseph Kony LRA commander comes from in Omoro district and Lapuda in Gulu district. Both places had settlements near river Aswa and they used the water from the same river for some of their domestic use. This invalidates the belief that the nodding disease was caused by poisoned food distributed during the camp era. If the food had poison, then all the areas which had camps and all the people who were in camps would have suffered from the nodding disease because the same food was distributed to those in the camps in Acholi land.

In regards to nutritious food, the Acholi had one of the best menu or food that contributed to good health and most of the foods were grown naturally on fertile soils without addition of any chemical to improve on yields. This was not the case when people were locked up in camps. They were surviving on handouts which they didn't know the source and how it was grown, and how it was stored. It could be true that the food distributed was of poor quality, poorly stored for a long period of time with poor moisture content and possibly expired and therefore was not good for human consumption. The Acholi had their traditionally well-structured food stores with good ventilation that they called 'dero'. It was in form of a grass-thatched hut but a little raised using poles without touching the ground. The Acholi are used to 'odii' (simsim and groundnut paste) but instead, cooking oil was distributed to them which was not as nutritious as the 'odii'. It was a disaster to exclude the odii from the menu of an indigenous Acholi for long. Other than cooking oil replacing 'odii' (simsim/groundnut paste), the people of Acholi were also vegetarians. The food menu of Acholi people was dominated by green vegetables, some grow naturally in a fresh fertile ground like local dodo, 'lala', 'akeyo', 'oyado', leafy 'otigo' among others. While some were planted like 'boo' 'malakwang' (spinach), 'otigo' (okra) to mention but a few.

In this case therefore, it was possible that lack of nutritious food and eating the same food from Monday to Monday and January to January for close to twenty years that the Acholi stayed in camps led to low body immunity, making some children born with a lot of things lacking in their bodies. One of the participant said;

“Lack of nutritious food that led to a deficiency of some food value like vitamin and others could have also brought this sickness because of the types of food eaten from the camps; which were far much lacking in nutritious value we used to eat while at our homes before the IDP camps,” Khalil.

However, there were also children who were born many years after the camps, where the parents were already at home eating various types of food but they had also contracted the nodding disease. This made it hard to zero on cause of the nodding disease to food distributed from the camps

5.2.4. The myth of bomb poison during the LRA war

During the LRA war in northern Uganda particularly the Acholi land, there were a lot of dangerous heavy war machines/weapons used in the land. Some of the weapons caused mass destructions in the area. Apart from the sounds of the gun shot, there were also smokes and smell of bombs that were used in the war. Some weapons used were land mines which were put under ground and when stepped on, exploded and scattered the object that stepped on it. However, this immediately caused instant deaths or injuries. The worse weapons were those that had long lasting effects especially those that produced smoke like the bombs; mainly used to destroy enemies from far and in large numbers. According to some respondents, the smoke that came out of the bombs contained bad chemicals which could have caused the nodding disease;

“Some of the bombs used during the war could have contained dangerous chemicals”
(Religious leader 4).

The notion that the nodding disease was caused by the effects of bombs needed more research to be conducted. A participant said according to some postmortem reports,

“Some children who died of the nodding disease had very tiny internal organs like the lungs, hearts and also kidney. One of the health center In-charge noted that some of the patients had some small metals in their brains.” (Health worker 2)

This could be the reason for mental disorder and stunted growth among most of the nodding disease affected children. The disease affected the brain and the nerves the more. That was

why most of the affected children had low senses (K. Akello, personal interview, Pader, February 11 2020). Looking at the nodding disease patients, one agreed with this, however this was scientific than cultural or religious hence, more investigations to confirm this hypothesis. This cause as well had some gaps because the bombs were all over in Acholi land where the LRA rebels operated but not all the areas were affected by the nodding disease. Similarly, there were so many parts of the world that had wars but the nodding disease was not heard of, except for a few countries like Southern Sudan, Liberia and Tanzania.

5.2.5. Myths related to Animals

There were quite a number of animals mentioned by some participants that appeared under mysterious circumstances and were killed by the people while others appeared and disappeared mysteriously. Some of the participants who witnessed and heard about this believed that they were the causes of the nodding disease. There was a belief of a black pig, a black cow and black snakes cited in some of the areas with high prevalence rate of the nodding disease. The coincidence was that all these three different types of animals were black. In most cases, black colors were associated to evil. To make matters worse, the other two animals; snakes and pigs were believed to be evil. One could easily say there was something in connection to these animals. As regard the cow, a participant said a strange black cow; believed to be demonic and sent to attack people and cause sickness, was sighted in Lamwo district, specifically in Palabek. Whatever happened to the cow no one knew, thus the eventual report of the nodding disease in Palabek (K. Akello, personal interview, Pader, February 11 2020). Indeed, Palabek was one of the worse hit sub-counties in Lamwo district to the extent that cleansing rituals were performed in a place called Pawena,

according to a participant. Some participants said the disease started from Palabek while others said it started from Okidi in Kitgum district.

There was also a scenario of a strange black pig sighted in Awere sub-county in Pader district where people slaughtered and distributed the meat among the people. Eventually, the nodding disease started from homes that ate the meat. When the sickness struck in these homes, people believed that the pig was a curse from Lagoro that was sent wondering to cast out evil from their community, unfortunately the people killed and ate it as was said by a participant,

“A pig (possessed with bad spirits) came in the center and was killed by some people. It was suspected that people who ate the pork got the sickness and the sickness started spreading, it was suspected that the pig was sent by another clan (Lagoro), and that it was sent with evil spirits in it”. (Cultural leader 1)

Similarly, according to the same cultural leader in Awere, very many black snakes were sighted on one of the trees for about two hours and disappeared all at once. This snakes showed bad signs of evil, however there signs were uncertain. (J. Okot, personal interview, Pader, Feb. 10 2020). A similar ordeal was narrated by a religious leader (Moslem cleric) that in 2008, very many snakes were sighted on a single tree in Pajule and on a similar incident, a snake with three heads was sighted still in Pader district (M. Khalil, personal interview, Gulu, Feb. 22. 2020). All these occurrences were attributed to Lagoro hill to be expressing its disappointment with the Acholi for abandoning the ‘Abila’ (shrines); which was their shield for protection against any calamities. On the other hand, among the people of Acholi, snakes symbolizes very many things not necessarily only evil but it symbolizes a lot more beyond evil, (According to the various participants, all the three black animals showed signs of problem which was to befall the Acholi land. They were

warning signs that were supposed to be acted upon immediately but were ignored for long. However, unless investigated further and confirmed, this assertion might still be a myth.

Among the Acholi people, black animals were used for rituals mainly the cleansing of evil spirits like 'gemo and lapiny' depending on the situation that led to the rituals. However, the Acholi did not use pigs for any ritual; being it cleansing or joy like marriage and others. This is because pigs were not considered clan totems. Culturally, some snakes in Acholi were spirits and they were kept in special places like shrines and caves but not all snakes were treated as spiritual. Some of the spiritual snakes were referred to as 'jogi'. They were of important when the Acholi people were in crisis like drought and famine among others.

5.3. Contemporary Religious Views on the Causes of Nodding Disease

The causes of the nodding disease had been advanced by the different categories of people including the different modern religious groups, i.e. Christianity and Islam with their various views. According to the Muslim, the nodding disease was caused by poor rearing of pigs and high level of consumption of pork among the Acholi. Pigs are dirty animals, they ate dirt like feces and push the same mouth into things people used, thus exposing man to poor health. They were also evil according to the Koran; surah Aljinn chapter 72 verse 56. It was therefore not surprising that the nodding disease patients behaved like they were possessed. It could have been the evil in the pigs that transferred in human beings (M. Khalil, personal interview, Gulu, Feb. 22 2020). This participant's opinion could be accepted on grounds that a black pig in Awere was one of the suspected animals to be the cause of the nodding disease. However, it was mainly the elders especially men who ate too much pork but it was the children who were affected by the disease. Unless, we are applying the Bible quotation which says 'it is the parents who ate the sower grapes

but it is the children who suffer”. Besides, the suffering didn’t discriminate whether it was a Christian or a Muslim family; who don’t eat pork.

The common view by the different religious affiliations was that the cause of the nodding disease was God’s punishment. The Acholi people were involved in several wars where so many innocent lives were lost. The people of Acholi were involved in war against West Nile; a fight that led to the loss of several lives. They killed other tribes as a revenge on Amin’s regime (M. Khalil, personal interview, Gulu, Feb. 22. 2020). According to this participant, even the LRA war was God’s punishment to the Acholi people for killing each other since they liked fighting. “Instead of killing other tribes, they should feel the pain of killing among themselves”.

Similarly, another religious leader from the Anglican Church said the nodding disease was a punishment from God as a result of sin. To him, the disease was the result of God’s expression of His annoyance on the Acholi people for their sins which were not repented for. The Acholi had killed so many innocent people in various ignorant fights. Some were pounded with pesto and mortar; now the Acholi had to pay for it heavily. It was very unfortunate that it was the wrong people paying for the evil act of the evil people. The Acholi people were even no longer catering for the orphans and widows as had always been the case. ‘We have now become selfish and irresponsible to our fellow brothers and neighbors, hence God’s punishment on the people who were once known for hospitality but now they are known for hostility’ (R. Opoka, personal interview, Pader, Feb. 12 2020).

5.4. Conclusion

The interpretation of the causes of nodding disease among the Acholi people is embedded in Acholi cultural religious methodologies which is specifically their belief in Ancestral spirits. The major causes of nodding disease as per the findings is spiritual which includes; evil spirits of the

dead, blood shed that soiled the land but not cleansed, neglect of shrines and bad spirit (gemo) due to improper burial among others. To Acholi, the findings seems more convincing because those who accepted to correct what had gone wrong believe that their children became better. However, this is not to disqualify the medical science efforts and findings on causes of nodding disease. Science has done a lot in the fight against nodding disease by treating the patients with epileptic drug to minimize seizure and village health teams are also active in the community where nodding disease is high by giving necessary health support within their means like health talk.

