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Cause and Illness Experience of “Nodding Syndrome” in Uganda:

Local Perceptions and Implications for Interventions

verfasst von / submitted by

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DEDICATION

To my son Jake-Abraham Ssali Mukooza,

born in Vienna, Austria on the 24th of January 2017, with whom I surmounted innumerable challenges during the writing of this thesis.

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LIST OF ABBREVIATIONS

CDC	Centres for Disease Control
DMO	District Medical Officer
FGD	Focus Group Discussion
GMH	Global Mental Health
HC	Health Centre
H4H	Hope for Humans
IDP	Internally Displaced People
LG	Local Government
LMIC	Low and Medium Income Countries
LRA	Lord's Resistance Army
MOH	Ministry of Health
NCD	Non-communicable Disease
NGO	Non-Government Organisation
NRM	National Resistance Movement
NS	Nodding Syndrome
UBOS	Uganda Bureau of Statistics
UPDF	Uganda People's Defence Forces
VHT	Village Health Team
VSO	Voluntary Services Overseas
WFP	World Food Programme

ABSTRACT

This thesis deals with the local perceptions about the cause and experience of "nodding syndrome" (NS) by affected communities in northern Uganda. NS is an illness that is until now not well understood. Victims are children aged between five and 15 years with recurrent head nods often followed by seizures as the major symptoms. Progression of the illness leads to death. NS has been confirmed in the sub-Saharan African regions of northern Uganda, southern Tanzania, and South Sudan.

The results of this study are based on multi-site ethnography carried out for eleven months between 2014 and 2017. The sample primarily comprised NS victims but also included were their caretakers, village health teams, public healthcare givers, and community elders. Data collection was through informal conversations, in-depth interviews, participant observation, focus group discussions, and key informant interviews. Analysis was inductive and followed the principles of grounded theory. Interpretation of the findings was within the syndemics conceptual framework and the social suffering theory.

My study findings show that the explanatory models local affected communities have about the cause of NS are embedded in time (the civil conflict period) and space (internally displaced people's camps) characterised by extreme levels of hunger and very poor sanitation. They also highlight the health consequences of war such as the breakdown of public health and transport infrastructure as well as the impact severe poverty has on the health of an already vulnerable population. Beliefs like witchcraft and spirits also feature in what people think about the cause and illness experience of NS and about the healthcare of victims. Without watering down the respondents' narratives and explanatory models, however, it is also evident that the media and past research activities have an influence on how NS is perceived. At a meta level, NS in northern Uganda is shrouded in structural factors that are political, biological, cultural, and socioeconomic in nature. These include, among others, a history of conflict and marginalisation, poverty and neglect, cultural beliefs and practices to do with appeasement of the dead plus the existence of widespread epilepsy and black flies breeding in fast flowing rivers.

ZUSAMMENFASSUNG (DEUTSCH)

Die vorliegende Arbeit untersucht, wie lokal betroffene Gemeinschaften in Norduganda *Nodding Syndrome* (NS) sowie dessen Ursachen und Krankheitserfahrungen wahrnehmen. *Nodding Syndrome* ist eine Krankheit, die wenig erforscht und deren Ursachen bis jetzt nicht vollständig geklärt sind. Betroffen sind meist Kinder zwischen fünf und 15 Jahren. Charakteristisch sind Symptome wie das wiederholte Kopfnicken gefolgt von Krampfanfällen. Die Krankheitsprogression führt zum Tode. Das Vorkommen von NS wurde in Subsahara-Afrika in Norduganda, Südtansania und Südsudan bestätigt.

Die Erkenntnisse der vorliegenden Dissertation basieren auf einer elf-monatigen ethnographischen Feldforschung die zwischen 2014 und 2017 in Uganda durchgeführt wurde. Es wurden Interviews und Fokusgruppendiskussionen durchgeführt, unter anderem mit NS-Erkrankten, deren BetreuerInnen zuhause und Gesundheitspersonal. Daten wurden zudem durch informelle Gespräche und teilnehmende Beobachtung gesammelt. Die Datenanalyse wurde induktiv nach den Prinzipien der Grounded Theory durchgeführt. Die Interpretation der Ergebnisse fand im Rahmen des *Syndemics Conceptual Frameworks* und der *Social Suffering Theory* statt.

Die Ergebnisse meiner Studie zeigen, dass die Erklärungsmodelle der lokalen Gemeinschaften über die Ursache von *Nodding Syndrome* in eine bestimmte Zeit (die Periode des Bürgerkriegs) und einen spezifischen Raum (Lager für Binnenflüchtlinge) eingebettet sind, und durch extremen Hunger und unzureichende sanitäre Versorgung charakterisiert sind. Die Ergebnisse zeigen auch die gesundheitlichen Konsequenzen des Krieges auf, beispielsweise den Zusammenbruch öffentlicher Gesundheitseinrichtungen und der Transportinfrastruktur, wie auch die Auswirkungen schwerster Armut auf die Gesundheit einer bereits vulnerablen Bevölkerung. Glaubensvorstellungen wie Hexerei und Geister haben ebenfalls Anteil daran, was Menschen über die Ursachen und Krankheitserfahrung von NS denken. Es zeigt sich auch, dass die Medien und vergangenen Forschungsaktivitäten die Wahrnehmung von NS beeinflussen. Auf der Metaebene sind strukturelle Faktoren mit politischen, biologischen, kulturellen und sozioökonomischen Aspekten verwoben. Diese beinhalten unter anderem eine Geschichte von Konflikt und Marginalisierung, Armut und Vernachlässigung, kulturelle Vorstellungen und Praktiken und der weitverbreiteten Existenz von Epilepsie und dem Vektor von Onchozerkose, der Kriebelmücke.

PROLOGUE

On the 31st of August 2014, my advisor Ruth Kutalek and I – in the company of a Gulu University student guide set off on what was my maiden trip to Akoyo. Akoyo is a village in Odek sub-county in the present day Omoro district which is 76 kilometres from Gulu town along the Gulu-Moroto road. While we rode in the four-wheel-drive (4WD), air-conditioned Land Cruiser car model offered to us by the University of Gulu, I could not help but wonder what life in this part of the country was like. After all I had never set foot in northern Uganda before this let alone travel to the home area of the still elusive Lord's Resistance Army (LRA) rebel leader Joseph Kony under whose rebellion local communities suffered maiming and several other untold atrocities in a two decade civil war.

The Gulu-Moroto road was a dusty murram road which, according to drivers who plied this route regularly, was impassable during rainy seasons occurring around April/May and late September/early November. During the wet season, the drivers either used a much longer route (which unfortunately was not cost effective since their clients could often not afford to pay more to cover fuel costs for the extra distance) or they sat back and did not ferry passengers at all until the road was in a much better condition for them to slowly manoeuvre. In addition, it came to my attention that community members moved much less during the wet season because for them this period was to engage in full-time garden work which was their primary source of livelihood. This implied that I had to carefully plan my travels during the fieldwork phases or else remain stuck on one end due to public transport problems.

It was evident right from the turn we made from Gulu town along this road that the people of this area were very poor going by the sorry state of the grass thatched houses in view. The few structures along the road were also an indication that they were sparsely populated, most likely as a result of the civil war that is documented to have claimed many lives. Springing up in my mind also was that they probably depended on subsistence cultivation for food because the gardens I could see were too small in size to be for commercial purposes and yet vast expanses of land lay bare. It was only in the few trading centres along the way that a good number of men were seen most of whom were consuming local brew or playing cards. This, I later realised, was a common practice (regardless of the time of day) in all the locations I went to during fieldwork which made me wonder why.

During the ride, we were told stories and shown features deemed key to the area. For instance it came to my knowledge that the deputy speaker of the national parliament was born in Odek sub-county which incidentally is where the first and currently highest number of "nodding syndrome" (NS) cases in Gulu district was reported and are located respectively. Learning that such a high profile figure was a kinsman living amongst NS affected communities was a detail that raised my curiosity regarding the impact this had on those afflicted and affected by the illness. As we approached Awere[1] trading centre, a mountain on the right hand side was pointed out to us as the place from where Kony obtained his so-called spiritual power to successfully wage war against the National Resistance Movement (NRM) under the leadership of Yoweri Kaguta Museveni now in power for the last 32 years. At the same time we were shown the primary school he (Kony) attended and the small church in which he sang as a lead choir member.

Inasmuch as I did not see the relevance of this information to my study interest at the time, in retrospect I found that it helped, albeit subconsciously, prepare me for the place I was headed to and ignited a curiosity about a number of issues that later turned out useful during my stay in the field. For example, if there could indeed be a connection between the civil war and the emergence of the NS illness especially since this sub-county, as mentioned earlier, had not only reported the first but also had the highest number of NS cases in the district.

We finally arrived at the Hope for Humans (H4H) NS victims care centre situated a few kilometres after we turned off the Gulu-Moroto road at Awere towards Lira district. H4H was a privately run facility offering healthcare services to children directly affected by NS. This Non-Government Organisation (NGO) was a neat place with well-laid permanent structures built with dark orange bricks and red iron sheets. It was well painted with provision for solar energy for members of staff in their living quarters and solar lanterns for the afflicted children's sleeping halls. The compound was well-kempt and so was the surrounding area which created an impression that there was hope for the affected children and communities. Little did I know that the "inner" community of NS households was an entirely different story altogether. Suffering is what defined them. Immense poverty and hopelessness was their story.

We visited a number of NS affected households during this pilot study and in all these homes almost all affected children were visibly heavily scarred while some additionally had very

[1] Awere is a small trading centre along Gulu-Moroto road and is the point at which one goes off this road to Akoyo village and farther on to Lira district.

large open wounds. Most of them appeared very thin and emaciated – a state that was honestly scary to the eye (if I may use this expression). It may take me a very long time to forget how frightened I felt when in one of the homes a 15 year old male victim who unfortunately looked 8 and could not walk or sit without support, spread his arms out to touch me after I sat close to him during our visit. In my mind I wondered how I was going to live with people this ill but more importantly how my humanly natural feelings and reactions would impact my research work.

To cut the long story short, in all similar circumstances thereafter something stood out partly to whose credit you are reading this prologue. A young man in the small trading centre in one of the locations where I briefly stayed during the fieldwork phase came and sat under the Olam tree (*te Olam* in Luo) early every morning with his radio loudly playing a song by a local artist – Labert Dickson entitled "*I will not give up*". Anyone who has walked this path will agree with me that there is a point (or several points for that matter) when one contemplates giving up and incidentally I was often at this point because of the challenges of ethnographic fieldwork hundreds of miles – in a very rural area for months, studying a poorly understood illness that claimed children's lives almost daily, away from my young children!

Listening to this song play practically every morning enabled me learn the lyrics by heart and thank God, these lyrics perpetually played out in my head that they were the force that kept me going with fieldwork (and later on thesis writing) day in day out.

1. INTRODUCTION

This thesis is based on research carried out between 2014 and 2017 on "nodding syndrome" (NS) in northern Uganda. NS is an illness that is until now not well understood (Winkler et al. 2018). Victims are children aged between five and 15 years with recurrent head nods often followed by seizures as the major symptoms (Spencer, Schmutzhard, and Winkler 2017; see also Dowell et al. 2013). The head nods are triggered mainly by cold weather conditions and the sight or smell of food by the victims[2] (Spencer et al. 2016). Progression of the illness leads to death but death also occurs as a result of drowning or severe burns sustained during the course of a seizure attack. NS has been found to exist in the sub-Saharan African regions of northern Uganda, southern Tanzania and South Sudan.

1.1. Study justification

1.1.1. Local perspective

Is it really possible for us to understand the NS epidemic and respond to it effectively simply by studying specimen and tissue samples in well-equipped science laboratories both within and out of affected countries? Would we not, like Singer and Baer (2012) argue, instead reach out to affected populations seeking to know their perspective about the circumstances surrounding the illness in an attempt to establish contextual factors that may be attributed to the emergence and experience of their health problem? Nichter (2008:2) raises a crucial point when he says that "each set of perceptions and representations frames thinking about health-related problems and guides the way in which people develop and access health interventions, allocate resources, and evaluate outcomes". For example, the perceptions people hold about disease and therapy have an influence on patterns of disease in the same way that the things they hold in high esteem like employment, wealth, marriage, and children determine their susceptibility to disease (Trostle 2005). Literature shows that there are discussions about the biomedical approach and empirical research characteristic of the developed world and an anthropological approach whose emphasis is on the sociocultural factors surrounding mental health as well as the benefits of the local perspective to addressing public health (Kirmayer and Pedersen 2014).

[2] In this thesis, 'victim' is used to refer to a child and/or young adult medically diagnosed as bearing NS.

Based on a small scale[3] study on the local perceptions of people in northern Uganda towards NS, Kitara and Amone (2012) concluded that communities in northern Uganda had varied beliefs and perceptions regarding what led to the emergence of NS. They went on to say that this posed the greatest challenge in the management of the condition thereby suggesting that a more comprehensive study be undertaken to explore the people's knowledge, attitudes, beliefs and practices towards the illness. This, and Mitchell et al.'s (2013) recommendation that lager studies from a cultural perspective be carried out to better understand NS and its impact on the affected population as well as necessary response measures to mitigate the harm it has caused were the basis for this study. Understanding the cultural beliefs and practices affected populations attach to an illness is also emphasised by Cohn and Kutalek (2016; see also Kutalek 2012) who argue that knowledge of cultural aspects is crucial in the management of life threatening disease outbreaks along with the consequences they may generate. In 2012 NS had only been officially reported in northern Uganda a few years prior (2009) and very little was known about it (Kitara and Amone 2012; Korevaar and Visser 2013; Mitchell et al. 2013; Winkler et al. 2014). Investigations into the syndrome began in 2009 and were mainly from a biomedical perspective seeking to establish the aetiology of the illness from more or less a purely biomedical point of view.

However, epidemiologists are mainly interested in the study of one or a few specific ailments within a given timeframe and so a number of aspects go unheeded, especially those not biomedical in nature (Trostle 2005). They focus on large populations and use quantitative methods of study to identify disease risk factors with the aim of helping people minimise their disease rate (Zuckerman et al. 2014; see also Trostle 2005). This raises questions such as – what if whatever is left out is what completes the puzzle? Indeed, research that is disease specific "misses important lessons that may be learned from a critical assessment of risk factors that are perceived or demonstrated to link several illnesses together, as well as from an examination of structural and ecosocial factors that contribute to the distribution of health problems and healthcare resources" (Nichter 2008:3). This link can only be obtained through a holistic approach and so I was propelled into exploring the NS affected communities' perceptions with the intention of making a contribution towards the process of filling up grey knowledge areas through an anthropological approach. Singer and Clair (2003:424) concur

[3] The study was not ethnographic but guided by a few interviews with a small sample of professional healthcare providers trained to identify and manage the syndrome in its initial stage. According to Nichter (2008), international health studies from a social science perspective around the year 2000, were mainly small scale surveys that utilised rapid assessment procedures and engaged in ethnographic studies that were not only focused but also brief.

through their submission that “an equally important contribution to our understanding of the classification of sickness comes from historic studies of the ways sickness categories and the nosological systems that encompass them are transformed over time in response to changing social conditions and events”. This transformation impacts the people’s thinking about health and illness and subsequently also influences the way they respond (Singer and Clair 2003).

1.1.2. Contextual factors

To begin with, the need for an anthropological approach to the study of health related social problems is based on the ‘shortcomings’ of the epidemiological approach which views diseases not as a consequence of factors on a broader spectrum but as resulting from within the close environment (Harper et al. 2013; Zuckerman et al. 2014). For example, civil conflict and its consequences, inadequate and inequitable access to social services, and poverty among other things, causes people to relocate which renders them vulnerable to new diseases and places them in a position to transmit diseases as well (Trostle 2005).

Secondly, I agree with Van Bemmel (2016:184) when she says that “we cannot understand the experience of suffering and health without paying attention to the context in which negotiation and meaning-making takes place”. Niehof (2008) also raises vulnerability as a contextual aspect that hinders a population faced with adverse conditions and ill-health from getting back on their feet which necessitates that intervention plans take context into account. NS affects children directly and children are documented as a good way of assessing whether the environment in which they live is physically and socially good or bad (Pike et al. 2010). Conrad and Barker (2016), point out that there is need to acknowledge the reality that some illnesses are embedded with cultural meaning which is also a contextual issue. They argue that “some illnesses are particularly embedded with cultural meaning – which is not directly derived from the nature of the condition – that shapes how society responds to those afflicted and influences the experience of that illness” (Conrad and Barker 2010:S67). Context, posits Kutalek (2012), also impacts the way health is perceived by especially vulnerable populations such as those experiencing civil conflict.

Thirdly, the world is a global village. Globalisation therefore plays into the contextual setting because of the involvement of forces of a global nature in matters of the people’s everyday life the world over especially in times of conflict and adversity. Global processes include movement of people, capital, information, goods et cetera which altogether have an impact on the population they are visited upon (Appadurai 2008).

In summary, contextual factors have central policy implications which is why the local perceptions of the NS affected population in northern Uganda were considered important in this ethnographic study. This was anchored in the hope that at the end of the day, the findings of this study and subsequent recommendations put across would play a significant role in better understanding this still poorly understood condition and add to the knowledge pool on how to better deal with emerging communicable and non-communicable illnesses especially in resource constrained communities in countries of the global South. Additionally, these findings may help reinforce already existent approaches that have been developed and revolve around similar principles which would further guide decision makers in different capacities into generating policies and programmes that are supportive of affected populations. The contextual perspective therefore played an important role throughout the fieldwork phase and entire study process of this project.

1.1.3. Under-researched new disease

Inasmuch as significant strides have been made by researchers to illuminate this illness, clear and concrete information about what it really is, its origin and how it can be treated is not forthcoming, first and foremost to affected communities. Furthermore, its aetiology and progression are still unknown implying that there is room for more public health knowledge generation about it since the syndrome "remains puzzling for investigators" (Mitchell et al. 2013:23). Korevaar and Visser (2013:149), agree that "although NS causes high morbidity and mortality in endemic areas and although it is beginning to receive more and more attention in scientific literature, the disorder is still poorly understood" and that "information on the syndrome is scarce and still little is known about it". Against this background, findings of this study were intended to complement research findings from other studies on NS and add to the body of knowledge on poorly understood illnesses from an anthropological perspective.

1.1.4. Positive impact on affected families

One of the roles of medical anthropologists is to assist in changing the world around them through their participation in applied research, policy advancement and advocacy (Singer and Erickson 2014). As a global health challenge, health science studies ought "to be more realistic, relevant and accountable to those in need" (Biehl and Petryna 2013:11). In this sense, the onus lies with anthropologists to help in overcoming "the inadequate translation of public health knowledge into effective action, largely because of social and cultural

boundaries" (Hahn and Inhorn 2009:5). One of the objectives of this study project was to explore the challenges that affected communities faced in light of NS. By informing policy and practice on how best to design and implement effective interventions (Janzen and Janzen 2000), the lives of affected communities would consequently be improved.

I have pointed out a number of issues which undergirded and justified this study. As a summary, however, these issues include the fact that NS is generally under-researched and therefore remains poorly understood. For a holistic approach, the anthropological perspective this study adopted was meant to complement biomedical studies which have dominated past and ongoing research into the illness. The study was also justified on the basis of the continued, progressive prevalence of NS within a region that has known decades of war, contained thousands of displaced persons from within Uganda and several from neighbouring countries like South Sudan amidst a well-documented history of marginalisation and poor socioeconomic conditions.

1.2. Study focus

The heart of the study upon which this thesis is based was the local understanding of NS by affected communities in northern Uganda. The study was an exploration of local perceptions (hereafter interchangeably used with local knowledge[4]) surrounding the origin, experience of the illness and care for the victims of NS following an ethnographic study design. This project was hinged on Hahn and Inhorn's (2009) argument that as anthropologists we are equipped and in position to enlighten key decision makers as well as illuminate grey or dark areas in public health from the perspective of the populations in which these problems occur. It would also be possible to use this information in the design of effective and efficient interventions with the aim of improving the quality of life which would translate into higher life expectancy. This is underpinned by the fact that "childhood is the foundational phase of human development and [children are] the most important target group for intervention" (Desai 2010:vii).

[4] In this thesis, local knowledge or local perceptions refer to the attitudes, beliefs and conceptions surrounding NS by the affected population in northern Uganda.

1.3. Theoretical framework in brief

During the data collection phase, the more data I collected, the more I wondered what it meant and pointed to. I began analysing the data at the same time I collected it and realised there were emerging themes that pointed to historical factors and large scale factors some of which were of a global nature. It was almost very clear in the early months of fieldwork that a number of factors were at play in the NS discourse, whether or not they interacted synergistically. In my search for a theory to hold the study findings together (Tsai 2018), I found the syndemics and biosocial perspectives most suitable in as far as the emergence and distribution of the illness is concerned.

To some extent, earlier studies show how a history of conflict affects the understanding of illness and the relationship between disease and culture. In fact, culture has sometimes been viewed as a "risk factor" for infection in light of assumptions about African "otherness" (Jones 2011:1). According to Singer and Clair (2003), medical anthropology has led to a more holistic view of ill-health by exploring the social and cultural context in which health problems occur.

The use of cultural psychiatry in view of individual day to day experiences for populations living and trying to cope with adverse circumstances can go a long way (Kirmayer 2006). Indeed, "to develop effective interventions, epidemiology must learn the importance of culture" (Trostle 2005:xii). The meanings local affected communities attach to the perceptions about what is happening to them and their children are a pivotal point in the management of the illness in their midst. In this sense, Singer and Clair (2003:424) argue that "from an applied standpoint, a nosology's value lies in its capacity to provide guidance for mobilizing effective responses in prevention and treatment". I use the syndemics conceptual framework and biosocial perspective to health (Singer and Clair 2003; Singer et al. 2011; Singer, Bulled, and Ostrach 2013; Singer et al. 2017) to argue that the perceptions that local communities have about the origin of NS and how the illness is experienced are hinged fundamentally on contextual factors. My findings show that NS is an embodiment and/or reflection of the affected communities' reality (circumstances under which they lived) over time and space. Secondly, I use the social suffering theory (Wilkinson and Kleinman 2016; see also Kleinman, Das, and Lock 1997) to undergird my argument that the pain and suffering affected communities endure under these ill-health circumstances is collective and orchestrated by

structural violence (Farmer et al. 2006) and historical factors/processes of political, biological, cultural and socioeconomic nature.

1.4. Research setting

This study was carried out in Gulu (now Omoro[5]) and Kitgum districts located in the northern region of Uganda. Uganda as a country is demographically divided into regions including: central, eastern, western, southern and northern.

Figure 1: Map of Uganda highlighting neighbouring countries and study area

Source: Google images. Accessed on 13.02.2018

Uganda's most recent population census was carried out in 2014. According to the National Population and Housing Census (NPHC 2014) report, Uganda's total population was approximately 34.6 million people. However, according to the Uganda National Bureau of Statistics (UBOS 2017), this figure was expected to rise to 43.6 million by 2017. Given the country's annual population growth rate of 3 percent, the World Watch Institute (WWI 2018) further projects that Uganda's population will have 130 million people in 2050.

[5] Formerly a county in Gulu district, Omoro district was created on the 3rd of September 2015 during the course of this study's field work activities. Nonetheless, the new district formally began operating on the 1st of July 2016. In this thesis, I use both Gulu and Omoro since most of my fieldwork activities were carried out before the changes were made.

While Uganda had 116 districts according to UBOS (2017), it is not unusual for new districts to keep being created and passed by parliament as time goes by. Several functions, as a result of the introduction of the decentralisation system of governance, now lie under the jurisdiction of the local governments (LGs) except policy making, standards setting, monitoring and evaluation plus national security issues which remain the prerogative of the central government. The northern region has 32 districts with a total population of close to eight million people (UBOS 2017). Cases of a mysterious condition (now known as NS) were officially first reported in only one of the 32 districts in 2009 but today, the illness is confirmed in eight districts (Landis, Palmer, and Spencer 2014; URN 2018) whose combined population is 1, 650,700 (UBOS 2017).

Uganda is documented as having one of the fastest growing economies (Harvard Kennedy School 2017) but millions of people still live in absolute poverty (on less than a US dollar a day). The northern region, at the time of the war and shortly after had poverty levels that were double the poverty rate of the rest of the country (Smith 2012).

1.4.1. Gulu and Kitgum districts

Gulu which means "pot" in the Luo language occupies 3,452 square kilometres and is home to Gulu University which implements the project[6] under which I obtained funding for this study programme. I chose Akoyo, a village in Palaro parish, Odek sub-county Omoro (formerly part of Gulu district) as my primary study site because of the high incidence of victims of NS in the area which also explains why the private care centre for affected children was situated in this area. Secondly, while many studies had been carried out and documented about the situation in Kitgum district, not much literature was available about the condition in this location and yet NS cases were reportedly existent years after having been confirmed in Kitgum district. Furthermore, Odek sub-county is the birth place of war lord Joseph Kony which made me curious about how the civil conflict impacted the people of this particular area and what the local affected community thought about this war in light of NS. This choice

[6] The Master Programme in Medical Anthropology and International Health (MA-MEDANIH) is a project implemented by Gulu University in partnership with the Medical University of Vienna with funding from the Austrian Development Agency (ADC). Its goal is to contribute to an improved holistic healthcare approach in health and the general well-being of populations in sub-Saharan Africa.

of location was, in addition, enabled by the willingness of one of the affected households to host me during the fieldwork phase[7].

Like Gulu, Kitgum is part of the Acholi sub-region. It is 3,960 square kilometres in size and about 108 kilometres by road to the north-east of Gulu. According to the NS cluster study carried out by Kitara and Amone in 2012, the highest burden of NS was mainly felt in Kitgum, Pader and Lamwo districts which is also attested to by findings documented by Otim and Odong (2013) and Colebunders et al. (2016).

Tumangur village in Lamit parish, Labongo-Akwang sub-county in Kitgum district was the second study site because of the unique position the location occupies in the history of the illness. This history consists of the fact that it is in this village that the very first cases of NS in Uganda were seen and officially reported which subsequently attracted a lot of national and international support. Establishing a relationship between the conditions surrounding the illness in both locations was the basis for the decision to make Tumangur village part of this project's study area.

1.4.2. Civil conflict in northern Uganda

To a large extent, the need for a study such as this was justified by the political turmoil that dominated Uganda's post-independence history in which various rebel groups mainly consisting of "displaced Acholi combatants" (Meier 2013:26) rose up to fight the NRM shortly after it ascended into power in 1986. As a region in a post-war era, the people of northern Uganda have had to deal with the effects of civil strife including but not limited to trauma, system/ social infrastructure break down, and ill-health characterised specifically by the still prevalent NS. This illness highlights issues of disharmony and social system breakdown consistent with a long standing history of conflict, very high levels of poverty and frustrations of neglect (Van Bemmel, Derluyn, and Stroeken 2014). Despite the fact that

[7] This home was close to the NS H4H care centre and one of the two NS affected children in this home was enrolled in the care centre for full time care. Her enrolment in this care centre also rendered it easier for me to take part in the activities of this facility where other such children were cared for (some round the clock) as a participant observer. A lot of controversy, however, surrounded the NGO that led community members into thinking the local proprietors were using the plight of their ill children to amass wealth. The proprietors in turn were aware of these hostilities and wanted so little (if any) to do with 'outsiders' such as myself who could potentially further damage their image through what we reported to have found. For this reason it was originally difficult to obtain access but because some of my study participants were in their care, I was, albeit with laxity, let in.

disease is a biological phenomenon, "'neglect' is inherently social" (Parker, Polman, and Allen 2016:S1).

For over twenty years northern Uganda suffered a violent civil war between the LRA and the Government of Uganda (GOU) which resulted in the relocation of a vast majority of the Acholi population to internally displaced people's (IDP) camps (Landis, Palmer, and Spencer 2014). This war took place in Acholi land (Kitgum, Pader and Gulu districts) before spreading to Lango (Lira and Apac districts) and residually to parts of Teso including Soroti, Kumi, and Katakwi districts (Angucia 2010; Muyinda and Whyte 2011). It began in the year 1986 when Museveni who hails from the southern region of the country ceased power after ousting the then military junta – the Uganda National Liberation Army (UNLA) led by Tito Okello Lutwa from the northern region. After its defeat, the UNLA retreated to Gulu, Kitgum, and Pader. The Uganda National People's defence forces (UPDF) is also documented to have "committed revenge in form of massacres and killings against the people of the north resulting into retaliation in form of rebellion due to pent-up resentment by the LRA" (Brown et al. 2012:1).

In what is commonly believed to be a rebellion against president Museveni's oppression of northern Uganda, the LRA performed untold atrocities on the Acholi people – who in essence were their kin since the army was led by an Acholi and comprised Acholi fighters. This was the case because Kony had failed to garner the support of other Acholi and so accused them for aiding Museveni and his government in masterminding his downfall. In 1996/97, the government of Uganda, as a matter of necessity, came up with the idea of protected villages for the security of civilians before later on moving the war affected population from their villages into camps run and manned by the government itself after it failed to contain the rebel movement (Dolan 2005; Branch 2007; Baines and Paddon 2012). These camps were far from safe even though the government put them in place purportedly for the people's own safety given the kind of squalid conditions under which the people lived. Shelter was in form of congested temporary grass thatched huts characterised by overcrowding. Access to clean water and sanitation facilities was more or impossible and it is under these conditions that children were born and raised (Invisible Children 2014). Reports indicate that close to two million people in the northern and eastern regions of Uganda were displaced (UNICEF 2001; UN 2004; UN OCHA 2005; UN OCHA 2005; UN OCHA 2005). Muyinda and Whyte (2011) report that almost 90% of the Gulu district population alone lived in IDP camp settlements between 1996 and 2004.

Lives were lost during this conflict, family disintegration was rife due to displacement, social and economic support mechanisms were disrupted, and people (especially children) suffered grave trauma. The traumatic experiences of the war, coupled with the lived experiences of grappling in the dark with NS do nothing short of eliciting fear, guilt, a sense of hopelessness and resignation for affected individuals and communities. Unfortunately, this trauma goes on to negatively affect them decades after the experience (Angucia 2010). During the civil war, it is the personal and communal lived experiences that were more disturbing. This is in comparison to major events like the forced displacement, operation 'Iron fist' and operation 'lightening thunder'[8] all aimed at seeing an end to civil strife and the restoration of peace in the region (Finnström 2008; Wilhelm-Solomon 2013).

War situations the world over generate painful experiences and give rise to a broken people with little or no form of security (Angucia 2010). According to the United Nations High Commission for Refugees (UNHCR 2008), there are few studies within the context of increased armed conflict. This is contrasted against an overwhelming increase in violence related displacement of populations the world over with a negative impact on the health experiences of affected communities. For instance "in the absence of or scarcity of food, women will forfeit their share for those who are pregnant and children. In worse scenarios, even the pregnant will let the children eat before they do, compromising the healthy development of their unborn children" (Pike et al. 2010:50). Socioeconomically, the Acholi heavily depended on international aid for their sustainability in the wake of the political upheaval which drove thousands into IDP camps (Dolan 2005). Humanitarianism, however, is not without controversies and is known to have its own "aspirations and contradictions" as noted by Fassin (2013:112). This kind of research therefore has overarching implications for not only sub-Saharan Africa but wherever conflict arises.

Previous studies show that war situations involving large scale displacement and the resultant living conditions have a link to Major Depressive Disorder – MDD (Mugisha et al. 2015). It is not surprising, therefore, that there (seemingly) is a relationship between NS and the extended history of conflict suffered by northern Uganda (Landis, Palmer, and Spencer 2014). One can

[8]Operations 'iron fist' and 'lightening thunder' are events that took place in 2002 and 2009 respectively and were sanctioned by Museveni in agreement with the Sudanese government. They were intended, in all manner of strength to end in the capture of Kony and subsequently the final cessation of the civil war. Operation 'lightening thunder' took place in 2009 after 'iron fist', had failed to bring Kony in despite being directly under the presidents command (Allen 2006). To date, the rebel leader is still at large although peace has returned to the region.

therefore not speak about NS in northern Uganda without talking about the LRA and the conditions surrounding this civil war. In essence, the two are intertwined. The specific role of the civil war in the emergence and spread of NS is not clear at this point (Westerhaus et al. 2007) but what is clear is that it did exacerbate the problem (Colebunders et al. 2014). In an ethnographic study Westerhaus et al. (2007) carried out to assess the impact of conflict on the spread of HIV/AIDS in northern Uganda, they concluded that while it is clear that the war had horrendous consequences on the Acholi population's health, what remains unclear is its specific impact on the transmission of the disease as well as prevalence patterns. For this reason, there is reasonable cause to believe that there exists an association between the syndrome and experiences surrounding it, with the period of civil unrest.

This line of thought is also underpinned by the fact that globally, NCDs such as mental illness and neurological disorders are recognised as a major public health burden amidst weak public health systems in post-conflict areas as noted by Roberts et al. (2012). During the two decade LRA/NRM civil war, public health infrastructure broke down and health services were almost inexistent. Going by the squalid living conditions of the people during their stay in the IDP camps, coupled with the poor nutritional and sanitary situation while there, it was of urgent necessity that some sort of mechanism be introduced to monitor and meet the their health needs at community level. Against this background therefore, GOU through the ministry of health (MOH) in 2001 introduced the concept of village health teams (VHTs) in the country's health strategic plan. These VHTs were to serve as an initial contact point within the community for members who had healthcare related needs. The VHTs offered very basic health information to community members, advised them on when and from where to seek healthcare services and acted as mediators between community members and higher authorities on health related matters.

1.4.3. Child vulnerability and the post conflict era

A child is a person whose age is below 19 years except if the law of a specific nation states otherwise (WHO 2018a). In Uganda, a child is one 18 years of age and below (Parliament of Uganda 2016). I adopted the Uganda definition of a child for this study. Study participants between 19 and 24 years of age are referred to as young adults. Child vulnerability is central to this study because of the war context in which NS is documented to have emerged and since it is children that are directly affected by the illness. At 98.8 %, almost all children in the northern region of Uganda are vulnerable (MoGLSD 2006).

The United Nations Development Program (UNDP) cites 35 countries as having entered the post conflict phase, 59% of which are classified as low income (UNDP 2007). Conflict brings along with it death, population displacement, disease, socioeconomic upheaval, social structure, and system disintegration – to mention but a few. It is even worse in countries of the global south where the pre-conflict era is often characterised by inadequate resources. With war, structures and systems that may have taken decades to build are lost which leads to stagnation of public health infrastructure long after the conflict has ceased.

As is the case in several conflict situations, women and children were severely affected by this war (Watts and Zimmerman 2002). Liebling-Kalifani (2013:175) writes of the immediate post conflict period in northern Uganda as being defined by a "breakdown of the health infrastructure in addition to posting the lowest health indices in the whole country". According to her, the region had the highest prevalence rate of HIV of 10.5% compared to the national average of 6.4%, the lowest contraceptive use rate at 12% where the national average was 23%. Mental illness and trauma was noted as affecting women in this post conflict era due to health complications that arose and rendered them infertile yet child bearing is held in high esteem in this region of the country (Isis-WICCE 2001). According to the 2017 global burden of disease (GBD) study, out of every 1000 live births in Uganda, 64.2 children below the age of five annually die. Life expectancy for females and males at birth has increased to 64.8 and 59.8 years respectively but despite this, mental health, obesity, conflict, and health issues related to substance abuse are impairing further progress (GBD 2017). The intricate relationship between poverty and ill-health is also inescapable which is why continued implementation of Uganda's health sector strategic plan under the wide sector approach is of paramount importance. The central tenet of this policy implementation strategy is to contribute to the national poverty eradication action plan as well as the sustainable development goals (SDGs); the brunt of which is felt by the people of northern Uganda due to historical, political and socioeconomic reasons.

In the Uganda Child Rights NGO Network - UCRNN (2009) audit report of social service delivery for children affected by armed conflict in northern and north-eastern Uganda, it is reported that on a general level, most government health facilities especially in the rural areas were destroyed during the conflict. Substantial resources for the rehabilitation of infrastructure and supply of functional equipment are therefore required. Access to health services by children was reported to be limited due to budgetary constraints for institutional capacity building and equipment. It was also a result of the people not knowing where to

access healthcare, poor road and transportation services and high poverty levels. Understanding and linkage of psychosocial predispositions with mental disorders by stakeholders was also found inadequate.

Health systems are "social and political institutions" (Kruk et al. 2010:89) in a sense that they are a community of healthcare givers to societies in need of their services and are run on the basis of government policies and often times funding (Kruk et al. 2010). These health systems comprise organisations, institutions and resources whose priority is "health actions where a health action refers to any effort, be it in personal care, public health or through inter-sectoral initiatives whose primary aim is to improve health" (WHO 2000:xi).

Betsi et al. (2006), among other publishers, document that the national health system is one of those institutions that suffer the most during conflict given infrastructural destruction, loss and disappearance to places of safety of health personnel, drug shortages et cetera. The poor access to social services that largely characterised the post conflict era also raised my interest in exploring how the NS affected population was dealing with the management of the syndrome and coping with the challenges that come along with caring for chronically[9] ill children in an environment of heightened poverty and scarcity.

Children's upbringing and treatment during childhood has been a central part of anthropological studies with a keen focus on the environment within which they live and the circumstances that render them easily susceptible to adverse conditions that cause them suffering and sometimes cost them their lives (Jamieson 1999). According to the Uganda orphans and vulnerable children's (OVC) policy, vulnerability is a "state of being or likely to be in a risky situation, where a person is likely to suffer significant physical, emotional or mental harm that may result in their human rights not being fulfilled" (MoGLSD 2006:21). Children in conflict areas or those recovering from long periods of war such as northern Uganda are among those who by the very nature of the environment in which they live, have been rendered vulnerable to among other things orphan hood and ill-health. To be vulnerable is to be in a situation where it is very likely that a negative outcome will arise (World Bank OVC 2018). Chambers (2009) submits that a vulnerable child is a deprived child who as an individual is exposed to difficult and stressful circumstances in form of poverty, abandonment and powerlessness all of which are out of his or her ability to cope with. This is also true for a

[9] NS is a chronic and debilitating illness because of the long duration of time it has affected its victims and the impact of their symptoms (Musisi et al. 2013).

vulnerable household and/or community. Lesser and Pope (2007) postulate that effort should be made to protect the biological individual from environmental demands he or she cannot meet. The people of northern Uganda have, for decades suffered armed conflict, social injustices and lived under extreme poverty. This situation has rendered the Acholi a vulnerable people whose children have in the process been exposed to NS among other undesirable things. Inasmuch as there may be attempts for children in war zones to exercise child agency with an aim of mitigating the adverse effects of the bad circumstances in their day to day lives, several aspects of their reality involve things beyond their control and which things they may be unable to cope with. For example conflict situations expose children to incidences of child abuse which is "any intentional non-accidental physical, emotional and psychological or sexual harm done to a child that endangers or impairs the child's physical, emotional and psychological or sexual health and development" (Desai 2010:337). Child abuse may be propagated by "older children, parents, relatives, caretakers, neighbours, teachers, employers, police or strangers; in family, neighbourhood, street, school, institutions, site of occupation or police custody; and because of adult-child power imbalance due to adultism and patriarchy, psychosocial problems or socioeconomic problems, and cycle of abuse" (Desai 2010:345). Since parents are the main caretakers of children, children are also easily rendered vulnerable to neglect when parents are incapacitated, unavailable or unwilling to carry out their parental role or are facing conflicts (Kadushin and Martin 1988; cf. Desai 2010). Desai (2010) further argues that as individuals, children with special needs, neuro-behavioural disorders, and with a disability or chronic illness are considered at risk and are more vulnerable to neglect. However, parental or situational characteristics such as incapable parents, substance abuse parents, HIV/AIDS infected or terminally ill parents and children of battered women including those facing conflict, (to mention but a few) are also a target for neglect. In their publication on child abuse and neglect in Uganda, Kaawa-Mafigiri and Walakira (2017) write about child maltreatment and present a widespread array of forms of violence and neglect suffered by children in Uganda against a weak justice and support system. Children are the foundation upon which a nation is built and for this reason their protection is paramount. Protection may be viewed in terms of provision of and adequate access to basic needs such as food, shelter, health, and the love of family. It may also be seen as being safe guarded against all kinds of violence and harm that may befall children (Walakira et al. 2017). Child maltreatment in all its forms gives rise to negative effects including but not limited to physical, mental, and behavioural problems (Kaawa-Mafigiri and Walakira 2017).

1.5. Thesis outline

In Chapter 1, I provide background information of the study project and begin by briefly explaining what NS is. This is followed by a detailed presentation about why carrying out this study was important. In this case, I highlight the need to explore NS from the local perspective and discuss the importance of taking contextual factors into account in this exploration. Furthermore, I present aspects regarding the fact that NS is so far under-researched which calls for more studies. To conclude the section on why this study was justified I write about the impact the study would have on the livelihood of the people by way of knowledge production which would in turn inform policy and practice in as far as interventions are concerned.

In this chapter, I also cover the study focus which was to explore the local perceptions that NS affected communities have towards the illness and then present an overview of the theoretical framework in which the study is supported. This framework comprises Merrill Singer's syndemics and biosocial perspectives to ill-health as well as Arthur Kleinman's social suffering approach. The chapter ends with the research setting in which I write about the civil conflict that engulfed affected communities for decades and how this may have impacted and exposed children to NS.

In chapter 2, I write about what is currently known about NS. This is done in sections including what the symptoms of the illness are, how it is treated, what its aetiology is and finally the epidemiology of the condition. This is followed by the research discourse into the condition first from the biomedical perspective and then the local perspective. I conclude this chapter with an overview of how diseases emerge before proceeding to the next chapter in which I cover anthropological perspectives and theories surrounding disease emergence and illness experience.

Under anthropological perspectives towards disease emergence in chapter 3, I describe key aspects within the syndemics framework to ill-health as well as the social suffering theory. I go ahead to present anthropological perspectives towards illness experience and give a detailed account of the local knowledge concept and Kleinman's explanatory models to illness as well as the narrative approach. Chapter 3 ends with an elaboration of how these perspectives, theories, and concepts relate to my study.

Chapter 4 is the methodology chapter comprising the research design, importance and clinical implications of carrying out research with children and the organisation of the study. The chapter also includes a detailed presentation of the field setting in which I write about issues of accommodation and food, weather patterns, research fatigue of NS affected communities, the local language, and the financial limitations of the study. I then proceed to show how the study sample was selected and data collected, processed, and disseminated.