CHAPTER SIX

PERCEPTION ON DIAGNOSIS, TREATMENT AND REHABILITATION OF NODDING DISEASE

6.0. Introduction

People used a lot of modern medicines and some traditional medicines as the therapeutic means of treating the nodding syndrome. These findings corroborate many similar findings from other studies. Scholars somehow agreed that modern medical treatment methods had been mildly successful in halting much of the progressions of the disease. Unfortunately, their success had been limited and consistent results are yet to be achieved. The conclusion was that no specific treatment had been found for the condition (Foltz et al., 2013; McGann, 2015; Irani et al., 2019; Ongaya et al., 2020). However, few studies like Atim et al., (2016) found that some people seek care from traditional herbalists or use herbal medicine to try and treat the nodding disease although the effectiveness of such medicines still remained a mystery.

6.1. Perception on diagnosis of nodding disease

The perception on diagnosis of nodding disease had been the dream of everyone to know exactly what the problem was, see the disease treated and cured. For treatment to be administered, one had to first be diagnosed and understand the cause, thus provide better treatment to eventually cure the disease. According to Dime, (1995), diagnosis among Africans is to find out if the sickness is physical or mystical. Similarly, the diagnosis of nodding disease among the Acholi was to understand the nature of the disease to treat accordingly. However, the cure for the nodding disease had been a night mare to many. This was because what was thought to be the solution never helped

in solving the problem. The nodding disease at the start was considered a medical condition and medical solutions were administered, however to the people's dismay, this never turned out to be a solution but a control. Simply because it wasn't curing the patients but just controlling, Africans needs holistic healing just as stated by Thorpe (1993), where the healer deals with the complete person providing treatment for physical, psychological, spiritual and social symptom. Failure of this among the Acholi made the cultural and religious people to start thinking outside the box for a better problem analysis and permanent solution. Subsequently, the religious people (the Born-again Christians) organized prayers and camped in one of the places in Palabek, specifically Pawena where the nodding disease had badly hit several children. Unfortunately, their prayers failed to yield the anticipated fruits. Therefore, another intervention had to be sought. It was from this point that culture had to step in because the Acholi believed in a lot of spirits that were volatile and caused a lot of destruction if not properly handled or not happy with the people. It was against this background that culture was to come up and play their roles. Fortunately, cultural intervention seemed to have provided a better way forward that eventually saw some change according to a participant as she was quoted saying;

“Acholi have ‘jok’, ‘cen’, ‘gemo’, ‘ayweya’ and ‘kulu’ which can attack and leads to calamities if not properly handled. ‘Lucluc’ (nodding disease) was ‘gemo’, it started from Palabek, where the born-again Christians camped for a week praying but failed. For me when I was contacted and requested by NUPI... we went early in the morning just in one day with just a sheep, brought together all the various chiefs from the different clans in Palabek who performed rituals (la tum piny) for Paromo, Ogili, Padwat, Labala, Acaa and Lacic. Each of them was to come with a chicken, they camped in Pawena hill.... Saliva was spat on the chicken, rituals prayers said, the chicken slaughtered and gizzards

opened... it revealed the secrets and what to be done to end the sickness. The following day early morning a gentleman called Danamajo made 'Agat', the sheep was slaughtered, cleansing rituals conducted and that marked the end of nodding syndrome, the children in Palabek were cured and since then there has been no new case of nodding syndrome reported in Acholi land'. (Acholi Traditionalist).

In the Acholi culture, any strange massive sickness was called 'gemo' (evil spirits). Once such was detected, elders and traditional leaders swung into action by consulting 'jok' in 'Abila' (spirits in the shrines) for what the problem and solution to the sickness could be. In this case, a whitish/light grey goat was used for rituals for the sick to get well. As regards sicknesses caused by 'cen' 'ayweya or 'jok kulu', a black goat was used for the cleansing and the sick get well. What the Acholi do is in line with what other authors say about rituals using animals and birds. Among these authors are Olupona, (2004), who said birds and animals are used for cleansing, some of the birds and animals are either slaughtered or buried alive. The only difference between Acholi culture and what Olupona said is that in Acholi, most of the animals and birds used for cleansings are slaughtered and some few left to move alive but not buried alive. At times a traditional healer was required but in case of his/her absence the elders and traditional leaders carried out the cleansing ceremony. Just as noted by some scholars, traditional medicine men plays leading roles in the diagnosis and prescription of medicine mostly based on medicinal plants, Soumonni (1968).

6.2. Treatment of Nodding Disease victims

The Acholi people survived on 'tum' (rituals) as the major way of treating sicknesses caused by spirits after diagnosis. This is according to a participant interviewed, (E. Luk, personal interview, Kitgum, Sept. 9. 2020). She said, 'Ajwaka' (witch doctor) always plays a leading role in casting

out 'cen' 'Cen' was the spirits of the annoyed relative who died but burial rituals were not properly followed. Any sickness that had defeated the modern medicines had a cultural solution.

However, there were some sicknesses that automatically called for cultural intervention straight away without trying any other means according to the behavior of the patient. A case in point was in 2006 when all the school pupils in Palabek Gem became mad, born again Christians camped and prayed for about three days but there was no change. The children were not getting healed, this could be because the problem was cultural and cultural solution was to be applied. The local leaders requested the Born-again Christians to leave, because the problem seemed more cultural. The elders and cultural leaders, with the help of NUPI (Northern Uganda Peace Initiative) came to action. They slaughtered a sheep, made the children step on the blood as a sign that the blood of the sheep had washed away the sickness from the children. The meat was used for feeding the spirits by roasting and throwing it to the bush with the belief that the spirits ate it and they were pleased with the living and set the children free from the sickness. Indeed, that marked the end of madness, the following day the children were all fine and back in the classrooms (J. Latigo personal interview, Gulu, Oct 1st 2020).

What the Acholi did was in line with what some authors as well said, among them is Westerland, (2006), he similarly described what the Ghanaians do, how animals are slaughtered and the blood poured on the patient's heads and foot. The only difference with the Acholi is that for the Acholi it's stepped on but not poured on the head. This was how the Acholi diagnosed and treated strange sicknesses. But for such to be effective, maximum cooperation needed to be observed. This was why cleansing rituals were not done in public places. Only a few important individuals who were to do the cleansing were invited to a specific secret place. This was mainly performed very early

in the morning at the foot or top of a hill or river banks where spirits were believed to reside and present at that time.

The nodding disease would not be a very big problem if the leaders in Acholi had one voice as it was the case in Palabek. It was unfortunate that the various cultural leaders had personal differences among themselves due to power rivalry. Some of the traditional leaders were reluctant to perform cultural activities if the problem didn't affect them directly while others wanted to prove their importance by making people plead for their help. Some of the cultural leaders feared to perform cultural rituals because of threats from political wings.

For rituals to be effective, there should be unity and no avenue for spirits to manipulate. "Moyo cere" (cleansing the hills) where various consultations were made from 'jok' on a specific issue or problem was done to end the nodding disease in Acholi land. Healing of the sick was not done and this explains why the nodding disease ended but the healing of the sick was realized. NUTI (Northern Uganda Transition Initiative) did not consult and use the right people for the cleansing. They bought cows, loaded them in a lorry, transported them to places where they slaughtered the cows and made people to eat, drink and enjoy themselves (J. Latigo personal interview, Gulu, Oct 1st 2020). But this was not how cultural rituals were performed. What they did was more of feasting than a ritual. Besides, cleansing was not done using cows but goats or sheep and not everyone ate the meat but specifically few people.

With the help of Lagoro, nothing would have defeated the Acholi community when it came to fighting bad things in the land. It was done with the Ebola. This was why it took only a few months in Acholi unlike in Liberia which took about one and half year to end. The same applied to Kony when he was sent out of Uganda, Lagoro instructed one of the custodians to take the spear and put

it at the border between Uganda and South Sudan to ensure that Kony never returned to Uganda (E. Luk, personal interview, Kitgum, Sept. 9. 2020).

The nodding disease had caught the attention of many people especially among the Acholi. On top of the traditionalists, modern medical practitioners got engaged in administering herbal medicine to the nodding disease patients. This yielded positive results as quoted by one of the respondents;

“Any sickness that made one dizzy or possessed was spiritual, rituals were to be performed and demons cast out. For the case of the nodding disease, after realizing that the disease was strange, we specialized in herbal medicine for treating the nodding disease patients by dropping the herbal medicine in their eyes, ears, mouth and nose. The treatment was administered from home, the medicine was given to parents to continue administering to the children. This yielded positive results to the children who received the herbal medicine, they got cured, since 2016 when the herbal medicine was given, those who got cured are healthy up to now”. (Pharmacist).

According to this participant, Gulu University Centre for Pharmaceutical Biotechnology and Traditional Medicine actively participated in treating the nodding syndrome using herbs that were administered to patients from their respective homes. The treatment was administered from homes because the herbal medicines were not approved by National Drug Authority (NDA), therefore its use was illegal and done on trial and error basis. The herbs were dropped in the mouth, nose and ears because they had high perfusion of mucus membrane and it was carried direct to the blood stream since the vein was close to the ears and nasal cavity. When medicine was absorbed, it closed blood drain barrier. This medicine proved to be effective when it was sampled on few patients who showed improvement, thus using the herbs for treating most of the patients. Much as the Acholi says the herbs had some positive impacts, some scholars who wrote about use of herbal medicine

to treat strange sicknesses seem to have doubt on the effectiveness of herbal medicine because its effectiveness is not evidenced, Atim et al., (2016), to him the effectiveness of such herbal treatment is a mystery.

The herbs were administered alongside rituals; where an elderly gentleman was involved in 'Agat' (spiritual aspects) of praying or interceding to the gods to answer the request and grant healing to the children. Making 'Agat' was a gift from God, not everyone could make the intercession prayer when it came to ritual activities. The person gifted with 'Agat' started the pleading prayer then the rest responded to make high frequency. The more the people the higher the frequency and the effective the 'Agat'. Anyone prayed but not the specific utterance of 'Agat'. 'Agat' was pleading to gods for blessings and healings (A. V. Lamwaka, personal interview, Oct. 12. 2020). It was just like in Christianity; anyone was able to pray for different purposes but not everyone had that special gift of performing miracle. The few who could perform genuine miracles with the help of the faith of the person being prayed for was considered special and gifted among others.

In this context therefore, modern scientists believed in the great contribution of traditional medicines because science could not provide solutions to every problem. This was why sometimes there were some patients who were referred from the hospital on doctors' advice to seek for alternative treatment from the culturists. This meant the modern scientists believed that some diseases were spiritual in nature and needed cultural intervention like the nodding disease. They as well acknowledged that the performance of rituals could be because of cultural influence of the society around. Even herbal medicine used by the Acholi people were now being modified, packed and used in other parts of the world. A case in point was black sesame which was packed in a bottle with some oil, left for some times to generate out the medicine in them and used as massage oil. Massage oil was also got from sheer butter mixed with other ingredients that were well packed

in bottles and used in many places. There were some visitors who came from the western part of the world to buy such herbal medicine and they went with them according to Dr. Lamwaka. This showed that the herbal medicine was not only alternative treatment of the nodding disease but complementary biomedicine.

The use of herbal medicine in the treatment of the nodding disease gave birth to the institute of Biomedicine in Gulu University from where the traditional herbalists were trained on the use of traditional medicine in treating some diseases. The first group graduated on December. 16. 2020. The use of the traditional medicine had officially been accepted by the president of the Republic of Uganda in September 2020 in the fight against Covid-19. This gave more value to herbal medicine and made the medical practitioners who prescribed or illegally used this herbal medicine to use them openly. Among the herbal medicine which was known countrywide for the treatment of covid-19 was covidex and covilyse which was mainly used in Uganda. This also proved the relevance of cultural practices in the fight against the nodding disease.

Among the Acholi of Northern Uganda, the spirits of the dead were feared so much because they believed that the spirits were always unpredictable. They could change anytime to be destructive in case of any mistake made by the living. When the spirits of the departed family members were not happy with the living, they attacked and caused destruction in form of natural calamities or sickness and death. When it struck through sickness, the most affected were mainly the children because the spirits wanted to communicate to the elders so as appease them. Children were attacked to make elders feel the pinch of seeing someone who was supposed to help them in their old age destroyed, hence act very fast. The Spirits did not attack randomly like other sicknesses that attacked both the young and the old. The spirits targeted the important age and sometimes persons

in the family so that the bite was felt and action taken. This was one of the ways the elders told if the sickness was spiritual or not.

When a problem was detected to be spiritual, the Acholi people had different gods that they consulted for solutions. Among them was 'jok olal teng' which was considered as the god that foretold the problems and provided alternative solutions to the problems. It was quite unfortunate that the Acholi people while in and after the camps neglected 'jogi'. This was one of the reasons why the diagnosis and treatment of the nodding disease had been a challenge in Acholi even after detecting that the disease could be treated culturally.

To the Acholi, there were some specific people and spirits which were very important in the society and without them things never moved on well. A case in point was 'Olal-Teng' who had an important role to play on the health of the people of Acholi as stated by a cultural leader. Unfortunately, it was no more, hence made it difficult for the people to have someone to sort out their problems. There were specific issues that needed to be sorted by a specific person or 'jok'. That was why partially handling the nodding disease had become a problem. This was also why even parents who tried to treat their children using herbs failed;

“The medical people tried to give her medicine but she had taken much drugs and now she refused. There was some slight improvement but not much. We tried traditional treatment without success. She was taken to Kitgum hospital for diagnosis and treatment, she has also been to rehabilitation Centre in odek; but all in vain”. (Parent 1)

However, there was a lot of controversy on the treatment of the nodding disease. Those who believed in tradition and cultural solutions to some of the problems especially those who defeated science, advocated for and believed that culture had the solution. They contended that even religion

was all about tradition although the religious people were in disagreement with those in support of culture as the solution to the nodding disease. On the other hand, scientists argued that the nodding disease was purely medical and should therefore be treated medically and this was what one of the medics said:

“Some tried local medicine but came back to modern medicine. The disease was not cultural or religious but purely medical” (Health worker 4)

Unless the three different categories of people, i.e. those who practiced and believed in culture, the contemporary religious people and modern scientists harmonized their ideas on the diagnosis and treatment of the nodding disease, the affected children would die of the nodding disease without recovery.

6.3. Rehabilitation of nodding disease victims

In regards to rehabilitation, most of the victims were rehabilitated socially and psychologically at family level. Most families never neglected their children but accepted them the way they are although there were few cases of neglect of the victims by some families because they looked at them as a burden to the family, however this was the minority, most families took proper care of their dear ones who were victims of nodding disease. There were Rehabilitation centers constructed to care for the nodding disease victims, one in kitgum district but it never opened due to reasons not clearly disclosed to the researcher. Another center was in Aromowanglobo in Odek Sub County in Lalogi county Omoro district call Hope for Humanity. It served for few years but was closed due to corruption and mismanagement. The researcher visited the center which has become resting place for cows. Below are the photos of the center after closure



Rehabilitation center for Nodding Disease patients in Aromowanglobo in Odek sub county Omoro district which has been closed.



The rehabilitation of the nodding disease victims wasn't taken as something serious. The family struggled with their patients until some of them got well while some are still sick up to now. There

was need for counselling the victims who recovered together with their family members for psychological and social healing which was never done. According to some participants, some of the children who recovered from nodding disease were still treated as social outcast. Some of them were stigmatized in public places while some were isolated from the rest of the children fearing transmission or aggression. This finding is in collaboration with the findings of Kristine, (2014). This finding is different from what Akwasi, (1985) found it. According to Akwasi, the sick were never laughed at because it's not ones will and there are many factors that leads to sickness.

Acholi people always use black goat for cleansing and the sick get well. They in most cases use animals and birds to purify the patient to enable him or her to once again live happily in the community in good health both physically and psychologically just as they did in Pawena in Palabek. What the Acholi did was in line with what other authors say about rituals using animals and birds for cleansing the victims. Among these authors are Olupona, (2004), who said birds and animals are used for cleansing, some of the birds and animals are either slaughtered or buried alive. The only difference between Acholi culture and what Olupona said is that in Acholi, most of the animals and birds used for cleansings are slaughtered and some few left to move alive but not buried alive. At times a traditional healer was required but in case of his/her absence the elders and traditional leaders carried out the cleansing ceremony. Just as noted by some scholars, traditional medicine men plays leading roles in the diagnosis and prescription of medicine mostly based on medicinal plants, Soumonni (1968).

The initiative of the Born-again Christians paved way for cultural institution in Palabek to take it upon themselves to carry out the cultural rituals. This was because what people looked at first as spiritual and the born-again Christians thought they would handle, turned out to be more complex to the extent that cultural leaders and elders had to seek for cultural solution. Fortunately, the

second option of culture became successful. This meant that traditions had to be followed because there were things that nothing other than tradition could handle more effectively.

Based on these findings, the study cannot conclusively claim that there is any definitive treatment for nodding disease. Participants seem to have some relief from using modern medicine and some traditional medicine as therapeutic means of treating the nodding syndrome, but the medicines being used are not treating the exact disease. A lot was done among them were; rituals were done, traditional medicines were given, prayers were conducted, counselling services were provided and some food was distributed by Caritas Pader an NGO and government opened two rehabilitation centers and medical treatment centers at healthcare facilities. Much as there was no clear and proper treatment for the nodding disease yet, there were no newer infection and the sick children had coped up with their conditions, and life moved on well or not well, the fact was that life moved on. Studies have reported that many players have supported children suffering from nodding disease and their caretakers. Much of this support however has been in form of medical and nutritional in nature. There have been mass distribution of the drugs against Onchocerciasis and aerial spraying of breeding sites of rivers to kill the black flies (Kristine, 2014; Gumisiriza et al., 2020). Studies also recommended access to care and motivations for health seeking, more outreaches for treatment of nodding syndrome could be instituted to increase access to the disperse and largely poor population (Mwaka et al., 2015). Further, addressing the complex psychosocial issues could prove as an important intervention (Abbo et al., 2019).

Whereas the finding show the desperate needs participants are making, the support has been minimum compared to the magnitude of the problems presumably because the past interventions have not eliminated the problem of nodding or that the capacity and techniques employed have not been the best. Also, many stakeholders fighting nodding syndrome lack capacity in term of funding

and support from development partners. Despite this, support in whatever forms such continue distribution of medicine, food and counseling services are not inevitable if we want to avoid further suffering of the children affected with nodding syndrome in northern Uganda.

6.4. Conclusion

The Acholi interpretation of the diagnosis, treatment and rehabilitation of nodding disease is embedded in the cultural and religious belief in ancestral spirits. The Acholi people appreciated the effort of modern medical treatment which have been slightly successful in halting much of the progression of nodding disease; many times, by using anti-epileptic drugs and mass onchocerciasis treatment. Unfortunately, their success has been partial and the consistency of results has yet to be achieved. The findings according to many scholars available conclude that there is no specific treatment that have been found for the condition (Foltz et al., 2013; McGann, 2015; Irani et al., 2019; Ongaya et al., 2020). The Acholi people continue to look for complete healing of the ND patients with the believe on culture and religion to give a permanent solution to the problem. According to the findings, the Acholi people went ahead to manipulate their cultural means of diagnosis, treatment and rehabilitation of nodding disease. This proved to be successful because it ended new cases of infection in Acholi land.