Chapters 5, 6, and 6 cover the study findings. In chapter 5, I present the lay perceptions affected local communities have about the cause of NS most prominent of which is the connection to the civil war as briefly mentioned in the introduction. At the end of each results chapter is a reflections section on the findings in which I endeavour to make sense of the findings relayed prior. Chapter 6 explores the illness experience of NS looking at the symptoms with which victims present, the day-to-day life with NS, and the lay perceptions towards the communicability of the illness. Chapter 7 is the third and last results chapter. In this chapter, I handle care related issues for the victims and affected households. I specifically present findings on the struggle for health care, the perceptions about the quality of healthcare service, the impact of access to health care on the lives of the victims, and the challenges surrounding the caregiving role.

The general discussion chapter 8 is a consolidation of the reflections presented at the end of each results chapter 5, 6, and 7. Furthermore; I discuss how context, which comprises time (historical political, social cultural; and economic processes/ events) and space (IDP camps, rural setting in the aftermath of the war) together play into the emergence and experience of NS. These two aspects are looked at in view of the syndemics framework which propagates the biosocial model to disease emergence and lays emphasis on context as being crucial to the emergence of diseases that arise in populations and play a huge role in exacerbating their spread and effects. I tackle structural factors including a long history of violence and war as well as marginalisation which partly led to prolonged periods of poverty and inequitable provision of social services like education, healthcare, and a proper road network showing how this rendered affected populations vulnerable and unable to deal with NS at the time of its emergence. In the discussion, I further show how issues of gender play into this NS discourse, cultural issues like patriarchy as well as the influence of the media and past research activities on the local perceptions toward the condition.

In chapter 8 I provide a roundup of the different issues that arise from the findings as discussed within the conceptual and theoretical framework used. I also give my final conclusions in line with my overall and specific research questions.

Chapter 9 is the final chapter. In this chapter I put across recommendations for policy, practice, and further research. These include efforts towards prevention of such calamities as disease emergence, healthcare provision planning, massive capacity building for disaster management et cetera. This is underpinned by the fact that part of my interest in the study was to provide baseline information for use by key personnel in the design and implementation of efficient and effective interventions for the NS affected population.

2. NODDING SYNDROME

2.1. Terminology and aetiology

NS (*luc luc* or *yengowic* in Luo) is considered "evolving" (Mutamba et al. 2013:989) and still mysterious (Spencer, Schmutzhard, and Winkler 2017). It is a disease outbreak with "previously unknown or unfamiliar characteristics" (Bukuluki et al. 2012:5) and is "newly recognised" (Kitara and Amone 2012:464) in northern Uganda. The illness transitioned from names such as nodding disease, seizure disorder, meal-time seizure, and head nodding (HN) disease to "nodding syndrome" (NS); which was agreed upon during the first scientific conference on the illness in 2012 from its primary symptom of head nodding and "its presentation" (WHO et al. 2012:1).

To date, the pathogenesis and aetiology of NS are still a mystery and yet almost all past and ongoing research into the condition has been aimed at trying to establish its aetiology. In this endeavour, NS has been associated with, among other health conditions, onchocerciasis, epilepsy, measles, autism, and the nakalanga syndrome[10] (Spencer et al. 2016; Spencer, Schmutzhard, and Winkler 2017). Föger et al. (2017:1) propose that NS and the nakalanga syndrome "are closely related and may represent the same condition".

2.2. Symptoms

According to Spencer et al. (2016:80), "NS is a largely age-bound (onset mainly between 5 and 15 years) progressive epileptic disorder with the core clinical feature of repeated head drops of variable duration and frequency in children apparently healthy prior to the onset of the head nodding attacks". Johnson et al. (2017:7), however, postulate that "the age of onset of nodding syndrome may be related to the initial burden of exposure to *O. volvulus* in early childhood". They further think that children are vulnerable and susceptible to acquiring the symptoms of NS because of their developing brain and immune system. The paroxysmal and repetitive head nodding most likely results from loss of neck muscle tone (Dowell et al. 2013; Mitchell et al. 2013; Winkler et al. 2014) and that the immediate cause of the nodding is a

[10] Nakalanga syndrome is a medical condition named after one of the gods of a Ugandan ethnic tribe called the Ganda. It was first described in the 1940's among a population living in Mabira forest located in the eastern part of Uganda. However, this illness is documented to have persisted only for a while and by the 1980's no more cases (in this location) were found to exist. Nonetheless, patients with similar features are reported to have instead been found in western Uganda, Burundi, Ethiopia, and some other parts of sub-Saharan Africa. Like NS, the cause of nakalanga syndrome has not been established to date (see Föger et al. 2017).

special seizure called an atonic seizure (Dowell et al. 2013). The head nodding symptom is sometimes preceded or followed by the onset of seizures often times under the stimulation of cold weather but mainly the presentation of food (Spencer et al. 2016). NS was in the beginning classified as a "new epileptic disorder of sub-Saharan Africa" (Winkler et al. 2014:86) although Johnson et al. (2017) say the clinical presentation of NS is quite peculiar in comparison to that found in other children with epilepsy.

Mitchell et al. (2013:22) argue that, "contrary to what has been observed in the majority of cases in Tanzania, in northern Uganda, the syndrome is rapidly progressive and results in severe encephalopathy leading to cognitive decline". Some victims further present with under developed sexual characteristics (Johnson et al. 2017). Death results mainly from secondary causes such as injuries sustained during seizures or malnutrition. Idro et al. (2014), however, observe that the syndrome may not after all be progressive and debilitating and could even be a reversible encephalopathy in some patients since improvement has been noted with consistent symptomatic treatment. This further confirms how poorly understood and mysterious it still is.

2.3. Treatment

There is currently no cure for NS but measures are in place to address symptoms as they present in victims. These measures begin in the home setting with immediate family and extend to the wider community including traditional herbalists as well as professional healthcare providers in both public and private healthcare centres. There are health centres (HCs) to provide symptomatic treatment for NS victims in all the districts where the condition has been confirmed (Idro et al. 2014). The treatment regimen according to Spencer et al. (2016) comprises correcting malnutrition, anti-seizure medication, special needs education, a high level of personal care and attention, local music, and dance therapy.

In 2012, the MOH co-opted a team of health specialists to develop guidelines for the clinical management of NS aimed at guiding professional health caregivers on how to manage NS victims in their care. Following the ensuing guidelines, victims in critical condition and whose lives were threatened by comorbidities were admitted as inpatients while the rest of the victims were attended to as outpatients. According to Idro (2014), affected families and households, for some time, received food rations from the GOU twice a month to help curb the malnourishment problem in victims. Sodium valproate, carbamazepine, phenobarbitone, and phenytoin were given to patients as first line anti-seizure medication whose doses were

adjusted to fit the intensity of the symptoms in different victims. Annual or bi annual doses of ivermectin also constituted the treatment regimen against the river blindness causing microfilariae (Wamala et al. 2015; Kitara and Arony 2017). Counselling and mental health services were provided to those with behavioural/emotional problems while language, speech therapy as well as activities to stimulate cognition were used.

2.4. Epidemiology

NS was first diagnosed in Tanzania in the 1960‘s by Jilek-Aall (Jilek-Aall 1962; Mitchell et al. 2013; Winkler et al. 2014). Decades later (1990’s), it was reported in Sudan (Lacey 2003). In 1997/8, cases with symptoms resembling those seen in Tanzania and Sudan emerged in Kitgum – a district in the northern region of Uganda (Landis, Palmer, and Spencer 2014; Iyengar et al. 2014; Wilmshurst, Kakooza-Mwesige, and Newton 2014; Mwaka, Kitara, and Orach 2016). Uganda’s Ministry of Health (hereafter referred to simply as MOH), however, says that 2009 is the year in which they received the first NS reports (Wadman 2011; MOH 2012; Wasswa 2012; Mwaka, Kitara, and Orach 2016).[11] There was speculation that the illness could be a new type of epilepsy (Winkler et al. 2014) that affected at least 3,320 children in the districts of Kitgum, Lamwo, and Pader (Kitara and Amone 2012; Mwaka, Kitara, and Orach 2016). The affected children lived in areas where *Onchocerca volvulus* (the river blindness causing vector) was prevalent, were malnourished, and had dropped out of school (Nduhura 2012)[12].

It was estimated that out of the over 3000 affected children in the two districts of Kitgum and Pader who had NS, 200 had died by 2012 (Kitara and Amone 2012). Mwaka et al. (2016) put the death rate of NS cases at 6.7%. To this day however, there still is no clear figure of how many affected children there have been over the years or how many have actually succumbed to the condition. Nonetheless, it is important to highlight that death often was in form of drowning in water bodies such as nearby rivers, wells, springs and even water basins (Bukuluki et al. 2012; Winkler et al. 2014; Mwaka, Kitara, and Orach 2016; Idro et al. 2016). They also were due to severe burns that affected children sustained when they fell into open fires towards which they were unconsciously drawn during a seizure attack (Kitara and Amone 2012; Spencer, Palmer, and Jilek-Aall 2013; Musisi et al. 2013; Idro et al. 2016).

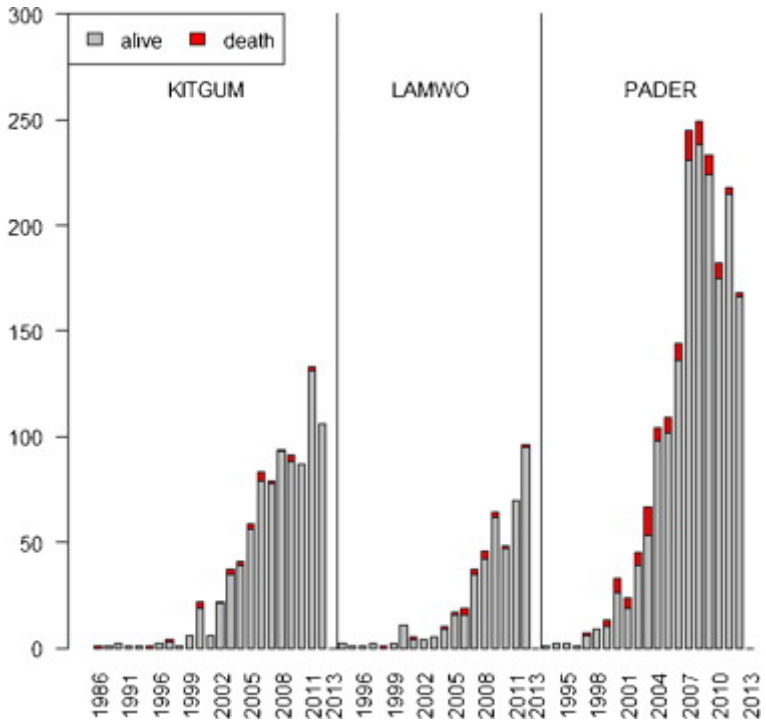
[11] Colebunders et al. (2016) states that these were retrospective studies but NS came to light in Uganda in 2009.
[12] Uganda’s cabinet minister of health then, in an official statement to Parliament.

During the initial response phase in 2009, Pader had the highest number of NS cases in comparison to Kitgum and Lamwo districts. However, the death rate of cases in Kitgum was significantly higher at 58% compared to 39% of cases in Pader (Mwaka, Kitara, and Orach 2016).

In the absence of a proper definition of an NS case, the first international scientific meeting on NS held in Kampala – Uganda from the 30th of July to the 1st of August 2012 adopted case definitions of NS (for details see WHO et al. 2012). These guidelines were used at community level to identify new and confirm already existing cases of the syndrome amongst affected populations during subsequent epidemiological studies.

In March 2013 a single cluster prevalence study using the new case definition was carried out by Iyengar et al. (2014) with the support of the CDC and MOH. Iyengar's findings revealed that there were 6.8 probable cases of NS per 1000 children aged 5-18 in the three districts of Kitgum, Lamwo, and Pader. A 2018 NS prevalence exercise carried out by MOH in northern Uganda revealed that in terms of incidence, no difference exists between males and females although according to Tumwine et al. (2012), in a study conducted in Mundri county – South Sudan, it was found that the ratio of affected males to females was 1:2. Landis et al. (2014) confirm that NS in Uganda was at its highest during the time local communities were displaced into IDP camps.

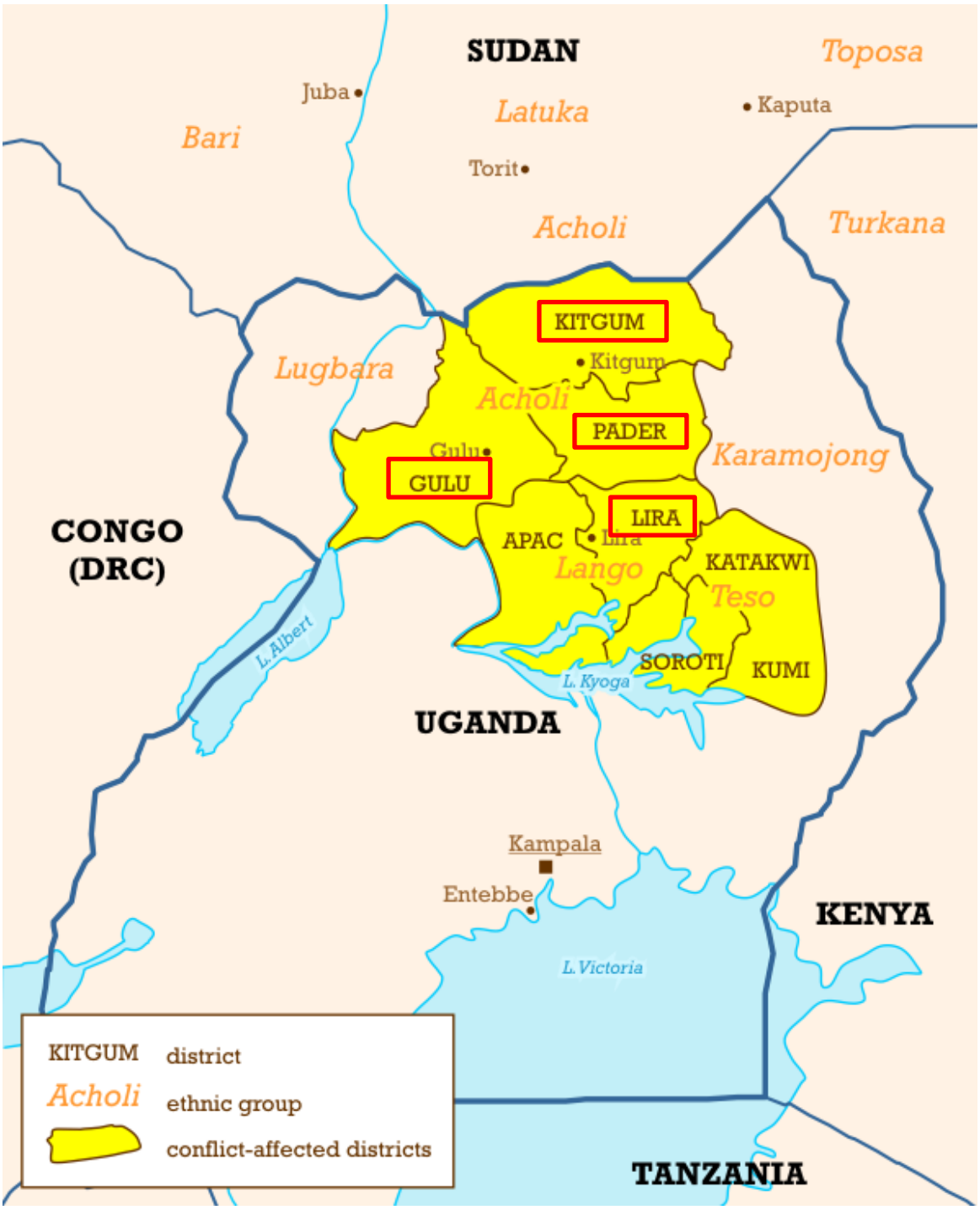
Figure 2: Nodding syndrome trend from 1986 until 2013



Source: (Colebunders et al. 2014)

Colebunders et al. (2014) argue that there were no new cases beyond 2013 due to the aerial spraying of black flies along the rivers Achwa and Pager to which the syndrome is attributed as of today. Interestingly, however, is that although originally reported in Kitgum, Pader, and Lamwo, the condition had spread over the years to include, Gulu, Amuru, Oyam, and Lira districts, all of which are located in the same region (WHO 2018b).

Figure 3: Map of Uganda showing conflict region and nodding syndrome affected areas



Source: Google images. Accessed on 03.12.2018

Key: Districts with cases of NS

2.5. Research discourse into nodding syndrome in Uganda

The investigation process began in 2009 and involved combined efforts between MOH, WHO, CDC, and other partners to determine the nature and aetiology of the illness. These partners invested time, money, and other resources in Kitgum that year trying to understand and control the disease (Sejvar et al. 2013).

2.5.1. The biomedical perspective

The belief that most of the disease resulted from poverty and poor nutrition from the long duration of encampment in the IDP camps of northern Uganda was also confirmed by a case control study conducted by CDC in 2009 which indicated that NS affected children studied were suffering from chronic malnutrition was statistically significant for vitamin B6 (Sejvar et al. 2013). In 2012, the University of Gulu which lies in the heart of the affected region constituted a research team headed by Kitara[13] which carried out tests revealing that the illness could be a result of either chronic malnutrition or a metabolic problem (Kitara and Amone 2012). In their publication on the neuropsychiatric perspectives of NS in northern Uganda, Musisi et al. (2013:1) concluded that this syndrome could be looked at as a "childhood complex developmental trauma disorder because of the trauma experienced during the civil war that may have led to severe prolonged depression".

Literature shows that NS has only been found in areas where onchocerciasis caused by *Onchocerca volvulus* (hereafter simply written as *O. volvulus*) is prevalent. According to Colebunders et al. (2016), NS could be combated by eradicating the river blindness causing black fly if the hypothesis is confirmed. In 2003, 93% of the affected children studied in southern Sudan by Richer of the United Nations International Children's Emergency Fund (UNICEF)[14] were also infested with *O. volvulus* – a parastitic worm transmitted by the black fly (*Simulium spp)*, which breeds near fast flowing rivers (Harding 2003). Colebunders et al. (2016) suspect that black flies are involved in the aetiology of NS and different kinds of epilepsy. Nodding syndrome is suspected to be an auto-immune disorder (Johnson et al. 2017). Dowell et al. (2013:7) suggest that "the disease is an auto immune seizure disorder –

[13] Kitara is a medical doctor and heads the department of surgery at Gulu University in Uganda. He is a native member of the Acholi ethnic community and has been at the forefront of research into the classification of NS.

[14] Richer, a tropical disease specialist from UNICEF carried out a survey to establish what could be causing the nodding disease in affected children of southern Sudan in 2003 and though not conclusive, her hunch was that the victims were all concentrated near the Yei river.

caused by auto-antibodies that the body makes against the parasite that, through a process of molecular mimicry, attack its own brain tissue".

Nonetheless, a conclusion has not been reached in as far as classifying NS is concerned and neither has there been success with attempts at treatment. In other words, the origin, development and management of the syndrome are yet to be definitely determined. As it is, Föger et al. (2017) put it clearly by saying that despite all progress that has been made in trying to establish the cause of NS, no single theory is convincing enough to bring an end to the discussion and that the illness still remains poorly understood.

For details on the aetiological risk factors investigated and presented in the first and second scientific conferences held in Kampala, see appendix 1 and 2 respectively.

2.5.2. The local perspective

Affected communities in northern Uganda have watched NS claim the lives of their loved ones given that the origin of this deadly condition and its remedy are to date still unknown. The mystery surrounding the illness has made speculation rife as to what it may actually be and what may have possibly caused it. In addition to biomedical research, studies documenting the affected communities' perceptions towards NS have also been carried out which has yielded some information about what these communities perceive of it. However, these studies have been few compared to biomedical studies and they have additionally been carried out only on a small scale. According to Mitchell et al. (2013), the people of northern Uganda were concerned about how they knew nothing of the illness in their midst even after several studies had been carried out.

A psychiatric team from the Department of Psychiatry at Makerere University (Kampala), in 2011 investigated the knowledge, attitudes, and practices of the people of northern Uganda to NS. Their findings revealed that NS affected communities linked the emergence of the health condition to the LRA/NRM war specifically the displacement event. Some local people in affected communities attributed NS to *cen* (a local term for evil spirits) which, for one reason, or another leave the world of the dead to haunt the living (Musisi et al. 2013). Study participants further described their affected children as bewitched and cursed as they lost them to drowning, fire burns, wasting away and sheer disappearance (Musisi et al. 2013).

Kitara and Amone (2012) in their study on local perceptions towards NS had a selection of health workers also attribute the emergence of this disease to war conditions which included the mobility of the people as well as the environment in which they lived. These health workers argued that because of the prolonged insurgency, many people lived far away from hospitals and HCs and that they did not get medical attention in time especially after getting fever. This, according to them may have led to illnesses which affected children's brains and led to convulsions resulting into NS.

In the same way, Mitchell et al. (2013) report that affected households strongly believe the cause of NS has a close link to the war in spite of advanced findings from past biomedical studies regarding its probable cause. Furthermore, inasmuch as NS is documented as being non-communicable (Dowell et al. 2013), a number of affected community members believe that it is possible for the condition to be somehow transmitted from one child to another.

NS is also perceived to have emerged due to the presence of vast uninhabited areas during the conflict as a result of displacement. Uninhabited fields contaminated by massive numbers of dead bodies during the conflict led to this linkage (Bukuluki et al. 2012).

NS in northern Uganda has additionally been associated with social and cultural issues including a history of civil strife, neglect, and poverty (Van Bemmel and Van der Weegen 2017). The severe trauma that affected communities as a result of the civil war endures to date. The consequences of this conflict situation in the midst of high rates of already prevailing poverty only exacerbated the problem.

Contrary to the situation in northern Uganda, in the first anthropological study on NS carried out in Tanzania by Van der Weegen (2015), the affected local population had doubts regarding whether the illness in their midst (commonly referred to as NS by the scientific community) was indeed similar to that reported in northern Uganda and South Sudan. This contrast is an aspect the researcher referred to as a shift in meaning of the illness in different contexts[15] (Van der Weegen 2015).

[15] The Ulanga community in Tanzania identified with *kifafa* (literally translated as 'little death' in Swahili and the local term for epilepsy) and *kifafa kia kusinzia* (literally translated as 'little death of head nodding' which is the local expression for NS). In the mid- 20th century Ulanga harboured camps where all persons suffering from epilepsy were sent to live. Their symptoms included generalised seizures and it is as a result of the rising population of these patients that the Mahenge epilepsy clinic in the vicinity was created by the physician in their midst then; Jilek-Aall. They have therefore lived with people exhibiting these same symptoms for decades and were surprised when suddenly the epilepsy they knew was labelled a new disease and given a new name – NS (Van der Weegen 2015).

3. ANTHROPOLOGICAL PERSPECTIVES AND THEORIES

3.1. On disease emergence

Disease is brought about through the interaction of many things including those within the body and within the surrounding environment. Castillo and Guo (2011), among several other authors, submit that for a disease to emerge or re-emerge a number of things or events often do simultaneously or sequentially occur. Medically disease is defined as "any abnormality of structure or function of the body other than that arising from physical injury" despite the fact that these injuries may also lead to disease eruption (Marcovitch 2010; cf. Bulterijs et al. 2015:1). Diseases may be completely new to a human host and therefore be said to be newly emerging. They, however, may have existed in the human population before but go on to appear in new locations, re-appear after apparent control or elimination or even in drug-resistant forms (Morens and Fauci 2013). The increasing movement of people across national and international borders, the flow of goods, food, capital even vectors and decision making power that characterises globalisation (Appadurai 2008), together with global demographic trends have enormous potential to lead to the spread of emerging infectious disease (Morse 2004). According to the institute of Medicine (US) forum on microbial threats (2006), displaced populations – a characteristic of the NS affected population in Uganda and South Sudan, are among the most vulnerable to emerging and re-emerging infectious diseases. Angier (2001:1) notes that "today, diseases as common as the cold and as rare as Ebola are circling the globe with near telephonic speed, making long-distance connections and intercontinental infections almost as if by satellite. You needn't even bother to reach out and touch someone. If you live, if you are homoeothermic biomass, you will be reached and touched." This is emphasised by the founder of Hope for Humans (H4H) – Gazda[16] who says that "disease knows no geography or boundaries and that it is quite possible that one day nodding syndrome will show up in the Western World" (H4H 2016:1).

I find Angier and Gazda's statements relevant to my study for a number of reasons. In the first place there has been a laxity in research towards finding the cause of this illness in Uganda (in

[16] Gazda, commonly referred to as Dr. Suzie at the NS care centre) is a graduate neurologist of the University of Texas health science centre of San Antonio and was until December 2017 (when the care centre officially wrapped up its activities due to lack of financial support from the government of Uganda) the managing director and co-founder of H4H, an NGO whose goal was to provide hope and restore dignity as they cared for children and families affected by NS in northern Uganda. According to H4H (2016), she had over 20 years' experience in the day to day practice of neurological medicine and related clinical research in the area of multiple sclerosis. A director of clinical integral research, Gazda also serves as medical director of the South Texas multiple sclerosis centre affiliated with the national multiple sclerosis society (H4H 2016).

comparison to the initial period during which NS was first reported and the region was awash with scientists trying to all make a contribution) and yet the need for fast and concerted research efforts in establishing its aetiology is critical. As presented in the NS communicability section of chapter 5, a number of respondents believed NS is communicable despite the official scientific position that it is not contagious (Dowell et al. 2013). Secondly and more importantly, is the fact that Gazda, to whom the latter quote is attributed, has had a hands on experience with NS victims at the H4H non-government organisation (NGO) since 2012. This experience, coupled with her expertise as a neurologist warrants that her statement on the possibility that NS could show up in the western world [if nothing is done about it today] be taken seriously.

Movement is of many kinds. It may involve short or long distances, may be within a given geographical area or transcend national borders but one thing is clear that when movement occurs, be it of humans or animals, a lot is carried along from the place of origin to the final destination. “When they travel, humans carry their genetic makeup, immunologic sequelae of past infections, cultural preferences, customs, and behavioural patterns” (Wilson 1994:39). Additionally, microbes and other living organisms move along too. In evaluating the impact of movement on disease emergence, one needs to gauge the likelihood of disease eruption and/or transmission to the new environment and population by looking for instance at social factors, cultural beliefs and practices, and the nature of the environment. Diseases may also emerge as a result of the inter-relationship between humans, animals, and the environment (Engering, Hogerwerf, and Slingenbergh 2013; Harper et al. 2013). The one World, one Health initiative was formed as a result of this trend and their mandate is to deal with diseases from a high level by focusing on the grass root causes of emerging diseases (Khan 2008) through a multi-disciplinary approach. These diseases affect both plants and animals, have a particular cause as well as recognisable signs and symptoms (Martin 2015).

Incidences of preventable diseases are high especially in Africa due to iniquities and inequalities that do exist both within and between regional and continental countries (WHO 2018b). This world body further more submits that these inequalities inevitably contribute disproportionately to preventable disease outbreaks which particularly affect those living in poverty. Also hard hit are displaced persons, women and children, and the old aged – which characteristics are all true for NS affected communities in northern Uganda. This therefore necessitates that a multi-disciplinary and multi-sectoral approach on the academic and policy front respectively, if the NS problem is to adequately be dealt with. Previous studies have

shown that a holistic approach has a greater potential of illuminating circumstances surrounding disease emergence which in turn helps in developing relevant and effective interventions (Trostle 2005). Better still, this approach would significantly contribute towards prevention of the new and re-emerging diseases phenomenon as is echoed by Kurland when he says:

"If we can understand an illness, we are in a far better position to prevent it than if we only find it and try to clean up the mess afterwards although cleaning up the mess is essential and must be considered" (Kurland 1990:114).

Understanding illness however requires that we know something about violence (Farmer 1996). But what is violence? Violence may be overt actions of aggression like war but also invisibly subtle in the form of symbolic and structural forms like impoverishment, food scarcity, discrimination, and rape inter alia (Rylko-Bauer, Whiteford, and Farmer 2009).

Briggs (2005) concurs with Kurland in his submission that rather than spend time and energy on expending solutions, effort should instead be directed towards trying to understand the problem. WHO (2018b) further documents that preventable diseases are either communicable of non-communicable and that in 2015, more than 70% of deaths worldwide were attributed to non-communicable diseases (NCDs). Malta et al. (2017) also postulate that NCDs are the leading health problem that culminate into early deaths the world over. Important to highlight also is that communicable and NCDs in the developed world and countries of the global south as well as among both the rich and poor are increasingly being linked (Harries et al. 2015).

At this moment in time NS may be viewed as a new, emerging and/or re-emerging disease. Much as its underlying cause is yet to be clearly defined, quite a significant number of strides have been made in research towards identifying what it could be and what may have caused it, albeit still at hypothetical level. Furthermore, although not medically classified as a disease yet, what is not in doubt is that NS produces a number of symptoms that may suggest the possibility of an underlying disease or the chances of developing one (Dowell et al. 2013).

Anthropological studies on how diseases emerge date as far back as the 19th century during which time colonialism was taking root and health interventions needed to be sought (Giles-Vernick et al. 2015). These studies were based upon the realisation that the biomedical approach alone was not successful in dealing with the problem of arising diseases and how they spread.

A case in point is Omran's (1971) epidemiological transition which was critiqued, among other things, as not taking cultural factors into consideration and being shallow on social aspects like poverty following the dwindling "popularity of including a broad range of social factors in studies of population health" towards the end of the 19th century (Trostle 2005:25). Furthermore, it was criticised for falling short in the recognition of mortality trends as being global in nature with a historical sequence (Caldwell 2001) just as the methods by which it had been arrived at were said to not have been sufficient enough to support it (Fleischer and McKeown 2014). The wide spread criticism of the epidemiological transition gave way to the socioecological model which seeks to incorporate social, cultural, economic, and political aspects within a time framework into the fabric of emerging and re-emerging infectious and NCDs (Kilanowski 2017). The socioecological model "recognises that a broad array of systems and interrelated determinants of health exist, acting either synergistically or antagonistically" (Fleischer and McKeown 2014; cf. Zuckerman et al. 2014:6). Proponents of the socioecological model believe that incorporating social, cultural, political, and economic aspects into the epidemiological model will "shed additional light on the ways in which 'upstream' global determinants differentially impact the health-states of vulnerable, disadvantaged populations" (Zuckerman et al. 2014:6). Large scale forces like marginalisation, inequalities, gender discrimination, war and politically engineered violence are sometimes determinants of who gets sick and who accesses healthcare (Farmer et al. 2006). Singer and Clair (2003) are also in agreement, going by their elaboration of the concept of syndemics in which they speak of the synergistic interaction between co-existent diseases and social factors at biological and population levels.

3.1.1. Syndemics and the biosocial model

In an effort to better explain disease emergence and distribution, medical anthropologist Merrill Singer in the 1990's developed and described the concept of syndemics (Singer 1996). As a theory, syndemics is an approach that views disease emergence and distribution as arising when harmful biological and social factors interact (Singer et al. 2017; see also Singer, Bulled, and Ostrach 2013). On one hand, the framework is undergirded by the suggestion that diseases emerge due to the synergistic interaction of pre-existing diseases. On the other hand, it suggests that social aspects within the day to day lives of human living make people vulnerable and susceptible to new and emerging diseases. According to Singer and Clair (2003:429), "a syndemic is a set of intertwined and mutually enhancing epidemics involving disease interactions at the biological level that develop and are sustained in a

community/population because of harmful social conditions and injurious social connections". This framework lays emphasis on the context within which the condition arises taking into account the role played by the political, social, economic, and environmental circumstances under which affected people live (The Lancet 2017). Mendenhall et al. (2017:951) speak of syndemics as "synergistic health problems that affect the health of a population within the context of persistent social and economic inequalities". In short, syndemics requires that attention is paid to the context in which health problems arise and are experienced. By looking at several factors (context) surrounding the emergence of diseases and their experience, the approach is also one that enables the effective management of health problems within given populations by making it possible to design timely, efficient and appropriate interventions. It further helps to know that the same illness is experienced and expressed differently in different environments which makes a syndemic not just about interaction of the biological but the social as well (Harper 2017). According to Hart and Horton (2017), critical health problems mainly affect structurally vulnerable populations which renders this approach all the more important to the study of health problems affecting them. Nonetheless, over the years epidemiological documentation on the syndemics theory has reported it as following a "problematic trajectory" (Tsai and Venkataramani 2016:2). This literature does not, for example show if there is an interaction between psychosocial and structural problems in populations where the two have been found to co-exist (Tsai and Venkataramani 2016). For this reason, in a hypothetical study to establish whether or not the variables co-existed in vulnerable populations, with 68 %, they concluded that there indeed was co-occurrence of mental health problems and structural problems in such populations. They went ahead and modelled the causal relationship between homelessness, food insecurity, mental health and HIV and concluded that the enumerated structural problems increased the risk of contracting HIV in a mutual interaction, albeit in varying degrees. This knowledge is important in the design of healthcare interventions in a sense that services are directed towards a specific risk factor well knowing that the risk of ill-health because of the said factor will be minimised both at individual and population level. Furthermore, it is possible to make informed decisions about which risk factor ought to take precedence in designing control and response programmes given that the degree to which each factor renders an individual at risk of ill-health is known.

Adopting the concept of syndemics in their study, Zuckerman et al. (2014) argue that in disease epidemiology, there is a meeting of aspects within the physical and social

environments giving rise to the emergence and transmission of acute epidemic infections and NCDs still on the rise in rich and poor populations, developed nations and Low and Medium Income Countries (LMICs). In a study aimed at verifying the reinforcing influence of psychosocial problems on unprotected anal intercourse amongst men who have sex with men in Shangai-China, evidence of a syndemic of psychosocial problems was found. The syndemic was also believed to have the potential to heighten risky sexual behaviour (Wang et al. 2017). In another study, Tsai et al. (2015) used the syndemics analytical framework to assess the effect of violence on the mental health of poorly housed women in San Francisco, California. Their findings showed an association between recent exposure to violence and low mental health which informed their conclusion that exposure to violence has adverse consequences on the mental health of the women that constituted their study.

The concept of syndemics is very closely related to and goes hand in hand with the biosocial model to health. This model emphasises the need to pay equal attention to multi-disciplinary insights for a holistic understanding of, among others, the impact of an illness on the health and well-being of affected populations, the effect on-going interventions have on the lives of these populations, and the way in which global health parameters shape the design of current and future interventions (Singer et al. 2017; see also Parker, Polman, and Allen 2016). According to Harris and McDade (2018), biosocial as a concept refers to two-way interactions or pathways linking biological phenomena to social and contextual processes over the course of life. In a review and analysis of interdisciplinary literature on war and health, Ostrach and Singer et al. (2013:258) conclude that “war is a traumatic and disruptive biosocial process that sets in motion dynamic interactions between diseases and other conditions that significantly increase war-related morbidity and mortality”. It, however, is not always possible to show how diseases at an individual level interact synergistically giving rise to bad outcomes. Nonetheless according to Singer and Clair (2003), it is possible to determine interaction between diseases using the syndemics theory when biological data sets for this purpose are used.

3.2. On illness experience

Illness experience as a concept first came into the limelight in the 1970’s when Eisenberg (1977) sought to make a distinction between disease and illness. One year later, Kleinman, Eisenberg, and Good (1978) elaborated the concepts of disease and illness in a cultural context and how they impact care. Disease, illness, and sickness in anthropology are linked

yet each remains unique in one way or another. Disease is categorised and defined in terms of change in biological functionality and is clearly distinct from illness (Kleinman 1988). Illness on the other hand has social connotations to it and is viewed as a social state that has lost value due to forces within ones social reality (Eisenberg 1977). Sickness, according to Kleinman (1988) is the understanding that populations attach to disease and illness as a result of external forces that may be social, cultural or political in nature. To be ill does not necessarily mean one is diseased (Helman 2007). Anthropologists are not only interested in states that are put out of order but go further as to elicit and examine the meaning they carry (Conrad and Barker 2010). These two latter authors additionally submit that the illness experience sheds light on the social context in which people are living as they deal with illness, the meaning of illness, and the ways in which affected populations adapt to life in these circumstances. A host of individual and cross-cultural differences in the course and prognosis of major chronic diseases are produced by cultural meanings, social response, and the social relations in which they are embedded and experienced (Good 1994). Literature also shows that beliefs about illness and health behaviour vary widely across cultures and among individuals within each given culture (Daley and Weisner 2003). Beliefs about the cause of mental illness for example include, *inter alia* stress and unpleasant past experiences, defiance, demon and evil spirit activities as well as biological factors (Biering 2007).

Conrad and Barker (2010:68) posit that "illness is the social meaning of that condition and that individual societies have unique interpretations of what illness is because each produces their own conceptions of reality". This reality is not static and is always changing with time. For this reason, local perceptions of ill-health along with the meanings and interpretations surrounding them are also bound to change. Kleinman and Benson (2006) submit that culture is important because of its influence on health-related beliefs, values, and behaviours. This is echoed by Kutalek (2012) who postulates that how illness is perceived and therefore experienced is hinged upon the ethnic and cultural background of affected communities as well as their socioeconomic situation.

The objectives and impact of contemporary approaches to mental health have, however, been recently questioned (Kirmayer and Pedersen 2014). Some of these critiques emphasise the difficulties and potential dangers of applying western categories, concepts, and interventions to such health issues given the ways that culture shapes illness experience. According to Helman (2007), culture has an influence on the language of pain or distress. This language includes culturally specific definitions of abnormality such as changes in behaviour, speech

dress or personal hygiene. For example Akello (2007) notes that children in post war northern Uganda hardly spoke about their illness experience due to extreme emotional distress as a result of exposure to atrocities and all kinds of human injustices during the war. Rather, they communicated their experience through pains and aches resulting from their belief of being attacked by angry dead spirits.

Cultural meanings influence the way an illness is experienced, how the illness is represented, the social response to the condition, and what policies are created in response to it (Conrad and Barker 2010). These meanings significantly impact the lived experiences of patients in many ways structuring their subjective experiences (Castillo 1997).

The syndemics approach does illuminate how illness experience is impacted by the context in which affected populations live. For example looking at migrants from the global south travelling to the west, evidence shows that the circumstances in which they travel expose them to physical risks with mental health repercussions (Willen et al. 2017). These mental health problems, the duo argue, are experienced in form of constant fear and anxiety, depression, post-traumatic stress disorders, and thoughts of a bleak future. A study of over ten thousand migrants living in open air encampment at Calai on the boarder of France and UK revealed that for example the gastrointestinal problems this population experienced were due to the shortage of and/or ingestion of contaminated food arising from the poor sanitary conditions under which they lived (Willen et al. 2017).

The impact of an illness, however, extends beyond the victims to include their caretakers in form of collective or social suffering (Kleinman, Das, and Lock 1997). Das (2015) brings insight to the healthcare horizon as comprising ones family, professional healthcare providers from a biomedical perspective, the state and the market. She posits that care and neglect are spread among all these entities at one point or the other. A number of scientists have described the illness experience of caregivers in many different ways. According to Kleinman (2012), the experience of caregivers is actually moral experience because from a human perspective, it is the right thing to do for anyone who has loved. Sometimes, care especially in the family setting, is extended as an obligation, to avoid guilt if not extended and for lack of an alternative. In other cases, however, the motivation behind caregiving is to foster closeness and the strengthening of relationships (McPherson et al. 2011; Nakigudde et al. 2016).

3.2.1. Social suffering

As a social experience, suffering is understood in a number of ways one of which is that it is regarded as experiencing pain together which shape individual perceptions and expression (Kleinman, Das, and Lock 1997; Hanna 2013) 'Social suffering' is a notion that has since the late eighteenth century been documented as used by several authors in reference to human affliction (Wilkinson 2018). It, however, was not until the late twentieth century that it was adopted as a concept in social science based studies to highlight problems faced by people in society. Kleinman, Das, and Lock (1997) made a sociocultural critique of biomedicine and detailed a social theory of the experience of suffering in which they look beyond the actual manifestation of pain to consider how the experience of suffering may be as a result of sociocultural forces within which affected individuals and communities live. Emphasis is laid on the importance of addressing human suffering in the " moral, cultural and political nexus" in which they take place (Kleinman, Das, and Lock 1997). Social suffering is one of the four major social theories key to the social science academic field. As a concept it is used to communicate the impact on humans that adverse circumstances like war and civil conflict situations bring about including physical, emotional and economic violence, among others things (Scheper-Hughes and Bourgois 2003). Kleinman (2006) submits that social suffering considers that socioeconomic and socio-political forces are sometimes the causes of diseases and that when people physically, emotionally, and economically suffer, they do so as a reflection of greater structural forces of political and socioeconomic nature. In this theory public health and social problems are treated as one and not two different entities. This, in a sense that all social actions have unintended consequences some of which affect human health and may cause social suffering (Kleinman 2010). Social suffering further holds that pain and suffering is sometimes caused and/or exacerbated by the very institutions that are supposed to provide care and mitigate or better still avoid it such as health care institutions. The theoretical framework requires that scientists focus on the misdeeds that are meted out on people in their attempt as researchers to make sense of the social situation and suffering of the populations under study (Wilkinson 2018).

Contemporary studies and writing on social suffering is intended to illuminate the many political injustices as well as material and social deprivations that a number of populations especially in the global south suffer (Wilkinson 2018). Beyond this, however writers on social suffering should endeavour to highlight "what suffering does to people" (Wilkinson 2014:113). In ethnographic enquiry, the approach has been used to enable people in pain

narrate their ordeal in order that they can get started on the healing process through narrating their stories (Kleinman 1999). The social suffering model was used as a candidate in trying to make sense of the high level of suicide cases among Tibetans living in China which pointed towards "collectively experienced structural and overt violence" (Craig 2012:1).

3.3. On health care

The healthcare system is a key component of social reality and is organised as a special portion of the social world through the interaction of social institutions like clinics and hospitals (Kleinman 1980). Social roles, for example the sick role or healing role as well as interpersonal relationships between the sick and the healers (family, traditional healer, medical doctor) are within the social domain (Kleinman 2012). Interactive settings, economic and political constraints, and available treatment interventions are also key constituents of social reality. However, the issue of efficacy is central to any kind of adaptive response to human problems created by sickness. Unfortunately, neglect has also been seen characterising illness prevention and control mechanisms (Parker, Polman, and Allen 2016).