CHAPTER SEVEN

EFFECTS OF CULTURAL AND RELIGIOUS PERCEPTION OF THE NODDING DISEASE ON SOCIETY

7.0 Introduction

The participants admitted that nodding disease has really done terrible harm in Acholi land. They raised concern on the long term effect of nodding disease on the patients, parents/caregivers and society at large. The participants admit with sympathy the suffering the children and parents of children affected by nodding disease go through with a lot of physical, emotional, mental and social negative impacts. This has led to a lot of trauma among the Acholi. The most common effect on patients are; mental retardation, stunted growth, sexual abuse of the victims, trauma, stigma, and multiple disability. While in the families they experience low productivity due to being at home always to take care of the children leading to poverty, trauma, single parenthood due to separation and divorce among the parents. Nodding disease has also made Acholi as a community to become cheap in the eyes of other tribes because of the way they handled the disease. The people became divided, and started the practice of individualism. The general impact of nodding disease that affected all the three categories of patients, parents and society were social, psychological, economic, and physical among others.

7.1 Patients

The way people perceived the nodding disease culturally and religiously, was quite traumatizing to the patients in one way or the other. This was based on the behaviors and the characters of the affected children. Some of the sick children behaved like mad people who could not take care of

themselves making them dirty, talking and laughing to themselves. Some muted or became aggressive which made people consider them possessed and so many factors were considered culturally that led to such behaviors. This partially explained why some people perceived the nodding disease to be a sickness which only affected the possessed or spiritually weak people in the society while the righteous were left free. This perception made some of the patients feel rejected and humiliated according to some of the participants interviewed. Such perceptions made some children to disappear from home and got lost where no one knew. There was need for psychosocial support as an important thing to arrest the situation before it was late that led to the disappearing of the victims. Scholars like (Abbo, et al. 2019), as well acknowledge the importance of addressing psychosocial issues of people suffering from strange disease. However, it's not only trauma due to stigma that makes the children disappear from home, some of them moved out of home due to mental disorder and failed to trace their way back home since some of the victims are said to be senseless to danger. A participant had this to say regarding the disappearance of the children;

“This unfortunate disease has led to the disappearance of many of our children. Some of them disappeared from home and died in the bush. Others drowned in water while the whereabouts of some were unknown to date, the way these children behaved, was like they were mad or driven by evil spirits”. (Cultural leader 2)

Some of the sick children who disappeared mysteriously from home and got problems, was due to a number of factors. Some of them were neglected by their families, the children felt unloved and decided to move out of home. It was at this point as suggested by Abbo et al, (2019) that psychosocial support was very important to counsel the parents of the victims to show love to their children for the children psychosocial healing. While others left home with the intention to go

about doing some work like going to bath or fetch water in the nearby water source, following family members to the garden and other.

Since the patients disappeared from home and they got lost or hurt in the wilderness, some families who really didn't want to lose their children resorted to tying them on trees on the compound like a goat to restrict them from moving away from home. Some were tied on the pillar in the middle of the hut especially when people were away from home. One parent said that some parents did this as a way of protecting their children, "When we went to the garden, we locked her inside the house fearing that she might disappear from home or men might rape her". The intention for the restriction was good but the environment where these children were confined was wanting. It was always dirty; sometimes when the garden was far from home and if all the neighbors were away from home, such children suffered harsh weather (rain) but no one seemed bothered about it. This even made the children to feel more neglected. Other than these explanations, other families tie their children because of fear of shame from other community members who looked at them as a disgrace to the community. This reason is similar to the findings of Akwasi, (1998), of shame, laughter and disgrace from the community.

The way some of the nodding disease patients whose numbers were not identified were drown in water was similar to the way some people like Rwot Oyuru died during the wars in Acholi land. However, no cleansing had been done up to today (O. Layeng, phone call interview, Omoro, Feb. 15. 2020). According to this participant and some others, there were similarities between what the nodding syndrome patients portrayed and what happened during the war. Possibly, there was some message being sent to the elders and cultural institution of Acholi for something which was not done.

Most of the nodding disease patients were mentally unstable and some few men took advantage of such girls. They were raped, impregnated and deserted. Most of the men who abused these girls were mentally sound married men according to some of the participants interviewed.

“My daughter is mentally unstable; men take advantage of her mental disorder by sexually harassing her. The first man who raped her was caught and taken to police, he is currently serving his jail sentence of seven years in Kitgum prison. After a year she was pregnant, she took us to two different men who all denied responsibility. Right now, the baby boy was three years and I take care of him as my own now. I don't want any man to come claiming the baby because they used and dumped my daughter”. (Parent 1)

The children were said to be senseless of any danger a head of them. Most of them behaved like mad people. In most cases, they were either tied on a tree or locked inside the house when family members were out of home. This denied them freedom of movement but it was for their own good. The Acholi land had seen high increase in mental illness after the LRA war, thus ranked top worldwide according to the New Vision report of 31st August 2008. This had been worsened by the nodding disease. There were many causes of mental illness and the nodding disease was one of them. In about half of the nodding disease homes visited, the affected children were mentally derailed, and some stayed at home under tight supervision, locked in the house or tied on a tree while others moved away from home to the nearby trading center.

Children with the nodding disease encountered a lot of challenges. Due to sexual abuses like rape, some of these children suffered from STDs/STIs and HIV/AIDS on top of unwanted pregnancies. A case was reported of a girl from Awere in Omoro district who was kidnapped on her way home, carried to the bush and raped by an allegedly HIV positive man on medication. The suspect was arrested but later released from police for a reason not disclosed as reported by Radio Rupiny in

their program of Abokalam between 8pm to 9pm on July 16th, 2020. The Resident District Commissioner and Local Council V Chairperson of Omoro district condemned the act and urged parents of the children suffering from the nodding syndrome and the community to be vigilant on such bad people in the community to make them face the law.

From the researcher's analysis, the situation the patients go through had a lot in common with what the people went through during the LRA war where women and girls were raped, and some were left pregnant with fatherless children. This partly explained why people considered the nodding disease to be another form of 'war' that the Acholi were fighting. However, some of the parents had given up on their children by saying that it was bad luck that had befallen their children and they were left with no option but to watch them perish. This made some parents to abandon some of these children without even clothing them as a participant was quoted saying, "Children suffering from the nodding disease were not dressed up, worse in families of drunkards".

Some parents considered these children useless and they were treated unfairly. Some families tended to love the normal children more than the sick children, thus made such sick children, so moody with low self-esteem and self-stigmatized. Some were not allowed to sleep in the same room with their fellow siblings simply because they were considered either aggressive and therefore could hurt their siblings at night when attacked or because they were dirty. Even when it came to eating, they had a specific separate plate. At times even where they sat and ate from was different as stated by one participant,

"The children affected by the nodding disease are treated differently from other normal children. For instance, they are served using different plates of food, some are put to sleep in separate rooms" (cultural leader 1)

In addition to that, most of these children were not taken to school. Some parents had biased minds about these children's education. They looked at sending these children to school as a waste of money. To some extent the parents were right because some of the victims have been so much affected that they can't school among the normal children unless they are taken to specific schools for the disable. Some of these children are just as reported in the Article of Global Health Action, (2014) indicating abnormalities among the patients ranging from stunted growth, mental retardation, paralysis, abnormal brain activity, uncontrolled saliva and poor eyesight among others. Research findings also found similar situation on the ground. Some of them who attend schools are very indiscipline due to mental retardation. A case in point was one who led a very serious strike in Awere primary school in Omoro district in 2019 yet strikes is very rare in primary school according to the district inspector of schools Omoro, (G. Mwaka, in a personal interview, Omoro, April 9 2020). A teacher in the same school Awere primary school confirm what the inspector said. She added that the boy has taken years studying primary five and six that his class mates were already in senior four, (A. Aloyo, in a personal interview, Omoro, April 10 2020). This also confirm the findings that children with nodding disease always don't perform well in school. Aggression among the nodding disease patients is common just like with other sicknesses as noted by some authors a case in point is Isiko, (2018). However, not all the children were severely mentally retarded, some had mild cases but some parents failed to take their children to school due to financial challenges. Therefore, the nodding syndrome had greatly affected the education of the children. This meant increased illiteracy in the Acholi community. Almost all the children with the nodding disease had dropped out of school due to their various disabilities, including mental illnesses that affected their class performance, and stigma from their fellow learners especially those who got attacked from school. A participant said,

“My two daughters had dropped out of school because the children in school laughed at them especially when they get ND attacks at school. They had frequent attacks when it was cold, sometimes the elder daughter got an attack on the way to school, it was worse when she was alone, she could just fall on the road”. (Parent 2)

Children with the nodding disease had challenges of socialization because in most cases the community looked at them as social outcast and their children rarely interacted with them. The few who interacted with them at times liked teasing the patients. They used them as play toys especially those who were humble. Although the nodding disease was non-commutable, people’s attitudes towards the disease led to isolation of the patients. The environment where these children live are more hostile to them due to community perspectives as noted in the findings both in interview and observations. Similarly, Kristine, (2014) noted the same in the research published. Some were stigmatized and they were called names like ‘lapoya’ (mad) which traumatized the patients the more, thus more self-stigmatized. In most cases the nodding disease patients were withdrawn from people except close family members for the case of those who were shown love. Those who had recovered or were mildly infected had challenges of marriage because the community had branded them as ‘lupoya’, ‘lugoro’ (disable). This made prospective lovers to fear marrying them because of such comments despite the fact that the patients were capable of giving birth to normal children. Those who had made up their mind to marry or get married to the nodding disease victims experienced a lot of social challenges in their marriage to the extent that it was true love that made one continue with the relationship as mentioned by the participant below;

“People have negative views on the nodding disease victims. A man married a girl having mild nodding syndrome and they now have two children, people call him the husband of ‘lapoya”. (Religious leader 3).

The nodding disease wouldn't have been a big problem but the greatest problem was peoples' perception and utterances that made the disease worse than it was. This kind of disease was inseparable from death. Due to various factors surrounding the disease ranging from people's perception, treatment and other factors. Just as it was the case in other countries that were affected by nodding disease like Tanzania, Liberia and Southern Sudan who witnessed a lot of death due to nodding disease, Northern Uganda wasn't any different, the people of Acholi witnessed very many deaths of the nodding disease patients, (Kitara, 2013). According to participants, many children with the nodding disease died of various causes among them were malnutrition, burns and drowning in water. According to a report from the Ministry of Health, 137 death cases were reported by 2018. The last death was of a child who had improved but drowned in water where he had gone to play (Aceng, 2018). The participants alluded that most of the death cases were from the community, very few death cases were registered from treatment centers. One of them also confirmed about the cases of death by saying:

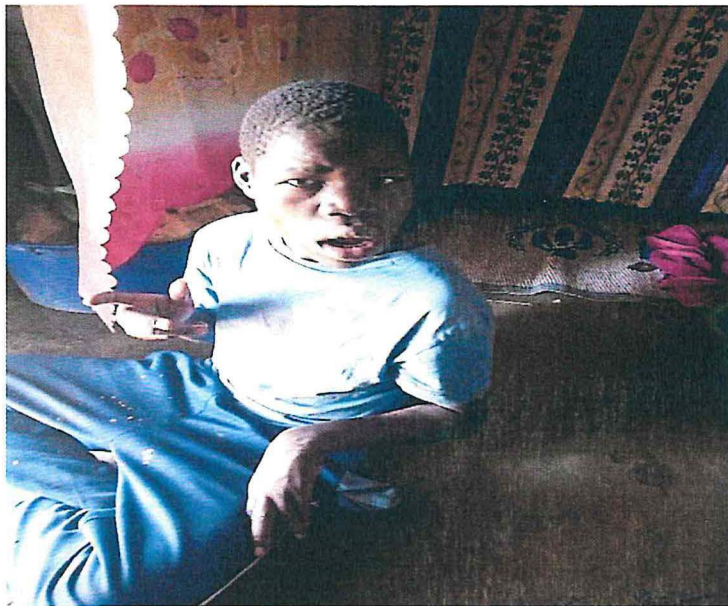
“The district witnessed deaths of the children with the nodding disease who were severely sick and taken to treatment center in Hope for Humanity, Aromoinglobo in Odek Sub County, Omoro district when the center was closed due to mismanagement. Most of the children who were brought back from the center died. Most of the children with the nodding disease died of complications like anemia and malnutrition”. (Health worker 1)

Some of the nodding disease children visited were malnourished. There was no proper feeding as they took their medicine. Due to malnutrition, some were stunted to the level of becoming crippled. They couldn't walk as a result of severe effect of the nodding disease. More than half of the children who were severely affected by the nodding disease looked younger than their age. The researcher visited four of the six homes with affected children aged 15 years and above, the

physical size of the sick children didn't match their age. The children were looking younger than their age. Other than age, some of them had paralyzed hands that couldn't hold things. According to their parents, frequent attacks led to fits and eventually the children became epileptic. According to a participant who was a health worker, the frequent fits had affected the brain leading to mental retardation. Due to attacks at the sight of food, the children rarely ate, while some lacked what to eat since their parents had no food, hence malnutrition. The parents of the children also complained that the drugs made the children over eat yet they lacked what to cook. This was because they were ever at home taking care of the children without doing any productive work the increasing poverty level (K. Akello, personal interview, Pader, February. 11. 2020).

Given the multiple effect of nodding disease on the patients, different families treat the patients differently basing on their perception on the patient. Some families treat their children with a lot of love and care while others take the children the way they are without much support for the patients' personal hygiene.

Below are the photos of the nodding disease victims in two different environment basing on perceptions as noted below;



Photos of children with Nodding Disease in Acholi sub region. Photos taken by researcher with consent from the victims' parents.

Below is the hut where one of the neglected nodding disease patient sleep.



7.2. Parents and Caregivers

Parents/caregivers of children affected by the nodding disease had faced a lot of challenges in caring for their children. Most of the homes visited were characterized by poverty, single parenthood, depression and bitterness. Some of them talked with a lot of emotion while others were relaxed and left the fate of their children in the hands of God. However, some of the participants who were not parents/caregivers as well talked with a lot of sympathy for the suffering children and their parents.

The cultural and religious perceptions of the Acholi people about the nodding disease was spiritual. This was because it made parents and caregivers of the affected children to have sleepless nights. The issue of sleepless night appeared in earlier research among them was Kristine, (2014) as parents think their children will be next. This researcher as well came up with the same findings, this means the situation wasn't good especially if it hits a neighbor's family.

The affected parents would be asked with a lot of emotion why them? If it was true that the disease was caused by evil spirits, God's punishment or whatever as stated by Akwasi, (1998), why was their family among the unlucky ones and not all the families around the areas? Some parents who couldn't withstand the stress committed suicide and died, while some parents died of stress or depression after witnessing what they had never seen before happening to their children, while others were still thinking of committing suicide according to one of the parents. She hinted to the researcher that she felt like committing suicide and dying because of over suffering, instead of her handling her children, another burden of grand children without any help from their fathers comes in, that when will she rest from the burden?. Her situation had been worsened by the problem in her eye sight which had just started, she couldn't see well when the sun was hot. She was from the garden but failed to do what took her to the garden instead she just fell down from the garden and returned back home a day before the interview. As if that wasn't enough, her husband had developed mental problem about ten years back as a result of what the family was going through.

Despite the effects of the nodding disease, more problems came up. This was one of the challenges parents and caregivers of affected children faced. There were worse situations in the field which put the researcher off topic at times. A case in point was seeing children being tied on the poles to avoid them moving out of homes, parents and caregivers narrating the plight of the sick children in tears and how the family had been greatly affected socially and economically among others. Honestly, the family of the lady mentioned above needed serious support from well-wishers. She painfully said:

“I keep the children single handedly, my husband has also developed mental problem. It is unfortunate that of my seven children, three are suffering from nodding disease and the elder one was always sexually abused by men, she was now having three children with

only the first child whose father was known but I don't know the father of the two young ones. I have to bathe my two young sick children and the three grandchildren, look for food for them...., at times I think of committing suicide". (Parent 3)

Most of the parents and caregivers attending to the nodding disease children needed constant counselling and frequent follow up as noted by Abbo, et al, (2019), for psychosocial support otherwise both parent and children can run mad. Most of the parents were worried that the children they were struggling and suffering for could die anytime. This made the parents who were already traumatized by the sickness of their children even more traumatized (R. Opoka, personal interview, Pader, Feb. 12.2020). Unfortunately, there was only one organization; Caritas Pader providing counselling services in Pader but they didn't even reach all the homes apart from some few. Unlike with the LRA war where very many NGO's rushed into the land to provide charity to the affected people, very few NGOs if any, came up to support those with the nodding disease. The disease also came at a time when families were apart, unlike the ancient times of extended families where support was easier to administer because the problem was easily noticed. This was possible because everyone was in the same compound and helping the member didn't require one to leave her own family and relocate to the other family in desperate need. This had increased the plight of the suffering families.

The parents feared leaving the children alone at home due to the fact that the children could disappear from home, get hurt or abused. This made parents to stay closer to their children throughout. Therefore, the parents couldn't engage in any productive activities to feed the family. To the parents and caregivers interviewed, this led to low productivity and a lot of problems within the family ranging from hunger, lack of clothes to loss of their idle land to land grabbers as noted by one of them;

“No garden work for parents, rendering their land unused leading to land grabbing. The parents/caregivers of the nodding disease children mostly had challenges of getting food to feed the children... the children on treatment ate a lot but the parents had no time for digging since they were always attending to the children.” (Religious leader 1).

Among the Acholi community, the main source of survival was garden work, and where one was unable to go to the garden, it meant lack of food and poverty in the long run. This was what was being experienced in families affected by the nodding disease. Above all, the children in productive age who should have helped their parents with work were unable to do so because of sickness despite the fact that they needed a lot of food. Families that lacked basic needs like food were always not happy and such families experienced a lot of domestic violence. The participants as well were so disappointed by the nodding disease. This was because it had wasted a lot of labor force as mentioned by one of them. The children who were within the active age bracket and who should have helped in increasing productivity were sick, hence holding everyone back to take care of them. Children were supposed to help their parents but for the case of the nodding disease, the reverse was true (the parents were helping their children).

According to a participant, the parents were more of slaves and watch dogs that kept and protected the homes all the time, “The caregivers of these children had become slaves because they were supposed to stay at home full time. They were non-productive since they were taking care of the children at home and taking them for treatment all the time” said Khalil. This made their hands-tied and put them in economic distress by attending to the patients empty handed (O. Layeng, phone call interview, Omoro, Feb. 15. 2020).

Parents of the affected children who also happened to be mothers mostly, were really suffering with their sick children in various ways because most of them were disabled. For example, most

of them were mentally retarded and had low senses to control themselves like controlling flow of saliva and attending to personal hygiene, thus making them ever dirty. In addition, they were unable to clean themselves. Most of the sick children were also unable to go for drug refill by themselves but it was their parents who went for drug refill. It was not easy for parents who moved over long distance to pick drugs. Some of them skipped for some months yet the drugs were to be taken constantly. Some had given up and their children were no longer on treatment, hence frequent attacks. Some parents complained that the drugs made their children to over eat the food which was even scarce. This was worse for parents with more than one sick child who became frustrated the more. Worse of all, they said the drugs were not even curing their children as explained by one participant.