Debates about health care are advocating for equity whereby there is access to healthcare services for all the sick. "Diversity competence" is the advocated way to go given that it focuses on inclusiveness, mutual respect and multiple perspectives" to healthcare provision (Kutalek 2012:1). Jansen et al. (2015) argue that one of the reasons populations dealing with mental health problems continue to collectively suffer is that intervention programmes are design to attend to individual and not social needs. Ricthers (2015; see also, among others, Richters and Sarabwe 2014; and Richters 2010) highlights the importance of sociotherapy especially for individuals and groups of people in post-war situations. They argue that healing only begins to take root for affected persons when trust is built to enable sharing of painful experiences with group members as well as obtain support. Looking at the Rwanda genocide, Richters and Kagoyire (2014) identify women as one of the categories that suffered the impact of the civil conflict and who, consequently, need to be included in healthcare provisions. In practice, the market model in which attention is paid to minimising costs and increasing efficiency has overshadowed principles of morality by attaching cost to priceless (moral/humane) aspects of caregiving and in a way commodifying the service. Furthermore, voices of caregivers have gone unheard or not been treated with the attention they deserve in ongoing debates about health reform in many a country (Kleinman 2012). Caregiving is "presence" involving a close and deep interaction with another human being, a "calling

forward or stepping toward the other, (…) listening intensely, indicating that the person and their story matter, and explaining carefully so that you are understood" (Kleinman 2017b:2458).

Caregivers of patients with mental and neurological deficits may face stigma and discrimination which inevitably impacts their experience (Mukolo, Heflinger, and Wallston 2010). In addition to stigma, literature shows that individuals who are exposed to or participate in violent acts are likely to develop violent behavioural traits (Slegh and Richters 2012). For this reason, women in conflict and post-conflict situations suffer gender based violence in addition to lack of support from male partners in the caregiving role. Caregivers – both family and professional, are also documented as feeling burdened. This emotion of burden has characterised the illness experience of caretakers and is described as the distress a caregiver experiences as a result of the physical dependence on them and mental incapacity of whoever is in their care (Poulshock and Deimling 1984). It is also described as the negative effects to the family resulting from looking after a care recipient (Nakigudde et al. 2016). In the discourse on caregiver burden, the concept has been split into objective and subjective burden. Objective burden includes events and activities related to the negative care giving experiences while subjective burden focuses on the feelings aroused in caregivers as they carry out their caregiving roles.

In their 2016 publication "The Passion of Society", Wilkinson and Kleinman proposed a new focus of the social sciences as being to passionately act on issues of suffering through the provision of healthcare services. This was inspired by the "discontent" of key persons like Wright Mills, Max Weber, and Jane Addams all of whom were "passionately struggling to create a more human form of social knowledge that was more responsive to peoples actual lived experiences" (Wilkinson and Kleinman 2016:199). Their argument was that this would be achieved through focusing social enquiry on caregiving services that attempt to address joint or collective suffering.

Existent literature records the impact of war situations on healthcare access and provision for example according to Fouad et al. (2017), health care systems greatly suffer due to infrastructural breakdown where health services cannot readily be accessed by affected populations. This situation is often characterised by destruction of physical health care infrastructure like hospitals and other health centres including equipment and medicines. Human resources tend to get dispersed too and in the case of displacement, these facilities are

also quite often difficult to access (Fouad et al. 2017). Drawing from earlier public health studies in northern Uganda, scholars have argued that the spread and manifestation of disease outbreaks may be made worse by the poor health care of the region (Van Bemmel, Derluyn, and Stroeken 2014).

3.4. Local knowledge

Local knowledge is important in medical anthropology because of its potential to contribute towards a better understanding of poorly understood illnesses. Originally, local knowledge was referred to as folk knowledge or indigenous knowledge (Hunn 1982), but the concept acquired new names with time including rural people's knowledge, indigenous technical knowledge, traditional environmental knowledge and indigenous agricultural knowledge (Sillitoe 1998). In addition, local knowledge has been referred to as beliefs, customs, practices, and local perceptions (Albuquerque et al. 2017).

Contemporary scientific research has involved the use of empirical evidence-based studies to generate and rally behind theories about nature (Hornidge and Antweiler 2014). Indigenous knowledge in this case denotes knowledge not from the west or knowledge against that of the west (Islam 2012). The concept is sometimes also used in reference to knowledge of the "other" (Tremlett 2003:1).

According to Hunn (1982), local knowledge was largely informal but came to the limelight in the 1960's and 1970's, when the concept was used to highlight differences between what was happening at the high nation-state level and the low grass-root level but also used in the development of communities that were seen as underdeveloped. It was during this time too that participatory research began to take shape by way of methodology where the relationship of the researcher and those under study was collaborative and fostered the involvement of stakeholders at different levels in an interdisciplinary approach which helped address issues of power in study projects (Sillitoe 1998). Local knowledge is still mainly viewed and utilised within the area of development programmes with a purpose of incorporating the ideas, beliefs and practices of people at the local level into their own development projects and programmes. This is contrary to the purely academic line of thought which led Agrawal (1995) to question the use of the term indigenous during debates on the subject in the later part of the 20th century.

For decades in academic discourse, use of the concept indigenous or local knowledge was mainly centred on the logic and structure of what constituted local perspectives as viewed along the lines of western intellectual principals in anthropology (Sillitoe 2016). Sillitoe (1998) further submits that anthropologists focused on enquiries along the lines of indigenous knowledge. These enquiries revolved around the people's understanding of their environment and how they sustained their lives. The main reason behind indigenous knowledge-based studies is to explore associations between the perceptions and practices of local populations with those of foreign researchers with the aim of obtaining deep insight into their view and to foster collaboration (Sillitoe 2016).

To begin with, while this was the case, anthropological studies revolving around local knowledge were found to be lacking in theory and methodological grounding but were instead caught up in a web of perspectives about what it was and was not, should be and should not be, what it ought to cover and not to, inter alia (Apffel-Marglin and Marglin 1990; cf. Sillitoe 1998). Secondly, what was not in doubt was that local knowledge led to the success of local development initiatives and was therefore regarded as important in anthropology but what was questionable was whether factoring the people's understanding and practices into planned interventions (Corbun 2005; Nichter 2008) would, without doubt, lead to the adoption and utilisation of these interventions. Citing an example of a project in Cameroon aimed at dealing with issues of land degradation, Sillitoe (2016) says that the project was bound to be withdrawn with very high losses because the perpetrators did not heed the voice of the people and thus postulating that "ignoring the voice of the people in such matters ends up as a very expensive venture and an offensive intrusion into people's lives" (Sillitoe 2016:225).

A proposal was then made to design a model that took development issues into consideration without devaluing anthropological principles and perspectives (Tripp 1985). This was in an effort to yield a participatory approach that would weave local knowledge into the scientific knowledge base within it (Schaffer 1989). However, "debates about epistemological issues surrounding the use of the term indigenous knowledge in relation to main stream scientific and technical knowledge, were not until the 1980's" (Lanzano 2013:3). Indigenous knowledge at the time widely became synonymous with environmental conservation and development, although it later paved way for the local knowledge concept instead.

Debates then shifted focus towards linking scientific research to the needs of the people for whose benefit it was to study them. It was not disputable that the increasing interest in

diversity was a result of the globalising world transformation processes and networks. Globalisation in this context meant that the world over, people at the grass-root local level were more connected (Stockhammer 2012). Diseases, for example, were appreciated in light of the knowledge local communities held which Tilley (2011) refers to as vernacular knowledge. Unfortunately, while local knowledge was acknowledged by colonisers during the colonial period, its importance slowly waned with time (Giles-Vernick et al. 2015). Contrary to the belief that this kind of knowledge is of little value, "Street science" – as Corbun (2005:1) refers to local knowledge, does not "devalue science" but rather gives weight to other kinds of information and involves other players into the inquiry and decision making processes.

For a time, debates also revolved around the production of this knowledge which is what gave rise to social construction theories. Emphasis was drawn towards and focused on knowledge in a development context by those for whom development initiatives were more important. Conrad and Barker (2010) advanced social constructionism in reference to a conceptual framework that puts emphasis on the cultural and historical aspects of phenomena extensively believed to have exclusively natural origins. In other words, the ways and means by which individuals and communities contribute towards the production of their perceived social reality and knowledge is what social constructionism examines (Berger and Luckmann 2011).

The way in which knowledge is understood in social constructionism is contrary to the western scientific perspectives whose values are rationality and positivism. Knowledge is an ever changing political and sociocultural construct. It is an "accumulation of social norms, rituals and practices that, far from being constructed in isolation from power relations, is embedded in them (or against them)" (Cooke and Kothari 2001:141). Human social activities give rise to and constitute social reality (Kukla 2000). "Individuals are then socialised into a system of beliefs, norms of behaviour and institutions which reflect and reinforce that reality" (Symonds 1998:7).

The approach viewed knowledge as a product of human relations in connection to their surroundings (Cooke and Kothari 2001). Cleveland and Soleri (2003) are in agreement when they say that ethnic ecological knowledge ought to be encompassed in a more holistic framework given that humans are seen as intricately and spiritually interconnected with nature. A few years later, Briggs (2005) submitted that time and space are involved in the wide array of perspectives of local communities as they view their reality. Golooba-Mutebi

(2004) concurs adding that this knowledge is not only generated from the individual's perspective in isolation but rather in interrelation with others and the environment within which they exist. Furthermore, Stockhammer (2012) as well as Ellen et al. (2013) observe that local populations engage in new knowledge sometimes transforming it in remarkable ways in a process described as hybridisation or blending. That said, inasmuch as the social construction approach is limited in a sense that it does not take into account discourses on the production of this knowledge (Sillitoe 2013), the foundation upon which it stands, I believe is the basis for the knowledge it yields through inclusive participation. Epistemologically, social construction takes into account the study participant's ability to produce knowledge and so pays attention to their contribution by letting them participate in the research process. Research is a complementary process where the researcher and participants support each other in a number of ways to generate positive outcomes. However, study participants tend to have a better understanding of issues within their ecological environment and sociocultural aspects which altogether help in the process of knowledge production.

3.5. Explanatory models

An explanatory model (EM) is a means by which individuals try to understand an illness afflicting them as well as communicate how they experience it. According to Kleinman (1988), the EM concept helps us understand what people think about their health problems and how these problems are interpreted by clinicians. EMs attempt to address questions such as – how has this illness happened? What has caused it? What impact does it have on me and how can it be dealt with (Kleinman 1980). According to Good (1994), disease is nothing short of an explanatory model. The EM method is used in both clinical settings and qualitative research as a way to obtain individual explanations of a particular phenomenon as well as collect textual data. Kleinman (1988), adds that EMs of illness help people recognise, explain, and respond to illnesses and their symptoms arguing that medical anthropologists have long emphasised the importance of EMs, or the narratives about the causes and consequences of illnesses from the sufferer's perspective, for actual health outcomes.

This approach is meant "to help explain five major issues concerning illness including aetiology, time and mode of onset of symptoms, pathophysiology, course of sickness and treatment" (Kleinman 1980:105). It also includes the healer's or care giver's understanding of the disease and hence is a feasible research framework for the development of knowledge that might be used to enhance therapeutic communication. The EMs of the professional healthcare

providers need to be evaluated and synced with those of the sick to ensure effective therapeutic interventions. Appreciation of their cultural values and beliefs would further help in better understanding their illness experience from a sociocultural perspective (Weiss, Raguram, and Channabasavanna 1995).

Using this theory in her study, Carpenter-Song (2009:67) sought "to ensure that clinical or diagnostic categories (or critiques thereof) were not imposed a priori" but through eliciting the patients (children in this case) and their parents experience of the illness. Her aim in the study was to establish how health problems are perceived by household members in view of their cultural traditions and beliefs. To explore how the victims made sense of their illness and their experiences of NS and to obtain the caretaker's individual explanations of the syndrome, I chose to adopt the use of this approach given that it has successfully been used by other researchers with similar research interests.

With the help of a series of specific open ended questions carefully arrived at during the process of developing the data collection instruments (see appendices 3-5). I was able to obtain information on my key areas of interest highlighting various dimensions of my study question. This enabled me generate a diverse array of perspectives from the different sample categories was generated.

3.6. The narrative approach

According to Mattingly and Garro (2000), the narrative approach is the foundation by which humans give meaning to experience – the basic way of obtaining an understanding of the illness experience from the perspective of the victims. From a cultural perspective, this approach enables sharing of distressful experiences, promotes understanding by the listener and allows for development of means by which healing can be fostered (Pike et al. 2010). This is evident in an experience Kleinman (2017a) shares about how the narrative approach enabled a victim of severe burns withstand the pain of having them cleaned and dressed and how he (in charge of comforting her during the painful experience) was able to gain insight into how she endured. Pike et al. (2010) however, differ positing that in cases of life stories laden with the pain of great loss and fear, the narrative may not offer sufficient support. Important to note also is Langer's (1991) caution regarding the attempt to find meaning (large or small) in instances of extreme atrocity which is more or less impossible. It is advocated that "all efforts at interpreting atrocity must begin with individual narratives of the unappeasable experience of durational time and advocates for cultivation of a language of diminished

possibility, an alarmed vision or an alerted way in which people look out for signs of impending atrocity and are prepared to respond" (Kleinman, Das, and Lock 1997:xvii). Evidence shows, however, that the meanings and interpretations that local populations attach to their experience of illness keep shifting with time, are audience based, and highly depend on the purpose of representing the condition in a specific way (Nichter 2008; see also Van der Weegen 2015). Becker (1997:17) cautions researchers to "beware politics in the people's narratives about illness experience. Narrative is always political, medical anthropologist's caution, because people choose which narratives to tell". "How those life stories are told, by whom, and the form that those stories take are fundamentally grounded in politics, history, and culture" (Kaplan-Myrth 2007:1269).

3.7. How these perspectives, theories, and concepts relate to my work

In reiteration, the aim of this study was to explore the local perceptions that NS affected communities have towards the illness. At the very beginning of my field work, it was clear that I needed to explore aspects to do with the cause and care of affected households. This realisation was both out of my own curiosity but also from the leading of the study participants as I elaborate in chapter 4.

The anthropological perspectives I present above relate to my study in a number of ways albeit some more specific than others. To begin with, as a still poorly understood condition being studied not from a biomedical but anthropological point of view, anthropological perspectives on how diseases arise and spread aided the study in complementing what biomedicine views as the cause and advancement of diseases. Specifically, I found Kleinman's (1997) submission that political and socioeconomic conditions are sometimes the cause of diseases relevant to this study's objective of what the cause of NS could be. Similarly relevant was the socioecological model (Zuckerman et al. 2014) which takes into account the role social factors play in disease emergence and spread.

The importance of the syndemics framework (Singer and Erickson 2014; Singer et al. 2017) to how diseases (new, emerging or re-emerging) arise in new populations or those in which they were existent at some point in time, (like Kleinman's social theory and the socioecological model), lay in its emphasis on the context in which such illnesses arise but additionally, in its recognition of the possible interaction of two or more existing diseases. As I expound in the next sections about what NS could be, there are a number of diseases within

NS affected communities that past research has associated the still unclassified condition with.

Furthermore, the narrative approach to data collection as described by, among others, Mattingly and Garro (2000) was very important for this study. This is because it enabled me collect in-depth information about the perception of NS from study participants which may not have been the case if other approaches like structured questionnaires had been used. The discourse on how illness is experienced from an anthropological perspective was likewise relevant on a number of fronts. Given that one of the my study interests was to explore how NS is experienced, conceptions of the body (Scheper-Hughes and Lock 1987; Kleinman, Das, and Lock 1997) were key in first of all establishing how pain and suffering is experienced and secondly how these conceptions could impact healthcare intervention planning as is the case in the Western world. Similarly, the advancement by Kleinman (1997) that cultural aspects have an impact on how illness is experienced were helpful in looking out for indications whether the NS lived experience of affected communities is in any way culturally influenced. The Acholi[17] have a rich culture ranging from language, food, the religious belief system, dress, dance, and music. In a number of instances indeed (details in chapter 5), aspects of the Acholi culture were depicted in their narratives surrounding the cause and experience of NS. Lastly, the role history plays in as far as the perceptions NS affected communities have towards the illness is in tandem with anthropological perspective aspects mentioned above. The submission by Scheper-Hughes et al. (1987) that besides what the body is, it is anchored in a specific historical moment is for example very pivotal for this study in light of the LRA civil war.

Inasmuch as there have been some studies on the local perceptions of NS, these remain limited in number and none was conducted with a purely ethnographic study design. What for instance stands out about this research project is that throughout my fieldwork phase, I lived within the affected children's households. Finally, local perceptions were my choice of topic because of the potential that study participants have to contribute towards knowledge production. Going by the strengths of social construction presented in the previous paragraph

[17] The Acholi are a Luo Nilotic ethnic group in northern Uganda; an area commonly referred to as Acholi land. This area comprises a number of districts including Agago, Amuru, Gulu, Kitgum, Nwoya, Lamwo, and Pader. Although Magwe is in South Sudan, it is made up of Acholi and therefore also known as Acholi land. The language of communication is Acholi which is formally known as Luo (Lwo). Acholi land occupies an area of 28,500 square kilometres or 11,000 square miles and borders with South Sudan to the North.

and considering that the aim of the study was to obtain a better understanding of a poorly understood illness, this approach seemed to be most appropriate.

Finally and over all, is the acknowledgment of the truth that suffering in these communities was collective (Kleinman, Das, and Lock 1997) and not only for the children who were directly affected but rather the entire community as shown in my reflections and discussion in chapters 5-8 ahead.

4. METHODOLOGY

In this chapter, I discuss the study methods used. This includes the study's research design, study sites, study population, sample size and how selection was done, methods of data collection and how data was analysed. In addition, I present ethical issues and considerations upheld in line with research involving children as well as the limitations encountered during the course and execution of the study.

4.1. Research design

De Vaus (2001) postulates that a structured form of enquiry is necessary to precisely and ably answer a given study's research question. This, he argues, would enhance the process of obtaining required evidence to support one's claim. This study was ethnographic and I used qualitative tools and techniques of enquiry to obtain an in-depth understanding of nodding syndrome (NS) from the perspective of the affected population in northern Uganda.

with ontological and epistemological properties adhering to a holistic approach in the study of cultural systems, processes and meanings from both emic and etic perspectives in a society's sociocultural context (Whitehead 2004).

Whitehead (2004) further submits that ethnography is largely dependent on fieldwork and involves discovery, making inferences and continuing enquiries as the researcher tries to realise emic validity. Liamputtong (2009) also relates the ethnographic approach to the interpretive theory on culture by Geertz (1973) which emphasises that to understand culture, we have to situate behaviours and actions within local frameworks and that instead of searching for universal laws, we ought to examine interpretations and look for meanings. This study design helped me gain insight into the everyday lives of NS affected communities. Because of this design, I was also able to obtain the meaning that people attributed to this new condition (Denzin et al. 1994). I was for example able to relate with the study participants at a level that yielded significant and useful information by living with them for months and participating in their everyday life activities in addition to engaging in both formal and informal discussions on the study topic. Whitehead (2004) argues that ethnography is an important research design because it is possible for researchers to use all methods of understanding the human conditions and not be bound by the use of qualitative or quantitative study labels in their attempt to understand context and meaning from the perspectives of their hosts.

Given the circumstances surrounding the emergence of NS, “mobile ethnography”, which Sheller and Urry (2006) say involves participation in patterns of movement while conducting ethnographic research, was also used in this study especially to trace the people’s movements during the time the syndrome is said to have emerged. This was to yield greater insight into what their narratives were laden with which further enriched my understanding of their illness experience. A case in point is there was a particular family in one of the study locations which led me to the different places in which they stayed during the IDP camp period. They showed me where fighting was intense and some of the places where they found rotting dead bodies in the bushes. With this movement I also recognised that the narratives of affected communities mainly revolved around their past and current reality.

According to Marcus (1995:98), “single-site ethnography can no longer be located in a world system” and because of this he proposed the approach of multi-sited ethnography which emerged by building on postmodern approaches. Mobile ethnography for example takes on “multiple trajectories in tracing a cultural formation across and within sites of multiple activity ethnographically constructing aspects of the system itself through the associations and connection it suggests among sites” (Marcus 1995:98). Through ‘co-present immersion’ the researcher at any one moment can apparently be situated within the respondent’s movement in which he or she employs a range of observation, interviewing, and recording techniques (Laurier 2002). Additionally, the researcher may conduct interviews during joint activities in which he/she and the study sample participate on the influence their movement has on their everyday life patterns (Sheller and Urry 2006:218). In my case, this mobility involved living in one of the former IDP camps with intermittent visits to two other former IDP camp sites following paths along which movement occurred during the time of the war and being a part of the same environment that affected communities were a part of during the time this still poorly understood condition emerged. A case in point is *Acholi boo*; Luo for ‘mass grave’ which is a place in Pader along the Gulu- Kitgum road where the war is said to have been so intense leading to so many deaths. During the war, proper burial of the dead was impossible and for this reason most of the dead stayed where they had met their death. Given the significant number of deaths in this specific location, the local community here nicknamed the area *Acholi boo* in commemoration of the many Acholi whose lives ended here.

Aside from the massive number of deaths, this location, according to literature and local affected communities was one of the areas where the places where the syndrome is reported to have been marked by a very high number of NS affected children (Colebunders et al. 2016). It

also was in this location that initial unpublished investigations culminated into the "meal-time seizure" label for NS affected children.[18]

Still in pursuit of a better understanding of the association respondents made of the condition to their stay in the IDP camps, I walked to healthcare centres kilometres away in order to appreciate the distance people claimed they had to travel to obtain redress for this condition upon their return from the camps. Indeed Boyle (1994) submits that of key importance to ethnography is that people's behaviour be understood in context. This was enabled through my engagement in mobile ethnography because in a way, I recreated the context to aid better understanding of the circumstances in which affected communities lived then. In this recreation process, informal interviews were conducted.

Maintaining both an emic and etic view to the study, I also tried to understand the components of the study population's cultural system from their perspective whilst attempting its analysis with existing paradigms from without the system (Pelto and Pelto 1978). It is important to note that the "importance of the etic view is partly due to the fact that any theories, hypotheses or interpretive frameworks brought by the researcher into the study may have little or no meaning within the emic view of studied individuals, groups or cultures" (cf. Whitehead 2004:17). For this reason, I was careful to separate my own understanding and interpretation of things from the respondent's ideas and views.

4.2. Importance and clinical implications of research with children

Hardman (2001) proposed that children as people should be studied in their own right and as social actors with varied lives and experiences. But "it is impossible to study children in contemporary societies without reference to how childhood is problematized" (Fassin 2013:111). Childhood is the first stage along the natural journey of a person to maturity. It comes before adulthood and should therefore take precedence over it. Morally speaking, children are viewed as innocent and vulnerable in the face of poverty, violence and disease and are viewed as a sinless, defenceless lot (Fassin 2013).

Childhood is considered a social construct and not a designated figure for instance in a qualitative study carried out by Rachita (2008) about how children across ages are perceived

[18] One of the health practitioners I interviewed in Kitgum spoke about how affected children started nodding only after food was set before them. He was there to investigate an unknown illness in the area and because the condition had no name at the time, in his report to his superiors he chose to refer to it as a meal-time seizure. (KI PH7)

by adults in India, maturation of children in view of today's democratised world and adult-child relationships occurs faster. The study also revealed that children are classified on the basis of dependency and incompetency that often are seen in many a marginalising practice in adult-child relationships.

Children have been a focus of the social sciences since the twentieth century (Hendrick 2005) but most often not as the subjects of research. The problem of children's invisibility and muteness in anthropological work has been of concern for quite a while (Global Human Rights Issues 2008). Now, children are increasingly seen as the subjects of research and as bearing something important to contribute to the questions at hand (Tisdall, Davis, and Gallagher 2009). It is the researcher's obligation, however, to ensure that care is taken to provide necessary protection against any kind of harm for the children within their study. In the case of ill children, their health and dignity ought to be preserved to the best of the researcher's ability. On this note, I would like to say that I did everything possible to ensure the safety of the children that constituted my sample by putting measures in place to protect the affected children from harm as well as uphold their dignity during the course of fieldwork.

The following ethical considerations were observed in line with upholding the ethical requirements of this academic research project and to avoid ambiguity and stigmatisation often attributed to scientific investigations (Keck 2011).

The study was undertaken after securing permission from relevant authorities[19] in Uganda particularly the Uganda National Council for Science and Technology (UNCST). For all interviews and FGDs, an explanation of the study purpose also highlighting what to and not to expect was done in order that study participants knew what they were consenting to. Affected children (regardless of their age and state of health at the time) were not in position to offer consent on their own. Consent was offered by parents and caretakers for all children who participated in this study. It was provided both in written form and orally although there were instances when it was just oral especially where interactions were more or less informal. Before tape-recording interviews and focused group discussions, explicit permission was sought from the study participants. Where respondents chose not to be audio taped (which

[19] For one to carry out scientific research in Uganda, clearance ought to be obtained from certified boards often attached to institutions of higher learning or hospitals culminating in final authorisation by the government of Uganda (State House) through UNCST. At the time my fieldwork was due to begin, the committee responsible for ethical clearance at Gulu University (which is located in the study area) was in recess and so I was referred to that of a major hospital in the same locality namely St. Mary's hospital Lacor (see appendix 3) before further review was done by UNCST and permission finally granted by the office of the president.

happened quite often) and where they did not want their photographs taken, I respected their wish.

As an ethical requirement also, it was necessary that a trained healthcare giver be close by during the process of interacting with affected children in order to handle any symptomatic emergencies in case need arose. Trained health care givers were therefore always at hand or in close proximity. In the Omoro district study sites, H4H had two full time nurses who were available 24 hours a day. Interviews and discussions were planned and held in locations close to this centre for this reason. Where it was not possible to hold them close enough, a bodaboda[20] was always available to quickly transport the nurse to the interview site when need arose. In Tumangur, however, the assistant and translator that I used was himself a healthcare provider with adequate training to handle such eventualities. To avoid causing emotional harm and further pain to them, conversations were also kept utmost 30 minutes long. Additionally, careful attention was paid to changes in them indicating tiredness so as to be granted a break as soon as this was sensed.

No monetary rewards were made towards participants for their responses. Nonetheless, there were instances where participants expected some kind of reward for their input. I carried along a bar of laundry soap and a kilo or two of sugar to the households I visited and as a token of thank you left something behind for their daily use. This I did until I realised that this affected the responses and narratives I obtained from some of the respondents when I was at some point asked by one what exactly I wanted to hear and that this is what I would be told. It also was causing uncalled for excitement among community members because suddenly every household beckoned me as I walked along the village paths to go to their home next. When I did not go, some came looking for me claiming they too had NS affected children who were in need of the "commodities" I was extending to the homes I visited[21]. For this reason, I stopped handing out soap and sugar but where genuine need was evident, monetary contributions, refreshments, food, and transport reimbursements were made.

[20] A bodaboda is commercial motorcycle commonly used for public transport in Uganda.

[21] The people in my fieldwork sites were really poor and it is for this reason that the permission I obtained from my projects review board at St. Mary's hospital Lacor categorically stipulated that respondents be given something in return for their participation in my study. This ranged from commodities like sugar, soap, rice, to monetary gifts like school fees for their children and pocket money. I must also add that it was a cultural practice to not go visiting another's home empty handed just like the hosts were in a way obliged to provide you something edible or otherwise.

4.3. Organisation of the study

Ethnography without fieldwork is a fallacy (Agar 1980). Classical ethnography, however, requires that the researcher lives among the study subjects for a relatively long time to obtain a good understanding of how they see life in this environment (Whitehead 2005). Spending time in the world of ones respondents includes "participating in their day to day activities, eating what they eat, learning their language, participating in cultural and religious ceremonies, observing them play, interviewing informants, taking field notes, inter alia, all of which help in obtaining emic validity that the ethnography aims at achieving" (Whitehead 2004:18).

Three phases made up this study, the first of which was committed to full time stay in Akoyo village, Odek sub-county in Omoro (formerly Gulu) district which is where the syndrome is said to have been first reported and the location where the highest number of affected households in this particular district are situated. It is also in this same village that H4H, an NGO whose mission is specifically to care for and see children with NS live a normal life, built its first branch. During the course of this study, a second branch was under construction in Tumangur village found in Lamit parish, Akwang sub-county, Kitgum district which was my other study site as shown in the proceeding sections. This phase lasted three and a half months from January until the end of April 2015. Prior to this, my advisor and I carried out a pilot in both locations between 25th August and 5th September 2014. Important to note is that I was the first researcher with an ethnographic study design to reside in one of the homes[22] of the affected children sharing in their everyday life. The home in which I stayed in Akoyo village had six grass thatched huts and a large dusty compound where papyrus mats and traditional stools were placed for us to sit. Learning that I would return and stay in the community for a long period of time gathering information on NS, *mego* Sabine offered one of the huts for me to take up upon my return if I so wished and this is partly how I made the choice of staying with the family later on.

[22] My advisor Ruth Kutalek and I first visited this home during a pilot visit we had to the area in August 2014. *Mego* (respectful term used in Luo for female elderly person) Sabine and her daughter- in-law Lucy commonly referred to as *min* (mother to) Achan were threshing and winnowing soybeans. We had been directed and led to this home by one of the employees of H4H after we indicated our need to identify households with children affected by NS. We had the opportunity to meet Achan during this particular pilot visit and while we had moved with a local guide for purposes of translation, *mego* Sabine could understand and speak English to an extent good enough to facilitate our communication.

This decision was also based on her ability to speak English to an extent that facilitated communication both ways because I believed that I would be in a better position to make it in an entirely new community given my extremely basic Acholi (Luo) language skills. She also had grand children who went to school and spoke English to some extent as well. But that notwithstanding, the affected child in this home had been identified as one of the worst hit and most affected children in as far as symptoms of the syndrome are concerned and so I deemed it a very good opportunity for me to obtain first-hand information about this particular victim by living in their home.

When I reached Tumangur village Lamit parish, Akwang sub-county in Kitgum district for field work studies, I was informed by the head of the VHT that one Karin van Bemmel, a PhD student from Belgium had just concluded her research around NS in this area. When I asked him if she lived with them, he said she did not live in the community but in Kitgum town from where she travelled daily to and fro for field activities. I have referred to her work a number of times in this thesis. In this location as well, I lived with a family my supervisor and I had visited in September 2014 whose NS affected child was 19 at the time. Unfortunately he passed away two months after our visit. I chose to stay here during the course of fieldwork in this location because of Job's key contribution to the community as VHT head. Secondly, he spoke English too and was at the helm of NS associated activities at grass root level in this region which made him a key informant. Finally, it was my wish to explore how affected households coped with the loss of a child to the syndrome.

Table 1: Tabulated time plan of fieldwork activities

Dates	Location	Activities
PILOT VISIT August- September 2014 (2 weeks)	Akoyo village in Omoro district and Tumangur village in Kitgum district	- Had initial contact with NS affected population - Identified possible hosts, study participants and other resource persons like guides and language translators - Obtained contact telephone numbers for communication while away - Identified requirements for fieldwork

		stay
FIRST PHASE January - April 2014 (4 months)		- Further learning of the local language - Got acquainted with family members and local culture - Selected sample, engaged in participant observation, carried out informal interviews, Key Informant Interviews (KIIs) and Focus Group Discussions (FGDs)
SECOND PHASE August – October 2015 (3 months)	Te Olam village, Odek HC III, Odek sub-county, Omoro district	- Expansion of sample - Participant observation - KIIs - FGDs
THIRD PHASE November-December 2015 (2 months)	Akoyo village in Omoro district	- Follow up on issues arising from data earlier collected - Further data collection
January- February 2016 (2 months)	Tumangur village in Kitgum district with visits to *Acholi boo* and Kitgum general hospital	- Sample selection in this area - Data collection
Total number of fieldwork months		**11 months**

This first phase involved further learning the local language and culture of the Acholi and getting better acquainted with my host family as well as members of the wider NS affected community. This was to help gain trust enough for respondents to freely open up during study discussions. It also helped me identify and select the study sample as well as an assistant to act as a guide through the village and provide language translation services since most respondents preferred to use the local language and I was not fluent yet.

To facilitate this, I often participated in activities such as shared meal time, performed house chores along with the rest of the family and interacted with community members especially when I went to fetch water at the borehole point where I met several people. In addition, I attended cultural ceremonies such as burial and last funeral rites, went out on market and auction days with community members- often walking very long distances at a time and attended church every Sunday.

As far as data collection in this phase is concerned, I mainly engaged in participant observation (PO) although I also carried out KIIs and some FGDs. I interaction with affected children very regularly during which time I engaged in informal conversations as much as possible.

The first part of the third phase which lasted five months was again spent in Akoyo village and home in which I stayed during the first phase. Narratives generated in the first phase brought to light salient issues that required subsequent follow up with additional conversations with some children, their caretakers and other members of the study sample. Subsequent follow up interviews were held with some children and care givers on particular issues as they arose during and after the initial stage of analysis. Padgett (2018) observes that apart from filling in missing information, follow up interviews are also important as a venue for pursuing leads from earlier interviews. Life histories will be tape-recorded and field notes taken. The phase also involved validation of findings generated from the earlier phases through checking for correctness with respondents from whom the information had been obtained. This was done through a one on one check where possible for individuals and through small gatherings with groups. I was in this study site for Christmas 2015 and New Year's Day 2016 before I moved to Tumangur village in Kitgum district which was my second study site.

From my fieldwork experience in the first study site (Omoro district), I found a way of being more efficient in Tumangur village. I was able to confirm with Job that I would stay at his

home and would require his assistance in mobilisation and translation during interviews. As a VHT member, Job was also on standby to offer first aid to affected children in case need arose during the course of our interaction. The thorough preparation that went into this phase enabled me complete all fieldwork activities more efficiently.

4.4. Field setting

In Omoro district, my field activities were centred within NS affected communities in Akoyo village, the H4H care centre and Odek HC III[23]. In Kitgum district, Tumangur village took centre stage, and to a small extent Kitgum general hospital. The study population mainly comprised communities living very close to rivers Achwa and Pager located in Gulu and Kitgum districts respectively.

A family had a different hut designated as a kitchen and another in which family members slept either singly or in groups. In some cases, teenagers had their own huts within the same homestead with boys separated from the girls. In Omoro district, I resided in a household with two NS victims, a 14 year old female and 18 year old male young adult[24]. This was upon an offer the family made during my pilot visit to this study site in 2014 along with my advisor Ruth Kutalek. During the same pilot, we visited a family in Tumangur with a 19 year old male young adult whose father was also the head of the VHT in Akwang sub-county (of which Tumangur village) is a part. Upon my request over a year later, his family agreed to host me from my field work studies despite the sad fact that his affected son had succumbed to the illness two months after we were there in 2014.

I had two fulltime field assistants, one in Omoro and the other in Tumangur whose duty was to help with leading me to affected households in the area, mobilising respondents for

[23] Odek sub-county has a Health Centre (HC) II in each of her parishes and one HC III to serve the health care needs of the entire sub-county. These HCs are manned by the government and patients are expected to seek government provided medical attention at these facilities in case of illness (more details on HCs are in sections ahead).

[24] The term young adult, according to Jarzembowski (2018) of the young adult ministry at the United States (US) conference for Catholic bishops, is one widely used in reference to everyone or to describe no one at all. A young adult is "a person who has achieved sexual maturity but whose character and personality are still developing as they gain experience" (Agnes 2013:218) and going by the findings of this explorative study, this definition closely describes NS affected victims aged 18-24 years old that were part of the sample. The Massachusetts Institute of Technology categorises young adults in the 18-22 or 25 year old age bracket where things such as reflective judgment, moral development or cognitive structural development are measured. Much as there remains a division within and between disciplines regarding the term, at the broader level, there is significant common ground.

interviews and FGDs as well as provide language translation services. The assistant in Omoro was 28 years of age, had attained a high school education and served as a Prisons officer in the capital city before he resigned and returned home. Job, my assistant in Tumangur was 59 years old, head of the VHT and although he had not attained a high school education, his over 20 year experience as a community health worker enabled him communicate and write well enough in English for the benefit of this study.

Economically, the people of Acholi land are mainly subsistence farmers whose major source of livelihood is tilling the land for food crops and in some cases cash crops. Animals are reared by not many households as a source of income to take children to school, facilitate hospital visits and contribute towards customary activities for which money is required. While in their homes before the war, people fed on beans (*muranga*), peas (*lapena*), ground nuts (*odi*), sesame (*nyim*), fresh or sun dried okra, soy beans (*soya*), greens (*Boo*), silver fish (*lachada*) and edible rats. This was eaten along with millet (*kal*) or sorghum (*kabi*), corn meal (posho[25]), sweet potatoes (*layata*) or cassava (*gwana*). Roasted maize, boiled raw papaya, and yams sometimes also made up their diet. Mangoes are a major food when in season from April to June and there is at least one mango tree in each family because it is the plant species chosen traditionally to provide sun shade during the hot sunny season. Tumangur, unlike Omoro had the added advantage of plenty of coconut trees which are in season all year round and a good source of nutrients. I observed this feeding culture during the course of my stay within the communities.

4.4.1. Accommodation and feeding

During the first phase of fieldwork, I travelled to this same village armed with a tiny mattress, a medium sized traveling bag with a few clothes. I also carried a gas cylinder which I later wished I had not carried because in addition to hardly using it, one day I returned home from my days' field activities and the 17 year old girl with whom I shared the grass thatched hut had lit it to make herself a cup of tea (according to her, the same way I sometimes did). The problem was not that she had lit it but that she had earlier confessed not knowing how to. She had fumbled with the process stealthily inside the grass thatched hut in which all my belongings were including earlier data sets that I had not been able to upload on a safe server

[25] Posho is a corn or maize meal made in form of bread. It is commonly known as ugali in neighbouring Kenya and Tanzania and is a staple food in many parts of Uganda. It is the main meal in boarding schools and has been crucial in feeding people in famine and hunger stricken areas because of the production of the crop in the country and its high energy content.

due to lack of internet access. Oh how I panicked thinking about the loss I would have incurred had the structure caught fire as they often did. Needless to say, I took better care and never carried the gadget back for the second phase.

I had also taken with me a 20 litre Jerry can, basin and back bag with my research tools. While it felt exciting, I could not contain my apprehension about staying in this very rural place for at least two months straight. I felt lucky upon arrival at my host's home because they had just returned from garden harvest work and so lunch (millet bread and odi with Boo[26]) was served which I hungrily devoured.

In the process of eating, however, a strong wind from nowhere came and literally chased us (and the family members with whom I was eating) from the spacious dusty compound into the main hut. We placed the papyrus mat where there was some free space and then I used my 20 litre jerry can, which thank God had water drawn from the borehole a few meters from this place on my way there, to keep the door in place because the lower tin cover was really too old to cover the entire door.

Incidentally, it is in this space I would later lay my small mattress and spend a night as my place of aboard for the next months. I certainly did not sleep that night for worry of snakes, rats and even animals getting in through the half open door only supported by my 20 litre jerry can of water. After the strong wind subsided, the 11 year old girl in the family was asked to help me carry my bath water and show me to my bathing spot in the nearby bushes. It dawned on me then that this homestead had no sanitary facilities and so for a number of days I walked a kilometre or so to the H4H care centre toilets to ease myself.

For months thereafter, I lived in this community and engaged in day to day activities like garden work and housework, attended cultural ceremonies like burial, traditional weddings and last funeral rites celebrations among others.

4.4.2. Weather patterns

Northern Uganda (like the rest of the country) has rainy and dry seasons. During the dry season which often runs from late November to April, temperatures soar to 40 degrees Celsius sometimes. The rainy season was known to run from May to June and then again September

[26] Odi is groundnut or peanut paste. They can be cooked singly or mixed together. Boo is a sun dried and hand crushed vegetable made out of young green leaves of a specific kind of peas. Odi and boo are often served as a mixture along with millet/sorghum bread or sweet potatoes and cassava.

to November with a slightly dry spell in between. This is a part from climate change that has interrupted the known weather cycle. I had received prior information (warning) that no respondent would be available during the rainy season as they all went and tended to their gardens almost all day long. With this in mind, which incidentally coincided with my ethical clearance permission, I carried out most of my fieldwork activities during the dry seasons. The challenge was that with temperatures ranging between 32 and 35 degrees Celsius almost on a daily basis, respondents were hardly in the mood of sitting down to conduct an hour long interview but it also was a real challenge for me (and my translator) to walk long distances in places where there were no other means, in order to reach each respondent.

4.4.3. Research fatigue

NS affected communities in Acholi land have for a long time now been frustrated and disgruntled because of the slow rate at which government and other stake holders are responding to their plight (Landis, Palmer, and Spencer 2014; Buchmann 2014; Van Bemmel and Van der Weegen 2017). I also found that there was ambivalence from community members in both study locations as to whether I was truly interested in their plight with my claim of a study aimed at helping science better understand the yet still poorly understood NS problem with which they were grappling in order to make further progress on how to better manage the condition. This scepticism was first of all hinged on my resemblance to the people who hail from the western part of the country which is the home area of the president who is disliked by many in this region. It further was because I had a field entry introductory letter from "the office of the president"[27]. Secondly, people had high expectations from previous research activities which remained unmet and therefore led to frustration for example hope for eradication of the condition or a better livelihood while they waited for breakthrough in research as far as a cure is concerned. This state of affairs initially made it difficult to obtain entry let alone the willingness of the people to engage in yet another study on 'nodding'. To say that some people (especially caretakers) in NS affected areas of Acholi land had had enough of people claiming to carry out research on NS would be an understatement. Some

[27] Uganda, as already mentioned is divided into regions and while these regions have several things peculiar to them, I will limit myself here to colour and body shape. My complexion and body shaped appeared to people in one of my study communities like that of those from the western region of the country. This region is where the president of Uganda hails from and his 32 year rule has been marred by nepotism and untold corruption which has won his tribes mates nothing but hatred. I was associated with the region and therefore with the regime and this earned me rejection and labels like "government spy". For about five days, it was meeting after meeting with local leaders trying to earn their trust and subsequently that of the local people regarding my stay in their community.

people clearly spoke of their disgust towards “people like you who come here to take advantage of our situation and leave our lives unchanged”.

Female caretakers in Tumangur during one joint gathering threatened to walk away if I said another word on the syndrome arguing that they were tired of researchers wasting their time with interviews and not helping enough with ensuring interventions are in place to help save their children.