“Most of the parents and caregivers are frustrated because their children are not getting healed yet on treatment for many years and they are facing a lot of burden keeping the children”. (Health worker 3)

Culturally and religiously, the nodding disease had been associated to evil which was tormenting the children. Due to this perception, the disease had impacted negatively on marriages. One of the worse effects was separation and divorce. Among the Acholi especially in the village settings, polygamous marriage was a common practice. When the nodding disease invaded the land and families, most men abandoned their families with sick children and fled to families with normal children. According to one mother interviewed, the husband abandoned her with her two sick daughters calling them ‘lyel ma kwo’ (a walking corpse). She had this to say “My husband left and went to stay with another woman whose children were normal, and said he could not keep walking corpse” (A. Joy, personal interview, Pader Feb. 10. 2020). Apart from Joy, another participant was quoted as follows;

“Divorce and suicidal tendencies are rampant among the parents and caregivers having children suffering from the nodding disease, some have committed suicide and died.” (Health worker 2)

A family taken care of single handedly especially by mothers just looked a struggling family in terms of provision of basic needs; the researcher thus noted hunger, poor shelter and clothing for the patients. Unfortunately, out of the homes visited, none was found with a single father. There is a proverb in Acholi that says ‘cing acel pe yabu dud’ (one hand can’t open the Anus). This was really a typical scenario in families affected by the nodding disease, given the fact that these children should be looked after from providing food, cooking, bathing, taking them for their treatment at the health center, to protecting them at home by one person. This was one of the reasons why the homes were more disorganized and were in absolute poverty, this has as well been noted by other authors finding, (Kitara, 2011). The rate of poverty was even worse to families that were already poor even before nodding disease. Besides, not all the families with nodding disease victims are poor depending on the status of the family before, the number of patients in the family and support from the relatives and other family members away from that home for example married daughters and working elderly children.

Conclusively, the way the nodding disease was perceived among the people both culturally and religiously as the greatest harm to the affected families. Parents and care givers had asked a million questions which remained unanswered. This was what hurt the parents and caregivers the most as they looked at their children get wasted without solution.

7.3 Society

Family is a basic unit of the society. This meant it was families that formed the society. Therefore, what affected families affected the society. The effects were characterized by poverty, trauma, and single parenthood, among others. Participants raised concerns on the long-term effects of the nodding disease on the Acholi society in the next generation. The Acholi had suffered for the last 30 years from the LRA war, Ebola and recently the nodding syndrome which hit the Acholi at the time when Acholi people were yet to recover from the war and its dreadful impacts. This led to a lot of trauma among the Acholi. Thus, the Acholi land couldn't rest from suffering for over 30 years, i.e. one problems after another. The made the Acholi become a laughing stock. Culturally, traditional leaders in Acholi would not wait for sickness to get out of hand, they intervened at the early stage. It was not easy with the nodding disease due to government policies at the start (A. Oloo, personal interview, Feb.19.2020)

According to participants, the way people perceived the nodding disease had a lot of negative impacts on the Acholi community. This had also made the Acholi to know their position in the current government that seemed not to recognize the Acholi in times of crisis and didn't take them seriously. So many factors both within and outside had hindered the fight against the nodding syndrome in Acholi. Some of these included; Religion where religious leaders didn't believe in traditional healing but prayers and government policy of regulating traditional intervention. Education made those who were highly educated ignore culture. Another barrier was class difference as the nodding disease was considered to be for the poor. This led to reluctance from all classes of people in the fighting against the nodding disease. This was because some looked at it as none of their business since it didn't affect them. For science/advancement/civilization, anything strange led to a lot of research to find the cause and the possible solutions. So, the fight

against the nodding disease was looked at as the work of science other than culture or religion. Poverty was yet another factor considered that hindered this fight. The people were willing to fight the nodding disease till the end but were limited by resources.

The nodding disease made Acholi to experience and witness increasing number of single parenthoods. Parents with children suffering from the nodding syndrome cried a lot for the suffering they went through because of the problem that befell their children. Most of the families who had children suffering from the nodding disease were mainly taken care of by women. Of about ten families visited, the researcher was able to find and interact with both parents (mother and father) of the patient in only one family. The rest of the families were headed by single mothers who took care of the family because the men had abandoned the family, married other women and stayed in their new homes. The nodding disease really separated families instead of uniting them in times of hardship. This was culturally wrong. Among the Acholi, separation and divorce was only accepted when it couldn't be avoided in cases like witchcraft, incest, indiscipline, adulterous woman, mental illness among others, and not just because of sickness of a child which required the two parents to instead look for the solution to the problem together. A participant noted that,

“Increase of single parenthood in the society, a lot of separation and divorce occurred in families mostly with severe cases of the nodding disease or infection of many children in the family. Most of the men ran away leaving mothers to care for the sick children single handedly. Even the sick girls were sexually abused and left with pregnancy. The fathers of the children were nowhere to be seen. This was something which was rare among the Acholi”. (Parent 2).

Acholi as a community saw lost a generation in the near future. Given the age group affected, there was a cut off continuity for about ten years (A, Lacambel, personal interview, Gulu, Aug.

29th.2020). He continued to say that this was why they think this disease had just been brought to us given the target age which was the most productive age. This was also in support to what a writer as well said, that some diseases were brought from out to affect a particular family or community (Kristine 2015). The impact of the nodding disease was going to be worse felt in the next ten to twenty years when the current fatherless children were grown-ups, and the current care takers of the patients were dead. There was going to be high rate of illiteracy due to lack of education, lack of parental guidance, increased street children and high prevalence rate of HIV/AIDS in this generation. Other than Lacambel as an elder, a medical worker as well was concerned about the same as she was quoted below;

“We are going to have a lost generation with lack of parental guidance, lack of education and possibly affected with HIV/AIDS and many homeless street children who will be thieves, murderers if not handled at this early stage”. (Health worker2).

The people of Acholi fore saw big challenges with the upcoming generation because of the challenges the land went through at the time of nodding disease. The people who were to guide the children were too traumatized to talk to the children and above all, some of the children were not mentally sound to understand. The situation was worsened by the individualistic life the people live today, i.e. families no longer joined hands in guiding and training the children. It was all about one for himself and God for us all. This was a very bad practice that didn't favor the orphans and children raised in single headed families especially by mothers.

Several unanswered questions still confuse the Acholi people to date, for example why the age group and why was the disease doted? (I.e. skipped some areas of the land and concentrated in some areas and families).

Culturally in Acholi, when a child was born with disability, that child was tactically thrown into a river in a pretentious way as if it was a mistake for the child not to be annoyed with the parent and curse them. Similarly, some of the nodding disease patients were real burdens to their family and the society at large. A child who was supposed to help the family was just being helped and everyone was in prison looking after the sick child without any work but the patient needed to eat. It became more of a burden and some of the families felt they shouldn't exist for them to be out of home prison and carry on with their productive activities. One of the participants quoted what some of those taking care of the children said; "Society treats these children as burden and wish them to die so that they rest", said Francis. Much as it was a practice in Acholi land to eliminate such people from society, Acholi had already gotten used to staying with people with disability due to Human Rights Declaration and whoever killed such children was considered a murderer and charged in court of law. The nodding disease made Acholi to get back to their old practice of abandoning their abnormal children due to the challenges faced in looking after such children. All in all, it was the minority who thought the children should die so as to rest. Others had the same opinion but they didn't say it out. The majority of the population loved to see such children alive and to die naturally not wishing them death as this might turn out to be something else like a curse in the family because they died as a result of family neglect.

The nodding disease had really made the Acholi to be a laughing stock. Ebola from Congo hit only Acholi land in the whole of Uganda in 2000. Kony war ravaged Acholi land for about twenty years until the elders and cultural leaders consulted 'lagoro' for cleansing rituals that was done to mark the end of the problems. If it wasn't for our own 'jogi' that protect us, by now things would not have been easy for the Acholi. A participant bitterly lamented:

“The nodding disease is not taken seriously both by government and local leaders which include cultural and religious leaders. The problems that affect the Acholi are never treated as priority, this has led to a loss generation. The Acholi are not contented on the way the issue of the disease was being handled. There was conflict of interest. The people of Acholi have been abandoned, no government or NGO was giving help to the nodding disease patients unlike during Kony war where many NGOs came and supported the people.”
(Religious leader 4)

As this participant elaborated, there were a lot of loop holes that had been pointed out by participants in handling the nodding disease. Some said the disease was being handled as if they didn't want it to end but kept it on for the reasons best known to them. Both the cultural and religious institutions admitted that they had not been able to do enough. Unlike the case with the LRA war and Ebola. Ebola was handled so fast and ended before spreading to the entire land, so why were we delaying with the nodding disease? By now many NGOs would have come up to care for the affected children and families but nothing of the kind has been done. Since there were misunderstandings about the causes of the disease, the society had negative attitudes towards the children and affected families. They had become social outcast. They thought it was a kind of punishment to them for their evil acts as was the case in any African society about any strange disease according to Akwasi (1985).

The Acholi elders and cultural leaders knew what was happening and what could have been done to solve the problem of the nodding disease but only one thing was required that was ‘unity’. For ‘jok’ to hear the cry of the people and work better one language had to be spoken and action taken and this was missing among the Acholi in contemporary times (J. Latigo, personal interview, Oct. 1st.2020). As of then, the church in Kitgum had summoned all the radio stations in Kitgum not to

host any traditionalist on air because they were indoctrinating people from religious teaching which had been preached and causing confusion to the people (E. Luk, personal interview, Sept.09.2020) and yet even religion was all about tradition and culture. This is because they also carried out their cleansing using religion by saying words in prayer form or praying while carrying out their rituals. No ritual was carried out without uttering words of prayer to the spirits. The division had created a loop hole in the fight against the nodding disease according to many participants. Another participant emphasized what Luk said as he was quoted saying:

Acholi are divided religiously, politically and economically. For cleansing to be done effectively, it needs unity. There are things that happens in people's life that nothing can handle apart from tradition. That is why people are stranded with 'luc luc' (nodding disease). There are things to unite us but culture has to be handled first. Gang otoo/too piny' (home was dead) because culture was abandoned". (Cultural leader 3)

Many participants were concerned about the bad things that were attacking the Acholi. A participant lamented, "There are many problems affecting the Acholi people and it is not taken seriously. It could be 'abila' like lagoro that was annoyed because it had been abandoned and needed 'tedo cere' (cleansing the hill). But it was hard to do it now because of changes in life which had divided people into religion, education, science, civilization, and economic differences", as said by Olaa. Indeed, a lot needed to be done in Acholi land so as to restore its lost glory. Indeed 'gang otoo' (home is destroyed) and something needed to be done for the restoration of the land and to have this done, disunity among the various groups of people needed to be addressed first. Much as there were internal problems, some participants blamed the failure in the fight against nodding disease mainly on the cultural leaders because they had not given it a trial to unite everyone and fight the nodding disease. May be if they had tried, people would have put

aside their differences and eliminated the nodding disease from the land. Findings on effects of the nodding disease pointed to failures both from within and outside which got the disease out of hand/control. The children who were suffering from the nodding syndrome were destined to continue suffering and hence die one by one until they were finished.

The Acholi people had a strong belief that river banks hosted all types of spirits, i.e. both the good and bad spirit. However, even if the bad spirit attacked the people it could still be restrained back through cultural activity of the cleansing ritual. According to a participant, this was exactly what was not being done correctly in Acholi; the nodding syndrome wouldn't have even taken a year in Acholi land. The biggest problem was that there were people in the government that loved to see the suffering of the Acholi people, they came up with divide and rule policy which derailed the people from doing the right thing to overcome any problem affecting the Acholi. This was because they wanted the Acholi land to remain vacant without its inhabitants and they take over the vast fertile land as noted by J. Latigo, in a personal interview, (October 1st 2020). With regards to river banks and spirits, a participant admitted in a personal interview that the two played a great role in the life of the people. It was just a matter of cleansing to sort out the problem as he said;

“Culturally, river banks are known as home for spirits. Cleansing of the river banks can sort out spiritual life but Acholi have changed, they are now behaving like mad people because of loss of spiritual dimension which used to help us put spiritual attack under check. You can't leave in spiritual vacuum; religion was about tradition” (cultural leader 3)

Parents, health workers, elders, religious leaders and cultural leaders believed that the nodding disease affected not only the sick children and their family but the entire Acholi land. This finding was in agreement with many other studies conducted before by other scholars. The children who

started treatment at the on-set of the sickness had improvement while those who used modern medicine later, i.e. after the advancement of the disease to another stage failed treatment and most of them died. This confirmed the report by the Minister of Health (Aceng, 2018). To the Acholi, the death of a child was more painful than the death of an adult. This was because children were looked at as the heir of their parents and future generation. It was also the children to bury their parents not vice versa. This was because there would be no one to bury the parents when the children were all dead. The burial of the parents would be simple like burying a dog where no one put much attention and emphasis. On the issues of the death, this was what a participant said;

“The death of the children with the nodding disease pains me. In Acholi death was robbery especially death of the children who are considered the heir and future generation”.

(Cultural leader 4).

Many people were in very bad state of life. The families of the nodding disease patients lived in poverty since they were not engaged in productive activities. This had been partly attributed to the outbreak of the nodding disease when a lot of resources like goats, hens and rams were wasted in treating the disease traditionally, by going to the traditional herbalists thinking it was epilepsy. If such animals were there, they would be helpful to the families. This was because they would multiply and some would be sold to alleviate the rising poverty. Unfortunately, they were depleted. This had been worsened by the COVID-19 pandemic since people were hit by hunger due to lockdown. The families of the nodding disease patients found it hard to feed the sick children who had high appetite for food, and they were supposed to eat frequently in order to avoid hunger which led to attacks. This was according to (Okello P D. Okao on April 23 2020 in a radio news read by Winnie Oyet of Mega FM), quoting the Local Council V Chairman of Omoro district who appealed

to well-wishers to support families of NS patients in Odek sub county in his native district. 'If the lockdown continues, many children with NS living in poor families may die', he added.

The sick children were not going to school, hence high level of illiteracy among the Acholi community. There would reach a time when the Acholi people would not get jobs in higher offices because of illiteracy and would instead serve as cooks, compound cleaners and Askaris in people's offices. The nodding disease had also created enmity in the society especially where cases of abuse of the patients was registered and arrests made. They ended up bringing bitterness and enmity between the offenders' and the victims' families according to some participants.

Gramam, (1998), some families had poor relationships among them because of cases of witch hunt. However, this was at the start of nodding disease when some families were affected while others were not within the same area. It first caused misunderstanding and witch hunt until the people started understanding the probable cause of the disease and the pattern of infection from one area to another randomly. The nodding disease increased trauma in the community, both the parents and children were running mad due to stress from the disease leading to increase in the number of mentally ill people in the Acholi sub region. Northern Uganda was ranked top worldwide with the highest mental case according to The New Vision of August 31st 2008 as reported by Conan Businge. Basically, children were the future of their parents since they were supposed to succeed them and swap their roles at some point. In the case of NS, parents would continue living a miserable life till death because there would be no one to support them at old age since the children were dying, some were crippled and helpless.

7.4. Conclusion.

The effect of cultural and religious perception of nodding disease on patient, family and society are both short term and long term. The finding show that nodding disease has led to a cut off generation. This will take Acholi people quite some time to bridge the generation gap of over fifteen years. The findings also revealed the harms done by nodding disease on the patient where most of them have multiple disability ranging from physical and psychological. The families are not spared either. There is high rate of poverty in such homes and trauma and stigma. According to the finding, Nodding is one of the worse problems that befell Acholi land after the LRA war.

CHAPTER EIGHT

CONCLUSION AND RECOMMENDATIONS

8.1. Summary

This dissertation tried to demonstrate the perceptions of communities affected by an unknown emerging disease where families of the affected children grieved not only their child's illness but a loss of social value and lineage. The loss and suffering involved with the nodding syndrome should be seen in the context of the wider suffering of a society disrupted by violent/ conflict. The memory of war was omnipresent and was also how the nodding syndrome was understood.

The Acholis' quest for understanding the mystery of the disease in their area only and at this particular time remained unsatisfied through attempts of modern science and dismissing scientific explanation of the nodding disease. The Acholi had attempted to conceive and interpret the disease beyond science as the philosophy in several African societies was that; where modern science failed, they resorted to their cultural and religious cosmologies, in search for meaning.

Based on this, the study qualitatively analyzed the cultural and religious conception and interpretation of the Nodding Syndrome among the Acholi of Northern Uganda. More specifically, the study analyzed the cultural and religious beliefs about the nature and manifestation of the nodding disease; examined the religious and cultural interpretation of the causes of the nodding disease; established the cultural and religious perception on diagnosis; treatment and rehabilitation of patients with nodding disease; explored how the Acholi traditional cultural and religious perception on the rehabilitation of the nodding disease children and their care givers; effects of the nodding disease on Acholi traditional cultural and religious perception on patients, family and society.

Based on the study findings, participants' perceptions and interpretations of the manifestations, causes, treatment and effects of the nodding disease were in agreement. The parents, health workers, elders, religious leaders and cultural leaders all agreed that the nodding disease manifestation started by the nodding of heads on sights of food. The sickness had been given the local name "luc luc" derived from the behavior of the patients of repeated the nodding of heads. The children got more attacks in the morning when it was cold. They also frequently fell down because of unconsciousness and they could not take control of themselves, and those at advanced stages become epileptic. Most of the participants said the patients' behaviors when attacked was like a person possessed by the evil spirits, some of them muted, others screamed, some talk to themselves while others became aggressive. They agreed that the nodding disease was spiritual which needed to be handled spiritually.

The causes of nodding disease to most of the participants was more than black flies as it was being assumed without confirmation. To them the cause was the bloodshed in the land given the timing after the LRA war-where a lot of atrocities were done in the land but had not been worked upon or what was not put right through ritual cleansing of the land to appease the spirits of those who died painfully among the Acholi and in the hands of the Acholi. This was also in connection to the neglect of the shrines and the gods "Abila" and "jogi" respectively. These two played important roles in the lives of the Acholi to earn blessings and evoke curses. It was a place of consultation and cleansing but since it had been neglected and ignored, cleansing also became a challenge. Some participants summarized the causes of the nodding disease as "gemo" (bad spirits) that attacked randomly. That was why it was hard to explain why some homes were affected while some were not within the same community. Some participants said, the Acholi probably understood the cause of the nodding disease but lacked unity to come together, and speak one

voice. They claimed their hands were tied due to a lot of restrictions on the nodding disease like carry out cleansing of the whole land.

As regards the diagnosis, treatment and rehabilitation of the nodding disease, the finding in collaboration to other findings agreed that people used a lot of modern and traditional medicines in treating the nodding disease with mild success of modern medicine. The study also revealed that some people sought care from traditional healers and local medicines used but the success of the medicine was still a misery. The conclusion was that there was no specific treatment found for the nodding disease.

The effects of the nodding disease as per the findings were both short term and long term. The findings more or less had removed many of the myths. The way the nodding disease was perceived among the people both culturally and religiously was the greatest harm to the affected children and their families. The people of Acholi were fore seeing big challenges with the upcoming generation because of the challenges the land was going through at that time. The disease was inseparable from death, the people of Acholi witnessed very many deaths of the nodding disease patients. This was due to various factors surrounding the disease ranging from people's perception, treatment and other factors. According to participants, many children with the nodding disease died of various causes among them were malnutrition, burns and drowning in water. The nodding disease affected not only the sick children and their family but the entire Acholi land. This finding was in agreement with many other studies conducted before by other scholars. The children who started treatment at the on-set of the sickness had improvement without cure while those who used modern medicine later, i.e. after the advancement of the disease to another stage failed treatment and most of them died. Other than death, there was a lot of mental retardation among the nodding disease patients, most of them who survived death were mentally retarded with multiple disabilities.