In one location in Omoro, I lived and interacted with community members for three weeks before I could carry out the first interview. It was alleged here that I should be a government spy masquerading as a researcher adding that after all government does not care about the Acholi. I also felt limited in some way when it appeared like I was at the mercy of my hosts to learn what I was there to learn. Without their goodwill and cooperation (Whitehead 2004), there would have been nothing to observe or interviews to carry out.

4.4.4. The local language

Inasmuch as I had embarked on learning the local language months prior to the start of fieldwork, I nonetheless needed a translator to ensure I did not misinterpret or misrepresent my respondents in their narratives. This back and forth translation during interviews and focus group discussions slowed the process down to some extent. The 45-60 minutes allocated to each interview also yielded less information at every sitting where a translator was needed. Matters were made worse with the affected children whose concentration capacity was poor due to the impact of NS on their mental capabilities. I dealt with this challenge through narrowing down the scope of the study and drawing focus on only three specific areas including perceptions of the local affected communities about the probable cause (which was actually their major interest), what constituted the illness and how they experienced it and finally how they attempted to address it while the search for its cause continued.

The language also became a barrier during instances of participant observation because I could not comprehend everything that they said in real time to try and follow it up with prompting. During the course of fieldwork I also realised that sometimes respondents were not fully honest or completely open in their responses and so informal settings (in the absence of a translator) were a better source of factual information and so language became a stumbling block. To solve this challenge, I kept the recorder on whenever in the presence of my respondents (regardless of the setting) having obtained their consent to do this at the onset

of the fieldwork phase. This helped me obtain language translations for such conversations which in turn gave me insight into what issues I ought to follow up with particular respondents.

4.4.5. Financial limitations

Northern Uganda is about 500 kilometres away from my home which is located in the central region implying that I had to find a place to stay close to the affected communities. Logistical issues surrounding this kind of arrangement were found to be very costly but my host families in both Omoro and Kitgum districts generously accommodated and fed me within their means. However, I extended assistance in kind through contributing towards the day to day requirements of the household such as laundry soap, sugar which in these areas is a luxury and rice among others. I also participated in performing house chores and garden work together with other family members and ate one meal a day just like the rest of the family did out of poverty. At the end of the day, a financial token of thanks was extended for their hospitality and providence. Given the time I was in the field and the size of families with which I interacted, expenses escalated so fast that I often felt constrained. However; despite stretching the financial resources I had at my disposal (thanks to my scholarship providers), living within the community enabled me obtain first-hand information through observation but also quickly gain their trust to openly share their experiences. The shortfall was counteracted by a smooth and fast data collection process which is how the situation was contained. This is not a new way of dealing with such problems in fieldwork just like Freidberg (2001:358) postulates that knowledge shared "helps compensate for some of the logistical difficulties of research in the globalised economy".

4.5. Sample selection

Child and young adult NS victims were purposively selected in a manner that ensured social diversity. Parameters considered included age, institutional versus home stay, boys, girls, social status of house hold in community, health status (very ill or improved), single or multiple affected family member(s).

The point of entry into the study sites in both Omoro and Kitgum districts was first and foremost based on the introductory letter I obtained from the National council of science and technology upon the approval of the responsible department in the office of the president of Uganda. The Resident District Commissioners (RDCs) of both districts were my first point of

contact before I was sent to the local government council chairman and further on to the District Medical Officers (DMOs). The DMOs of the districts in which the families under study are located approved my entry into the study sites by virtue of their offices and membership on the NS task force[28] because they, by virtue of their employment constituted the NS task force in these two districts. Through my advisor's students in the master of medical anthropology and international health programme at Gulu University[29], I had first contact with the gatekeepers in both Akoyo and Tumangur villages. These students hailed from these communities and so had first-hand information on who the exact gate keepers were and how best I could have access to the affected children and their caretakers which advice I followed to get to the first study participants and certainly to find a place to stay within the affected communities. At some point, as need arose, recommendations were made by respondents about who else may have the information I required and so the sample was constituted. Some respondents narratives also served as pointers in given instances about what and who to follow up for corroboration, an in depth account or simply clarification.

The sample was spread out to include children eight to 18 years of age as well as young adults aged 19-24 years. What mattered was that they hailed from either of the two study sites in Gulu and Kitgum districts. I decided to select this age group basing on the assumption that they were in a better position to articulate their experience of the illness. However, findings showed that it was not entirely the case. A traditional health practitioner from Odek sub-county was spoken about in several interviews and for this was reached out to for his contribution. Health practitioners, LG officials from each of the two districts directly in charge of government interventions in line with NS shared their opinion on NS situation in their communities as well as other KIs as were recommended by respondents or referred to in different narratives. Here below is a summary of the study sample size. For details on the composition of the individual study participants, see appendix 3.

[28] The NS task force was a four or five member team headed by the DMO in Gulu district and by the LG council five (LCV) chairman in Kitgum district. Their main role was to follow and manage events surrounding NS within their areas of jurisdiction.

[29] My scholarship was secured through funding by the OeAD for the project Master of Medical Anthropology and Internal Health at Gulu University coordinated by my advisor Ruth Kutalek. In August and September 2014, she conducted lectures with this class at Gulu University in my attendance. It was during this period that we together also carried out a pilot to my study sites in Odek sub-county and Tumangur village in Kitgum district.

Table 2: Tabulated summary of sample size

Location	Category	Gender/No.	Location	Category	Gender/No.
Odek	Victims	F- **5** M- **6** = **11**	**Tumangur**	Victims	F- **3** M- **3** = **06**
	Caretakers	F- **5** M- **6** = **11**		Caretakers	F- **3** M- **5** = **08**
	Public health workers	F- **2** M- **4** = **06**		Public health workers	F- **0** M- **1** = **01**
	Key informants	F- **2** M- **2** = **04**		Key informants	F- **0** M- **1** = **01**
		32			**16**
Total sample					**48**

Key: Female -F Male -M

4.6. Data collection

I used qualitative data collection methods including Participant Observation (PO), In-depth Interviews (IIs), Key Informant Interviews (KIIs) and, Focus Group Discussions (FGDs) to obtain the sets of data collected during the different fieldwork phases. Inasmuch as all the above mentioned data collection methods were used, I would like to point out that PO and informal conversations were the primary mode used almost throughout the data collection process especially while interacting with the victims. Of importance also is that during the course of fieldwork, conversations with affected children were mainly on key study issues for short periods of not more than 25 minutes at a time. This study was purely qualitative and so only interview guides were used.

In designing the data collection instruments, an interview guide comprising a combination of aspects within the Illness Perception Questionnaire (IPQ), Explanatory Model Interview Catalogue (EMIC) and, Short Explanatory Interview Model (SEMI) advancements (see table

below) of Kleinman's EM questions was used in the formulation of questions for the study participants according to the study objectives. As a reference point, the criteria put in place by WHO et al. (2012) during the 2012 scientific conference were a very influential part of this development.

Table 3: Aspects from the three explanatory models

IPQ (Weinman et al, 1996)	SEMI (Lloyd et al, 1998)	EMIC (Weiss 1997)
• Identity • Causes • Consequences • Controllability • Timeline	• Naming the condition • What causes it? • Is it an illness? • What do you see about it • What you can do about it. • What your doctor can do about it.	• Patterns of distress • Perceived causes • Disease specific queries • Seeking help and treatment • General illness beliefs

The questions were translated from English to Luo[30] and a pre-test done with five Luo speaking students from my advisors medical anthropology class. This pre-test was done to ensure retention of the intended message. Consent was sought for every participant and was obtained both orally and in writing or simply orally when, for one reason or another, it was not possible to get it in written form.

Interviews were audio taped upon receiving consent from respondents. The interviews in the local language were carried out in the presence of a field assistant to help in translating the interview sessions from English to Luo and back. I took notes in English while the audio recordings contained both English and Luo. At the end of each day, my field assistant and I collectively transcribed the interviews into both Luo and the English language. I, however, also carried out interviews without a translator for participants who spoke English well and those who spoke English and preferred that the interview is done with no one else present. To ensure confidentiality, some study participants who provided information that they thought was very sensitive requested that they not be tape recorded.

[30] Luo is the traditional language of the Acholi ethnic community itself part of a vast Nilotic community. The same language is spoken by other people of the same community wherever they may be found including Kenya, Tanzania, and South Sudan.

FGDs, audio recordings were made and notes taken during the discussions. Transcription was done verbatim into both the Luo and English language and once it was complete, a member from the group was randomly selected to confirm that the said transcription was a true record of what transpired. This was done in such a way that my assistant read out the Luo transcription of the discussion to the selected member who then agreed or corrected errors on the spot. It was done this way because a number of the caretakers (with whom FGDs were done) could only read and write to a small extent and yet validity of the data was important.

Qualitative data collection methods including observation of the victims, observation of their caretakers, close and extended family members, community members, and one to one conversations with victims were executed. I also had KIIs, one to one interviews with the victim's caretakers, joint conversations with the affected children in a similar age group as well as with their individual family members and from the neighbourhood.

Once out of the field, I had a colleague who taught the Luo language in a higher institution of learning cross check the transcriptions against the original scripts for consistency with the respondent's message. To ensure confidentiality, this information was saved under security protection of passwords on all electronic gadgets used. Transcriptions had pseudo names and so does this report except in instances where respondents preferred that their true identity be revealed. Important to note also is that the entire collected data set was not diverted for any other purposes other than utilised for this study.

4.6.1. Focus group discussions

FGDs were conducted with the caretakers of children with NS in alignment with "a rich tradition in anthropological and cultural psychiatric research documenting substantial cross-cultural variation in how mental health problems are understood, expressed and experienced" (Carpenter-Song 2009:71). The FDGs were aimed at identifying a range of opinions on what the condition was and their experience of it in view of their caretaking role for NS victims while individual specific conceptions, beliefs, feelings and experiences were obtained through informal conversations. Each FGD comprised at least eight participants. Mobilisation of these participants was done by the local field assistant with whom I moved in each of these areas. This assistant sometimes helped in identifying locations of the respondents, securing the venue for the interviews and also in the translation process. Few FGDs were attempted with the affected children because it was difficult to mobilise them and get them in one location on their own let alone hold their focus for about 30 minutes.

4.6.2. Key informant interviews

KIIs were held with public health medical practitioners, local government officials and NGO representatives. This is because they were an important part of the intervention process towards the NS affected population since it was first reported and as such were deemed resourceful in sharing information already at their disposal. An in-depth interview guide was used in holding interviews with these key informants. All categories were fluent in English and so the interviews were carried out in the English language. The public health practitioners agreed to have the interviews audio taped but a number of NGO representatives declined as well as the local government officials. In cases where interviews were not recorded, I listened as best as I could and took notes to the best of my ability. I transcribed both the interviews and notes at an opportune moment and followed up by phone on issues that required clarification.

4.6.3. Participant observation

This was the principle method used for mainly the child victims but also included their caretakers and the household members of affected families. I was interested in how family members act and interact with their affected kin, to know what the family fed on and housing situation in the face of NS. Additionally, my interest was to see what took place in the day to day running of the household from which victims hailed. A journal to record observations made on aspects such as the physical state of NS victims, whether or not they are regularly fed, how often and on what, their daily engagements, how many caretakers there are in the family for each affected child and what the care takers coping mechanisms are, to mention but a few, was kept. In this journal were also personal reflections on issues that caught my attention and things I intended to seek more information about either from the same participants, different ones or other sources like secondary literature. This was subsequently done through one of the other data collection techniques afore mentioned. Important to add is that I participated in a number of day to day activities with the affected children and their caretakers as I observed what went on. I slept in the same house as the other family members[31] took part in the garden work, cooking, fetching of water, and cleaned the compound making me no "alien observer" (Bruner 1986:9).

[31] Round mud and wattle hut with a single entrance and no windows. The roof was made of straw which was sun-dried over time. Four of us occupied this hut.

4.7. Data processing and analysis

According to Corbin and Strauss (1990), the process of analysis involves examining the nature and constituency of something for insight into what it's use could be. The insight obtained is then used to make a conclusion about it. In line with this submission, data generated from primary and secondary sources in this study was examined to make meaning out of it first in relation to the research questions. Secondly, it was used to obtain emerging themes. This was in line with the interpretivist paradigm which views the world as a construction of discursive and social phenomena laying emphasis on the interpretation or meanings of given occurrences as it enables the researcher "view the world through the perceptions and experiences of the participants" (Thanh and Thanh 2015:24).

Interviews were straight away analysed to make meaning of it. Tape-recorded data from each interview or FGD was downloaded and stored on the computer laptop during the first phase but this kind of transfer was not sustainable because of battery charging challenges given that the study sites were very rural areas without electricity. One small shop in Gulu had a solar charging point but the shop attendant had to go for garden work first thing every morning and only returned to open the shop at around 13 hours which often coincided with the time available to engage with study participants since they too returned home from the day's work at around the same time. To deal with this challenge, attentive listening to the respondent's narratives taking notes manually was the alternative used which complemented information gathered from PO. These data sets were analysed during the time of fieldwork so that emerging concepts/issues could immediately be followed up in subsequent interviews and discussions. This initial analysis also provided leads for further refinement of the research questions as the study progressed.

At three, sometimes four week intervals, I often took a break from the field to Gulu town where it was possible to transcribe tape recorded interviews as well as reflect on the just concluded data collection exercise. In general, data analysis started as soon as data collection started and continued throughout the data collection process until several months after I had exited the field, completed transcription which was six to eight months later.

The general inductive method which involves condensation of raw qualitative data texts into a brief summary format, establishing clear links between the study objectives and summary findings arrived at from raw data and developing a framework of the underlying structure of experiences or processes in raw data was primarily used especially during field work. This

method is a simple straightforward approach for deriving findings in the context of focused study or evaluation questions and since I had specific research questions to begin with, I found it feasible including the fact that it could be used manually. Analysis allowed for discoveries to emerge from the data in an inductive way rather than for it to involve verification of hypotheses (deductive analysis). According to Corbin and Strauss (1998:12), in inductive analysis "the researcher begins with an area of study and allows the theory to emerge from the data". This type of analysis is of benefit to researchers whose interest is to obtain emerging themes from their collected raw data.

The approach is commonly used in health, social science research and evaluation fields**.** I used an integration of morality and structural vulnerability in a bid to understand the perceptions local affected communities have about the cause of NS, their experience of the illness as well as healthcare aspects in the midst of this situation. For example, it was my desire to establish whether structural and cultural factors interacted and subsequently had an impact on victims in form of stigmatisation. During the data analysis phase, codes were generated in alignment with structural vulnerability or morality. Points of interaction were sought which ultimately pointed towards structural and cultural aspects as the predisposing factors.

4.8. Results dissemination

The study results are presented in this thesis and primarily focus on the views of the people in affected communities (emic perspectives). However, also included are etic perspectives which comprise my interpretation and the opinions of others not part of the study sample. The different perspectives are clearly indicated as such within this thesis. I relay my findings using "thick description" (Geertz 1973:5) to indicate the need to explain in as much detail as possible why people think and behave the way they do and that there are often many meanings attached to both perceptions and actions.

5. WHAT CAUSES NODDING SYNDROME

In this chapter, I present the understanding and judgment of the victims, their caretakers and community members about the probable cause of "nodding syndrome" (NS). Historical, social and cultural factors came into play whenever study participants spoke about what the cause of this illness could have been. However, biological and environmental factors were also raised.

The emergence and onset of the syndrome was largely linked to the 20 year long civil war in which context respondents spoke about mobility and displacement into IDP camps, hygiene and sanitation within these camp settlements, the weaponry used during the war and malnutrition as a result of displacement. Mentioned also were cultural factors which revolved around the violation of their beliefs, cultural norms and values as well as actions of ancestors and spirits resulting from the civil conflict. Additionally, the syndrome was linked to supernatural forces (spirits, fate, and magic), environmental factors such as black fly infested rivers, animal ticks, and to a minimal extent biological factors such as heredity.

5.1. Association with the civil war

5.1.1. Mobility and displacement into internally displaced people's camps

The civil war was at the core of respondents' narratives regarding what may have caused NS. Emphasis was placed on the requirement that local people in the war torn area had to relocate from their original[32] places of abode into IDP camps for their safety against rebel attacks. Narratives showed that not everybody was willing to leave their home for the camps but that relocation was mandatory for everybody. According to respondents, it also was done very hurriedly leaving the people no time or opportunity to organise themselves before their movement.

> We did not have time to organise ourselves for life in the camps because it was an order from government which we heard over the radio that everybody should go to the camp in 48 hours whether one wanted to or not. (C3)

This change in environment is an aspect which was cited in almost all study participants' accounts about what could have probably caused NS. The association was made considering

[32] These settlements were on customarily owned land where members of the same clan lived close to one another on their forefathers' land.

that before the onset of the civil war no such symptoms had prior been reported in their communities either as affecting children or adults.

> Before the war, when we were in our homes, that thing was not there but when people were in the camps that's when we started seeing those things [in reference to NS]. (C2)

Some respondents wondered whether signs and symptoms of this syndrome did probably exist in their community before the war, albeit without their knowledge. But where this line of thought arose, respondents hastened to add that if this had been the case then the symptoms in the past were either different or their magnitude was not to the level that their children presented during and after the war. This argument was premised on the fact that symptoms of this kind could not go unnoticed unless they were insignificant in intensity and/or rate of spread.

> …if these things [NS] had been there before the war then we would have known. If they were there then perhaps the signs were different or not as much. (C2)

Study participants contrasted the home situation with events during their displacement and mobility to the IDP camps set up by the government. When asked to relocate to IDP camps, the people hurriedly put together a few things with which they would travel and these included items such as clothes, papyrus mats for sleeping on, sauce pans, plates, cups, jerry cans and basins as well as some food but they basically differed from family to family. Speaking of the hardships they encountered while in the camps, reference was made to the rudimentary structures which people hurriedly made to accommodate their families. Testimonies also indicated that sometimes as many as 12 people shared a small hut with all their belongings and because the huts were so close to one other, overcrowding was not simply limited to people within a single household but spread out to include congestion of huts in the entire IDP community.

> War is a very bad thing. It is bad because like in the case of the LRA war, we were in our homes where we lived with our families and relatives close together like you can see now. We grew food on our land and had enough to eat and even sell to take children to school. But one day, without any kind of preparation, we heard an announcement over the radio that we had only 48 hours to organise ourselves and go to the camp. It was an order and no one was supposed to stay behind. Some people actually decided to run to town instead of going to the camp. Others really had problems during the walk to camps especially old people, pregnant women and children because some camps were really far. We walked but in fear of landing into a rebel ambush. We could not cook for fear of giving away our position because of the smoke and these journeys took days. Upon arrival, we had to quickly make

> some shelter for ourselves and since people were many and the resources were few, we scampered for the few available building materials so that we all could have something over our heads. The huts were so congested and small because the entire family, sometimes as many as 12 had to squeeze inside with their things. (K1)

Respondents also mentioned that these traditional huts were thatched with dry spear grass or straw which made them easily catch fire given that open fires were used for cooking and lighting. In addition, I was told that many fires often broke out burning several huts at a time. Consequently, families spent several nights in the cold until they had a new roof to the burnt down hut during which time children especially fell sick as a result of continuous exposure to the cold.

> Because we cooked with open fires like you see here, many huts would catch fire burning the few things the people managed to bring along with them and leading also to sickness like malaria due to the mosquitoes that bit people while they slept out in the cold for days. (K1)

Findings further revealed that the onset of signs and symptoms of NS was either during the people's stay in the camps, on their way back home from the camps or shortly after their arrival back home.

> About this child, it began a long time ago in 2004 when he was 5 years old. We were in the camp. Like when you bring food like this and he has to eat, he begins shaking his head like this, and if he picks up the posho and wants to put it in the mouth he will lose the way and will drop the posho down. (C2)

> In 2008 when people were returning from the camps that's when this thing started. We knew it was a strange disease from the way he walked and talked. He also had a problem with eating and would breathe very fast. (C4)

> We heard about NS in 2012 in a report over the radio about NS-like symptoms in Aromo-Wanglobo[33] when people were already home again from the camps. A focal person from the national MOH based in Gulu town went there and came up with a statement of what it was. Before that, we had not heard about it. (K2)

The field voices presented above show that affected local communities looked back at historical events that coincided with the outbreak of this previously unknown condition.

[33] Aromo Wanglobo is a village in Odek sub-county, formerly part of Gulu district but after formation of new districts is part of Omoro district where signs and symptoms of NS were first noticed among children at a primary school. Prior to this, the condition had been reported in other districts like Kitgum and Pader but not Gulu. After the mentioned initial Uganda MOH report, a community survey was carried out by the VHT, through which it was established that there actually were over three hundred cases of children in the community with similar symptoms. An elder offered land to a private organization which wanted to set up a care centre for these children because of their growing numbers and it is for this reason that the only privately owned NS care centre is situated in this village.

Before the onset of the 20 year civil war in northern Uganda, people lived in "un-protected villages"[34] outside of the camps during which time NS was unheard of. Symptoms associated with NS first came to light when the people, due to displacement as a result of the war, were temporarily re-settled in IDP camps by the NRM government for their safety against rebel activities.

This condition did not, however, begin and stay in these camps but continued affecting children several years later during the course of their return to their original settlements around 2006/7 and much later while they were well settled in their former homes in 2012.

5.1.2. Hygiene and sanitation in internally displaced people's camps

Descriptions of what these camps were like also revealed that not only were they overcrowded, but the sanitation condition was also deplorable.

In some of my interviews with caretakers, It was found that because there was not enough space and material resources to erect bathrooms and toilets for each household, shared shanty facilities were used by large numbers of people which meant that they filled up fast and when this happened people resorted to using open spaces and the few nearby bushes to ease themselves. This compromised hygiene which led to the outbreak of diseases like cholera, diarrhoea, dysentery, and typhoid. According to study participants, mainly children were affected which culminated into a considerable number of deaths.

> There was very little space in the camps to accommodate everyone and so each family could not have their own toilet. Few shallow units were shared amongst many people and they filled up fast. Some people opted to use the bushes within and close to the campsites because even the few toilets available were often not well built and not clean. I think this is how mainly children got diseases like cholera and diarrhoea and sometimes dysentery as well as typhoid which killed many of them. (C3)

The dead people killed during the fighting compounded the already terrible sanitation problem because they often times were not properly buried but instead decomposed in the bush or were buried in very shallow graves within the camp settlements themselves.

> …also those who died during the war and had not been properly buried but left in the bush just like that added to the bad hygiene, because people would go to the bush to fetch firewood and they would find rotting dead bodies. In some cases the camp dwellers would dig some very shallow graves to

[34] As opposed to "protected villages" (Dolan 2005; Branch 2007; Baines and Paddon 2012; Branch 2013) that were created by government during the war in a bid to safe-guard local communities against rebel attacks.

> prevent the dead bodies from just lying around but soon they would be uncovered especially when it rained. (C3)

Water for drinking and for general use was obtained from boreholes within some camps but also from the Pager and Achwa rivers (in Gulu and Kitgum districts respectively) depending on where the camp was located vis-à-vis the people's closeness to the water source. Since these rivers were not close enough for all camp inhabitants in the various locations, people also fetched water from wells to which some respondents additionally attributed NS because according to them, the water in these wells was not clean.

These same water reservoirs served as the people's major sources of water upon their return home at the end of the war. This was in addition to the few existing and still operational boreholes. However, the challenge was that a lot of activities also went on in these water bodies (both during and after the war) rendering them dirty and unhygienic. For example they were used as toilets for several community members, trapped running water from rotting dead bodies in bushes and were also used for washing and bathing both by humans and animals. The people's inclination towards the sanitation situation as a probable cause of NS was that just like cholera, diarrhoea, and typhoid could arise because of poor sanitation, so could NS. Some respondents believed that NS may have come up as a result of the unhygienic conditions along with other factors.

> In the camps, we got water from boreholes but some people who did not have access to nearby boreholes got it from the well or the river. The problem is that this water was always dirty because people would wash, bathe and use these water sources as toilets. There also were rotting dead bodies in the bushes and when it rained, the water from these bushes would also flow into these wells and rivers. They were very unhygienic to the extent that they caused diarrhoea and typhoid. Who knows, perhaps they also caused this 'nodding'. (C2)

5.1.3. Malnutrition during and after the war

The people of Acholi land have their source of livelihood more or less tied to a particular place which is their customarily owned land. The environment plays a key role in aiding production because natural water sources are within the vicinity. Extended family ties and social support networks also contribute to much needed support in as far as the livelihood of the people is concerned including but not limited to garden work, animal rearing, domestic work and caring for the sick and elderly. Displacement during the civil war, however, led many to experience nutritional hardships during the time they lived in the IDP camps as echoed in the statement below from one of the respondents.

> Imagine, we get food from gardens here, water is very near and we work as a family on our ancestors' land. In the camp we had no access to gardens or granaries and food was hard to get. We were scattered and had no place to dig except few vegetables here and there. (C5)

Visible signs of ill-health in NS affected children pointed towards malnourishment which many (especially children) suffered during camp times where feeding was limited to once a day or sometimes nothing at all and was largely dependent on humanitarian aid.

> Malnourishment presents in many children suffering from NS. It was actually too much during the war. (PH4)

The malnourishment that ensued as a consequence of inadequate food supply partly explains why study participants from different categories as shown in the following field voices believed NS could have actually been sparked off in children whose growth was still at an under developed stage making them vulnerable compared to adults.

On the same note, the long period spent in the camps during the war is believed to have heightened the nutrition problem because procreation occurred in which many children were born into an environment with not enough to eat. These children were born to mothers who were in most cases malnourished themselves to adequately provide for the growing foetus while in the womb, not to mention the young child after birth.

> We spent a long time in the camps where food was hard to get and not enough. Children mainly were malnourished while women got pregnant and had to go through child birth when even they were malnourished. I think NS has a connection to this malnourishment because if you see children with "nodding", they look malnourished. (K5)

In one of my FGDs with caretakers on what they thought caused NS, two male parents spoke about their puzzlement regarding the cause of NS saying that mothers may have had something in their bodies that was helping in the transmission of the illness to children while they were still in the womb or in their formative years shortly after birth (for those victims who were born during the camp period and after). These parents raised what they thought could have been the problem arguing that because food in IDP camps was insufficient, poor feeding of pregnant women may have pre-disposed their unborn children to the syndrome. One father went on to say that the poor feeding may also have affected breast milk production and so the lack of an adequate supply of breast milk could have also played a part in the emergence of NS in children at a very young age given that they were already at risk by virtue of the environment in which they were born.

> My thinking is that mothers did not eat well when they were pregnant in the camps and so it affected the baby perhaps because of less breast milk and all the other problems we had in the camp. Some children were born in the camp and then years after our return home, they also began showing signs of nodding. (C6)

The malnutrition situation is said to have continued in the villages upon the peoples return due to the distorted ecosystem and damaged environment as well as challenges involved in rebuilding a destroyed social support system where land disputes were top on the list.

> This malnutrition became a problem during camp days when people did not have enough food. Unfortunately when the war was over and they came back home, instead of digging straight away, they had to first deal with land wrangles since boundaries had been moved or destroyed. Also the land had very many remains of the war for example dead bodies, land mines and things like that so people did not work like before. (PH5)

Humanitarian aid in form of food from the World Food Programme (WFP), the Norwegian Refugee Council (NRC) and the Red Cross (RC) was supplied comprising soya beans, cooking oil, maize (corn) flour, beans, and coated seeds for re-planting. This was in response to the acute problem of malnutrition suffered especially by children during the people's stay in IDP camps. However, the narratives of affected populations also point at this food as having had something to do with what later happened to their children in form of a "strange condition". This association was made based on the fact that early symptoms were closely tied to the sight, smell and even taste of food and while not every Acholi lived in the camps during the civil war, humanitarian food is reported to have been consumed by displaced persons both within and out of these camps.

For example among some of the affected households, it was strongly believed that NS was caused by humanitarian food supplies. A particular affected household in Akoyo village narrated that during the civil war they fled and lived in Gulu town out of not wanting to stay in the camps and so never once setting foot in the camps. Nonetheless, they too somehow had access to the same humanitarian food that was distributed to occupants of the IDP camps which is the common denominator that they shared with people in the camps during the civil war. To their surprise, it was also during this period that NS signs presented in their now 17 year old daughter.

> This war in northern Uganda was certainly a problem because of some of the food from those international organisations. The other cooking oil that they were bringing, that cooking oil was not good. It was in a jerry can, like this one (shows and hits on a yellow quarter litre jerry can) and if you kept that cooking oil, it would stain the jerry can. Her (the affected girl) signs began

> when we were in town 2004/5 and in 2007/8 we knew for sure that she had NS because they got worse. I think because of that food because this thing started in the camp and we never set foot in the camps but used to get camp food in the town where we were. (C7)

> You know, during camp days, people could not dig and so food was provided by relief agencies. Some of this food had chemicals and we do not know if these chemicals were dangerous or not. Partners like Red Cross also provided coated seeds for planting but since people did not have food, they washed the seeds and cooked them which led us into thinking there could be a connection between this food and NS. (C3)

> Some of the soya that was brought seemed quite old perhaps because it had been stored on concrete floors. Some of it was spoilt, had bones and larvae but we simply picked the bad stuff out and consumed the 'thing' [in reference to the food aid]. Also, the cooking oil seemed to have had problems, like it was animal fat or something. (C5)

During the course of following up initial reports about the break out of a mysterious disease in Pader (which was then part of Kitgum but is now an independent district), a senior and experienced health practitioner from a general hospital in the vicinity was tasked to find out what the problem exactly was. His recollection of events further revealed that indeed children in the age range of five to their mid-teens presented with symptoms that were peculiar when food was set before them.

> Once food was set before these children, they began nodding their heads like they wanted to sleep and were not therefore able to eat. Whenever they reached for the food and tried to put it in the mouth, they would nod (demonstrating) like they want to sleep with saliva running down their mouths until the food was taken away from them. Upon seeing this I wrote a report documenting what I had just witnessed and because this condition did not have a name at the time, I decided to call it a 'meal time seizure'. (PH7)

This account also reflects why some of the participants think NS was caused either fully or partly by the food they received from humanitarian aid agencies during the civil war arguing that only children were affected because their bodies were not strong enough to fight the intrusion and dangers the food presented unlike adults whose bodies were able to ward off any potential danger from the same food.

5.1.4. The weaponry – guns, gun powder and bombs

Guns were used in the LRA/NRM civil war like is the case in any other modern day war but so were machetes, large sticks or logs as well as stones for those who were not 'privileged enough' to access guns. Noteworthy also is that the areas which suffered the biggest brunt of the war are also the same places that are clustered with cases of the syndrome. For example

Tumangur in Kitgum district, according to study participants, is one of those villages that were hit hardest in Kitgum district while Odek sub county in Gulu district, which is home to Joseph Kony the leader of the LRA, was hardest hit in this location. Incidentally, this is also where Aromo Wanglobo is situated and the place where the condition was first reported in this district.

> I have a strong feeling that this disease has a connection to the weapons that were used during the war because here in the whole sub county, it is our village where fighting was greatest. One could hear gun shots and bombs from around there (pointing) and even smell gun powder from the camp where we were. I do not know if it is the sound, the chemicals or the destroyed environment by both weapons and dead bodies but I feel it could have been the cause of NS. (C8)

Bombs and chemicals of war such as the gun powder that was used were specifically raised by some respondents as being probable causes of the NS problem. This is because fighting between government forces and the LRA rebels was sometimes close to designated camps. The point raised in this regard was that during the process of firing gun shots, the smell of gun powder lingered in the IDP camps' atmosphere where it is believed to have been inhaled by the camp inhabitants. This powder's toxicity, narratives show, could have been responsible for the break out of NS in young children who relocated with their families to IDP camps. Some respondents believed that children born during camp stay and children who were born later on to parents who had inhaled it during their stay in IDP camps may have been affected during the course of prenatal development or breast feeding.

> The other thing was too much gun powder of the weapons that were used during the war. This powder could have had an effect on the people. There was too much fighting down there (pointing to a small forest along the path we were treading upon). The fighting was too much and yet the camp was just a few meters away there (again pointing in the other direction). We could smell this substance and we breathed it in also. (K6)

A father and caretaker in the same village argued that if a pregnant woman had inhaled gun powder then this toxicity could have perhaps easily been passed on to the unborn children while in the womb or through contaminated breast milk after birth.

> But it could also be that the chemicals from the guns which they inhaled stayed in their bodies and were transferred to the babies before birth or during breast feeding. (C6)

Their narratives also show that the Uganda Peoples Defence Forces (UPDF) had the upper hand in as far as munitions are concerned while abductees and lay people who fought to save their own lives and those of their loved ones mainly used traditional tools like spears, bow and

arrows, machetes, hoes, logs, and stones. Some respondents pointed to the government as having spread whatever caused NS to their children through the gun powder saying that government had neglected them for so long after all and probably wanted to wipe them out.

> The gun powder used in the fire arms must have had something in it spreading NS. Most likely it is government that wanted to wipe out the Acholi after neglecting us for so long. (C8)

> For us in northern Uganda we just gave up because this government does not care about us since it came into power. We suffered during the war because of this government. They had guns for fighting but our children who were abducted and people in the villages used just pangas, sticks, and stones to defend themselves. I think government just wants all the Acholi dead and they used this war to kill us with NS. (FGD5)

> This government knows the cause, it knows the cause. Me I think the government had something which they were spreading using their guns to make our children sick. (C8)

Not only was it adults that believed the NRM government had a hand in the cause and spread of NS, children did too. For instance a sixteen year old victim in a family with five affected siblings in Tumangur expressed his apprehension about the then upcoming presidential elections scheduled for February 2016 – just a month away at the time of this interview. He was worried that if the sitting government (NRM) did not win the election, war would erupt again which would this time perhaps simply kill all the affected children. Prompted into explaining why he thought so, he said that the past war brought the disease and he hears that it was government responsible because it wanted the Acholi to die. Since they still haven't died, government would make sure they die this time if there is another war after they have lost the election.

> I have heard people say that the government brought this disease to kill everybody. We are still alive because there is some peace now and we can get medicine but I am worried that after the elections on the 18th of February if it does not win, the war may start again and this time we will all just die. (C8)

Respondents believed that only children were affected because their bodies were still growing and so they could not resist the negative impact of the gun powder which was possible with adults. Child bearing mothers, it was argued, that though they themselves were not directly affected, they were nonetheless able to transfer this 'toxic' gun powder chemical to their unborn children during pregnancy so that at the time of their birth, babies were already pre-disposed to acquiring the illness. This hypothesis was used to explain why children kept on

exhibiting signs of NS after people had long left the camps and why even children born several years after resettlement in earlier homes still began showing these signs.

Respondents also spoke of the loud sound the gunshots and bombs made during fighting in the civil war that sometimes went on for hours and days nonstop. Still because the camps in which displaced people resided were often within the same areas in which this fighting took place, it was argued that young children's brains may have been damaged in some way by this noise which may subsequently have triggered NS.

> You know, the sound of these guns and bombs was also too much in this area (Tumangur). The fighting was where you see those trees and for children sincerely, I do not even know how some of them survived with that sound. (C8)

Findings showed that actual sight of committed atrocities (in many instances of relatives) was very traumatic especially for children whose ability to easily cope was lacking. This inability to cope by children was thought by some study participants to have made children more susceptible to NS.

> During the war my children witnessed a lot of killing with their own eyes and this could have affected their brains. When it started with my daughter, she would run and run very fast into the bushes shouting that someone wanted to kill her with a panga and when I took her to hospital she was given medicine for 'nodding'. (C10)

Another father who lost all his three children to the syndrome narrated his ordeal saying that one evening his wife and children heard shouting in the neighbourhood where unknown people were asking everybody to open the door to their houses or they would set them on fire. His immediate neighbours were his parents and brothers with their wives and children each in their own traditional huts. During the scuffle, his wife and children stealthily managed to run and hide in the nearby bushes.

> I was the first to run and hide but I did not go far. My children and wife also managed to escape to the bush. Our other relatives were in those huts you see there (pointing) and they were pulled out, beaten and killed with machetes and big sticks like that one (pointing to a log of firewood). (C10)

Prior to this event, his wife and children, then 8,10, and 12 years old had the previous day collected firewood, some of which were large logs and it is these that the attackers used along with machetes to end the lives of his parents and other family members.

While in hiding he realised that these attackers were not LRA rebels but the *amuka militia* (local militia) who had been mobilised from amongst community members to help in keeping the community secure. His own brother- a member of this local militia was actually also part of the attackers that came that night wherefore his children witnessed everything that happened.

> My children saw everything that happened and although my family survived, from that day, my children were not the same. This is how nodding also came in. I think their brains were disturbed. (C10)

His children died because of the persistent symptoms of the illness despite the medical regimen to help contain the seizures they frequently had. Their bodies slowly weakened because of poor feeding which was partly due to the frequent seizures. Furthermore, the burns they sustained from falling in fires due to the seizures were too difficult to treat with herbs and yet the nearest HC (Pajimu HC III) was about 12 kilometres away and therefore very far to reach on foot which further compromised health seeking for adequate treatment.

An eighteen year old NS victim, who also participated in the civil war as a child soldier upon his abduction, had the following to say about the cause of NS.

> Me: What do you think caused NS?
>
> Him: Elders say it came from thinking so much.
>
> Me: At the time it started for you, were you thinking so much?
>
> Him: Yes. I was thinking so much about the past.
>
> Me: What exactly about the past were you thinking about?
>
> Him: I was thinking about the war.
>
> Me: Why?
>
> Him: I was abducted by the rebels and participated in the war for a few months and I escaped. I think this NS came as a result of this fighting during the war because I used to have bad horrors in my mind all the time.

5.1.5. Government of Uganda and the emergence of nodding syndrome

In almost 50% of the FGDs held with caretakers within this study, emphasis about what may have caused NS was placed on the current government. Group members argued that the NRM government had for a long time kept the northern region of the country marginalised by not equitably meeting the people's needs. It was believed that when GOU saw that the people of

northern Uganda were resilient, it sought a way to have the Acholi finally 'wiped out' and this is said to have been done through the introduction of NS.

> Government has come here or sent many researchers asking us questions about NS and even taken samples from some people. In hospitals doctors claim to test if our children have NS but we never get to know the results. What is government hiding about this condition, why does it not give us clear information? (FGD5)

> Government has kept silent and paid a deaf ear to us for years now. We hear nothing from them and receive little to no support. Even local council government leaders are nowhere to be seen except during election time when they come to ask us for votes. From the look of things, it appears government knows exactly what is going on and they do not care. (FGD4)

Circumstances surrounding NS were over time also handled by government in a manner that raised questions in the minds of affected communities. A case in point is the VHT and media fraternity in Kitgum which were often silenced and castigated for speaking negatively about NS related matters.

> What would you think if government is always painting a good picture about NS and the plight of affected communities and yet the situation on the ground is actually different? Reporters have been barred from government meetings and discussions on NS in this district because government claims they are tarnishing its image by reporting negative things about the situation which actually is the reality in affected communities. (FGD6)

Study findings show that there was perceived neglect by the government towards NS affected communities. Government was also said to have sabotaged individuals and groups whose interest was to come to the aid of affected individuals and households citing cases of hostility towards the media and community representatives for reporting deaths and possible new infections in their villages and generally downplaying the people's plight.

In this regard still, post mortem issues upon the death of their loved ones were a basis for suspicion towards government in as far as knowledge of what led to the emergence of NS is concerned.

> Why would a government hospital like Kitgum general hospital (KGH)[35] not readily carry out a post mortem for an NS patient who has died while

[35] NS was first reported in Kitgum district and so it attracted a lot of public- both local and international attention. As a result, a section at the general hospital- originally the night commuter's wing during the war was assigned to patients of NS as a clinic of its own. Handling inpatients and outpatients, the unit has a full time Principal clinical officer fully trained and qualified in mental health issues. He was one of the initial researchers into the condition when it was first reported. The clinic was equipped with an ambulance to quickly respond to emergency NS cases in the rural areas but in some unfortunate cases, victims died in this clinic during their

> admitted in their NS ward? And if the post mortem has finally been performed under pressure from the victim's parents, why is it then a hustle for the report to be passed on? (C8)

> The cause of their death is really NS. Because according to their parent's explanation, it starts like malaria. A child may start by complaining of coldness, fevers, vomiting then later seizures come in and they die when getting seizures like that. These bodies were always taken to Gulu Referral hospital for post mortem where a sample from the back of their heads would be extracted for testing. But we have not received any results yet. (PH6)

Here below are some of the questions that were asked by a father whose son passed on in the NS ward at the government hospital for whom everything in this regard seemed suspicious.

> Does government already know what surrounds NS, wondered several caretakers. Why is there no feedback about screenings and examinations done, why no post mortem reports even when our children die in major hospitals like Kitgum general hospital? Why are they swift to offer support after our children die and not before? (C8)

5.2. Supernatural causality

Affected communities also attributed the cause of NS to ancestral spirits locally known as *cen*. This was based on three things, first that the cause of the syndrome to date has eluded everybody and so could be anything, secondly that in spite of available health care interventions, affected children were not getting healed of the problem but rather continued dying of it and finally that in their culture, there existed evil spirits (*cen*) which if not appeased caused suffering sometimes in form of strange illnesses so that people are reminded of their cultural obligations to them.

> NS may have been caused by *cen* because until now the cause is still unknown and the drugs are not healing the children. *Cen* also brings strange things like this so that you do not forget your cultural duties. (C5)

> We mobilised all households with affected children and about two hundred people gathered under those mango trees over there on the agreed Saturday. A cultural leader we had asked to come and help asked us for seven animals (mainly sheep) to be used in the appeasement ceremony. The sick children were asked to make a circle and one by one they were sprinkled with an animal blood mixture this man had made from slaughtering some of the animals in the hope that they would be healed but it did not work because the children are still dying up to now. (FGD4)

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admission. Despite the support of the clinic towards NS affected families, questions were raised about how information was relayed to bereaved relatives. Often a post mortem is not carried out and reports not made at all or if made, this is under pressure from the parents and in which case they are produced late. In the case mentioned above, the report was given to the parents long after their dead son had been buried and after they insisted on having this report availed to them.