The findings further established that many girls affected by the nodding disease had been sexually abused by men and left them with either pregnancy or STD/I. The girls gave birth to fatherless children. This added burdens to their parents who were struggling to take care of them. There was also high rate of poverty among the nodding disease affected families. This was because they always kept at home to take care of the sick children and no productive work was being done. In addition, the children in productive age who should have helped their parents were the ones being taken care of by their parents.

There were a lot of loop holes that had been pointed out by participants in handling the nodding disease. Some said the disease was being handled as if they didn't want it to end but kept it on for the reasons best known to those on the forefront in the fight against the nodding disease. Both the cultural and religious institutions admitted that they had not been able to do enough. Unlike the case with the LRA war and Ebola. Ebola was handled so fast and ended before spreading to the entire land.

Basing on the findings on cultural and religious perception on the manifestation of the nodding disease, culture and religion were in agreement on the manifestation of nodding disease. They agreed that it was spiritual. But when it came to solving the problem, religion and culture failed to agree on the steps to be taken. In view of this, the two worked out their solutions differently and culture slowed down its move to alternative solution to the nodding disease.

8.2. Conclusion.

The cultural and religious interpretation of nodding disease among the Acholi people is embedded in Acholi cultural religious methodologies which is specifically their belief in Ancestral spirits. To Acholi, the findings seems more convincing because those who accepted to correct what had gone

wrong believe that their children became better. However, this is not to disqualify the medical science efforts and findings on nodding disease. Science has done a lot in the fight against nodding disease by treating the patients with epileptic drug to minimize seizure and village health teams are also active in the community where nodding disease is high by giving necessary health support within their means like health talk, therefore their efforts is not ignored but recognized.

To crown it all, Cultural and Religious construction of disease is a negotiated process in dialogue within a specific religion and cultural society. The cultural and religious experience and explanations attached to physical symptoms of disease indicates a significant relationship between culture, religion and health. Whereas biomedicine postulates a universal understanding of disease, findings from Acholi demonstrate cultural and religious specificity of illness experience, differing from one society and religion to another. Understanding the cultural and religious beliefs of society is a springboard for designing a holistic therapeutic approach for diagnosis and treatment of disease. However, the fact that some cultural and religious beliefs and myths about disease, and in the specific case of nodding disease have scientifically been proved to be untrue, calls for a plausible scientific explanation, in the absence of which, it becomes quite difficult for cultural societies to review their constructed beliefs about their health.

8.3. Recommendations

The study therefore recommends expanded support interventions for both parents/caregivers, including counseling, improvement in household income and nutrition support and improved clinical care and all symptomatic control measures available. Response to nodding disease has been poor compared to other earlier problems that was in Acholi land, nodding disease has been handled with a lot of laxity as if people are now tired of problems in the same area all the time.

The researcher further urge the cultural institution to carry out cleansing of the land. The various cultural leaders and institution in Acholi land led by the paramount chief and his executive should come together and cleanse the land to end the nodding disease (healing the sick) as it was done in Palabek in Acholi land as a whole not living it to the leaders in the affected areas only.

Further to that, Religious leaders and institution are to continue with prayer and both physical and psychological support. The various denominations should come together in the struggle led by ARLPI but not left to only one religion or to those in affected areas. Religious institution under the umbrella ARLPI were known for active intervention when need arise but for the case of nodding disease, they didn't show up, it was some churches around Laceykocot who organized one day prayer but not under the umbrella of ARLPI. Let ARLPI continue providing psychological, spiritual and economic nourishment to the people of Acholi. Conclusively, religion, politics and modernization should give cultural institution chance to carry out cleansing rituals ("moyo cere") to eliminate the cause and provide everlasting solution/cure of ND in Acholi sub region.

Government should encourage the involvement of NGOs to help in the funding and implementation of some of the government programs aimed at mitigating the effect of nodding disease on the poor community in northern Uganda. When the government is at the forefront in the fight against nodding disease, many well-wishers would come in to help and reduce the plights of these children. There is also need for politicians using the plight of the people for their selfish gain lobbying for support from foreign countries for their benefits should ensure the assistance reach the rightful beneficiary. Matters of health shouldn't be taken advantage of at the expense of the dying victims. Nodding disease affected household needs to be supported economically to empower them to provide food and other basic needs to the patients. Parents/caretakers of nodding disease patients have limited time to look for means of survival because of being at home taking

care of the patients to avoid them being wasted and hurt therefore they need support external support.

Girls suffering from nodding disease needs support of sanitary towels. Most of the female patients the researcher interacted with don't know about sanitary towel and knickers because their families can't afford buying for them since the family also struggle to provide what to eat. This made many men to take advantage of them. Those men who rape, impregnate and abandon these girls with nodding disease should be arrested and made responsible for their act they are leading to increase of fatherless children among the ND patients. There are also some men who abandoned their families with ND. There is need for counselling and united them back to their families to take care of the children jointly. Rehabilitation centers to be resumed with more recreation facilities to provide psychosocial support to ND patients.

8.4. Suggested areas for further studies.

The study was conducted on cultural and religious perception, a similar research can be conducted on other aspects like psychosocial and economic.

Another research can be conducted on why the spirits targets only children but not both children and adult.

Why nodding disease affected only Acholi land yet other parts of the country also had wars which eventually had bloodshed.

More research to be conducted to get to the actual cause of nodding disease not guess work or assumption as was the case with some findings. This will help to get treatment that cure the patients' not just controlling or stabilizing them. Lastly, more research is to be conducted in line of culture and religion since a lot of scientific research was conducted but no positive results.

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APPENDIX A: OBSERVATION CHECKLIST

Attitudes of caregivers, parents, society and family members towards nodding disease patients

The environment the nodding disease patients was placed in.

General treatment of the nodding disease patient by their family/care giver and society.

Names used for calling the nodding disease patients.

Observation of the rehabilitation/treatment centers

Healing process or improvement of the patient

Living condition of the patient and the family

Relationship between the patients and the family members

General effect of the disease and treatment on the nodding disease patient

APPENDIX B: INTERVIEW GUIDE

INTERVIEW GUIDE FOR CARE GIVERS/FAMILY MEMBERS

1. Do you have any family member with a unique sickness?
2. If yes, how do you call the sickness and why that name/
3. Have you ever heard of nodding disease?
4. Do you have any family member with nodding disease?
5. How do they describe it?
6. How does the disease manifest itself?
7. What could be the cause of the disease?
8. Was the patient on treatment, if yes what kind of treatment and from where?
9. What was the time and season of attack, what do they do at the time of attack?
10. What are the major challenges that you face as a family or caregiver of patients with
Nodding disease basin

INTERVIEW GUIDE FOR PATIENTS WITH NODDING DISEASE

1. How old are you?
2. Are you at school? If yes which class, if no why?
3. What do you think bring this kind of disease, was it connected to spirits or culture?
4. Why do you think the disease has attacked you not any other person?
5. Does your family treat you equally with other children in the family without nodding disease?
6. When you are attacked by the disease, what happened?
7. What kind of treatment have you received for the disease?
8. Have you ever been in rehabilitation center? If yes, what are the benefits and challenges you faced from the center?
9. Has the disease affected your learning competencies in any way? If yes explain how?
10. How has nodding disease affected your social life?

INTERVIEW GUIDE TO ELDERS, TRADITIONAL CULTURAL AND RELIGIOUS LEADERS

1. What was your cultural/religious perception on nodding disease in Acholi land, and why Acholi land not any other place?
2. On cultural or religious perspective, what do you consider as the causes of nodding disease?
3. Why the disease call nodding disease, how does it manifest itself?
4. Did such disease existed before, if not why do you think it's coming up at this time not before and when was it discovered?
5. Comment on the different treatments offered to nodding disease patients
6. Why does the disease targets only children 5-15 years?
7. As cultural/religious leaders, what effort have you made in the discovery of the cause(s) of nodding disease?
8. What was your intervention on nodding disease, have you in any way tried other alternative other than medical effort in the diagnosis, treatment and rehabilitation of patients and families affected by nodding disease, if yes explain?
9. As a traditional cultural/religious leader what's your general comment on nodding disease in Acholi sub region?
10. What are the effect of the cultural and religious perception of nodding disease on the patient, family and society?

INTERVIEW GUIDE FOR TEACHERS AND HEALTH WORKERS

1. Do you have children with nodding disease who come for services at your facilities?
2. How does the disease manifest itself that make you differentiate it from other disease?
3. What was your attitudes towards nodding disease patients that you handle in the school/health center?
4. What kind of treatment provided to nodding disease patients, do they complete the treatment?
5. Do the people consider the treatment at the Health center beneficial to them, if not why?
6. Do the patients show any improvement after treatment?
7. Do the patients complete the treatment at the health center, if not, was there any alternative treatment they receive?
8. How was nodding disease diagnosed?
9. Does the disease have anything to do with culture, spirits, behavior or ancestors?
10. In your own view what could be the cause of nodding disease?
11. Who are the most affected and why?
12. Was there any rehabilitation services provided to the patients of nodding disease?

APPENDIX C:

CHECKLIST OF RECORDS AT HEALTH CENTRE

1. Records of reported cases of nodding disease at the health center.
2. Records of nodding disease patients on treatment.
3. Register book of patients with nodding disease who are still receiving treatment at the health facility.
4. Records of nodding disease patients with improvement.