While still connecting the cause to the civil war, some respondents looked at what their cultural practice omissions were, what they possibly had done wrong and what ought to have been done for the dead in their communities to avoid their (the spirits) retaliation by punishing them with this kind of illness. Furthermore, it was believed that because of the way people were displaced into IDP camps, the settlement conditions hampered the observance and performance of cultural rituals for the dead (as is common practice among the Acholi) which angered the spirits of the dead. When death happens in Acholi land[36] mourning takes at least five days sometimes extending to two weeks if the dead were an elder and respected personality in the community. Depending on his or her religious affiliation, a prayer session is organised according to the deceased's former religion for their send off. The community gathers for days and nights for those able to stay at the wake the entire time and assists in activities such as collection of firewood and cooking for the guests, fetching water and generally keeping the bereaved company. Otherwise, some people go to their gardens in the morning first and then gather for the evening and night at the funeral grounds carrying with them some food, firewood or water to help in sustaining the mourners. It is an expensive occasion because often a lot of food is prepared involving several slaughtered animals, music from hired sound systems played for people to be kept entertained as they keep vigil during cold nights, as well as the purchase of large amounts of alcohol, both locally made and commercially distilled from other parts of the country. All this with an aim of a proper send off for the dead in order that the deceased's spirit rests in peace and in gladness so as not to return and wreak havoc on those left behind in form of disease and misfortune.

Burial, in Acholi practice, is also in a well dug, decent (not shallow) grave to avoid cases of dead bodies being dug out by witches and wizards for "consumption". Therefore mourners, especially close relatives stay behind for at least three extra days at the funeral site after burial so as to guard the tomb during the night. It happens this way because witches and wizards (I was told) dig out dead bodies during night fall but after the third day – according to their belief system, the dead cannot be dug out and "eaten".

NS as a curse, a common belief too, was an issue also raised. Findings show that when someone dies in the Acholi culture and the cause of death is not readily known then the

[36] I was able to attend at least three burials and a last funeral rites ceremony during my field work stay in Gulu district. My explanation therefore about what happens in such situations is based on my observations and the enquiries I made during the time of my stay in this region.

deceased person's spirit returns to affect the family in form of a curse. Since many have died this way over the years during the war, some respondents believed the curse is upon almost all families which is why the NS problem is rampant.

> There were cases during camp days when girls would go to collect fire wood and find dead bodies of those who had been killed by the rebels. After wards, some strange things began happening to them and the elders thought that these strange behaviours were due to the fact that the girls had noticed what they had. Most of the parents began thinking that it is demons because of what their children saw when they went into the bushes to cut grasses for the houses or fetching firewood. But slowly, they realised it was not the case after performing some cultural activities. (K3)

> There are people who had died long ago but cultural activities like last funeral rites were not performed for them and it is like people were not remembering them so we thought that it is their spirits that were disturbing but also those who died during the war and had not been properly buried but left in the bush just like that because people would go to the bush to fetch firewood and they would find bodies. Like while in the camp, there was a day the LRA killed about twenty three people and they were put in a very shallow grave all together. When it rained, the top soil was eroded and the remains were swept everywhere including water sources which some people attribute to this illness as well. (C3)

> The other belief is that when someone dies and the cause of death is not readily known then the spirit comes back to affect the family in form of a curse. Since many have died in this way, the curse is almost upon all families which is why the problem is rampant. For example if I got married somewhere and my husband starts disturbing me, I would return home crying out for help. If my family did not help me and I went back and died, then it would be a curse on my family and any girl from this family would be like that. (C3)

Customary practices and rituals could not happen during the time of the civil war and so many dead spirits were understandably therefore not appeased. Citing cases of dead bodies littered everywhere and rotting in the bushes, some respondents also thought that this may have affected the soils on which they later cultivated food as well as the water they drank from the river including boreholes that may have not been dug deep enough leading to the emergence of NS.

> During the war, the rotting bodies contaminated the river water especially whenever it rained and water flowed. The soil we were growing food on was contaminated because in the process of digging some people found dead human parts on their land. Even some of these boreholes from where we obtained drinking water were not dug deep enough so running water would get into the water source. Children's bodies are weak, so consuming all these "funny" things I think is how NS emerged and even continued spreading when we came back from the camps. (C2)

5.2.1. Evil spirit *oteltok*

In the past, narrated one parent, there was a kind of disease caused by an evil spirit known as *oteltok* in the local Luo language. Believed to be of supernatural origin, when *oteltok* attacked a child, it would bring about stretching of the child's neck and the child would be very stiff with the back muscle also severely stretched. In his opinion, it could be this condition that decided to show up again because even *oteltok* only used to attack children. When this happened, family members would only hope that they were on good terms with these forces to keep their children from being attacked.

> I do not know where oteltok came from but it was a spirit which grabbed children and brought about strange behaviours in them. This happened when there was no harmony in the family. That disease was also selective like NS, not catching everyone but only choosing children. I do not know if it has come back in a different form or what. (C2)

In puzzlement and clearly searching for answers, this parent attributed NS to spiritual origin. In recollection of a disease causing spirit in the past whose symptoms were similar to those brought about by NS, he wondered if *oteltok* of the past had re-surfaced or that the spirit medium had sent another disease in form of NS. Other respondents likened NS to the devil saying that the ways of this illness are so unpredictable that one cannot imagine what is going to happen next.

> It is unpredictable and I cannot understand it. It can be like a devil, very selective so I cannot tell. (C2)

Symptoms of NS struck this child or that child without a clear cut formula for example in a family of eight the fifth child would get affected while the others remained their normal selves. In other families, all the children were found to have fallen victim which is why respondents likened the condition to a spirit similar to the devil.

In other instances, however, it was viewed as having been sent by God as seen from the field voice below.

> Only God brought that disease, only God. God planned this for us and we ought to accept it as our fate. (C4)

The belief that God was responsible for the emergence of NS among the Acholi is something not very many respondents raised. Nonetheless, those who believed it did so considering that the condition had eluded the scientific community for so long to the extent that a cause has not yet been found even after so much research has been done.

> We should all just accept that this problem was brought by God because if not, why has the cause not been found by all the researchers who have been coming here asking questions and taking samples? (C10)

5.2.2. Magic and/or witchcraft

Witchcraft as a possible cause of NS is a belief many parents and caregivers shared when they described the condition of their affected children specifically in reference to the time they first realised the strange way in which they were acting. This perception, it was found, occurred when little or nothing substantive was known about NS during the time people stayed in IDP camps. It was also found that notions of witchcraft came into play whenever anything negative such as death or misfortune happened and people could not find an explanation for it fast enough. A case in point is a family whose relatives began passing away at very short intervals of time (one or two months apart) during the time I carried out field work.

In the instances that occurred while I lived among them, the actual cause of death was bio-medically confirmed[37] but the bereaved believed it was witchcraft citing land disputes as the reason why a particular relative wanted to harm the rest of the family. NS was in the beginning also mainly viewed as a work of witchcraft which prompted affected households to straight away resort to the same means (seeking the help of witchdoctors) to have the problem solved. But first, affected households had to figure out why anyone would want to bewitch them before going on to imagine who the responsible person could be. It is at this point that they finally zeroed down on an *ajouga* that they themselves would turn to for help.

On the contrary, those who thought the source of NS was an illness which could be treated with culturally known traditional herbs, resorted to looking for traditional herbs in the fields with which to treat it while those who associated it to diseases like any other were focused on seeking help from HCs but were constrained by factors such as the long walking distances to the then few and ill equipped available health facilities. This was the case during the initial post conflict recovery stage where most health infrastructure had been destroyed during the civil war.

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[37] A pregnant woman with her fifth child died on her way to hospital where she was being rushed on a "bodaboda" (commercial motorcycle commonly used for public transport in Uganda). She had four children prior by caesarean section. Already in labour, the potholed roads on her way to hospital and the "urge to push" led to a ruptured uterus which eventually caused her death before she even got to hospital. In the second instance, a child who had been born under difficult labour circumstances had a blocked blood vessel in the lungs which as she grew up became worse. At the time of her passing she could not breath unaided and neither could she stay on the oxygen support in hospital all her life and upon being discharged, she succumbed to death which was instead attributed to powers of witchcraft as was the case with the pregnant woman.

> We waited six months before going to a HC because we thought that maybe someone was bewitching us so we decided to use witch doctors in search for a solution. (C11)

> The community is handling the problem their way. Those who think it has medical roots rush to HCs for help, those who think it is a work of spirits or witchcraft seek redress from cultural icons like witchdoctors and yet those who believe in God run to church as the only source of help in their situation. (PH3)

It was noted that several affected households turned to herbs and traditional healers in the quest for a remedy at the start of presentation of NS symptoms and some continued with this approach even after the introduction of biomedical interventions for the condition by MOH.

A directive was made by way of messages over the radio and through posters prohibiting caretakers from taking affected children to traditional healers but rather rely on HCs only for treatment but there were testimonies from victims themselves and several caretakers that despite this directive, they still obtained herbal medicines from traditional healers which they used concurrently with the drugs from HCs. Use of herbal medicines only was reported to largely occur among affected households whose caretakers were old aged and frail, whose NS victims were too weak to move or be moved here and there let alone to far off HCs or those with financial challenges to transport patients to these HCs. Additionally, some caretakers resorted to the sole use of herbal medicines because they had lost faith in the interventions provided by the HCs and private NGO for their inadequacy and inefficiency.

> Government has helped by sending us doctors to check on us sometimes and bring us drugs. The problem is that sometimes you would go for re-fill only to find they have not brought the drugs yet from town saying Kampala has not sent them. Even the drugs were not healing the children so for us we decided to continue with our local medicine man although we do not want anybody to know because they may throw us out of the group of people receiving drugs from the nurses. (V3)

5.3. Heredity

A connection to heredity was made by a small section of the respondents in trying to explain the cause of NS. Although raised by not so many respondents, in cases where it was mentioned respondents strongly believed the problem run in families given that in most cases victims were related in one way or another. Going by the Acholi land settlement culture for example which was such that members of a said clan lived on the same vast piece of land, It also was found during my fieldwork studies that affected communities lived very close to one another and more often than not were actually related.

It was also not unusual to find that among inhabitants of these households were people who were not affected by NS despite the fact that they lived within the same communities, shared everything with those affected except they were not blood relatives.

In an interview with one of the caretakers whose extended family had many NS victims, it was puzzling for her to see that the condition seemed to affect relatives. She is quoted here below as saying:

> You see, I was born here and most of the affected families in this community are my relatives because according to our culture members of the same clan settle on the same piece of land which belonged to their ancestors. (C3)

In this regard additionally, there also were different stances assumed by some study participants about what the condition (NS) itself was. During the time I carried out the second part of my fieldwork studies, some respondents had obtained information from acquaintances with access to publications about the syndrome in which it had been classified as a new epilepsy disorder. For this reason, while I asked about how this condition emerged, these particular respondents first of all wanted to make it clear that NS had nothing to do with epilepsy as reported.

> Before we even speak about what may have caused this condition, I would like to point out that NS has nothing to do with epilepsy as some researchers I hear have concluded. It is just being nicknamed epilepsy but it is not epilepsy. (C8)

5.4. Vectors

While some study participants made mention of the black flies in river Achwa and Pager as being in a way responsible for the emergence of NS (mainly those with training in public health), the majority did not actually believe the rivers could have had something to do with its onset. This rejection, findings show, was hinged on the fact that signs and symptoms that presented in NS victims were new having not been seen in the past yet these communities had lived for many years in the same locations. Secondly, questions were rife as to why (if black flies – *Simulium* had a role in causing NS) only children were affected and not the entire population that lived along these water bodies.

> The condition is common along river Achwa in Gulu and Pager in Kitgum so it could be water related, water based, water borne or water washed. It should be transmitted via black flies infested with the parastic worm *O. volvulus* but not directly. (PH2)

> If you analysed the areas where NS is found, you will find that it affects communities that live close to either river Achwa in Gulu or river Pager in Kitgum. For me I think something in or about these rivers is responsible for NS. (K4)

The majority of study participants rejected this causal hypothesis and also a December 2015 report from the MOH in which it was concluded that the eggs and larvae of black flies living close to these rivers were actually responsible for the emergence and prevalence of NS in Acholi land.

> For me I do not agree with those claiming NS came about as a result of these rivers. We have lived here all our lives, our fore fathers too but this thing has just come up and was never known to have existed before. And if NS is caused by these rivers, why does it affect children only and not us adults also? (K1)

Positively related narratives, however, also indicated that scooping clay for pottery and other economic activities from the Achwa and Pager rivers could be the responsible culprit in as far as the cause of NS is concerned. In this case it was believed that black flies living near infested rivers were responsible for transmitting NS when the water table level is low due to hot seasons, irregular rain patterns or human activities.

> About these rivers, we do not know exactly what connection there is but probably when the water table is low say during the very hot seasons and when people scoop clay and use the water for their animals then a vector transmitting NS is able to breed and cause havoc. (PH2)

In Tumangur some respondents believed that the vectors responsible for the transmission of NS were also attacking and causing NS in animals. Instances of domestic animals and pets experiencing NS like signs were shared too and in one particular case I personally witnessed a lamb exhibit seizure like signs. The owner saw the episode first and called me to witness what was happening to the lamb which had strayed and been found lying in the nearby bushes days later. Speaking about what he thought was happening he said, ‘look, is this not what is happening to our children? Does it mean that animals have also begun getting affected with NS now?’

Upon my further exploration of the matter, it was established that the same signs had been witnessed in two domestic cats from separate households and a domesticated dog from yet a third household within this same community. This animal behaviour was reported in Tumangur after people learned about the incidence of the lamb. Before that, owners of the said pets had only shared their animals’ strange behaviour with very close friends for fear of

stigmatisation of their families in one way or another. Incidentally, the households in which these incidents happened also had NS affected children prior to the said episodes.

In conclusion of this section of the chapter, not many affected children spoke about what they thought caused NS. This inability was mainly attributed to the age of onset of their symptoms which ranged between 5-8 years of age for respondents comprising the sample. Their parents and caretakers reasoned that the children were too young to comprehend what was happening to them when signs of NS started, not to mention what was causing these symptoms. Their (the victims) responses to what they thought caused NS were therefore practically what they often heard their parents, caretakers and community members speak about as the cause of NS.

5.5. Reflections on the findings

5.5.1. Association with the civil war

The findings presented above show that almost all respondents perceived the emergence of NS as being closely linked with, if not directly embedded within the actions of the LRA and UPDF during the civil war. Among other things, issues raised included massive displacement, the drastic change in environment and congestion in the IDP camps which together heightened the potential for disease emergence and/or transmission.

Within this war context, however, respondents had different explanatory models although it was found that several households also had more than one explanatory model with which they explained the possible emergence of NS. This diversity of local EMs rotated around the said communities' circumstances at the time, which is akin to what Beals (1976) says about different points of view that are used in the explanation of the same phenomenon like they are puzzle parts and pieces. But even while an affected household had more than one model or shared a similar model with other households within the affected community, there was often quite a difference in terms of detail and emphasis. For instance while one of the models was about humanitarian food aid, a given household placed emphasis on the coated seeds while another on the cooking oil which stained the jerry cans in which it was distributed.

Disruption and disturbance to the social existence of NS affected populations in northern Uganda were at the heart of the participants' narratives because the signs and symptoms of the illness as adopted by WHO (2012) during the first ever international scientific meeting on NS on the 30th of July-1st August, 2012 held in Kampala, were first noticed during this war.

The strong link of NS to the war has been a theory also raised over the years in scientific studies carried out with an aim of establishing the possible cause of this phenomenon (WHO et al. 2012). NS is almost always spoken about alongside the LRA civil war specifically because it is during this war time that the first signs of the illness were noticed (Landis, Palmer, and Spencer 2014). Ostrach and Singer (2013) emphasise how conflict and violence have the potential of giving rise to and exacerbating the risk of diseases and death as a result of this kind of social circumstances. That notwithstanding, it is not easy to outline the exact impact the war had on the outbreak of this new illness although it certainly did play a role (Colebunders et al. 2016).

Noteworthy also is that people were ill prepared for this displacement having been coerced and forced (Pham, Vinck, and Stover 2009; Wilhelm-Solomon 2013; Landis, Palmer, and Spencer 2014) into relocating. According to the Human Rights Watch (HRW 2005), on the 4th of October 2002, GOU ordered all internally displaced persons in northern Uganda to go into government protected camps within 48 hours arguing that the national army could only protect the people if they were in camps secured by the government.

The UN (2004) reported that given the insecurity at the time, food deliveries to IDP camps sometimes did not occur, resulting into extended periods of hunger which subsequently led to malnutrition. Infant feeding practices are reported to have been poor due to the low quality of food coupled with its inadequacy in these temporary settlements (MOH 2000). While clean water from protected sources was available, its access was compromised by the prevailing insecurity and large numbers of displaced people who made waiting times high (MOH 2000). The regional insecurity was compounded by failure of the government to provided adequate security for the displaced persons which led to the daily movement of many camp dwellers including children (‘night commuters’) out in search of shelter in hospitals, schools, municipal buildings, verandas, parking lots and other open spaces (Women’s Commission for Refugee Women and Children – WCRWC (2004). Hope for Humans (2016), argues that children living under the poorest conditions and have a history of internal displacement seem most susceptible to the syndrome. Similarly, Nannyonga and Sumpter (2017) observe that NS mainly affects children whose living situation is characterised by food inadequacy, unclean water and very poor shelter. The physical environment in which people lived during the war as well as the social circumstances of the time are indeed enacted in the NS affected children.

Earlier studies show that the conflict left many people in Acholi land prone to hunger, malnutrition, disease, psychological trauma, and the long term effects of living displaced and disrupted lives (Bukuluki et al. 2012; Mugisha et al. 2015).We ought to recall that NS has been confirmed in two other East African populations namely South Sudan and southern Tanzania but while northern Uganda and South Sudan suffered internal displacement due to civil conflict, this was not the case in Tanzania. Despite the fact that the context in which NS in southern Tanzania arose is not linked to civil conflict, history has it that many years ago, people with *kifafa* (swahili for epilepsy) from all over Tanzania were sent to Mahenge-Ulanga. Shelters known locally as camps were provided by the catholic mission in this area to help feed and care for them (Van der Weegen 2015). The association of the NS epidemic in northern Uganda to the civil war in which child violence and maltreatment were high (Human Rights Watch 2003), points to long periods of food insecurity and high poverty levels as being to blame (Bukuluki et al. 2012; Kitara and Amone 2012).

Landis et al. (2014) show a possible relationship between the annual incidence of NS and the annual number of conflict incidents. This supported an association between NS and the violent actions of the civil conflict (Bukuluki et al. 2012; Kitara and Amone 2012; Sejvar et al. 2013). According to Landis et al. (2014), first unofficial reports of NS first came up in 1998 during the civil war and declined between 2008 and 2011 coinciding with the cessation of the war and signing of a peace agreement between GOU and LRA in February 2008.

Landis et al. (2014) further argue that there were numerous reasons why conflict theoretically could be associated with NS. Exposure to warfare chemicals was readily posited but dismissed as highly improbable given the known neurotoxic properties of such substances, none of which causes repetitive head nodding from atonic seizures, let alone a progressive seizure disorder. “Sudanese communities affected heavily by NS also experienced war and displacement but reported no symptoms consistent with neurotoxic exposures when questioned in 2002” (Landis, Palmer, and Spencer 2014:3). Moreover, children in Tanzania with signs similar to those of NS acquired the brain disease in the absence of war or civil conflict (Spencer, Palmer, and Jilek-Aall 2013). Psychological trauma arising from war activities has also been thought to cause NS although this kind of illness has not been reported in other war-torn areas. Interestingly, of the children that participated in the LRA/NRM civil war, none constituted the NS cases despite having committed serious atrocities (Landis, Palmer, and Spencer 2014). Violation of human rights during the war period has been widely

reported (Human Rights Watch 2017) but none cites NS victims specifically among this category of people.

5.5.2. Link to hygiene and sanitation in displacement camps

It is well documented that poor sanitary conditions are a breeding ground for diseases (new and old) and one would not be wrong to imagine the conditions in the IDP camps may have had a role to play in the emergence of NS. Hygiene and sanitation are key determinants of good health that if compromised, the probability of disease breakout is rendered high. Inasmuch as NS may not be directly attributed to poor sanitation and hygiene during the time people lived in IDP camps, this situation certainly was bad enough for the people to have pointed to it as a possible cause of the syndrome.

According to this study's narratives as seen from the results section, hygiene and sanitation in the camps was extremely poor. Bøås and Hatløy (2008) describe the sanitation situation in these camps as appalling. Water bodies became damping grounds for all kinds of waste including dead bodies. Dolan (2005) for example writes that in 1988, the NRA killed nine men and damped them in a stream. Public health studies write about the risk inadequate water supplies, sanitation and hygiene have towards disease outbreak (WHO/UNICEF 2008).

Children in the camps were affected with diarrhoea, cholera and malaria with several recorded as having lost their lives daily (WHO 2006). These disease outbreaks were attributed to the contaminated water people collected from rivers, wells and streams as well as the inadequacy and poor state of toilet facilities in the camps. Indeed, Landis et al. (2014) report that NS may probably be of environmental origin. In South Sudan NS reportedly affects populations displaced due to civil war. But while there was not a civil war at the time children began presenting with symptoms of NS in southern Tanzania, the environmental conditions in which this affected population lived were not any different from those experienced by the people of South Sudan and northern Uganda during the time this condition emerged in all three locations. Specifically, they were all poverty stricken people who lived in shanty surroundings whose sanitation and hygiene situation was not good and would therefore easily lead to disease outbreak (Jilek-Aall 1962; Roberts et al. 2012).

5.5.3. Malnutrition during and after the war vis-à-vis nodding syndrome

Vulnerability of a people, as Spiegel (2004) argues, is heightened by food insecurity and living conditions that increase their susceptibility to disease. In a 2009 study by the CDC on children exhibiting signs of NS in affected communities in Kitgum district, it was found that most of the children were malnourished and had Vitamin B6 deficiencies including minerals zinc, copper, selenium, and magnesium (Sejvar et al. 2013). This was attributed to the poor access to food that was experienced while in these camps, the type of food that was brought to their aid by humanitarian organisations and the way symptoms at onset presented in affected children (Winkler et al. 2008; Mitchell et al. 2013; Dowell et al. 2013). In reminiscence of life before the IDP camps, some displaced persons tried to re-enact it by growing vegetables on small pieces of land when available within the camps. This is underscored by what Tošić and Palmberger (2016) conclude that in mobility, people on the move have their past and present merge in their everyday life no matter where they end up. Given the nature of the IDP camp settlements, aid was paramount to secure the nutrition aspect of the people. The WFP/NRC with funding from the Norwegian Ministry of Foreign Affairs was responsible for the planning, management, and distribution of this food to over 60 IDP camps in the districts of Kitgum, Pader and Gulu. For food distribution to thousands of people, it is not surprising like some respondents shared, that at some point households obtained rations that were close to expiry, and some even already expired which was interpreted by the people as a deliberate move to endanger them. Indeed Spencer et al. (2013) suggested a possible link between fungal contamination of food and NS. With trust issues towards the government, some people blamed the government for sneaking the “bad stuff” as they called it, into the warehouses of the international organisations faulting government and not the agencies themselves.

Kitara and Amone (2012) document that according to reports of the WFP which was responsible for supplying food to displaced persons during their stay in IDP camps, people only had access to up to [sic] 60% of the daily calorie uptake requirements. This was in tandem with this study’s findings in terms of narratives on access and nutritional content. Though not conclusive, this inadequate food access may have actually caused the malnutrition problem especially in children and pregnant women. 1.54 deaths per day for every 10,000 people in the Acholi sub region are also documented by WHO et al. (2005). The camps did not cater for agricultural activities like food production and so children who were very young at the time of displacement and those born and raised in this environment, I was told during my fieldwork stay, developed a poor work ethic whereby they were not as able and

knowledgeable at engaging in productive work for self-sustainability especially after their return home after life in IDP camps had come to an end.

Furthermore, conscious that the programme would be unsustainable should the war go on for many more years, a plan was designed to enable the population engage in additional food production to supplement what they received as rations and so coated seeds for re-planting were at some stage provided for this purpose. However, given that some households were in immediate dire need of food at the time, rather than re-plant, they instead washed the seeds and cooked them for a day's meal and later attributed the illness on this same food which again in Spencer et al.'s (2013) publication on environmental, nutritional and infectious factors of NS in Mundri county, South Sudan is one of the factors that is reported to have happened when people got so desperate. The revelation that families resorted to washing off the pesticide that coated the seeds they had been given for planting by humanitarian aid agencies and instead consumed them is indicative of the desperation to survive amidst scarcity of basic needs associated with events such as war and displacement (Westerhaus et al. 2007; Pham, Vinck, and Stover 2009).

Malnourishment was not only limited to the time people lived in the camps but continued to prevail even after their return to the original places of abode at the end of the civil war, over ten years later. This state of affairs is attributed to, among other things, their prolonged stay in the IDP camps where no farm work took place but instead people almost entirely depended on food supplies organised by the government through humanitarian agencies (Smith 2012) like WFP, RC, NRC and UNHCR. According to Wilhelm-Solomon (2013), in mid-2008, there was significant confusion among recipients about the future of food support and indeed, at the end of the same year, relief food shortage attributed to a worldwide food crisis led to a two month wait during which the people further lost hope. This caused anxiety among those living in the camps because they believed food support had ended which led people to imagine it was no longer an option for them to continue residing in the IDP settlements for as long as food aid was lacking (Wilhelm-Solomon 2013). Secondly, consumption of the replanting material meant that there was no supply of seeds to plant for them to get out of the bad nutrition situation. They subsequently were kept in the same malnutrition situation for much longer. This situation was not helped by the confusion caused by the World Food Programme (WFP) and other humanitarian organisations over how long relief food would be distributed. While the plan was for humanitarian organisations to go ahead with the provision of food aid,

this exercise had come to a complete end by mid-2009 save for the extremely vulnerable (Wilhelm-Solomon 2013).

Without continued access to food in the camps, people had no other option but to return home. During my fieldwork process, I also learned that the adult population at the time of displacement grew old and weaker due to the prolonged stay in the camp and so could not engage in farm work as productively as before upon their return home. The youth, who at the time of displacement were children themselves did not have an opportunity to practically engage in farm work while in the camps but grew up depending on aid. This redundancy caused by the displacement seriously compromised the ability of the youthful population to engage in food production while back in their communities which in turn affected household nutrition and further perpetuated malnourishment (Baines 2009; Baines and Paddon 2012). Depending on handouts and free basic utilities like food, soap, clothes and beddings in what key informants called the 'dependency syndrome', food production was compromised which further fostered malnutrition at home.

5.5.4. Toxic substances as cause of nodding syndrome

The civil conflict in northern Uganda involved various weapons used by the Uganda government and LRA rebels and narratives from a number of respondents suggested that the chemicals from these weapons could have been the cause of NS. This finding is not isolated to just this study.

NS was not experienced among the people of northern Uganda but only became evident during the era of the rebels. Affected communities believed that the war brought the illness because a lot of guns were fired and the heavy ones shook the ground. Some people thought the Sudanese government's attacks on northern Uganda with chemical weapons during the civil war was associated with NS claiming that the ground may have been contaminated as a result of the munitions used leading to brain damage (Van Bemmel, Derluyn, and Stroeken 2014).

Besides the fact that the symptoms of NS were first realised during the war period, the peoples association of the condition's emergence to the war was based on their mistrust of the president and his government. Perceptions in this regard revolved around poisoning and are rooted in the peoples mistrust of government which it was believed may have been on a mission to wipe the Acholi out. Historical factors, both political and social economic once

again are at play here because of governments track record of neglect of the people of northern Uganda as seen in my detailed presentation on the structural historical perspective in the general discussion chapter 8. In addition to the history of neglect of the northern region, the fact that it is only the Acholi affected in the entire country led many respondents to imagine the government was out to wipe them out as a people. A researcher from Ghent University who I was told had just left Kitgum at the time I gained entry into this study site in 2016 shared a similar report (Van Bemmel and Van der Weegen 2017).

Angucia (2010) makes a very interesting submission when she says that when a people are suspicious of those whose mandate it is to protect them (like was the case with the Acholi and many others in similar situations) actually complicates matters in as far as relationships and expectations between ethnic communities and the leadership is concerned. This, he goes on to say is made once in civil rebellions such as the civil conflict between the NRM and LRA for government to ensure security for its people as is mandated to.

The genesis of mistrust of Museveni and his government by the Acholi can be traced back to the peace agreement between himself and the then president of the republic of Uganda, General Tito Okello Lutwa (an Acholi) which was signed in Nairobi in December 1985. It is common knowledge that Museveni disregarded this oath and went ahead to overthrow Lutwa taking power in 1986 (Dolan 2005; Allen 2006; Finnström 2008).

This led to conflict between the formerly Tito Okello Lutwa Uganda National Liberation Army (UNLA) comprising soldiers from the northern region and the Museveni National Resistance Army (NRA) who among other war tactics “took” heads of cattle away from the Acholi which was interpreted by them (Acholi) as a way of impoverishing them (Finnström 2008:106). Food granaries were not spared either along with sexual molestation of both men and women, (Veale and Stavrou 2003; Dolan 2005; Finnström 2008; Angucia 2010).

The Acholi’s mistrust of Museveni was again reinforced during the Betty Bigombe peace talks with the LRA rebel commander Joseph Kony in 1994 when he, during the course of ongoing peace negotiations by his state minister for the pacification of the north, suddenly gave the rebel group an ultimatum to surrender within the course of seven days or be crashed. Literature documents that this and many such ultimatums came and went but the war never ceased prompting the Acholi to imagine that the president never at any one point had intentions of ending the war (Dolan 2005) or it would have been a thing of the past by then.

Operation iron fist 2002 is yet another example to cite which led to suspicion by the Acholi of Museveni's intentions. Having commanded some of the operations himself from a base in Gulu (Allen 2006), Museveni's 'operation iron fist' saw the death of many including abducted persons and notably children who he collectively referred to as rebels (Allen 2006). It is during this same period that the Barlonyo attacks happened which claimed the lives of many civilians not to mention the several acts of violence including sexual assault and looting on the Acholi by the national army claiming to protect the people. Suspecting the government to have had "other agendas" (Allen 2006:52) a number of analysts submit that inasmuch as the LRA capacities were underestimated, most of the armies used by the government were returning soldiers from a controversial mission in the Congo who not only were undisciplined but were also said to be carrying diseases and so Museveni wanted them out and used this as an opportunity to get rid of them. Dying in large numbers in Sudan (Dolan 2005; Finnström 2008), these dead soldiers were rumoured to have been the source of the Ebola virus that ravaged the north a few years prior only to have the whole saga covered up by the same government (Finnström 2008). When the Acholi claim that 'government knows the cause of NS' they in essence are saying that this unexplained condition in their midst could be the chip that the Museveni regime was using to 'finish them off under cover' especially since all other means have failed to get the job done. Important to note also is that this war also extended to some parts of North-Eastern Uganda (Obalanga in Teso land for example) but the local people were not displaced into camps like it was with the Acholi and as far as I know, NS has not been reported in these communities. Might Bøåz (2015) be right in concluding that one of the reasons for the war was the interest the NRM soldiers had in the productive farms in northern Uganda? Perhaps for this reason the Acholi are also right in imagining the government wanted to wipe them out.

This therefore still raises significant questions about the relationship between the IDP camps and the syndrome's onset.

5.5.5. Supernatural causality and witchcraft

Seeing that the NS problem was killing many of their children even after several options had been tried ranging from herbal medicines to biomedical remedies provided by the government, sections of the community in Tumangur decided that the cause of NS must be ancestral and spirit related. This was the case also because science had so far not been successful in finding the cause. Findings reveal that NS was also believed to have been caused

by spirits (*cen)* of those who died during the war – out of which were bad spirits (*jok*). As Allen (2015:362) clearly asserts, "witch-hunts, sorcery, possession by spirits and tales of blood-suckers, zombies, and shape-shifters abound.

Belief in witchcraft is rife among the Acholi and misfortune is often first and foremost attributed to this. According to Ashforth (2005:xiii), "no one can understand life in Africa without understanding witchcraft and the related aspects of spiritual insecurity". By ascribing the misdeed to witchcraft, one is able to cope with the pain brought about by this kind of situation because some kind of explanation is better than none at all. In a way the pain seems less since anger is directed towards what one believes is the source of their suffering. According to Finnström (2008), testimonies of former LRA rebels reveal that ancestral worship was popular in this region but the practice was forbidden by the LRA who used high handed means of killing old women and men who engaged in the practice with an aim of restoring moral order. Some people deliberately destroyed their own shrines or let bushes grow around them as a way of protecting themselves against the wrath of the rebels. This meant that ancestral worship during this period was not possible and these unmet obligations to ancestral spirits are what some respondents attributed the emergence of NS to.

Other studies have also linked the origin of NS to the supernatural. Van Bemmel, Derluyn and Ströken (2014) established in their study that some people believed that NS was not a medical problem but a spiritual one while others were of the view that it did not make sense to investigate this syndrome through the laboratory because demons could not enter under a microscope slide to be seen. Baines and Paddon (2012) also document that people in Acholi land believed that the spirits of people who suffered a violent death became *cen* and that so many *cen* were roaming the land since the war. Some reasoned that if a person is unjustly killed, the person dies angry. In retaliation, the spirits wreak havoc in form of death, ill-health and sometimes misfortune which is why NS was blamed on this spirit by a section of the respondents. Similar to this study, previous scholars reported the affected people's belief in the link between NS and the mass killings which took place during the civil war period (Buchmann 2014).

5.5.6. Vectors

Other explanations of possible causes included black fly infested rivers (Achwa and Pager), which were secondary to the causal explanatory models highlighted above. To an even much less extent was mention of animal ticks, heredity and fate. It was found that it is mainly health

practitioners who argued along lines of black flies as probable disease carrying vectors of NS. Practicing clinical officers and medical students have access to information regarding new advancements in research and it is against this that I believe their argument was based in which they attributed the origin of NS to river Achwa and Pager in Gulu and Kitgum respectively.

Studies to situate the NS epidemic in northern Uganda (Kitara and Amone 2012) show clusters in communities residing along the fast flowing river Achwa in Gulu and the Pager river in Kitgum district adding that this is indicative of a really high possibility of there being a relationship between the two (the rivers and the illness). Infested with black flies mainly in rainy seasons, these communities are also known to highly suffer river blindness due to *O.volvulus*; the vector responsible for its spread (Dowell et al. 2013; Mitchell et al. 2013; Landis, Palmer, and Spencer 2014; Winkler et al. 2014; Colebunders et al. 2014; Winkler et al. 2018).

Colebunders' 2014 publication on a new hypothesis highlights why children are more susceptible to the ailment by suggesting that while their parents may have developed immunity over time due to continued exposure to black flies before settling in IDP camps during the civil war, the children born during this period did not have the opportunity to build their immunity through getting in constant touch with the pathogen. He further argues that this explains why adults are not infected with NS. For those non immune adults in the same locations, it is possible that the reason behind their safety is they likely have not been exposed to infected black flies long enough to have adequate amounts of the infection if the NS pathogen is a micro filarial endosymbiont (Colebunders et al. 2014).

Very recent findings indeed indicate that black flies play a role in the transmission of the parasitic worm *O.volvulus* that either directly or indirectly causes not only NS but also other forms of epilepsy in onchocerciasis endemic areas (Colebunders et al. 2016). However, while in some instances respondents in these communities contended with preliminary research findings as reported by government (The Daily Monitor 2015) associating NS to onchocerciasis, a number of participants openly rejected them. When GOU on 21st December 2015 launched their official position from research findings regarding what causes NS in Uganda, affected communities in both Gulu (where I was conducting field work at the time) and Kitgum districts (where I went after Gulu) were very quick to angrily dismiss these findings claiming the river was in place long before the syndrome. The Acholi are not an

isolated case in this discourse. A related example is that of the Chamorro local affected communities on the Island of Guam[38] who rejected theories of causation to *Lytico-Bodig* – also a poorly understood illness. Reports indicate that *Lytico-Bodig* (local chammoro term for the Alzheimer disease) may be caused from eating flour made from the inadequately detoxified *fadang* nut of the cycad plant but the local population rejected this theory (Keck 2011). A related theory was that the source of the disease was that people ate bats which fed on toxic *fadang* nuts. Other rejected aetiological theories include the aluminium toxicity hypothesis that the "low calcium and magnesium concentrations in the soil and water cause an excessive absorption of aluminium" leading to the Alzheimer disease (Keck 2011:107). Keck is also not in agreement with advances that the disease resulted from genes transmitted during incestuous actions. While the medical cause(s) of *Lytico-Bodig* remain unknown, it is thought to be caused by a combination of an unknown genetic predisposition and an unknown environmental factor (Keck 2011).

Colebunders et al. (2014; 2016) also affirm that although the civil war may not have been the direct cause of NS in northern Uganda, it certainly did provide an enabling environment for its break out (see also The Daily Monitor 2015). For example when people sought safety in bushes close to rivers with infected black flies, they were rendered vulnerable to their bites and prone to being bitten by the disease causing vector. The inability for the GOU to implement eradication measures such as the use of black fly larvicide because of the war also exacerbated the rate at which the population was exposed and rendered susceptible to this condition. He also points out issues of immunity before and after the war started. During the time people were in IDP camps, the hardest hit areas had a large amount of black flies reproduce during these long periods of the peoples absence and upon their return (where children had low or no immunity whatsoever) susceptibility was really high coupled with the late exercise of aerial spraying to kill the black fly larvae which was upon the recommendation of the WHO Kampala 2012 scientific meeting on NS.

[38] My choice of research focus was in part motivated by Verena Keck's study of the Chamorro on Guam Island. The study was on neurological diseases known to have existed since the nineteenth century (Keck 2011). In this anthropological study, Keck sought to find out the perceptions the Chamorro had about the possible cause of these diseases whose aetiology, like nodding syndrome, was still poorly unknown. The findings of my own study bear strong resemblance to her study findings which serves to highlight the conflict local populations have regarding the bio-medical and their own understanding of their condition. In Moss' review of Keck's book; A search for a cause which was published out her findings in this study, he submits that Keck was very careful not to criticise medical assumptions made of the diseases.

Other questions that arise include why children particularly have been vulnerable to NS and why other regions of the world that have experienced long civil wars have not reported cases of NS (Van Bemmel, Derluyn, and Stroeken 2014). One could argue that children were more vulnerable to the emerging NS because they were too young to cope with the traumatic experiences of the long civil war compared to adults. The people's narratives show that affected communities are waiting for the scientific community (read doctors) to establish the aetiology of NS and subsequently provide the 'right' treatment to heal their sick rather than the current situation where they die even when on a specified treatment regimen from health care centres.

It suffices to add that the explanatory model that different respondents chose to explain the probable cause of NS was dependent on issues revolving around the self and interaction with their reality, be it political, social, economic or environmental. Their perceptions were also laced with feelings of hopelessness in view of the period it has taken to establish the syndromes' cause and considering that local and international support has dwindled over the years. Winkler et al. (2018) actually submit that NS should now be categorised by WHO as one of the neglected tropical diseases.

5.5.7. Hybridisation of lay and biomedical perspectives

Culture and biology exist in a relationship that is dialectical (Weaver, Meek, and Hadley 2014). In this study, respondents sometimes merged aspects from the biomedical field with those that had cultural or social roots in what I choose to call hybridisation of lay perspectives with biomedical perspectives. This was done as they spoke in about what may have caused NS but also in describing the illness experience as well as healthcare related issues.

It was, for example evident that the people were not ignorant of disease causation as seen from a biomedical perspective, but they chose to acknowledge sections of it and yet rejected others like in the case of the NS classification in recent reports and publications as a new type of epilepsy (Colebunders et al. 2016; see also Idro et al. 2016). Advances in biomedicine have been documented to have the potential to yield particular behaviours in people and affect their experiences, among other things (Conrad and Barker 2010).

The results presented above also highlight an intermingling of local and biomedical perceptive towards disease origins in what is commonly called hybridisation. Terminologies like *luc luc*, literally translated as nodding in Luo were for example used alongside NS or

simply “nodding” from “Nodding Syndrome” which was the medically assigned name for the condition (see WHO et al. 2012). Some respondents were found to bear hybrid explanations for the emergence of NS for instance a father to one of the victims thought the origin could have been an evil spirit *oteltok* or the dirty water people used while in the camps. While some families believed it was a work of witchcraft and therefore sought redress from an *ajuoga* (literally translated as healer in Luo in reference to a witch doctor or traditional medicine man)[39], they also took their ill children to formal HCs for anti-seizure prescription drugs. In the event that death of their kin occurred in a healthcare facility, they demanded for a post-mortem report to establish what is written as having caused the victim’s death.

The specific aspects put across were also not purely (for lack of a better expression) lay or biomedical, but some did overlap and were cross cutting. In a bid to explain the origin of this condition, affected communities drew on whatever resource they had both from their understanding of how diseases are aetiologically classified in the biomedical field as well as from their psycho-social world. This is shown by the results in which submissions sometimes cut across both the physical and social domain in explaining the probable cause of NS. Analogies are a great help in aiding the understanding of ill-health (Biehl and Petryna 2013; see also Kirmayer 2000) just like “images around which an illness narrative can take shape” (Good and Del Vecchio Good 1994; cf. Nichter 2008:43). It also is attested to by Farmer and Good (1991; cf. Lynch and Medin 2006:287) who present an example of a case in Haiti in which, a man exclaimed: “I understand that a virus causes AIDs but the question is who sent the virus!” during an awareness rising campaign about how HIV and AIDS are related. This example points to the fact that while acknowledgement was made of the biology behind disease causation, the cultural orientation of witchcraft was also maintained. In the same way, Evans-Pritchard (1976) shares one of his experiences with the Zande saying that they acknowledged the natural way by which people become diseased but greatly desired to establish the witch responsible for starting the ill-health process given that they also believed illness was a result of witchcraft.

[39] During fieldwork I learned that there were two kinds of traditional healers in Acholi land. The traditional herbalists who used knowledge of nature often passed down from earlier generations to offer medication in natural plant form to their clients. The other kind was the *ajuoga*. This was a medicine man commonly known as a witch doctor who, along with his treatment concoctions, claimed to use supernatural powers for his trade. It, however, also came to my notice that there existed a very thin dividing line between the two because for economic reasons herbalists too are now found to claim the ability to use supernatural powers in their healing activities. This was due to the large clientele base, the *ajuoga* had in comparison. For purposes of clarity, in this thesis, I maintain a distinction between a medicine man (witch doctor) who I refer to by the Luo local term *ajuoga* and a traditional herbalist.

To redirect this discussion to the perceptions of affected communities towards NS, the affected population acknowledged the classification of symptoms in biomedical terms even coining their own ("fitting") along the same lines used in reference to fits or seizure episodes, adopting the use of NS (or simply "nodding" or 'nodders') to refer to the condition and victims respectively. NS was also blamed on witchcraft which was practiced in this population too claiming that enemies "sent" misfortune in form of NS to affect children and cause suffering and ultimately death in the homestead. Attributing it to envy, this envy was due to a variety of factors like relationships, wealth, and superiority – to mention but a few. For instance when a wife imagined that her co-wife was jealous of her because their husband loved her more than herself or loved her children more than her own then this was ground enough for her (the co-wife) to bewitch the other set of children either some or all of them by appealing to supernatural powers who then sent disease in form of NS.

Synergies between the biomedical and anthropological models of how disease and illness is defined and experienced are crucial in understanding what informs the people's perceptions and what interpretations accrue as a result. It is closure of this gap that will then lead to proper management of the phenomenon as continued research is done.

5.5.8. Conclusion

The perceptions that study participants had about the emergence of NS were embedded in contextual factors over a long period of time. They, however, also kept changing from participant to participant and from time to time. In some cases it appeared like it was some kind of a memorised script that one recited without much thought which also pointed towards contextual and circumstantial influences. Indeed two respondents asked what I wanted to hear so they tell me exactly that. The lack of consistency was a result of a number of factors including expectations and strategic positioning for some form of benefits or reward. This situation arose from both internal ethnophysiological[40] processes and external influences comprising cultural, social, political, economic, and environmental factors as well as genuine ignorance and/or confusion about how to perceive the condition but also as a result of conviction at a given point in time.

[40] "Ethnophysiology is the study of how bodily processes are understood in different cultures and how such understanding influences perceptions of health, physical development, illness, medicines and diet" (Nichter 2008:25).

6. THE ILLNESS EXPERIENCE

This chapter focuses on the narratives of the victims, their caretakers, healthcare providers, community members and key stakeholders about their experience of "nodding syndrome" (NS). It also tackles the presentation of NS and its severity as felt from the local people's perspective. In addition, the chapter highlights the impact of NS on affected communities and what affected communities think about its communicability.

In response to my question on how they would describe the lives of NS affected children in their community, respondents looked at different parameters, including but not limited to the physical appearance, feeding or nutrition, the victims' past and present visible health status and they spoke about the environment in which affected households lived.

As already mentioned in preceding chapters, it has been a long period of time since NS was first reported in northern Uganda but for lack of a known cause and cure, the condition continues to relentlessly trouble its victims until their death. A number of affected children have died in secondary circumstances as a result of the symptoms of the illness while some have lived with it for 10 or more years. At the time of collecting this data set, I observed that the symptoms associated with the illness still troubled many children and these symptoms sometimes differed from child to child. For this reason I decided to delve into this subject, findings of which are detailed here below.

6.1. How nodding syndrome victims present

6.1.1. Signs and symptoms: the victim's perspective

My focus regarding this particular study objective was primarily towards the victims of NS or the children/young adults diagnosed as suffering from NS. Responses at the time of data collection were obtained from victims depending on their age (12-24 years old), willingness, and ability to share their experience. However, given the detrimental impact of the illness (as is presented further on in this chapter) specifically on the mental capacity of the victims, a number of affected children in the sample were not able to verbally, audibly and/or coherently share their illness experience on their own. This was, nonetheless, made up for by their primary caretakers who described what they observed from their ill dependants in the process of taking care of them. I also relied heavily on my position as a participant observer to obtain as much insight as I could on this matter.

Older victims (15-24 years old), and those in a much better health state (last seizure at least two months prior to the interview), spoke about their symptom experiences from the time they were able to recognise them. But even then, they still did not say much because of the physical and emotional strain the illness had put on them. Regardless, those who were able to spoke of how difficult it was for them when symptoms (especially seizures) set in and how they subsequently felt.

Some victims stated that they were able to tell when a seizure attack was looming but once it eventually occurred, they were unable to recall what had happened during the process. What they were sure about, nonetheless, was that they had strong headache episodes, seizure attacks (which they referred to as 'fitting') and general weakness.

> I see a person coming to attack me and when I try to dodge, I fall. I do not know what happens after, it is my friends or people at home who tell me what happened after my recovery. (V7)

> I see red and sometimes darkness but after that I do not remember anything else. When I wake up I realise something happened because I feel terrible headache and sometimes find I have soiled my clothes. (V2)

Most affected children said that they did not feel anything before the attack but only knew from friends and family after it had happened. Regarding how he felt before he got a seizure, Thomas, an NS victim from the Odek sample said:

> I do not feel anything before. I only wake up and find myself lying down but without energy and sometimes with a terrible headache. But ask my mother, she knows. (V8)

In one household in Tumangur, the parents of an older victim told me (in his presence) that on several occasions, he shouted and spoke continuously while under attack saying that one day he would swallow all his tablets at once so he dies. With a shocked expression, this 24 year old young adult looked at his mother with teary eyes and said quietly:

> Mother, I never knew this. Why did you not tell me before? I could easily kill myself without my knowledge. Please take all the medicine away from where I can find it and hide it so that I do not kill myself since I never know when the "thing" is coming. (V10)

The seizure attacks were loathed by almost all affected children because they often wet and soiled their pants which made them feel really embarrassed and small after the incident had run its course. A key informant shared about an occurrence at one of the primary schools in the vicinity where a 16 year old girl was forced to drop out of school because younger pupils

always gathered around her whenever she had these symptomatic attacks during which she was stared at and later made fun of to a point that she could not stand it any longer.

> For those above 15, some have low self-esteem and some drop out of school because they feel ashamed. You know when in primary school, people do not behave maturely. If one falls and starts getting fits, people will gather and start making fun and that will become the topic of the day so they will keep discussing and in the end they feel out of place. I know of a 16 year old girl who was forced to drop out of her primary school because she felt embarrassed every time she fitted and small children made fun of her. (PH4)

In some cases victims did not have seizures at all during an attack but felt general body weakness, nodded their heads continuously like the heads were being pushed from behind or suddenly started behaving in an unusual way for example staring in space or at one thing while doing something else altogether or shouting suddenly and running off to the bush like they were being chased. Some lost control of their excretory organs and either passed urine, stool or both during a seizure attack.

> I do not have fitting problems, my only problem is general body weakness and I feel very weak sometimes. (V6)

The special needs teacher at the H4H care centre in Odek attested to this saying:

> They also feel weak in their bodies. You may see the body weight and think they are strong but if they say I am feeling weak, accept it because if you try to force a child with 'nodding' to do something, you are causing problems for that child, accept it. You are not feeling it but the person telling you is aware of what is going on in their body. There are others who say that almost all the time they feel sleepy. These cannot sit in class because every time they need to be doing something to keep them from sleeping. They also feel dizzy that keeping a child with NS standing for 15 minutes will be causing problems. (K3)

Walter, a 16 year old male affected child in one of the primary schools in Odek answered in the affirmative when asked if he had a health problem adding that the problem was "nodding disease". Asked how he knew it was this, he said:

> I did not know that I had 'nodding' until I heard people say that I was a 'nodder'. I come here for re-fill because the drugs they give me have helped me live a better life. I do not get 'fitting' like before and I am able to help the family with garden work and even walk two kilometres to school which I could not do before. The bad thing is that when you come here, you are told of drug 'stock outs'. I went to the care centre to see if I could get the drugs from there but was told the only drugs they had were for those children under their care. I am asking that they take us to higher hospitals like in Kampala where they can heal us completely. (V6)

This affected child looked physically healthy, with well-toned muscles most likely from the daily two kilometre walk to and from school and garden work which he testified to sometimes be able to engage in. He looked well fed also (going by his physical appearance) but wore a "blank" facial expression that to me seemed to communicate frustration and/or hopelessness. I wondered if he ever smiled let alone laughed because he just kept saying he does not think about anything. He said he preferred to sit and be left alone. To an onlooker, his posture and whole self, communicated sadness.

> I have lost hope that it (NS) will go away because it has overstayed. (V6)

Agnes, a 20 year old female was declared an NS+ victim which classification signified that she had both NS and epilepsy. She had a 17 year old brother who had NS only and both of them lived in Tumangur as the only children born to their parents. In her account of the illness, Agnes visibly looked frustrated and mentioned that she was disgusted of the constant seizures she suffered which kept her stuck in primary four at school while her colleagues continued on to primary seven. In fact, she had suffered an attack even the day before we held this interview but had recovered enough to willingly and actively participate. During the interview, she spoke about how she wished she would die since the illness was disturbing her a lot.

> I feel stuck because of this 'nodding' and see no future. Can you imagine at school the teachers tell me to repeat primary four year after year and yet my colleagues are now in primary seven? For me I just want to die because I see no future with this disease. I cannot even do things a grown up girl is expected to do like cooking because my parents fear I will have seizure attacks in the process. I cannot have a family of my own because I cannot do these things. I am useless; I wish I could just die. (V11)

From the voices above and several others within the study, the symptoms of affected children were more or less the same including seizures, headaches, head nodding and fatigue (to mention but a few) albeit to a varying extent. Victims also spoke about how being ill and experiencing these symptomatic attacks made them feel especially regarding future family life and social economic activities.

At the HC III in Odek, Rose aged 38 walked into the office for her prescription drugs when her turn came at which point I asked Justin the clinical officer on duty that day if I could interview her. With his consent and that of the patient, I asked Rose what her problem was and she, without any hesitation responded that it was "nodding". Turning to Justin I asked what explanation there was for NS at her age to which he responded that it was normally

strange and rare, usually affecting only children between five and 15 years of age. According to her, the problem started in 2006.

> It started like a spirit. It would attack me at night and I would feel like it wanted to throw me down. My husband was scared and he left me. Now I am alone after having produced five children who are all normal and do not get this head nodding and epilepsy. (V13)

I was told that she was not epileptic in 2006 when her symptoms presented and that when she got attacks, she would feel that her head was very heavy and would feel a strong headache too. Later on she began having seizure attacks.

> It throws me down and I lose consciousness but the people who see me when it happens, say that I have fits. (V13)

However, a senior health practitioner at the HC concluded that it was most likely only epilepsy not coupled with NS.

> There are different kinds of epilepsy. There is one called focal point where you find that one gets partial seizures with just part of the body shaking and also generalised seizures. But for her, it started with the head which is similar to 'nodding' although I think it still is epilepsy. (PH4)

One parent vividly recalls how embarrassed his now demised 19 year old son felt when he wet his pants in his presence during an attack, something that happened on many occasions when he had symptomatic attacks. He reminisced that:

> We were sitting around here from where we are now talking. He suddenly kept quiet and had a staring look which always happened when the thing was coming. It did not last long but I realised he had wet his pants. When he came back to his senses, he clearly was very embarrassed that he stood up and began walking away. I said to him, my son, do not feel bad…it is the disease which makes you do this but it will go away. He then spoke up saying 'I am useless and it is better to die because now see what the disease is making me do'. (C8)

This parent went on to share that after this kind of scenario the son would often say to him that he was useless and would not amount to much if the illness was even leading him to soil his pants even though he was an adult.

> Kinyera (V5), a 15 year old male victim, came and sat next to me last November and I said Kinyera, you do not look happy what is the problem? He said, madam for long I have not been happy and have been thinking how am I going to be? I am now 15 years old and I am short, cannot work in the garden, wash and even bathe. I see that I am no longer growing, how am I going to be? Then he started shading tears. From there I took him to a private room and asked Kinyera, what happened to you that made you start thinking these things? He said that the step mother abuses him that he better

> die because even if he gets cured, he is not going to give any help but is going to be fed like birds which are just fed and do not participate in looking for food. He added that 'actually sometimes I feel like crying and think that maybe I should not eat so that I die because I am just a burden to my father'. (K3)

The above quote is of a caretaker sharing the feelings of the affected child under her care at the institution. Some victims chose to have hope and look at the positive side of life which also enabled them to have dreams for the future. Those who were able and willing to shared their feelings with me. The willingness was hinged on the medium of communication (language) and trust. My Luo was not good enough to sustain a conversation such as this and neither was their English. I also realised that it took a very high level of trust in a person for the NS affected children to share their inner most thoughts. Their trust was therefore mainly in primary caretakers with whom they stayed most of the time and who directly provided and had responded to their needs over a relatively longer period of time.

At the time of this study, an 18 year old NS sufferer (Fred) had a 16 year old partner who was NS+. She was pregnant with his child and they lived together in his mother's home in Tumangur. Fred shared that though there were challenges involved in this kind of relationship given that they both were affected, he decided to look at the positive side of the story and try to live a relatively normal life like others do.

> As you can see, all four of us children born in this home have 'nodding'. Our sister died and left behind that two year old baby you see there. I decided to not simply sit and wait to die but to try and live a normal life like others. She (pointing) is my wife and she is even pregnant now. (V12)

> I want to be able to wear a uniform and go to school like the other children and become a nurse when I grow up. (V14)

> When I grow up, I would like to become a *lafony* (teacher in Luo) and to have my own home as a married woman. (V1)

The younger victims in this category of the sample did not think much about the future but relied quite a lot on what their parents and caretakers said of the condition.

> I just want to play football but I keep feeling headache. My father says that I shall be well and grow up to attain my hearts desires. (V15)

6.1.2. The caretaker's perspective

The caretakers too were affected by the fact that their close relatives were ill. As a result, they experienced the illness in their own way alongside their directly affected kin. Moreover, some caretakers were of advanced age and others physically challenged. The aged caretaker

scenario was attributed to bereavement where younger relatives died either during the war or of HIV/Aids. Inevitably, grandmothers, elderly relatives or siblings had to assume responsibility under such circumstances. There were families whose caretakers ranged from 55-85 years of age and while of these, some were physically able bodied, others were physically weak and obviously in not a good health condition themselves.

They got food from neighbours and well-wishers once in a while which was not sustainable. It was at this point that world vision international[41] came to their aid by providing food for the two to feed on for some months and ensuring a new hut is constructed for them. An old lady aged over 85 years in Tumangur was abandoned with an NS affected child of 16 whom she hardly could care for. The hut in which they were abandoned soon collapsed to the ground for lack of timely maintenance. They got food from neighbours and well-wishers once in a while which was not sustainable. It was at this point that world vision international came to their aid by providing food and ensuring a new hut is constructed for them.

> It is not that we do not have relatives at all but they left us and want nothing to do with us because Sam has 'nodding'. I could also not just leave him like that but because we are both helpless, the house fell and it is the neighbours who helped us repair it a bit. World Vision came and helped us also with food and other necessities because I cannot leave the boy here alone as he is and do not even have the energy to go to the garden anymore. (C18)

Parents and caretakers also shared what they observed and perceived of the illness in the children under their care partly because a number of victims were not able to speak about their own illness experience. Findings show that their focus was mainly on how the victim's behaviour had changed as a result of the illness and how this impacted them as caretakers and family members.

> It was disturbing her a lot that she often would become weak and fall. In the evening she had stomach ache. It started as epilepsy but later included NS. At first she had ringworms, the ears were not working well and white stuff was coming out of them and that is when she started falling like something was pushing her from the back. We knew it was nodding because during mealtime, she would stretch her hand beyond the plate. Nowadays she is very wild, moving everywhere and she does not like kids. The mind is not settled since those days and the symptoms appear any time. If you stay a little longer here actually you will see. Unfortunately she cannot tell you her own experience because she does not know. Only somebody else can tell you. (C7)

[41] World vision international is an NGO which seeks to address causes and effects of poverty through development, relief and advocacy:

> They cannot work for long because they are weak due to the infection they have and cannot work in the field for long because if they take long working in the fields then it comes. They cannot last even two hours because even at the centre, we have our small kitchen garden but there are children who cannot even do cultivation work at all and yet it is a small garden whereby we want them to learn how to hold a hoe and plant some vegetables like onions, egg plants and others needed in a kitchen garden but they cannot. And the relationship between doing garden work or doing some hard work and the attack is unknown. (K3)

Many men and women said that the caretaking role had tired them. They recommended that they be relieved [of this burden] by having all affected children withdrawn and taken to a central institution where they could be taken care of by paid professionals as seen from the field voices here below.

> These children should be taken to the same place and be kept together for them to get the drugs they need consistently and not to mix with other children. This will help them get the care they need to get cured because as caretakers in the homes, we do not have time to take care of them since we have to go and work in the garden, attend family gatherings or go somewhere like weddings or any traditional ceremony. So when we are away, there is no one to stay around looking after these affected children. The child may deceive you saying I have taken my drugs and yet they have thrown them away or damped them somewhere. So for me, if there was a place where they are continuously monitored, they can take care of the sick children to monitor them if they have taken the drugs because we caretakers have to go and look for food and what they will eat. This role is very tiresome; I feel very tired. (C7)

An employee at H4H corroborated this when she shared as here below:

> I think parents are tired of their children because even when the child is not badly off, they come here at the care centre and plead begging that their children get enrolled. Even the children themselves come who you see are not doing badly. Like that girl sitting there (in reference to one such patient), she has been coming here every day to plead for a place. But I think it is also because of the food they see these children here eating, the uniforms and the buildings. For example Opio also was in our day care programme and when he got better he was phased out and recommended to join a normal school but he never wanted to go to a normal school because there they have no breakfast and no lunch. He wanted to stay here and so he came from home every day still but after talking to him and telling him that if it is hunger that causes him to do that, we would talk to the parent about the feeding and I think it worked because he no longer comes around (K3).

A sombre mood was evident in these communities and this was not limited only to those directly affected but households without victims as well. Indeed, before the demise of Job's 19 year old son, Job himself was challenged when he attempted to offer his son hope.

> He used to call himself a 'moving corpse'. And if you told him to stop saying this about himself, he would say 'If you are saying I will heal, just show me one person who has been healed of 'nodding' as proof' (C8).

The only thing several respondents said they did not know was when the ill children would die but they were certain that that is what would finally happen.

A 17 year old sister and primary caretaker of an affected younger brother lamented that:

> This disease is very painful, even more than HIV because if you see how these children are suffering (shakes her head sideways and pauses for a number of seconds). With HIV if you are having it, you can do something like work or take care of yourself but this disease… (Shaking her head still). (C12)

This girl was the head of the household, having lost their father during the civil war and their mother simply walked away from the family most likely due to trauma. I met her at the HC close to where I lived in Tumangur after she had been waiting for the healthcare givers for re-fill of her brother's medication who could not make it himself given the 14 kilometres walk to and from the HC[42].

A senior health practitioner in Odek put his focus on behaviour saying:

> These affected children have some strange behaviour which has come because of the problem. You just look at any and know that something is wrong with this one. Even when you have never interacted with this person before, you can just see. (PH4)

6.1.3. Symptom triggers

Speaking of symptom triggers, respondents raised a number of factors as being responsible for triggering the onset of NS symptoms in the victims. Narratives included cold weather, the position of the moon, meal time as well as inconsistency and /or change in the drug regimen. For several others, however, symptom onset was not particularly triggered by anything in particular and could occur at any time.

> It also normally disturbs him during time of eating. When he is seated like this, the boy will pick up the millet bread and get stuck with the bread in the hand without even eating. It will start like it is choking him, stretching the child then he will fall down lose his senses and will not know what happened. (C11)

[42] This detail is important to highlight and is discussed in detail later as one of the challenges affected families had in as far as healthcare access was concerned.

> It started when this boy was in school the other side of Pader. He came home to visit and when he was about to start eating the food he had been given, he started acting like someone was pushing his head from behind until he fell down. When interviewing the child for registration at H4H, he could not speak. Even at home, it was the same story. Sleeping with food before him went on and did not stop. (C5)

> Anytime she loses her senses. Like now she is a bit okay but if you stay here for one hour you will see. (C7)

One clinical officer pointed out that symptoms, especially seizures do attack patients any time of the day but are more severe at night because it is cooler then. This corresponded with the observation that cold weather does trigger seizures in almost all NS victims going by the fact that it is often very cold at night and many of these families are too poor to afford blankets. In my host family, the affected 14 year old had very bad seizures sometimes every night and almost none during the day when it was warmer. Her mother also spoke of the position of the moon as a trigger factor.

> When it is cold, it will be disturbing the boy very much. It can disturb him from morning to morning. It is actually worse when it is cold and for our neighbour Thomas, It disturbs him when he is going to sleep probably because it is cold in the evening but in the morning he feels okay. (C2)

> She also falls when the moon is high up and when it is moving away. Sometimes four times a day here and at school. The wounds on the face are because she falls on stones and hits her fore head on the floor repeatedly. (C1)

For 12 year old Moses, symptoms were triggered mainly when he was standing but not while sitting and they occurred at least three times a month. They only reduced with the medication he received once a month from the HC after his ailment had lasted three years. His sister had passed away of uncontrolled NS induced seizures which affected her ability to eat. Too weak to leave her bed, she developed an incurable infection from the sores that ensued as a result and soon after died.

> She was having frequent episodes of seizure attacks and therefore could not eat. Because she was always confined on the bed, she developed sores which made her even weaker. She could not be carried to hospital because of the very long distance of about 10 kilometres on foot. They stay in Lukoro, Binya parish and so she died like that. (PH4)

6.2. Day-to-day life with nodding syndrome

My intention here was to establish how victims lived with the symptoms of NS. Almost all the victims who could share their feelings and experience of this condition considered NS severe. According to them, the symptoms of NS were difficult to live with for as long as the

cause is unknown and there is no cure in place. This was because victims were no longer able to do what they once did with ease for themselves.

> Living with "nodding" is a problem because the drugs we give are only to reduce the symptoms. A disease with no known cause or cure for sure is a true challenge. (PH5)

> With this disease the children can do nothing for themselves and everything has to be done for them. When they have seizures throughout the day for many days, you feel like you are also a 'nodder' because caring for them is not easy. (C3)

> I used to be able to sell produce from the garden and meet my needs because we all would go to the garden and work together but now because of the disease they cannot work anymore and I am almost always here taking care of them which interferes with garden work even more. This disease for sure has made us beggars. (C1)

Several parents and caretakers also described how challenging it was to live with NS from the perspective of the symptoms (especially seizures) and the ability (or not) of the victim to manage tasks like personal hygiene and house work on their own compared to earlier times when they were not victims of NS.

According to one of Vicky's caretakers, her symptoms were so severe that they thought it was going to kill her. This was in reference to the seizures she suffered frequently before they were able to acquire medical intervention to help contain the problem.

Simon's father spoke of severity in view of the fact that the condition lasted too long.

> We were seeing him like he was abnormal, like he was running mad so we were taking it as something minor but when he reached the age of seven, we started seeing that this thing is beginning to be chronic. (C2)

An employee at the H4H NGO spoke of severity by addressing the fact that ultimately affected children have died, one at a time because of no cure. This, she emphasised by saying that:

> Regardless of whether the child has frequent or infrequent symptoms, for as long as this child is not declared free of the illness, then it is always a severe condition. While it was obvious before medication was provided that the children had severe symptoms, it is very difficult to tell how severe the condition is after the victim has been on medication for a while because most affected children actually have a reduction in seizures with medication. Coupled with good nutrition, they even look healthy but when a seizure suddenly occurs it is so bad you who observe it can never forget it. Beware also of the time when the child seems stable because when the attack comes, it will have come to kill. (C5)

NS affected children physically, socially and psychologically. Physically, victims were found too exhibit stunted growth and underdeveloped sexual characteristics.

6.2.1. Stunted growth

Narratives included terms such as “stuntedness” which were used in reference to physical stunted growth of NS victims. Other expressions used to describe the NS condition included madness, malnourishment and poor hygiene- to mention but a few.

> If you look at such a child, you may think that he or she is 7 years old and yet they may be 14 or 15 years old. That is what I have seen here. (PH5)

> This ‘stuntedness’ is partly attributed to poor feeding because even us health workers sometimes have a problem accessing food for example meat here is slaughtered only on big days like Christmas or may be independence day. People buy greens from the market at Malaba and when you ask them why they do not grow their own greens given the uncultivated land you see around they claim they do not grow such crops because the animals (goats, cows, sheep et cetera) eat them. What happens is that these animals are secured on trees during the time when planting, weeding and harvesting is going on which is practically done at the same time for the entire community and towards the end of January and early February, the ropes are cut off of the animals in every household to enable them move around freely and fend for themselves before they are secured again when the next planting season begins. Problems arise when some animal owners cannot afford ropes for their animals or simply do not secure them which culminate into quarrels and fights over eaten food. (PH5)

In school, children are not given any food. They are supposed to carry packed lunch which they do not carry because they can only afford one meal back home and nothing extra. Few who have food left over from the evening meal eat that before school and stay without eating any other thing until they return home in the evening, often after walking very long distances. This applies to both affected and unaffected children but the repercussions of poor nourishment and signs of stunted growth are mainly more pronounced in the NS affected children.

On the contrary, they also were seen to have an increased appetite eating double or thrice the portions other children their age eat. They also felt hungry almost all the time which drove some of them into the act of theft where they would get into gardens not their own to uproot cassava for example which they consumed raw to ease the hunger pangs.

It was observed and also shared on numerous occasions by several respondents that the symptomatic drugs affected children were consuming led them into having a heightened appetite which therefore necessitated that meals are provided not only in large amounts but

also several times a day. As a participant observer of affected children during meal time at the H4H care centre in Odek, I witnessed children being served substantial portions of food but after they ate their share, they almost always wanted more and more servings. One day, one of these children angrily proclaimed *dek titiri* literally translated as little food, while sadly looking at the portion he had been served. At this moment staff members broke out in conversation about how the medication causes these children to eat too much which in turn affected the care centres food supplies.

> They are stunted and many clearly look malnourished. The way I am seeing, their problem is about feeding. The care takers sometimes do not look after them well. They do not care for them correctly, me myself when I see them, it is a problem of nutrition. (K1)

> For me I've failed to know it. I have seen clients physically they are stunted, as if they are malnourished. So I've failed to know about it. (PH5)

6.2.2. Changes in cognition and temperament

Affected community members also spoke of violent behaviour in the affected children that caused them to engage in fights and rude talk almost all the time. These violent attacks were not limited to their peers alone but extended to include elders like their teachers, caregivers and visitors like myself. It is partly for this reason that affected children were sometimes thought to be mad.

> When you see these children for the first time, you cannot help but think they are mad or mentally disturbed. This is what comes to your mind first. They really look mad the first time you see them. (C14)

Demon possession is what Walter who is a clinical medicine student from one of the affected communities likened the behaviour of NS victims to.

> The affected children look demonic, like they are possessed. They speak of seeing people with spears, the dead, hell and things like that. My brother even speaks of conversion with Jesus Christ. He says people should stop drinking alcohol and going to discos or they will go to hell. (C13)

One of the long serving employees at the NGO care centre said that her first impression of the affected children was that they looked like they had a serious mental problem which affects their learning ability.

> They also have low learning ability and that is why they were providing them with food supplements but now they have stopped and the children are now worried. This NS has affected children's learning capacity and that is what I can say as a teacher. You have not to teach much and when you do,

> you should not go deep because their learning capacity is impaired and has resulted into learning difficulties. Some have a severe problem in the learning field, others moderate while others mild. Severe in a sense that they walk, wash, bathe and do other things but while they have stayed at the centre for longer than a year, they still do not know how to hold a pencil. So that is according to my department. (K3)

Respondents also spoke of violent behaviour in the affected children that caused them to engage in fights and rude talk almost all the time. These violent attacks were not limited to their peers alone but extended to include elders like their teachers, caregivers and visitors like myself. It is partly for this reason that affected children were sometimes thought to be mad.

> As I talk now, there are few cases of fighting especially at the care centre although at their homes some parents also do complain. But there are also parents whose tone is not good on the seizure. The way they talk to the children – ever rude, shouting what would you expect from a child who is sick. (K3)

> Achan likes fighting with stones and sticks which brings anger and hatred in relatives here. Me I fear Achan. She once threw a stone at me also. (C1)

Full of uncontrollable anger, Achan started fights with colleagues (boys and girls, younger or older than herself) for no apparent reason on almost a daily basis which I on several occasions witnessed personally since I lived in their home during my field work stay in one of my study sites. This was her trademark and what she was best known for at the care centre that on one occasion, one of the teachers slapped her for her aggressive behaviour which was not exactly the right behaviour either. She then took off running for over a kilometre back home in anger and decided she never wanted to return to school again.

During such times her medication would be interrupted given that in the morning and afternoon, patients obtained their medication at school. Feeding at the centre which is regular and highly nutritious would also be compromised until she somehow was persuaded to return. This, she eventually did do most likely for feeding purposes because hunger problems for affected children were really serious in individual households[43].

NS child and young adult victims also felt different from the others in a sense that some of them were severely scarred and therefore visibly looked different with these scars. Some of them were also short while others looked too small for their age, had undeveloped or under

[43] The usual days schedule involved garden work without breakfast until around two or three in the afternoons. It was only after their return from the garden that the day's meal was prepared and then had earliest at five o'clock in the evening.

developed sexual characteristics, could not ably do what others their own age easily did and were treated differently by their parents, caretakers and the community. This affected their esteem and subsequently the way they behaved. Several girls preferred to be left alone and were timid while the male victims exhibited very aggressive behaviour.

The term ‘nodder’ (denoting one with NS) was a label also frequently used to identify affected children. This label created a feeling of segregation which in turn affected their self-esteem. They developed feelings of embarrassment and felt ashamed of themselves. To compound it all, the fact that the cause and therefore cure are still unknown created fear and apprehension in them about their future.

For NS victims above the age of 15, the low self-esteem was in part due to the seizure attacks they suffered and for which they were made fun of by especially unaffected young school going children and a number of community members too. However, it was found that some respondents also used a variety of inherently segregative and devaluing terms such as ‘nodder’, coined from the primary symptom of nodding one’s head continuously, moving corpse, and moving coffin in reference to affected children.

6.3. Communicability of nodding syndrome

Affected communities seemed convinced that this illness is communicable even with information being passed on to them from different medical sources like the CDC, Uganda’s MOH, scientific researchers with whom they interacted, stating the contrary. Some caretakers wondered whether to separate and isolate the NS affected children from those not affected lest the latter end up catching the disease. Narratives revolved around saliva mainly as a mode of transmission among things like skin contact and that NS could be airborne.

Some caretakers only practiced specific preventive measures at the beginning of the epidemic during which time they had no access to information regarding the syndrome. After awareness raising was done that the illness only affected children in the age range of between five and 15 and that it was not communicable, fear of communicability reduced. However, some did hold on to the belief that it could be transmitted from one person to another arguing that scientists cannot be sure this illness is not communicable before they know the cause and its proper aetiology. Secondly, they on several occasions had observed cases with similar symptoms emerge within families that originally had only one affected child which science at the time could not explain.

> I think that this thing can be got if you drink water from the same cup as a 'nodder' because of the saliva so we separate the cup and the plate only but sleeping and playing, no. (C2)

Several affected children went to the same schools as those not affected and shared the same working space and desks. They, however, did not have collective school meals to warrant separation for parents who would want this for their unaffected children.

Sharon, a 17 year old female and the only one affected in her family did not also know how and when her NS symptoms started but was told by family members that they started while the family was in the IDP camp. She attended primary school until she dropped out in the third grade because of this condition. At the time of the interview, Sharon was married to a man without NS and together they had one child close to 2 years of age. She and her husband lived with her mother who insisted that her daughter stay with her for close monitoring since the husband was thought to not be able to care for her when she got attacks[44]. These attacks were characterised by seizures and according to her, they sometimes started while she was sleeping. She also spoke about feeling a "heavy heart" especially when it was cold but she could also not stand the heat in the garden which caused her dizziness when she went for garden work.

Some caretakers spoke about their separation of NS affected children from not affected siblings. This separation included not sharing the same sleeping space and utensils such as cups and plates during meal time. For others it extended to not having any contact with children that were not affected such as playing or carrying younger unaffected children within the neighbourhood.

> We try to separate things because we do not want the disease to spread through saliva but the neighbours do not let her carry their children or play with them. (C7)

In some cases, separation was because of the seizures that often came on in the night waking up everyone in the household if they all slept together. To accord other family members an opportunity to rest, the victims were separated for this reason as well as for reasons of their poor hygiene since they eased themselves on their beds which was inconveniencing for the other members of the household.

[44] When an unaffected man married an NS affected woman, it was believed that they would not be able, let alone willing to manage the tedious caretaking process victims of the illness required. This was also partly because of the gender roles where caretaking was primarily the domain of the women folk.

> The reason we let him sleep in his own house (read hut) is because he is now a man and in our culture a man should have his own hut. But he fits at night and when he does, he shouts very loudly. Before we separated him, he would wake everyone up whenever he shouted and it would be difficult to go back to sleep and yet in the morning people had to go and do garden work. This became difficult because of lack of sleep. Secondly, he cannot go to the toilet himself and soils his clothes when he is sleeping or when he gets fits. The smell used to be too much in the joint house which also affected the others so we had nothing to do but separate him. (C9)

While not many saw need to separate the affected from those not affected, some families were nonetheless really sceptical about claims that NS is not communicable and therefore made sure the affected children for example used utensils relegated to them alone, did not eat together with the rest of the family as is normal cultural practice and did not share beddings with siblings that were not affected.

> For us we have this protective measure of giving him his food alone, ensuring he sleeps alone, he eats alone during meal time and we have been doing this because we are not sure if that thing can be transmitted from one person to another. Here he has a separate plate and cup. We have eight children where he is the eldest but we do not want the thing spreading so we separate. (C2).

When prompted to elucidate on why he still harbours the notion that NS may be communicable in spite of all the awareness raising that it is not, this parent went on to say that it is very hard for them to understand things from the medical perspective and what exactly the doctors do. He cited examples such as:

> Maybe it is the drug that has weakened the disease so that it is hard to catch people now but in the past it used to catch people because while they were in the IDP camps, it was not uncommon to find a family of six with all six children affected but upon return to their homes and with drug administration, it started reducing and the situation is now different. (C2)

Moreover, he thought NS catches adults too saying that:

> Near Awere there in the valley, an old person has it. I think he got it from the overcrowding in the camp and is receiving treatment, from Hope for Humans here. (C2)

Different respondents shared their thoughts about whether they believed the syndrome could be transmitted from one person to another.

> If they share a cup of water then it shall be transferred and there is no difference. The thing can catch any one, children and adults alike. By adult I mean 19 years and above. Since I have been working here for three years now, at the beginning during our admission exercise, there were children who were having only epilepsy, who were only epileptic and there were

> others who were only having nodding and not epilepsy. In the middle there, we started seeing that children who were only epileptic had also started nodding and we think that maybe that thing is transferred through the saliva because some of them share cups when taking the medicine. That is why I personally think it can be transferred this way although it has not been confirmed yet. I have never seen it on any adult though. Okay, there are other patients who are now adults but they got infected when they were children. (C3)

> Of course yes it can be transmitted from one person to another because this thing if you share food, even the saliva and this cup for drinking water and if a person shares the same room with this 'nodder' but it is children not adults who get affected. (C4)

Another long serving employee at the same institution had this to say.

> We have fear that one can get infected through body fluids like saliva and urine since the mode of transmission is still unknown. (K3)

In regard to how they manage the situation between the epileptic and those affected by NS, one of the care takers at the care centre said:

> During the training we had, offered by the MOH about how to tell who is affected and who is not and also how to handle the affected children, we learned that nodding cannot be transferred from one person to another just by touching or taking care of the sick. This gave me the courage to work in an institution that cares for these affected children but I also was able to raise awareness in affected communities so that children are not feared or segregated against. (K3)

Health practitioners, on the other hand, were more relaxed and had no fears of catching the illness. This was attributed to their training and professional background, the on the job workshops they often had as well as exposure to information from their superiors. However, it was not the case with the several illiterate and poverty stricken households deep in the rural area who were not as privileged. The different opinions were also due to the fact that care providers in the home setting observed developments such as other children in the household exhibiting the same symptoms too after contact with affected children to which they had no answers.

> We the health workers were so fearful, we thought that maybe it can be transmitted but when we were trained that it is not communicable, we interact with the children freely. (PH5)

Focus of some caretakers, however, was on taking care of their loved ones whether or not the illness is communicable.

> I do not worry about transmission issues because the disease is in the family and it is my responsibility to take care of the children. I bathe them, give them food and generally do everything without discrimination. (C5)

Many caregivers had uncertainty about how protected they were in their line of duty and if they ought to be on the lookout for potential risk activities in the course of their work. They reported that during the time the phenomenon was first noticed in their own community (Aromo Wanglobo), no kind of preparedness was in place for its management despite the fact that cases of the same condition had been identified and reported in Tumangur-Kitgum district. Hurriedly, volunteers were sought out for some to be trained about handling NS victims. According to an employee who participated in the training, the exercise was done by persons who knew almost nothing about the condition themselves, save for the fact that they had some kind of medical training. In fact, said a respondent who herself was a trainee, that the community members whose family members and neighbours had presented with symptoms knew a lot more than the trainers during this particular training session. This lack of proper training, coupled with an inefficient mechanism of information flow is what rendered an already vulnerable populace even more vulnerable, observed a public health practitioner with the non-profit organisation – Voluntary Services Overseas (VSO).

Here below is a verbatim excerpt from one of the interviews I had with a caregiver at the H4H care centre on the subject.

> Me: Before you took on this duty as a care giver, were you given any training about what to do, what not to do and how to protect yourself against possible risks involved?
>
> Her: No.
>
> Me: Do you think there are risks involved?
>
> Her: Yes. Because we are also worried you know. We may keep on helping these kids but later we may also be involved.
>
> Me: Last time we were sharing about the fact that the centre admits children with ‘nodding’ only and epilepsy only and that over time, those who came in with ‘nodding’ only ended up with epileptic kinds of symptoms and vice versa. Are the parents aware of this trend?
>
> Her: Yes some know but others think that their children had both the whole time.
>
> Me: On average, you have 18 children still enrolled. How many of these would you say have obtained the other set of symptoms that they did not have.

> Her: They are four children. These have been at the care centre for four years but this started happening after they had been there for two years.

In conclusion of this section of the findings, NS was experienced collectively by the victims, their caretakers and the communities within which they lived. It was also experienced rather differently by the different categories as seen from the field voices above which further emphasises the need to delve into what this meant for respondents as individuals and as a collective body.

6.4. Reflections on the findings

The findings presented above illuminate how NS is experienced primarily by the affected children and young adults, how they felt as they lived with this condition and the impact the symptoms had on them. This is in agreement with Charmaz (2000) who suggests that in studying the illness experience for chronic illnesses[45], attention be paid to the sick or victims. At a secondary level, they illuminate how family members and the community are affected by the illness. The perspective(s) of the parents/ caretaker's, healthcare providers, as well as the opinions of community members and key informants are also covered. A number of models emerged to explain the illness experience of NS in northern Uganda. Like was the case with perceptions about the cause, narratives about the experience of NS revolved around more or less similar biological, social, and cultural factors. They also reflected the impact of the changes that occurred due to forced displacement during the civil war as well as structural factors such as a history of deprivation characterised by grave poverty levels. In this particular regard I identify with Farmer (2006; see also Baer 1996 and; Scheper-Hughes and Lock 1987) who submit that the people's bodily self, becomes an embodiment (Csordas and Csordas 1990; Krieger 2005) of their social and material surrounding which are multi-dimensional in nature. Desjarlais and Kleinman (1997) cite the importance of anthropology in examining the impact of larger forces on not only physical but emotional health as well. In the reflections here below and the general discussion further ahead attempt to do exactly this. What is believed about sickness, the behaviour sick people exhibit along with their treatment expectations and how family and health practitioners respond and treat sick persons are all aspects of social reality. Particular aspects of social reality are therefore what disease and illness are representative of (Kleinman 1980).

[45] NS, according to Musisi et al. (2013), is a chronic and debilitating illness because of the duration it has affected patients and the effects of the symptoms on them.

Inasmuch as the symptoms for NS were more or less similar for affected children, the choice of words, metaphors and narratives to describe the illness experience was often based on the conceptualisation they had of what may have caused the illness, what they heard the community members in their surroundings say as well as their perceptions of the body and bodily processes. It is argued that science is "the thought organisation of experience and that the most obvious aspect of this field of actual experience is its disorderly character where for each person it is a continuum, fragmentary, and with elements not clearly differentiated" (cf. Simons and Hughes 1985:12). For example those who believed epilepsy did exist in their lineage described the symptoms and experience tending more towards epileptic symptoms like seizures while those who believed the cause to be the trauma caused during the war described their experience in terms of images surrounding the war such as munitions, dead spirits and sounds in their brains and dreams. This is in line with Anderson and Bury's (1988:2) argument in which they say that the "illness experience is related to the environmental conditions, material resources and demands of contemporary culture and societal structure".

What the findings show regarding the meaning study participants attached to their experience of NS is aligned to what Newman and Newman (2012:13) submit when they say that "the meaning we make of our experiences changes over the course of life [with time]. This meaning is an attempt for us as humankind to make sense of what we go through mentally, socially, and biologically (Broberg and Klingberg 2017).

6.4.1. Trauma

To a large extent war actions surrounded the expressions of NS victims in their experience of the illness. Expressions such as "I see people chasing me with pangas wanting to kill me" and actions of running off into the bush for safety pointed towards post-traumatic stress disorder (PTSD) which came as a result of the civil strife. Important to highlight also is the fact that respondents also sometimes assigned biomedical terms such as headache, fitting (coined from fits), and body weakness to their physical symptoms. In other words, even though some respondents thought NS to be of cultural origin, their communication of the physical symptoms was closely related to the biomedical world which in consistent with the notion of hybridisation and is indicative of the interaction between the biomedical and cultural systems in health related issues.

In their study, Musisi et al. (2013) found that all eight cases that comprised their 2010 study sample had extensive psycho-trauma histories related to the armed conflict in northern Uganda. They argued that NS could be a cultural presentation of the psychological effects of protracted/repeated mass war-trauma in children in northern Uganda/South Sudan. Earlier investigators reported severely traumatised children especially with parental/attachment loss who, initially, exhibited signs of anxiety, helplessness, and hopelessness. This was followed by profound depression, social detachment and withdrawal, failure to eat with resultant failure to thrive, wasting, and severe malnutrition. Similar to findings of this study, in their publication Van Bemmel, Derluyn and Stroeken (2014) argued that NS experiences are connected to trauma of past events. Furthermore, in interviews conducted by Feldmeier, Komazawa and Moji (2014), mothers of children with NS spoke heavily about the trauma experienced during the civil war where they believed that NS was linked to their presence in the IDP camps into which the Acholi were forced during the civil war from 1986 to 2008. According to Buchmann (2014:71), "the loss and suffering involved with nodding syndrome are seen as a continuation of the confinement and trauma once caused by war". Ojewska (2017) also reports about the trauma that the people of Acholi land live with in form of nightmares arising from the war.

The impact of losing loved ones coupled with having to deal with psychological trauma in the absence of a social support network rendered affected communities vulnerable to developing long-lasting emotional and behavioural problems as echoed by Roberts, Patel, and McKee (2012). According to Musisi et al. (2013)(2013; cf. Landis, Palmer, and Spencer 2014:1), a number of NS victims also suffer from developmental trauma disorder with acute and chronic depression plus psychomotor retardation. Violent acts may have been due to memories of the war that linger on in these NS affected community members both young and old. Scheper-Hughes (2015) speaks about how acts of violence can transform social and individual personalities playing out eventually in future domestic settings.

6.4.2. Stigmatisation

Inadequate access to knowledge regarding the condition in the midst of affected communities was reflected in the way it was perceived but also into how victims and affected households were viewed by the wider community.

Almost all narratives of the illness experience from the different categories of respondents were centred on the behaviour of the affected children and the situation in which this

behaviour occurred. Epilepsy and therefore NS (having been classified as a new epileptic disorder) are very stigmatising illnesses going by their symptoms and just like Pierret (2003:8) submits that, “interpretations of the meaning/significance of coming down with an illness have dwelled on the notions of shame and stigma”.

Williams (1984), in his Schneider and Conrad (1983) book review, for example, postulates that social construction of meaning studies mainly dwelt on stigmatised illnesses such as epilepsy. They go on to argue that public ignorance of epilepsy causes negative and a discriminatory attitude towards persons suffering from the condition. This was true of NS among the affected communities because while patients and to some extent affected households were stigmatised, the reasons behind this attitude were due to limited knowledge about what surrounds the illness. Such grey areas included what causes it, how it spreads, who is susceptible.

Goffman argues that stigma is socially constructed and embodied in the “language of relationships”. Social dimensions of illness as addressed by Kleinman in his 1988 publication as well as social suffering (Kleinman, Das, and Lock 1997) are central concepts in the discussion. “A stigma, then, is really a special kind of relationship between attribute and stereotype, although I don’t propose to continue to say so, in part because there are important attributes that almost everywhere in our society are discrediting” (Goffman 1963:4). Social exclusion including stigmatisation are in part a product of how labelling and observation of the diseased is done (Goffman 1963).

“Expectations of devaluation become personally relevant once official labelling occurs during contact with treatment” (Yang et al. 2007:1527). Hinged on relationships and context, Major and O´Brien (2005) concur by adding that stigma is indeed a mark that labels people as different and consequently yields devaluation. “Stigma threatens what matters most” (Yang et al. 2014:1528). For NS victims, what matters most are their relationships to family and friends without which some victims wished they would die to escape the negativity their illness sometimes caused. Viewed as burdens and useless, most affected children felt worthless and devalued opting for a way out of all their pain and suffering. Going by the labels ascribed to victims as seen in the results section, NS could as well be one of the syndromes Hughes speaks about in the “twilight zone of psychiatric phenomena as being phenomenologically categorised under the unfamiliar ways of being ‘crazy’” (Simons and Hughes 1985:3). Its effects, included discrimination, rejection and loss of self-worth seen in several other studies

conducted for example in China, Europe and North America (Yang et al. 2014). They were not comfortable speaking to anyone about their condition and how they felt because of the perception that anyone not like them was obviously judgmental of them and could not be trusted with matters so personal and close to their hearts. This implied that for disclosure to be made, their trust had to be earned. In the meantime, they confided in particular persons who they felt at ease with and definitely trusted.

Scambler and Hopkins (1986) speak of two kinds of stigma including felt and enacted stigma. The former is the feeling of shame associated with a particular stigmatising illness like epilepsy while the latter refers to "acts or instances of discrimination against people with epilepsy on grounds of their perceived unacceptability or inferiority" (Thomas and Nair 2011:159). Both types of stigma were observed and spoken about in this NS study. Older affected girls and boys either showed signs or openly spoke about how shaming this illness was and how this happened. Several had loss of self-esteem and exhibited signs of timidity as a result. They were not comfortable speaking to anyone about their condition and how they felt because of the perception that anyone not like them was obviously judgmental of them and could not be trusted with matters so personal and close to their hearts. This implied that for disclosure to be made, their trust had to be earned. They did however open up to particular persons who they felt at ease with and definitely trusted.

Findings show that stigma was felt and experienced as a result of deviation from societal expectations. For example, culturally there are roles such as tending to garden work and within the marriage institution that are expected of each member of the family at a certain age. NS impacted victims in such a way that they could not participate in garden work and ordinary home tending which yielded feelings of stigma.

7. NEGOTIATING CARE FOR VICTIMS

This third and last chapter of the findings highlights issues to do with care for the "nodding syndrome" (NS) affected children in northern Uganda. One of this study's objectives was to establish whether or not affected children were in receipt of any kind of care for their health condition. If they did, what kind of care was it? From where did they get it and what (if any) influenced their choices? From the respondent's narratives on this matter, key themes emerged showing how health care giving and seeking decisions were made and what NS affected communities thought about the appropriateness of the care provided.

7.1. The care setting

Almost all NS affected children received some form of care for their illness. This care was primarily offered by immediate household members within the home setting but extended to institutional care in some cases. For some affected households, health care was sought from traditional healers in what I will refer to as an intermediary setting (neither home nor institutional). Out of disgruntlement, some parents decided to withdraw their ill from institutionalised healthcare altogether in order to keep them solely under their watch until they passed on.

7.1.1. The home environment

In this setting, care was provided by members of the nuclear family with especially biological mothers as the primary caretakers. The mothers were in some cases complemented by fathers, siblings and other family members. It was not unusual, however, to find households where primary health care giving was done by female grandparents, siblings, aunts, and step mothers (see appendix 6 for details).

Affected households that constituted this study did not have homogeneity in as far as care taking was concerned. Caretakers ranged from underage siblings to aged grandmothers and while some families had many inhabitants, only one person was responsible for the caretaking role regardless of how many affected children there were. Caretakers whose affected children had died prior to the study constituted the sample for the study's enrichment but also included were two caretakers whose ill children died during the course of the study.

The form of care provided in the home setting included, but was not limited to, fending for the affected children, bathing and feeding them, carrying them from one place to another (for those too weak to move on their own) and washing their clothes. This care involved doing for the affected child whatever they could not do on their own depending on their health state. Some affected children were able to take care of themselves because of the anti-seizure medication they took but for those who, for one reason or another could not help themselves, everything was done for them by their primary caretakers as depicted by the field voice below.

> The problem with this disease is that the child cannot do anything for himself. I have to do everything for him for example I feed him, bathe him, clean him when he soils his clothes then wash the clothes, carry him from the house and back. It is worse when it rains because you have to move him from the rain and yet he is so heavy. He cannot also turn himself when he lies down so I have to wake up in the night to turn him. If only this happened for just a few days but it is on a daily basis. My back aches, my shoulders, I feel weak because of doing this work. If only this happened for just a few days but it is on a daily basis. My back aches, my shoulders, I feel weak because of doing this work. More so there is no time to go and work in the garden so even the food supply is very limited now. (C1)

Culturally, girl and boy children have roles to play in the Acholi tradition and parents have expectations of each of their children which when sabotaged by an illness such as NS create a feeling of loss and confusion about what to do by the victims' family and the community within which one lives. Socially and economically for example, family members together engage in food production and animal rearing to sustain the family's livelihood. Girls are also a source of wealth through bride price and when marriage is no longer possible for the girl child because of NS then feelings of displeasure set in and lead to abandonment and segregation even from biological parents.

7.1.2. Institutionalised healthcare

7.1.2.1. Government aided hospital and health centre care provision

According to a healthcare provider in the area, Odek HC III was set up before 2008. However, it was closed during the war and reopened years later when the war situation stabilised. The facility had 14 members of staff, two midwives, two enrolled nurses, one nursing assistant, one laboratory technician, one laboratory assistant, a health assistant, four support staff and two clinical officers. According to this respondent, while the facility was a good place to work, it was far away from Gulu town which is the centre of all activity and for this reason all staff members stayed within the HC premises to foster fast response to patients.

At the HC III in Odek, NS patients were attended to specifically on Wednesdays unlike other patients who came in daily. This was attributed to their huge number which often led to extremely long waiting times if patients with other ailments visited the HC at the same time. This arrangement was also made in order for the healthcare givers at the HC to focus on the needs of this category alone and have time to respond to severe cases in time. Typically, care in this setting involved counselling, management of seizure symptoms if children had episodes while at the HC and provision of further doses of anti-seizure medication in what was locally and commonly referred to as re-fill.

However, most of the parents and caretakers of NS affected children did not know the names of the drugs they obtained from these institutionalised care facilities. The prescriptions were written in their hospital visiting books but because most of them were unable to read, they never knew what drugs they were.

> I do not know the drugs Simon was getting there because it was always brought in a *kavera* (polyethene bag packaging for tablets). I do not know the name. What I know is that the tablet was small and white. (C2)

> These people did not even tell us why they were giving us those drugs because they did not even test but just said that you go and try this drug because we are still investigating. I always asked for the name of the drugs but was told, 'it is written in the book' but I cannot read so because I did not know the name of the medicine, I could not even try to find it at drug shops. Sometimes it was a small white tablet and other times it was yellow. When you ask why, they tell you, the other one was not working well so we have changed. Or we have stock outs of the other one so we are giving this one. (C11)

Medicines dispensed at public HCs were the same medicines that the NGO H4H administered to affected children in their care. Prescription and dosage was determined by health personnel when they visited once every month and one of the roles of the nurses at the care centre was to ensure the children within their care took the prescribed drugs in their proper dosage and at the right time daily for as long as they were at the care centre. But like parents who obtained medical treatment from public HCs, the parents of children at the care centre did not know the names of the drugs their children were getting and neither did they ask.

> With nodding, the cause is not yet known so at the moment we are just managing symptoms to stabilise the children because there is no known cure. Most of them appear with that sluggish behaviour, others come with drooling saliva and others are so weak that their caretakers need to be guided on how to take care of them otherwise they can easily be abandoned. (PH5)

Where possible the caretakers helped their patients go along with them to these monthly visits but this depended on availability of transport in cash and/or in kind, ability of the patient to walk to the HC and sometimes their willingness to. Where it was not possible for one reason or another, the caretakers took it upon themselves to go to the HCs and obtain the re-fill mainly because it is them whose task it was to care for the children when they were under attack which involved a lot of tedious work and contributed to not attending to other activities because one had to stay with the patient almost throughout the day.

> We go for re-fill every month and the doctor said it is better that the sick child comes along. The problem is that the HC is very far and we have to go there on foot. If there is money we use bodaboda but many times there is no money and the child cannot walk such a long distance so I go alone. I have to go because it is me who suffers when the child is very sick and this happens when he skips taking drugs. I have come to collect drugs for five patients because they cannot come on their own. Three of them are in my family but two are my neighbours. We rotate like this, when I come this time, another one comes next time provided we bring their medical record books. But the doctor prefers to see the child but sometimes it is not possible because even when you find transport to bring the child, the waiting time here is very long the child can easily get an attack and disturb. (C2)

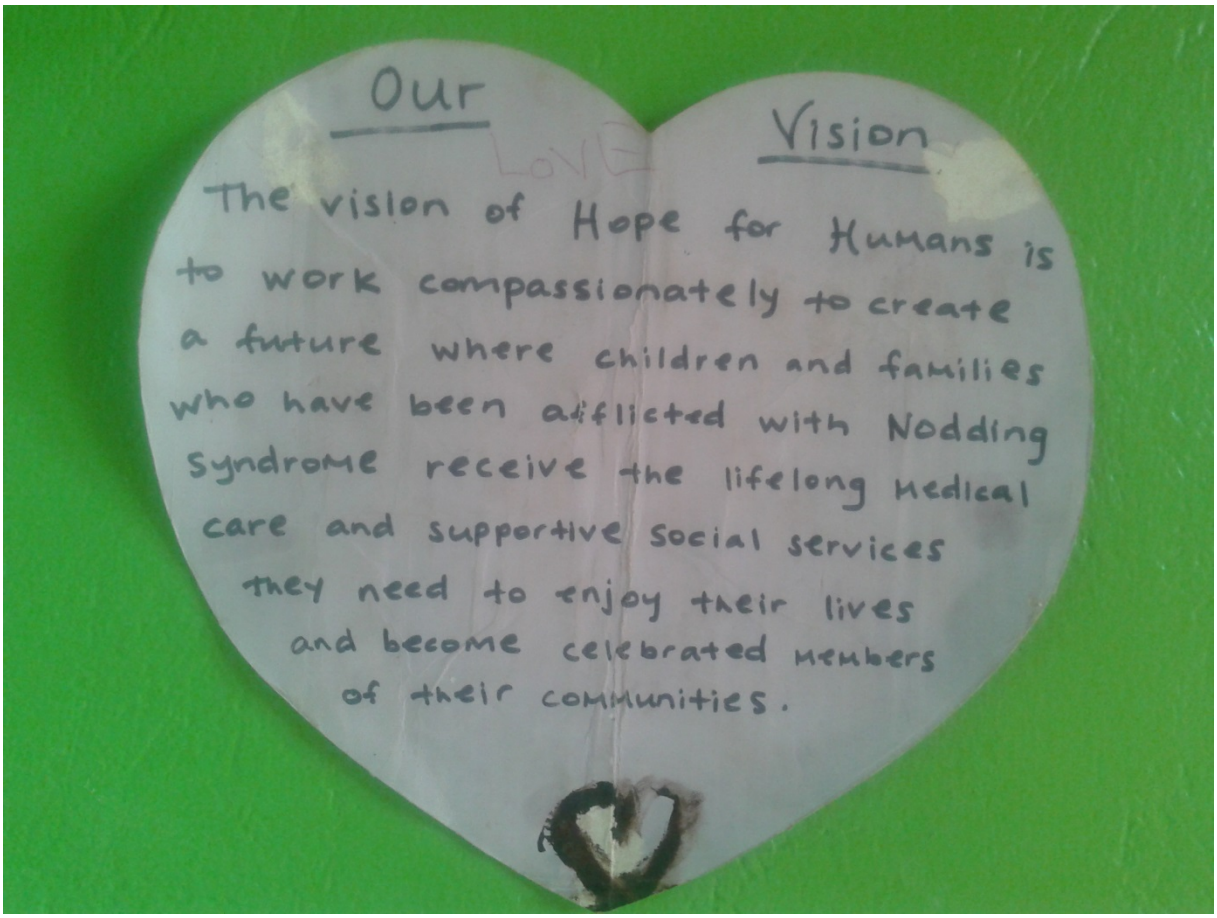
7.1.2.2. Non-government organisation care setting

Health care for affected children was, however, not just limited to the home setting but also extended to public medical health care facilities as well as the privately owned H4H which is a care centre specifically providing general care to NS affected children in northern Uganda. This care centre was founded at the time the outbreak of NS was first realised in Gulu district. It began operating in 2012 and more than half of the affected children who constituted this study's sample in the Odek study area were either under full (day and night) care of the care centre or had been under their care before being phased out for normal school attendance. By the end of this study, construction work of the care centre's second branch in Tumangur, Kitgum district had been completed although operations had not yet begun by the time I left the area at the close of fieldwork[46].

[46] The NGO's branch in Tumangur village, Akwang sub-county, Kitgum district (which was my other study site) was under construction at the time of this study and so did not cater for institutional care of affected children in this area. For two months prior to the conclusion of my field work, the NGO had begun reaching out to affected children in their homes. This activity involved registration (in liaison with the VHT) of households with affected children eligible for enrolment either full time or part time in the centre. It also supported the MOH in dispensing of symptomatic treatment given the delays sometimes experienced in the exercise which were partly caused by lack of facilitation resources by the district outreach team and a not yet operational HC II.

One of the activities of this care centre was the provision of healthcare services to NS affected children by way of dispensing drugs, dressing wounds, treating minor ailments and relaying information to higher authorities where serious cases needed urgent and/or more qualified attention from better equipped HCs. With two full time nurses; one male and one female present 24 hours a day, healthcare provision was guaranteed given availability of necessities. Other activities included screening for newly affected children which technically involved following the WHO guidelines of identifying who was and was not affected (see appendix 1). This was followed by enrolment into day care (8-10 hours) or 24 hour boarding care of patients deemed to be in need of more intensive care and close monitoring. While at the care centre, the ill were taken care of by full time caretakers from different professional backgrounds[47] who ensured they were fed, bathed, took their medication and were given basic education skills by special needs teachers.

Figure 4: H4H vision in one of the classrooms



[47] Employees here comprised male and female registered nurses, special needs teachers, male and female caretakers, a part time nutritionist, cooks, cleaning staff, watch men most of whom hailed from the affected communities themselves.

Community members were also taught how to deal with affected children in order for their livelihood to be made easier even when the actual cause of the NS condition was yet to be established. This was done through awareness raising community outreach programmes.

> Before the phasing out of those children who had improved enough to leave the care centre, we all participated in awareness raising because we had foster children whereby you had to go and visit the child at their home every month but this was for only those in the day care programme. For those not admitted at the care centre, general outreach involved the nurses rotating monthly in the field on monitoring visits during which they also taught caretakers on how to handle their ill. (K3)

Affected children whose health status was deemed to be worse than that of the others were taken on for a 10-24 hour watch period within the organisation's premises under whose employ were fulltime nurses available day and night and caretakers to provide the required help. A nutritious diet comprising meat, eggs, vegetables, grains and seeds was one of the key pillars of this care centre and for this a fulltime cook was employed to ensure the children were fed three to four times a day and had their meals on time. With donor funding, the organisation had permanent buildings to constitute classrooms, separate boarding area for girls and boys who needed close and specialised round the clock care. Available also was a library with books donated by well-wishers abroad which library was open to the entire community with an aim of increasing literacy levels in this area, encouraging a reading culture and passing on general information.

> We have departments like nutrition where children get food, nutritional supplements and sometimes basic necessities like sanitary towels. We also have a learning session where we help the children since we are special needs teachers. There is a security department and finally caretakers who help to monitor the children's well-being, hygiene et cetera and the nurses who deal with their medication. (K3)

While H4H provided this kind of environment for the sole purpose of looking after NS affected children in these communities, there were NGOs like World Vision, WFP, Food and Agriculture Organisation (FAO) and the Lutheran foundation which also came to the aid of affected families at the height of the NS problem by providing, food, beddings, cooking utensils etcetera, to further improve the livelihood of these families.

> The care centre has helped us because it gives good food to the children like meat and eggs which we cannot afford. They also eat three times a day which is good. There was a time when we even got blankets and other things for the children from the centre. When the child dies, the centre also contributes to burial expenses like providing the coffin and something for the mourners to eat. (C1)

I witnessed several episodes of symptomatic attacks experienced especially by patients at H4H in Omoro district. Notably, the children enrolled for day and fulltime care in this institution were those found to be very ill and therefore needed to be closely monitored. In this case, more specialised interventions like a very highly nutritious diet[48] and emergency attention as soon as need arose, were provided. These attacks were found to occur anywhere – be it at school, while one walked, sat sharing in conversation, engaged in household activities such as cleaning the house, fetching water or cooking, mention it. During seizure (fitting) episodes, it was also common for non-victims (those not directly affected) in close range to gather around the victim and stare at them for as long as the seizure episode lasted. To make matters worse, if it happened in a public place it was an occasion for especially younger children to laugh as one would from something they found profoundly entertaining. However, when it happened in the presence of family members (mature or otherwise), health practitioners and/or trained community members like VHTs and staff of H4H, care would be taken to conceal their nakedness in a bid to preserve their dignity. Caution would additionally be exercised to minimise harm.

But while I witnessed several seizure attack episodes in these affected children, I will refer to just a few. For example, on the 20th of February 2015, I set out from where I lived within the community (about 1 kilometre away) and went to H4H where I wished to lend a helping hand to the staff of the institution that day as I engaged in participant observation. This, it turns out is a practice I was preoccupied with on several occasions, during the time I spent in this community. Despite it being a planned activity, often times it was also due to a missed appointment with a respondent when I went to their home and found they were not there as agreed or because they had to cancel for one reason or another.

On this day, I sat with some of the staff members in the social shade strategically built to offer one a view of the entire premises. As one of the patients – a girl of 15, was slowly walking on the veranda of the classroom block in front of where we sat, she suddenly fell on the ground with a great and loud thud. It was because of a seizure attack that I estimated to have lasted about 60 seconds.

[48] This diet consisted of porridge from maize flour with milk, cassava and potato tubers, rice, meat, beans, boiled eggs, greens which were served according to a meal roster including food supplements to those severely malnourished.

Figure 5: Plumpy nut supplement to NS victims

Each time a child at the H4H care centre had a seizure, the duration it lasted was taken and recorded by one of the professional healthcare givers on duty. The nurse who was sitting with us at the time it happened, run to her with a *kanga*[49] as soon as she noticed the attack, which cloth she used to cover the victims lower body as she stood watch until the episode ended. At this point, a colleague helped her carry the girl to one of the rooms for her to receive first aid[50] and rest.

Another patient was Walter, a 16 year old male from a family of eight headed by their mother. Out of the eight, he and his 14 year old brother had NS. Not quite sure when the problem exactly started, he had been told that symptoms were first realised in him while they stayed in the camp. He did not feel unwell at the time of the interview session but indicated there were times when he felt bad and this presented in form of headaches and fitting which occurred when he missed any of his doses of the symptomatic treatment that he was undertaking from Odek HC III. On one hand he was happy that the treatment gave him a chance to live a more or less normal life because since its commencement, he could work in the garden and help his family with food production as well as go to school about two kilometres away on foot which he could not do prior to this. On the other hand, however, he was sad that on several occasions

[49]A kanga is a piece of cloth used by women in many African societies to wrap around themselves from the waist down, either on its own or over their main attire. It is used to shield ones nakedness or to protect their clothes from getting soiled in the process of doing house work, used as a mat in case need arose and there was nothing to sit on, used to render ones informal outfit formal in especially traditional settings, etcetera.

[50] The first aid was by way of cleaning wounds in case a patient sustained injuries during the seizure episode. Otherwise, the affected child would be taken to a safe place to lie down and sleep until they woke up and received their medication as usual.

when he came to the HC for "re-fill" (term locally used to mean acquiring a new dose of medication which was administered monthly), he was told that there were no drugs ("stock-outs") and that the HC was still waiting for replenishing from the district health offices responsible. After several failed attempts, Walter decided to seek for possible re-fill from the NGO care centre where he unfortunately was also not successful because they only had drugs for their own "clients" as they in this case were referred to. Situations such as this stirred up worry and a sense of hopelessness because affected communities believed that when the symptoms recurred it would be terrible and sometimes difficult for one to pull through but die which is why he appealed for treatment at a "higher" (read more specialised) hospital with the ability to figure out how to conclusively heal the condition.

7.2. Struggle for healthcare decisions

The lack of access to healthcare is what determined how healthcare decisions were made. Access to healthcare took on a number of forms. Some victims only received care in the home setting, others received it from the home and institutional (public and private) settings while others additionally sought remedial care from the intermediary setting of the herbalist on top of the home and institutionalised care settings. For one reason or another, movement within these circles occurred concurrently and sometimes in linear progression where a patient would first be taken care of at home only, then they would access healthcare from public or private care centres before further on going to traditional healers. Over time, some affected households chose to focus on just one care setting and this category chose the home care setting. Presented in the next section of this chapter is what influenced the decisions and perceptions about the healthcare sought and provided.

Decisions to seek healthcare were influenced, dependent on and hampered by a number of factors either singly or jointly. These factors included aspects such as long distances to HCs, inadequate availability of drugs at HCs, long waiting hours at HCs, and the age/health condition of the caretakers in the home setting, among others.

Notable, however, is that some of these caretakers were children themselves who somehow had to find a way of situating themselves in an otherwise adult centred healthcare system. For example, one morning as I walked to meet my planned respondents of the day I met a young girl sitting on the veranda of one of the buildings of the newly constructed H4H care centre in Tumangur. Looking weary with her feet very dusty – a sign she had come on foot from very far off, she enquired from me when the facility opens to attend to clients thinking I was an

employee there. She said she was there to collect medicine for re-fill for her NS affected brother who she cared for. I took interest in her case and requested an interview to get a more in-depth understanding of this aspect of care to which she agreed.

Cinderella was 17 years old and lived close to Pajimu in Akwang sub-county. She had a 14 year old brother with NS and sister older than her by one year. Their father died during the civil war and their mother, presumably from trauma, abandoned the family and her whereabouts are not known to date. The siblings live in their 27 year old uncle's home but he is an alcoholic and all he does is drink local brew the whole day, every day. The elder sister has a health condition which makes her incapable of taking care of their brother whose NS symptoms began in 2007 on their way from the IDP camp. The symptoms included very frequent head nodding and seizures that they thought he was going to die. It was at this point that they visited Pajimu HC III where they received medication for his symptoms which led to his improvement. However, for a number of months, the HC had no drugs every time she and her brother went for re-fill. The reason they were told was that the government had not sent a new consignment yet. After several failed trials at Pajimu HC III, Cinderella said she heard about H4H and that it had started a branch in Tumangur. She decided to try and see if they had medicine that could help her brother because he was in very bad shape having had seizures for three consecutive days at the time of our interview. This girl kept saying she was very tired as a result of taking care of her brother without help and yet she also had to find food for the family and go to school at the same time. She had obtained a scholarship world vision international to finance her education but the scholarship had ended and so she was also looking for a source of income to pay fees or lose out on education which, according to her, would be the end of their family.

Albeit in rare cases, affected children too endeavoured to seek help on their own mainly out of desperation to guard themselves from a fall back to the debilitating state of constant seizures and nodding caused by non- adherence to the drug regimen that required that medicine be taken regularly and consistently. This search for help was not only for relatively grown up affected children but also the young ones who had registered some improvement in their condition from earlier treatment.

A case in point is Walter the 16 year old from *Te Olam* who upon realising there had been no drugs at Odek HCIII for three times consecutively upon his going there, decided to walk nine

kilometres to H4H in Aromo Wanglobo in the hope of obtaining the drugs at this privately owned NS care centre.

> I decided to try the H4H in Aromo Wanglobo because for three times (once every month) when I went to the HC in Odek I was told there were no drugs for re-fill. I was beginning to feel like the symptoms wanted to return and I did not want to go through this ordeal again. I had heard about this centre and that it offers care and treatment for NS affected children and so I came to request that they enrol me too and provide the drugs I need but they refused saying that at least me I am not as badly off as the other children meaning I can survive without their help and that the other children needed their help more. My wish is that a higher hospital which can help us get healed completely is found to take of us. (V6)

Vicky, a 16 year old originally from Awale which is several kilometres away from Aromo Wanglobo is another child I one morning met sitting on the veranda of the grass thatched hut obviously to shield herself from the rising sun at the H4H care centre in the area. This is the same place I often sat whenever I went to wash my clothes because the borehole was located at the care centre although the public was permitted to use it. She seemed in a sombre mood and began speaking to herself in Luo looking disturbed. My interpreter joined me shortly after and also took notice so we decided to follow her up upon realising she too was a sufferer. In an interview the next day with an extended family member (after we obtained consent) living in the neighbourhood of the NGO, we came to learn that she had left their home in Awale where she had a father albeit an alcoholic and four brothers who did not care for her and instead so her as a burden since she was not contributing to the household chores and garden work given her condition. Her mother had passed away and her male relatives did not view themselves as caretakers for the sick so in a bid to fend for herself she found her way to the H4H NGO to plead that she be admitted[51].

Daisy, an eight year old girl who lives less than one kilometre from Odek HC III had come to collect her medicine for re-fill during the time I volunteered at the HC. Given the effects of NS specifically stunted growth since victims had a problem eating, she looked like a three year old that I was curious about where her caretaker or guardian was given that she had walked into the prescription room alone. Justin the clinical officer on duty replied almost as fast as I had asked saying that:

[51] After several attempts to be accepted and enrolled under the care centre, I found that Vicky, upon my return to the community for the second leg of my fieldwork studies, had indeed been finally taken up for fulltime care in the facility. This meant that she lived at the care centre 24 hours a day with access to food, boarding facilities and everything else like basic education that the institution had to offer. Unfortunately, I also learned that a few months into her stay at the care centre, a community member attempted to rape her while she slept but was saved by the caretaker who was also sleeping in the same room as the affected children she cared for at this facility.

> This one here, the mum stays in the centre there (pointing in the direction of Odek trading centre) there, there, but she cannot bring her daughter- she always comes alone and the problem is that if the child does not care much about her well- being, he or she may throw away the medicine on the way back home and say it was not there. The problem is that some parents have now become indifferent. They are not helping the victims, leaving them to take care of their own situation. (PH2)

All she wanted was to live a symptom free life at least given that a cure was not in place as yet. Daisy expressed how terrible she feels when she has seizures and has an attack.

> I try to get the medicine myself because I do not feel good when I start fitting. I get terrible headache and feel very weak afterwards also but this happens only when I do not swallow medicine. My mother is busy most of the time so I come alone. (V16)

7.2.1. Government policy

In 2012, a number of local and international organisations came up to try and support the affected communities in whatever way possible. Food items, clothes and other household items were distributed to community members with affected children, which according to some respondents prompted them to follow the government directive not to take NS affected children to traditional healers or risk losing all manner of support from government and the other agencies since permission had to be sought from LGs before anything went down to the affected communities.

It was mandatory that healthcare services are sought from recognised HCs and not traditional healers or *ajuoga*. This message was relayed to affected communities by word of mouth using VHTs, the private NGO H4H, local radio and print media as well as posters. Whoever defied this government order faced exclusion from government support. This is what prompted several affected households to seek healthcare services from medical health care centres alone.

> The government gave a condition that no one should take children with nodding to witch doctors but only to the HCs. They told us whoever took their child to those people would not get any help from government and at that time they were distributing food, clothes, blankets and other things to households with 'nodders' which I did not want to miss so I took the child there. (C1)

Furthermore, in the initial years after the emergence of NS, there was quite a lot of support from local NGOs, the business fraternity, the international community and well-wishers from within the local Acholi community in form of food stuff and cloths for affected communities. With this kind of subsidise many affected households were motivated to go to HCs where the

distribution was often done and in the process received treatment for their ill. The choice of which HC to visit was subsequently determined by whether or not the HC had donations to make.

> For us we used all methods like going to witch doctors, using traditional herbalists and the HCs but when the government told us not to take the children anywhere else except the HCs, we had no choice but to comply because if you did not then your child would miss out on whatever support they were receiving from the government and yet we needed those things like food and clothes. Unfortunately, much as they wanted us to go only to HCs, nowadays you can go there three times a month and there are no drugs. It happened to me for many months I resorted to going back to the traditional medicine man although I do not want them to know. (C1)

7.2.2. Health seeking and perceived cause of nodding syndrome

As already mentioned in chapter 5, the origin and cause of NS was attributed to a number of factors one of which was witchcraft. It helps to also recall that the onset of the first signs and symptoms of NS was during the time people resided in IDP camps during the war period. Trauma arising from the war situation had a hand in whether or not people sought healthcare and adhered to the treatment regimen provided by healthcare givers once they decided to visit medical health care centres. Respondents who believed NS was a result of witchcraft at the onset of these first signs and symptoms made a decision to seek help from an *ajuoga* in order to have the problem resolved. This process involved figuring out why anyone would want to bewitch their child or children. It then progressed into their imagination of who this person or people could be before finally zeroing down on an *ajuoga* who they would turn to for help.

> We waited six months before going to a HC because we thought that maybe someone was bewitching us. What we did was to also look for a witch doctor in the camp who could tell us who was bewitching us and to help the child also. (C2)

> You see, witchcraft is very common here in our community. People are always bewitching others for any small reason. For example if they think you or your children are better than them and their children, they can decide to bewitch you. The other thing is that men here have many women and a co-wife will bewitch you and your children so that she keeps the man alone and your children die or become failures. When I saw this thing attacking my child I straight away thought about my co-wife which is why I also went to a witch doctor to bewitch her and to find a solution for my child. (C4)

Although in the beginning this was the case for several affected households, meeting up with similar cases at the *ajuoga's* place indicated to them that it could be something else and not a work of witchcraft. It was at this point that some considered using herbs from traditional herbalists in a bid to remedy the problem.

> We have really suffered with this problem of nodding I tell you. At first we thought someone was bewitching us but when we went to see a witchdoctor about it, we found other parents with children behaving like our own also in search of answers. This is when we knew that this could be a new disease and so we tried to use other means like traditional herbs to try and see our children healed. (C2)

The respondent's narratives show that there were limited health services during their stay in the IDP camps which were provided by humanitarian agencies like the RC. As a result, access to professional medical healthcare services was not possible for this emerging condition in their midst while in the camps when the problem was noticed first.

> Access to medical care was almost non-existent because the health facilities were outside and far from the camps. Because of the insecurity, they had no personnel and no drugs. In the camp, treatment was given by humanitarian agencies but I think because people were very many and falling sick all the time, drugs often run out and were only limited to things like pain killers plus malaria drugs sometimes. Even then it was children and HIV positive patients given priority. Herbs were our only option and yet they too were hard to come by as we were not at home and security prohibited us from moving from the camp premises. (C7)

On the contrary, those who thought the origin of NS was a disease like any other opted for the traditional way of dealing with ailments. This healing process involved home remedies such as the use of traditional herbs obtained from nearby fields and bushes given the nature of their new settlement. When this failed to alleviate the problem, help was sought from traditional healers within the camp setting who provided this kind of service at a fee.

> Me, I did not even think about witchcraft but because hospitals were far and we could not leave the camp, I straight away tried to use herbs which I could find here and there. (C5)

Upon the people's return home from the IDP camps at the end of the war, the decision to seek medical redress from a healthcare facility was for many the only option left after the *ajuoga* and traditional herbal medicine had yielded no visible results. Unfortunately, there was very little the people could do due to inaccessibility of far off healthcare centres. This was due to the healthcare infrastructure breakdown during the time of the insurgency.

> When I tried the *ajuoga*, the thing did not go away so I resorted to traditional herbs collected in the fields nearby but still it did not go. I decided I would take the child to the hospital, unfortunately in the camp it was not possible we had to wait until the war was over. The bad thing again was that after the war, Odek HC III was not operating for some time which made things even worse. (C17)

Some respondents confessed to having gone ahead and used all possible means including witch doctors, herbalists and the healthcare centres as a means of trying to see their loved ones healed.

> The community is handling the problem their way. Those who think it has medical roots rush to HCs for help. For those who think it is a work of spirits, help is sought from cultural icons like witch doctors and yet those who believe in God run to church as the only source of help in their situation . (PH3)

> Every tribe has a traditional belief system and so do we. In our home when I was growing up my parents never took us to a hospital and only used local herbs from bushes and gardens here and there. For serious cases, they consulted witch doctors and things got better after that. This is what I know, so when this condition affected my children I could think of nothing else but local herbs. Even when government stopped us from going nowhere else except the health centres, we still go to them otherwise I would be lost culture wise and also since even the medicine we get from the HCs is not healing our children. (C1)

Some of the affected population's belief that GOU played a role in the emergence and continued prevalence of the syndrome influenced the healthcare seeking decisions they made. One official from the Northern Uganda Rehabilitation Programme (NURP) spoke of government as not providing adequately for the health needs of the people in general but particularly those of the NS affected communities. This raised questions of whether or not it was partly responsible for the emergence of NS which speculation also impacted the affected population's choice of where to seek help. This state of affairs only reinforced the people's mistrust of government and her officials which in turn gave reason to affected communities to build resistance to any interventions government came up with in the name of helping deal with the syndrome. Where services were utilised, it was for lack of options but even then, they were always sceptical about what it is they were actually being fed. The NGO H4H, in this case was the preferred option because (in a way) the people trusted them and adhered to their instructions regarding how to help their affected children improve.

> The people are poor and can therefore not afford to access health services on their own. How can we seek help from public or government healthcare centres and yet the same government could be responsible for this new disease? (C5)

Private healthcare givers were opted for in this case for consultation on what may have befallen their children. The belief that government had a hand in its emergence trickled down to the interventions which were also quite often marred with controversies that appeared to

suggest that government was really not out to help affected communities out of their predicament.

7.2.3. Access to healthcare vis-à-vis availability

Visiting HCs was also in part due to logistical issues as well as general service access challenges. Factors included things such as the long walking distances to the then available health facilities given they were in the initial post conflict recovery stage where most health infrastructure had been destroyed during the civil war.

While some patients appreciated the need to seek medical attention from health facilities, the facilities usually were a quite a distance from where the outbreak of NS was situated (in the IDP camps) and later on, from many a sufferer's home. For instance in Tumangur, the nearest health facility was Pajimu HC III which was approximately 14 kilometres to and from Tumangur. Without means of transport – no public transport vehicle exists between Tumangur and Pajimu and the few commercial motorcycles or bodabodas available charge very exorbitantly, people had to either use bicycles or go on foot. Few people could afford owning one but it was also very risky to carry a patient who could have a seizure attack anytime on the way and fall off the bicycle so they were rarely used.

Given their health status, most of the patients could not go on foot because of the long distances therefore parents and caretakers chose to use traditional herbs in the hope that they would be of help in containing the symptoms.

There are challenges that get in the way of effective management of the condition in institutional settings like the H4H NGO also:

> We lack resources and one of them is transport since they are talking of children coming for the day care service. We really feel that if possible, they should get something like a van to pick these children up and drop them to the centre every morning and back home in the evening from the centre. Secondly, I may not be a medical person but I see that the way they are keeping the medication is not all that very safe. Where they dispense the drugs and keep them is not very good because right now as I talk, they are keeping the drugs in the office, packing them in a box where sometimes rats come and play. (C3)
>
> Children were withdrawn from here by parents because of the distance of about 10 kilometres that they sometimes had to foot. (PH4)
>
> The biggest problem Tumangur had until a few months ago when this HC II began operating was the distance. For patients to get medical attention, one

> had to go to Pajimu HC III which is about 14 kilometres away. To make matters worse, like you have also seen since you live here, there are no transport means. There are no vehicles on this road working as taxis; we have to use either bodabodas which are few and extremely expensive or bicycles which not many people have also. But now, imagine a 'nodder' who you know can fit (have seizures) anytime, how do you transport him or her on a bicycle or bodaboda? We had two cases here who were badly off and so the father tried to use a bicycle but a few metres away from home, the child started fitting and fell off the bicycle. Luckily he did not hurt himself. There is an ambulance which was provided by government after we raised this issue for patients who are badly off to be picked by the ambulance and taken to the unit for nodding at the general hospital in Kitgum but when you call them, they always say they have no fuel. (FGD6)

In addition to the long distances to the HCs, those who chose to seek medical attention from HCs often had to wait long hours before being attended to partly because of the large numbers of patients given the few facilities and also because it was common practice that the staff at these public facilities started working late (sometimes as late as 11am) even though they were supposed to start at 8am. In both study sites, I personally observed that often, the first patient arrived at around 6am but the overall number of patients rose to the tune of 60 and more by 12 noon. This trend, coupled with the fact these HCs were understaffed to allow for division of labour, patients waited really long hours before they could be attended to which led to frustration, discouragement and resort to alternative means of redress.

> Me I gave up on going to the HC for re-fill. The first reason is the place is very far I always walked for a long time and in the dry season it was too much for me because it would get too hot. On reaching the HC, the doctor takes an even longer time to come and work and when he does, they tell you the ministry has not sent drugs yet. This happened about three times and that is when I decided not to go back. (C3)

> I come from Binya parish so I am supposed to get medicine from Awere HC III but every time I go there they said they do not have it that is why I decided to come here at Odek. I collect medicine for five 'nodders', one is my own child and the others are my neighbour's children. These children cannot come here since this place is very far and you have to wait a long time for you to be attended to. We come in turns with the other parents. Many parents in our place there have decided not to go to the hospital anymore because of this reason. I start moving at about 5:45 am to come here because we live very far and I come on foot. I do this to avoid the morning heat when the sun starts shining so hard. What is frustrating is that this is the third time I am being told there is no medicine and my son is very ill because he has not had medicine for three months now. (C16)

While patients were struggling to deal with the long distances and waiting times at the HCs, employees at the healthcare facilities had their story too. Among other things, healthcare givers at Odek HC III spoke of no need to hurry to work when there was nothing they were

going to do given that the drug consignments they had requisitioned for months ago were yet to be received.

The greatest challenge they cited was that they often run out of drugs. Anti-seizure drugs run out so fast but new stocks were hardly received on time. Speculation surrounded the bureaucratic procurement procedures from National Medical Stores (NMS) as voiced by a senior healthcare giver at the HC. The fact that the drugs were expensive and that the LG had logistical facilitation problems was said to all together lead to this situation. The drugs that were often out of stock also greatly affected the healing progress of the patients as a result of compromised adherence to recommended doses at particular times during the course of their treatment.

> The drugs are provided by the district but they are always seasonal. They bring the consignment once a month for example if they bring it on the 23rd then they bring again on the 23rd of the next month. Meanwhile the MOH should also ensure that their drugs do not get finished because if there is shortage, those who will have improved fall back, fits and they will not be able to do well. Nowadays there is a shortage of medication especially the Sodium Valproate even now as I am talking, our reserves are exhausted. One day all of us went following the children after all were found falling here and there. We were like dogs looking for meat because all the children were like drunkards. We had to pick them one by one taking them to their respective homes. I do not know if this one will have the same side effects but with the other one, all the children were weak. But it took a very short time before the Sodium Valproate was brought and the children were put back on it. (PH2)

As if that was not enough, if a patient walked a very long distance to the HC twice and there were no drugs to carry home, they would be discouraged and not return.

A number of caretakers raised concern about how the private healthcare facility was benefiting at the expense of their plight arguing that donor money was being to other use other than better providing for their ill children. Against this, some parents chose to withdraw their children from the professional healthcare system and instead fully care for them at home.

> For example some parents say that now because of this NS problem you are getting a lot of money and yet our children are the ones who are suffering, it is us who are supposed to be paid because our children are sick and we will get nothing from them. You are there at the care centre that you are working on nodding children, and yet this disease has no cure, you are only getting money. They have built a huge school in Amulata which is from primary level to high school. Their home was grass thatched like you see here but now they have built a permanent home. Where does all this money come from? Dr. Suzie from the US should also ask herself this question because she went to their home in the beginning and now she sees the difference. She wonders why we the staff here in the field are getting little money while the directors at the head quarter get a lot of money yet we are the ones taking

> care of the children. Now I hear there is no more money coming in that is why we have not enrolled new children. But most of the staff members are also planning to leave. (K3)

7.3. Perceptions about the quality of healthcare services

Victims determined the quality of healthcare services on the basis of how frequent their symptoms were coupled with their intensity compared to their frequency and intensity after they used medication obtained from professional healthcare centres (public and private) in search for a remedy.

Appropriateness in this case meant how well the affected child felt from the moment he or she began taking symptomatic medicines and on how often symptoms occurred while they were on medication. Victims who were able to express themselves on the matter said for as long as they were swallowing their medicines they had no problems adding that problems arose when symptoms resumed due to in availability of drugs at the health care centres. This explains why some patients would move on their own from one HC to another in an attempt to obtain a re-fill lest they have a relapse. While this intervention helped in the interim, affected children who were able to expressed their wish for a total cure to be found because there were many challenges attached to living with the illness as the situation is now. Once a month, a medical team of senior doctors came from Gulu town to check on the condition of the children and take note of any new developments in as far as the illness is concerned. It was also because parents sometimes complained that their children were not improving. In such instances, the health personnel at the HC had to wait until the medical team came to solve the problem either by changing the drug or increasing the dosage. A senior professional healthcare giver at Odek HC III concluded that with consistent drug administration, improvement was noted in the victims of NS and that for over a year no new cases had been reported.

> In the past children would fall a lot but now it can even take six months. It could be curable because if you get it before it has increase, it has put a kid on fire then it cannot get cured. But if it has destroyed the kid completely, it cannot be cured. They have not found new cases. It has yet stopped with these people. (C2)

Caretakers and key informants interviewed on whether healthcare services to NS victims were deemed appropriate had mixed feelings. While some thought that the anti-seizure medication was appropriate, a fraction had misgivings about the kind of treatment victims of NS were receiving from treatment facilities. On the one hand, a number of caretakers who had lost their loved ones to the illness wondered how they could say that the treatment is appropriate when

their once living kin had succumbed to the ailment even though they adhered to all instructions of the healthcare givers regarding the treatment regimen. This was also the case for caretakers whose children were still alive but still getting seizure attacks due to the inconsistency of drug supplies at the HCs.

On the other hand, caretakers whose affected children had witnessed a significant reduction in seizure attacks due to the medication thought that the treatment was appropriate to a given extent although they hastened to add that ultimately appropriate treatment is that which would result in the complete healing of the victims knowing that they would not die from the illness as was the case at the time of this study.

> I cannot say that the treatment is appropriate when it is not curing but only reducing the symptoms. But because I see victims improving as a result of the drugs administered, I say this helps to reduce the suffering of the child and the caretakers can also do some work and rest. (C1)

The other case is of Olive who was enrolled at the centre because her health condition was really bad. However, her mother was angry due to the centres policy of asking parents to go and work in the care centre gardens from which food for their children would be obtained. They were also asked to bring firewood once every week to help cook food for the affected children enrolled at the care centre.

> They ask us to work in the garden and bring firewood and yet they (the centre proprietors) get money from abroad to do these things. (C4)

> Yes, there are also other reasons parents are reacting like that. You know, for this organisation that I am working with, parents are given other conditions like they have to do garden work. The organisation is hiring gardens from the community around and asking parents to come work in these gardens. In addition to that, the parents are also supposed to bring firewood which the centre uses to prepare food. But for the two things I have told you, the parents are not happy. They say that the organisation is getting a lot of money from these people from the US and instead of buying the firewood they end p disturbing them to bring from their homes and yet the children are no longer going to help them. (C3)

7.4. Impact of access to healthcare on victims and affected households

7.4.1. Hope versus hopelessness

Access was found to be a source of hope for a number of victims and their caretakers. This hope was derived from instances when victims were regularly able to receive anti-seizure

medication from HCs which led to a reduction in the frequency and/or intensity of seizures that they suffered which helped improve their overall livelihood.

> When the drugs are available at the HC and my child gets re-fills every month it helps because then the fitting goes down and even if it happens, it is not as frequent and he does not fall hard like before. This helps all of us because he then can do things like eating, going to the toilet and bathing on his own. We are also not very worried that he will hurt himself because we see that he is better. Because of this we can also go to the garden and do some work which is not possible if he is fitting all the time because there are no drugs. (C2)

The feeling of hope was shared by a number of caretakers whose dependants responded positively to the medication. There were cases, however, when the anti-seizure medication provided either did not have an impact at all or it had a negative impact on the victims. Negative given that the seizures instead increased and were very forceful in nature. For these victims and caretakers, this was a hopeless and very trying situation.

> For us the medication we get from the HCs does not change anything. In fact, there was a time the child was given drugs when we went for refill but those drugs just made matters worse. He could fall almost all the time and the falling was very strong even stronger than the other times. When we reported this to the nurses, they told us they had changed the drugs because the other ones were out of stock. We have lost hope and are only waiting to see happens tomorrow. (C11)

> Agnes is always sad and saying she wants to die. Sometimes she decides to cook even though she knows that she can start fitting and fall in the fire. One day when I told her she should stop cooking, she said she cooks because she wants the fire to burn her and she dies. She feels hopeless about getting healed. (C19)

Some caretakers' narratives indicated that they were burdened in their role as caregivers because of the physical and emotional energy (to say nothing of economic constraints) it cost to look after the affected children under their care. As their advocates in this sense, it was found that their attitude in as far as executing their duties was concerned had been negatively affected. As caretakers, they felt neglected which in turn extended to the victims. This, in a sense that while the children were under their care and looked primarily at them for support, as caretakers, they were humanly unable to perform as well as expected of them as care providers. Several of them felt frustrated due to the enormity of the task at their hands whose end did not seem close. Cases were cited where it was feared that because of one reason or another, the condition of some children was worsening as a result of their caretakers not taking good care of them. It was also sometimes attributed to lack of readily available medication to be taken consistently enabling the containment of the symptoms.

> The problem with this disease is that there is no cure and it affects our lives a lot since you cannot do anything else when looking after the sick child and yet you have other children to also provide for. Now I left everything to God, I tie him on a tree with a rope so that he does not hurt himself by drowning or falling in open fires if he wanders off, then go and do garden work to get food for the rest of the family. (FGD5)

> What do you do when there is no medicine at the HC for three months and the child is fitting every time? That is my co-wife's child. She went to enjoy life and left the child here. Me I also have my own children to look after. (FGD4)

Hopelessness and the burdensome nature of the role were expressed in quotations like the one here below:

> My wife left me with three young children aged 12, 6 and 3 two of whom are 'nodders' because she no longer wanted to struggle taking care of them so she went to Opit trading centre near Gulu town to find another man and start afresh. I wish this child could just die. One day I will look for a full pit latrine around here and throw her there then I will also take my own life. I feel very tired of this situation. (C15)

7.4.2. Stigmatisation, displacement of anger, and frustration

Stigma and the alienation that came with the NS condition led some individuals and households to not reveal that they too were culprits of the illness. The decision to seek medical attention would expose one as a 'nodder' which status attracted labels and segregation for especially older victims. This fear of alienation by relatives and friends (often times leading into family disintegration) also had a bearing on how the care for NS affected relatives was approached. The home setting care process was marred by emotional, economic and physical violence whose effects were felt most by the affected children and which in turn only served to exacerbate the already bad situation.

Most of the affected children had encountered some form of segregation and abandonment from family or community members. It was both overt and covert and took on several forms ranging from being banished from home, being separated from unaffected children in their day to day lives, verbal abuse, use of derogatory language towards them, physical violence and deliberate denial of access to basic needs.

All caretakers spoke about how caring for NS affected children impacted them as human beings and the impact it had on their day to day life. While they wished their ill dependants would get well, their narratives were heavily laced with the burden they shoulder. Findings show that a number of caretakers displaced their anger and frustration on the children in their care due to the challenges involved in the unending caretaking role. This behaviour was not

limited to a specific category of caretakers although it mainly was from step mothers and fathers.

Some affected children were neglected and abandoned by their fathers and sometimes mothers. This category of fathers did not provide for their families and never took part in taking care of their ill children. Instead, they spent hours on end in the local trading centre taking alcohol. One mother, I was told, decided to walk out on her family and go try to start another family elsewhere. I met her ill children in one of the study sites, one of whom died during the course of this study's fieldwork.

In my observation, abandonment was not only physical but emotional as well. Where a family had both NS victims and unaffected children, it was not unusual for the ill children to not be spoken to, praised, or allowed to take part in family activities where they were emotionally involved. On several occasions, they were ignored and left alone for the most part of the day while the rest of the family went on with their lives as usual – smiling, laughing and seemingly oblivious of the needs of their ill.

Derogatory and abusive language was in some instances used in direct speech to victims by close family and primary caretakers such as fathers, mothers and siblings. It did not stop with family but often times extended to include community members as well. Domestic violence, its dangers notwithstanding, child abandonment and name calling were all means used by some parents and caretakers to cope with the frustration of the caretaking role.

> There is one in Akoyo Lomech in the home of Labongo Alexander. The man has two wives and both wives have children who are affected but he does not like the first wife and only likes the second wife and her children. He is the one who calls his children moving coffins. They are a boy and a girl from the first wife. They are here at the care centre with us but she is the only one who comes to check on them, bring firewood and do garden work. But she said that she is also about to leave the children with their father and return to her parents' home. Another example is Kinyera's dad because his mum died when were still in the camp and the father got a new wife but this step mother does not like Balaam and the brother, does not give them food with the other children and has separated even their own hut. And when they return from the care centre the mother says they have already eaten at the centre and have no share at home. Kinyera's brother was also admitted at the care centre but was phased out. The father says that it is the care centre extending Kinyera's days on earth otherwise he would have already buried him a long time ago and would have forgotten him. They do not like him that is why he is being enrolled at the care centre full time. (K3)

One of the children in an employee's foster care at the NGO came and requested her to go and talk to their dad to stop calling them moving coffins.

> He is always disturbing our mum and does not notice us maybe because we are affected. Nurse and the field officer talked to the man but after, he went drinking, returned and beat our mum hard saying she was the one who had reported him. (V17)

Beating affected children, with sticks and sometimes dangerous objects like pangas was reported by some child respondents and community members. This was said to almost always be accompanied by abusive and derogatory language.

> There is a certain lady who came to us at the care centre complaining that her husband was violent especially when he returned drank. He would beat up the children, saying they are living coffins that would not help him. He never wanted to sleep in the same house together with them or even touch their cups. Later we heard that their mother chose to return to her parent's home because they had grudges between them and he took all the children from her. He now beats the children seriously. Yesterday one of the children came to us asking the field officer to take him to Odek so that he goes and reports his father to police because he is going to kill him. He beats him sometimes with a panga. On Sunday, the child came with a swollen neck. One day, he even grabbed these children while they were on the way to school. He punishes them when he is drank and the child told us that he drinks like four times a day, in the morning, mid- morning, early evening and late in the evening. And when he comes, he begins beating everybody. He does not care that the children are ill with NS and mentally disturbed. We have not heard from this child since Monday when he came, picked his medication and then disappeared. At lunch time we did not see the boy meanwhile he was hiding somewhere in the bush only waiting for sleeping time so he sneaks into the house. The boy would cry the whole day. (K3)

Running away from home and hiding in nearby bushes is what this 11 year old victim of physical violence chose to do. He sought help from persons he thought could help but when it was not forthcoming, he resorted to finding his own means of survival.

Affected children especially teenage girls were also sexually assaulted by community members and in some instances even caretakers. Many cases of rape were reported in Tumangur village given that the affected children there were older (above 18 years of age) compared to those in Odek. This was the case despite security that had been provided by two police officers. Most offenders reportedly were family members or had a close relationship with their victim's families giving them better opportunity to take advantage of them.

Economic violence which involved withholding of basic necessities was also another way by which violence was suffered by the victims.

> Opio had a wife but they are now separated most likely because of his drinking problem since he was not providing anything, not even working in the garden and the woman had nothing like a woman would have in a home. The wife decided to go away with another man leaving all the children

> behind. She left last year and the daughter was already like that (read ill) but instead of Opio being close to the child and taking care of her, he decided to let the child stay with pigs, not even giving food or taking her for medication. Actually he was not bothering. After like a month after his wife had left, he over drank and said that one day I will look for somebody's latrine and damp Sarah there and then me myself will hang myself and die because I cannot manage taking care of her when she is not even going to help me anymore. (C3)

> So I came and told my mzee who asked one of the family members to take care of the child. Opio's aunt Grace agreed but she and her son are now complaining, worried that how will she take care of her grandchild once her pregnant daughter in law gives birth and Sarah since they do not know how the disease is transmitted. There is nothing in Opio's house and he provides nothing for the child. (C3)

As a result of the negative treatment, affected children were psychologically traumatised and this subsequently affected their self-esteem. They were made to feel unworthy and of no value hence viewing death as a better option.

7.4.3. Repression

Rather than deal with the enormous strain of emotions their situation aroused, many a caretaker chose to find means of repressing the pain and one of such ways was through alcohol consumption and drug abuse.

Findings show that consumption of alcohol (which was excessive for men than women) was used to ward off worry, stress, and misery associated with NS especially by parents of affected children. I once asked the old lady in whose home I stayed in one of the locations during fieldwork, why she consumed alcohol every day and she was quick to answer "how else would I survive in the face of this NS. This helps me forget and reduces the pain"

Moses in Tumangur has three affected daughters aged 20, 19, and 17 plus two affected sons 16 and 14 years of age. Asked about how he coped, he was quick to share that:

> People speak about me, saying that I am a drunkard but the reason I drink is to forget the problem I have of my children who have 'nodding'. I tried everything I could to see that they improve but nothing changes. Even the medication we get from the government is not helping as if it is even making them worse. I drink to forget, I tell you I drink to forget. (C11)

Some caretakers lived in denial while others chose to accept their living situation. I learned that through denial – acting like everything was okay and life was business as usual with no ill-health problems to worry about, some caretakers lived a more or less normal life. However, the same respondents spoke about accepting what they were going through as fate. In other

words, there was a thin line between denial and acceptance as coping mechanisms. At a given time, these caretakers were in denial of what was actually happening and at other times they acknowledged what was before them and chose to accept it.

> Me I think this child is sick like all other children fall sick and will get healed with time. I do not believe in these 'nodding' things after all what is nodding? No one knows even the so called researchers. (C4)

A few minutes later,

> Frankly I do not even know what to say. I think this is something from God that I have to deal with. My child is having 'nodding' and there is nothing I can do except to accept it as Gods wish. (C4)

7.5. Victim coping mechanisms in the face of nodding syndrome

Even though they were ill and did not know when a cure would be found, some affected children chose to remain positive and optimistic, holding on to their dreams in the hope that this would help them live another day and another and yet another. They often spoke of the future in terms of what they envisioned themselves as being professionally. In this regard, the majority wanted to be teachers because these were the most friendly white collar professionals they had mostly encountered in their lives given that in these communities, the children rotated around school, the health care centre and their home. Others spoke of desiring to be drivers and motor vehicle mechanics while girls mainly chose hair dressing, tailoring and being home makers.

Most victims put their faith in the ability and power of the supernatural to bring them healing while others additionally trusted that there would eventually be treatment that would be able to completely heal them of NS.

> I believe that God has power to heal and will cure me one day. I also think that although the drugs from Odek are not helping much now, one day they will give us drugs which will help us get cured. (V6)

Counselling was one of the mechanisms that parents and caretakers employed to enable their ill cope with the illness.

> These children are always speaking of dying but what we do is keep close to them, speak to them, counsel them, monitor them and get them to open up to us so that we get the thought of death out of their minds. (C3)

> Agnes is always sad and saying she wants to die. Sometimes she decides to cook even though she knows that she can start fitting and fall in the fire. One day when I told her she should stop cooking, she said she cooks because she

> wants the fire to burn her and she dies. From that day I started talking to her on a daily basis about how we love her and that she should not kill herself because of 'nodding'.(C19)

Prayer was also identified as one of the ways in which affected children and households coped because of the hope it provides in the ability of a supernatural deity to bring total relief someday. It was also the victims way of saying that they accepted the condition in which they were and that nothing could be done about it other than healing by supernatural power.

The 14 year old girl in my hosts household said she was not worried at all about what tomorrow would bring and that even if she is alone in the night when her symptoms mostly strike, she knows that all will be well because of the daily night prayers she says before bed time. Some healthcare givers, many caretakers and several community members confessed that this hope is what kept them going and that it brought real positive change in the affected children. In a way, some affected households had accepted the situation as being out of their means to handle and rather than live the rest of their lives worried or bitter, they chose to believe in the supernatural.

> I do not worry about anything because I pray every night before I sleep and when I pray, even if I am alone in the house I do not fear because I know God will help me. (V1)
>
> For me, my hope is in God. I know that even if anything happens to me I will go to heaven so I do not care whether 'nodding' or what. (V9)
>
> Praying has helped these children a lot because you find them walking very long distances to go to church. While there, they sing laugh and dance which takes their minds off the disease. When they come back home their minds are in a better state. (C8)

Affected girls especially above the age of 18 desired to be independent by settling down with men willing to take them on as wives. It was evident to them as victims that their caretakers were sacrificing a lot in the process of taking of them and that with time this tended towards resentment as they obviously were increasingly viewed as a burden. By getting married, it was imagined and hoped that the caretaking role or burden for that matter would shift from their primary caretakers in their homes of orientation to their spouse thereby also reducing the emotional strain it had on them as patients and recipients of this care. Though not as common as it was with the girls, it also was found desirable for boys 18 and above to find partners with whom to settle down in marriage.

> I have a girl who has NS and she has a boyfriend who is normal and that man is serious and wants to visit them at their home. But we are worried if

> he marries the girl and the girl gets pregnant and gets seizures in that condition, will he still accept her? That is the biggest question. So we decided that if he wants to marry the girl he should sign an agreement with the local leaders and family that even if the girl ends up like that he will be with her. They have not done it yet but the relationship is still going on. (C3)

7.6. Reflections on the findings

Negotiating health care by NS affected communities in an unpredictable setting was a real struggle (Wilhelm-Solomon 2013). With NS still unclassified, care givers in all care settings were not very certain about how it ought to be treated. This is echoed by Bury (1982; cf. Pierret 2003:4) when he speaks of uncertain symptoms, treatments with uncertain effects and uncertain durations as responsible for compounding the problem of uncertainty and impact of the illness to the bodily, psychological and communal experience of chronic illness. Das (2015:43–44) speaks about how "biomedicine is embodied in local strategies of care" which was found to be true for affected communities who embraced biomedical options along with traditional strategies of dealing with NS. The results show how affected households approached healing their ill with traditional herbal medicine, using the services of the *ajuoga* but also walking long distances to public and private healthcare giving facilities for biomedical prescriptions. Similarly, victims and caregivers adopted the biomedical term 'nodding syndrome' for the illness which they used alongside its Luo translation *luc luc.* I also witnessed caregivers taking care to clean and protect the victims' bruises or open wounds from possible infection using local herbs as well as creams and antibiotics obtained from local drug shops. According to (Das 2015), a combination of familial care with biomedical health provision or institutional care may generate positive outcomes.

The social cultural context in which NS emerged was at the helm of decisions of healthcare seeking that affected households and communities made. The displacement of people into IDP camps, fleeing of healthcare givers and personnel from healthcare centres, breakdown of social support networks which local affected communities depended on, inter alia, left them with few options at the time. People held on to tradition which propelled them into seeking help from traditional herbalists or redress from witch doctors about who could possibly be bewitching them. And inasmuch as social support networks back home had disintegrated due to displacement, they nonetheless built new ones to help support one another in the face of challenges in camp settlements, as was culturally the norm. Through these networks they not only managed to deal with day to day survival challenges in an IDP camp setting but also learned of the existence of an emerging new and strange condition in their midst (Finnström

2008). Additionally, the networks also enabled people identify who had what healing gift and it is through this channel that witch doctors and traditional herbalists were identified during their camp stay. The shared biological problem in a social setting that warranted search for a solution gave rise to social support networks which extended beyond camp stay into the communities. Through conventional social support networks comprising primarily nuclear and extended family members, affected households identified with one another and were a source of comfort for one other. Poverty appeared to be a strong determinant of the health care decisions affected communities made. This is in tandem with what Leatherman (2005) highlighted in his article on the relationship poverty and ill-health have with spaces of vulnerability in which he argued that decision making ought to be understood among other things, within material conditions.

Biomedical healthcare in the IDP camps was limited to illnesses such as malaria and colds based on the fact that health care centres were vacated due to displacement and had neither personnel nor drugs to attend to the sick. NS affected persons therefore had no room of choosing to seek medical care from health care centres while in the camp and were left with no option but to resort to available resources. The influence of their traditional value system on decisions of healthcare seeking are what formed the basis of later actions for instance the ritual spirit appeasing ceremonies such as that performed in Tumangur upon the peoples return from the camps. It also is for cultural reasons that despite the government's directive regarding health care for NS affected children, that some affected households continued visiting witch doctors and traditional healers.

Fatigue of caretaking led caretakers into wishing the children could be taken off their hands so they could have time to live and do what they did before this situation befell them and more or less imprisoned them. Some thought that this was the best way to protect the other children from potential infection given that they thought NS was transmissible from one person to another. To put it bluntly, they were, for several caretakers (primary and otherwise), considered a burden. Giving care to NS patients was a fulltime unpaid occupation that drained the physical and economic resources of the caregivers. As fulltime caregivers, they were unable to engage in any other kinds of activities especially income generating ones and consequently struggled with choices of providing basic needs to unaffected children and those with NS in a setting of meagre resources. This dilemma was partly due to lack of support from, among others, the government of Uganda and the imagination that affected children would never grow to realise their full potential in life. In terms of the burden of care giving,

the study also revealed child violence and maltreatment, isolation, stigmatisation, abandonment, and rejection as well deprivation due to high levels of poverty. In alignment with previous studies of a similar kind, child violence and maltreatment are consistent with symptom-specific caregiving burden, deprivation and poverty with financial burden while stigmatisation falls under social burden of care giving (Kurzban and Leary 2001).

With regard to decision making, the patriarchal nature of the society was set in motion as the men then decided what happened with the sick. This is especially if it involved women having to leave home in search for healthcare services from often far off HCs and/or traditional healers which on several occasions involved financial expenses and not attending to garden work. Herbal remedies were therefore an easier choice because they were obtained from fields within their neighbourhood and appropriated according to knowledge passed on from their forefathers or ancestors. These did not take up as much time as visiting HCs and did not involve walking very long distances, using money to get to the HCs, long waiting hours, drug stock outs and all the challenges associated with medical HCs as were cited by respondents. Where services of the *ajuoga* or traditional herbalists were sought, cash payments were made. The *ajuoga*, however, often asked clients to bring along animals like goats or sheep and birds like chicken or doves for use during the spiritual rituals.

There were cases when patients were too ill to be taken for treatment at HCs. This happened sometimes after the primary caretakers grew weary of walking long distances and so simply stopped taking their ill there anymore. The long distances were sometimes not the problem but the long waiting hours for service at the HC and the several times they found no drugs had been received from the MOH yet. Symptomatic treatments to help patients culminated in reduced presentation of symptoms especially seizures. These anti-seizures included carbamazepine, sodium valproate and phenytoin which helped reduce the frequency and strength of seizure attacks subsequently leading to a slightly improved quality of life for not only the victims but entire affected communities. The improved life quality was attributed to the pain alleviation and reduction in seizure attacks also reduced the incidence of the secondary consequences of the symptoms which among others were falling into fires and drowning. As such, victims, their immediate relatives and the wider community lived in relative peace.

Whenever it was accessible, medication significantly improved the symptomatic attacks of the victims and as a result they had hope for a cure and a productive future. This, however, was

not the case for those who for one reason or another struggled to access drugs either for economic reasons, distance from their homes to the nearest service providing HC, or the general shortage of drugs at available health care centres in the vicinity. The constant episodic attacks due to irregular drug uptake also contributed to yielding a sense of hopelessness in victims who looked at death as their remedy.

Given the nature of NS and that its victims present with neurological and psychiatric symptoms, the condition is stigmatising and leads to social exclusion (Nakigudde et al, 2016). This is attested to in a number of publications on social exclusion and other stigmatising illnesses. Good healthcare principles call for treatment of patients with dignity which for some means inclusion in the social fabric of society despite their condition (Richters, Rutayisire, and Dekker 2010).

In 2009 when NS was first reported, local and international interest towards mitigating the pain affected communities endured on a daily basis were visible (Mwaka, Kitara, and Orach 2016). Reports by the respondents indicated that the Lutheran foundation, World vision, the business community and others provided affected communities with food, beddings, and shelter for those in dire need. WHO, CDC and other researchers came into these locations to investigate the cause of NS and what it could be (WHO 2012). The government of Uganda, to a given extent, supported these initiatives by granting researchers permission to carry out investigations and procuring consignments of ivermectin and anti-seizure medication for the victims and sprayed black fly breeding rivers with larvicide (Idro et al. 2014; Kitara and Arony 2017). After a few years however, all this support and interest suddenly ceased to be. The initial response which brought hope to affected communities gave way to a lacklustre way of attending to affected communities by the government. Government representatives whose mandate it is to provide health care to her people also grew hostile towards whoever brought the subject up.

8. GENERAL DISCUSSION AND CONCLUSIONS

Introduction

How and what exactly led to the emergence of "nodding syndrome" (NS) is a gigantic puzzle not only for the afflicted population in northern Uganda but for whoever learns of its existence – lay people and the scientific community alike. This discussion focuses on the emergence and illness experience of NS in view of the anthropological perspectives and theories on disease emergence, illness experience and health care presented in chapter 3 of this thesis. In this chapter, I consolidate issues arising from the study findings – reflections of which have been made in the preceding chapters. I use the syndemics conceptual framework (Singer 1996) and social suffering theory (Kleinman, Das, and Lock 1997) to show how historical and structural factors of political, social, cultural, and economic nature may have interacted and made the Acholi highly vulnerable and susceptible to illness, especially the still poorly understood NS (Korevaar and Visser 2013; Mitchell et al. 2013; Winkler et al. 2014; Spencer, Schmutzhard, and Winkler 2017; Föger et al. 2017; Winkler et al. 2018). From the respondents' narratives and explanatory models in the findings chapters 5, 6, and 7 it is clear that the aforementioned factors had a role to play in the emergence, susceptibility and distribution of NS in northern Uganda. These factors are also seen to influence the way in which the illness is experienced and addressed.

8.1. Time and space vis-à-vis nodding syndrome

Time (the war period) and space (IDP camps) are crucial to this discussion, first, because the local perceptions surrounding NS are embedded in these two broad themes. Secondly, particularly because while the LRA/NRM war also extended to some parts of North-eastern Uganda (Obalanga in Teso land – see figure 3), the local people in these other areas were not displaced into camps like it was with the Acholi. However, more importantly is that NS, as far as I know, has not been reported in these communities to date.

In many ways NS is an embodiment of the affected population's reality long before their stay in IDP camps during the recent civil war period. Kirmayer and Pedersen (2014) submit that social processes over time and space have the potential to interact giving way to local biologies.

This is also reflected by Lock (2017:1) as she says “I argue that an anthropology of embodiment should be situated in time and space and recognition given to local biologies as a subcategory of situated biologies evident globally”. Furthermore studies have shown that “beliefs about the causes of mental suffering have included underlying biological and biochemical problems, unconscious psychodynamics stemming from prior experience, deviant behaviour, social stress, demonic possession or evil spirits, divine punishment, and many others depending on culture and individual variations” (Biering 2007:793).

The emergence of NS was closely linked to the civil war. During this time, events like massive displacement, violent operations like ‘iron fist’ and ‘lightening thunder’, as well as disease outbreaks including cholera and malaria were common within the currently NS affected population. This is akin to what Castillo and Guo (2011), among several other authors, posit that for a disease to emerge or re-emerge a number of things or events often do simultaneously or sequentially occur. The drastic change in environment, congestion, and the poor sanitary situation in the IDP camps are together believed to have heightened the potential for disease emergence and/or transmission. This is in line with the submission by the institute of medicine (US) forum on microbial threats (2006) that displacement raises the risk of contracting emerging and re-emerging infectious diseases by those led to relocate. The syndemics perspective indeed suggests that social aspects within the day to day lives of humans make people vulnerable and susceptible to new and emerging diseases where war and atrocity are specifically associated with high levels of health-related morbidity and mortality (Singer et al. 2017; see also Singer, Bulled, and Ostrach 2013). Kleinman et al. (1997:ix), also argue that the pain and trauma of atrocity gives rise to among other things, health problems and that who is suffering and how they suffer is sometimes [sic] a part of an intricate flow of power and resistance in social relations.

The role of context is also being increasingly recognised amidst the complexities of reality and the numerous views of the people involved (Briggs 2005). One of these roles is enabling a better understanding of the impact of context over a period of time and in spaces of deprivation on population health. NS emerged at a time and in a space where there was fusion and interaction of several processes and activities of a local and global nature. For example while the fighting factions were local, global processes were involved through the ammunition that was used, the historical colonial era that led to the disgruntlement by the people of the northern region as well as humanitarian agencies that came to the aid of the people while they lived in the camps. Appadurai (2008) and Angier (2001) relate to this when

they speak of the enormous potential to stimulate disease emergence and spread that increasing movement of people across national and international borders, the flow of goods, food, capital, even vectors, and decision-making power that characterise globalisation have.

Tenets of Singer et al.'s (2017) syndemics approach and biosocial model to health are clearly reflected in the narratives regarding the circumstances surrounding the emergence of NS. Biological factors such as black flies and the epilepsy epidemic in the region were raised alongside social factors including the circumstances under which people lived during this time which were characterised by abject poverty, lack of access to basic social services and neglect by government. These biological, social, and global factors seem to explain the emergence of NS within this population from the biosocial perspective. Indeed according to Erikson (1993), biological and psychosocial factors are said to be at play in the experience of human life but their modification in a particular context may also give rise to disease and/or ill-health.

Contextual factors played a central role in informing the explanatory models affected communities held about the origin of NS. What they believed about the origin of NS, the behaviour the victims and their caretakers exhibited, as well as the healthcare issues surrounding the illness were in one way or another tied to both their past and present social reality. This underscores the need to pay attention to contextual factors if we are to understand the meanings attached to the experience of suffering of this population (Conrad and Barker 2016). Events and social processes situated within time and space underpinned local narratives in as far as the emergence and experience of NS in this region is concerned. Conventional knowledge and all ways of understanding, according to the social constructionism school of thought are "relative and sustained by social processes" (Burr 2003; cf. Bisht 2008:2).

Acholi land is documented to have suffered a long history of violence that can be traced as far back as the 19th century (see Angucia 2010) most recent of which is the LRA/NRM civil war. The displacement, violent operations like iron-fist and lightening thunder, socioeconomic upheavals arising from extended periods of marginalisation (Branch 2013) punctuated by disease epidemics including the notorious Ebola haemorrhagic fever (McPake et al. 2015) altogether constituted the social reality of the people of this region. The need to pay attention to contextual aspects under which NS sprang up is important because these aspects point us to forces and processes beyond the individual and local affected population which rhymes with what Singer et al. (2017) put across in the syndemics and biosocial conception of health.

Kleinman et al. (1997) also emphasise the role political and socioeconomic forces (over a period of time) play in disease emergence and how they impact illness experience.

8.2. Colonialism and local politics in a contextual perspective

The findings show that affected communities attempted to understand NS in light of political and historical factors including marginalisation and the recent LRA/NRM civil war among several contextual factors as having rendered the Acholi vulnerable and therefore susceptible to NS. Historical factors are reported to often be at play with other biosocial factors in increasing the risk of emergence and/or re-emergence of diseases among populations like the case study of Buruli Ulcer (BU) in Cameroon by Giles-Vernick (2015). The subjugation and marginalisation of northern Uganda is easily traced to colonial times where the Acholi were relegated to constituting the armed forces while other regions of the country received infrastructure and opportunities for a good education and healthcare services rendering them better developed and well equipped for well-paid employment (Finnström 2009). Like Farmer et al. (2006) argue, structural violence is at the core of public health problems like is seen in this case. It is this subjugation that over time led to aggrievement by the Acholi and culminated into the LRA/NRM civil war. This colonial history and how it impacted the Acholi sub-region illuminates how global factors affect the health of a disadvantaged people (Zuckerman et al. 2014). It also is in tandem with the submission that diseases are attributable to longer-term powerful forces (Harper et al. 2013) with a historical sequence (Caldwell 2001).

Marginalisation is largely responsible for the socioeconomic upheavals suffered by the northern region of Uganda (Branch 2013). The population was clearly neglected and deprived going by the inequitable distribution of social services including no road network to easily connect it to the rest of the country for profitable economic transactions and poor social service access because they were lacking (Mwakikagile 2009). Neglect is inherently social and its dimensions namely what is considered a priority by control programme designers, social relations, and governance are also often neglected (Parker, Polman, and Allen 2016). Giles-Vernick (2015) speaks of BU in central Cameroon as a locally important but neglected illness but so is NS in northern Uganda. Despite the fact that effort was made by the international community through biomedical research to establish the aetiology of NS, this support has greatly waned which calls for concerted effort locally and from the global health initiative (Winkler et al. 2018). Indeed WHO (2018c) proposes that for progress to be made in

the organisation's targets towards tackling the global mental health problem, there is need for joint commitment at global level to ensure funding as well as greater focus directed towards mental health policies and services at country level. Findings highlight the frustration NS affected communities have especially towards government for not addressing their plight as citizens of Uganda by providing the necessary support primarily through the healthcare sector. From this perspective on both the local and international scene, one would be right to equally call NS a neglected condition.

The impact of displacement into IDP camps and ecological disruptions brought about by the war affected the ecosystem both in the communities where the people lived before they relocated to the IDP camps as well as in the camps themselves. The local population interacted with the environment before displacement through activities such as farming and fishing (The World Bank 2012) but this was not possible for years due to displacement. Instead farm land and the water bodies in the area were filled by those who were killed during the war. In their day to day lives, they established a connection with the ecosystem that ensured their livelihood and an environment in which the people adapted and co-existed with other organisms. This is an affirmation of the fact that when people are displaced as a result of conflict, poverty or any other structural problem, they are made susceptible to new diseases and are prone to passing diseases on to people in their new location (Trostle 2005). Structural factors, for example, were also linked to Ebola which first emerged in the DRC (then Zaire) before spreading to Acholi land (Allen 2006). Interestingly, however, meta-level structural factors were hardly raised or mentioned in several forums as playing a role in the emergence and spread of Ebola (Jones 2011). The spread of Ebola, according to Jones (2011:1), was due to "inequality and inadequate provision of healthcare, entrenched and exacerbated by a legacy of colonialism, superpower geopolitics, and developmental neoliberalism". This being the same region, the same forces are deemed to be at play in the emergence and experience of NS.

NS has been called a nutrition problem and that once this is corrected, the problem would be solved. Important for this discussion, however, are the factors that led to malnutrition. These factors include political events and processes like displacement but malnutrition for this population also stems from the long history of marginalisation, neglect, and inequitable distribution of national resources in what Farmer et al. (2006) call structural violence. It also is attributed to issues of climate change, land disputes linked to cultural gender subordination of women, and the poor work ethic adopted by the youth due to extended dependence on humanitarian aid.

Displacement affected social ties, networks and social economic activities such as food production which also led to serious food insecurity (Wilhelm-Solomon 2013). This situation culminated into malnourishment (Kitara and Amone 2012; Sejvar et al. 2013) for especially children during the people's stay in IDP camps. The redundancy caused by the displacement also seriously compromised the ability of the youthful population to engage in food production while back in their communities which in turn affected household nutrition and further perpetuated malnourishment (Baines 2009; Baines and Paddon 2012). The compromised access to farmland and granaries back home, disintegration of social support networks and abrupt change to dependence on inadequate humanitarian food rations only heightened the nutrition problem. In addition, the time spent in the camps did not allow for maintenance of individual, familial or clan land boundaries back home. Land disputes, upon the peoples return also got in the way of food production (Wilhelm-Solomon 2013). These disputes arose out of arguments regarding land ownership as boundaries were no longer as clearly demarcated as they had been before the war. The disputes that accrued delayed commencement of activities on the land until they were settled – an exercise that cost time and money. The problem was also compounded by the fact that many families were affected and lacked or had inadequate resources to speed up the process and yet until then, food production would not take place on the said land. These disputes were settled through a number of well-coordinated activities such as stakeholder meetings, women's groups meetings and awareness rising through drama and music activities (For more details see Hannay and Scalise 2015). The land boundary issue was also partly due to destruction by war time munitions, human activity and in some instances overgrown vegetation (Wilhelm-Solomon 2013). Zeller (2013:205) on the subject is documented as saying "the physical landscape has changed dramatically as the UPDF used scorched-earth tactics as part (or arguably under the pretence) of counter insurgency measures". Land, a key factor of production without which activities such as food production would be in jeopardy had become of political and social interest once again in Acholi land (Zeller 2013).

Structural factors also influenced the way in which NS was experienced in a sense that healthcare infrastructure was under developed as a result of marginalisation. But where it was existent, it had suffered the consequences of the war which is akin to what Fouad et al. (2017) put across. In addition to the inadequate capacity to provide for the people respondents also blamed poor healthcare access to lack of political will as seen from the field voices. Findings revealed that major hospitals were far away from the camps and the nearby HCs were also

deserted and could not be reached because of their confinement in the camp. Rebel activities and the need for civilians to stay within the confines of the camps for their safety affected healthcare provision and access. Indeed one of the regulations for the displaced people during their stay in IDP camps was that they should not go beyond a kilometre if they left the camp say to fetch water, collect firewood or ease themselves because the further they went, the greater the risk would be to fall into rebel hands (Dolan 2011). Inasmuch as the UPDF was meant to provide all round protection to the people in the camps, they were few in number and could therefore not efficiently do the job which is why the radius was limited. Health personnel at HCs fled for their safety because of the war situation rendering the health care provision system non-functional during this time (Namakula, Witter, and Ssengooba 2016). This notwithstanding, socioeconomic and cultural influences also heightened the problem.

8.3. Culture and nodding syndrome

Populations toward which interventions are directed often have a set of values and beliefs upon which they base their interpretation of and deal with given health conditions (Good 1994). The Acholi have for a long time also had a cultural belief system with a strong set of customs, values, norms and practices embedded well within their ethnic fabric. Some of these beliefs are centred on food, dress, religion as well as death. Chapter 5 illuminates the meaning the Acholi attach to beliefs surrounding death such as the need to appease dead spirits (*cen)*. Ancestral worship and invocation in Uganda is, however, not limited to the Acholi ethnic group alone but is reported, *inter alia*, among the Baganda in central Uganda, the Banyoro in the southwestern region and the Madi in northwestern Uganda (Allen and Storm 2012). NS was partly attributed to the population's failure to perform cultural rituals accorded to the dead such as provision of a decent burial and carrying out last funeral rites ceremonies. Additionally, traditional religious practices like ancestral worship could not be performed during the people's camp stay (Finnström 2008).

From the results we also see how an evil spirit (*jok*) known as *oteltok* was considered by a fraction of respondents as being responsible for the break out of NS as some form of punishment. These unmet obligations to ancestors and other dead kinsmen are what some respondents deemed to have resulted into the emergence of NS. In addition to the earlier sections within this chapter, these local perceptions are aligned with Kleinman's (1988) submission that the understanding that populations attach to disease and illness is influenced by external forces that may be social, cultural or political in nature.

The cultural practice of communally sharing drinking water from the same cup and eating from the same bowl was thought to be a means of transmission of NS from one affected child to another. Furthermore, belief in the *ajuoga* among the Acholi is a common feature. In such cases, one event leads to another without the events being linked (Vyse 2013). Magic and witchcraft are a reality and ever present truth for many an African community (Kutalek and Prinz 2007). Witchcraft is used as an explanation of negative circumstances and situations that befall them and this was true for NS as well. It is documented that "from our stand point [as anthropologists], we sometimes can see that some of these beliefs and practices are perhaps not right in and of themselves but be that as they may, the beliefs people hold concerning causation of disease are to them solid and their practices in this regard therefore follow a logical sequence of those beliefs" (Good 1994:39). However, it is important to note that beliefs about illness and health behaviour vary widely across cultures and among individuals within each given culture (Daley and Weisner 2003) which is revealed in the findings as briefly summarised above.

Culture is seen to have been central to the decisions affected households made in their negotiation of health care. For many, the *ajuoga* were the first category of healthcare givers they resorted to during the IDP camp stay. At the end of the war, customary rituals and practices where possible were fulfilled alongside visits to public HCs as traditional herbs became a part of their daily routine. The extent to which affected households sought healing from the *ajuoga* led government to prohibit this community from attempting to obtain healing for their ill children from the *ajuoga* and that it should only be sought from recognised HCs. This new government policy rhymes with the observation that cultural meanings influence the social response to illness and what policies are created in response to it (Conrad and Barker 2010). This case also serves to show that culture has an impact on health-related beliefs, values, and behaviours (Kleinman and Benson 2006).

Helman (2007) espouses the influence culture has on the language of pain or distress and how it includes culturally specific definitions of abnormality such as changes in behaviour, speech, dress, and personal hygiene. The findings herein show changes in these parameters as seen from the example of victims and affected households who believed NS was an attack my an angry or evil spirit. Some claimed the spirit(s) took a hold of their brains which gave them many nightmares and throbbing headaches. For others, it was their limbs which led them into falling for lack of control and balance.

The inability for victims to fulfil cultural roles and duties ascribed to their age group shaped their language and speech through phrases about uselessness and being of no value. For example, the female child is culturally seen as a source of wealth through dowry when she comes of age. This is because dowry in the Acholi culture (I was told) comprises as many as 30 or more heads of cattle in addition to a substantial amount of money. Given that NS has no cure to date and has debilitating effects on the victims, afflicted female children were spoken of by some of their family members as being useless in this sense.

In some households, male victims were regarded ‘of no use’ because of their perceived inability to engage in productive garden work as well as sire many female children to bring wealth into the family through dowry.

8.4. Poverty and the illness experience of nodding syndrome

While structural factors were at the helm of poor healthcare services in the region and while the war had a tremendous impact on available healthcare infrastructure, access to quality healthcare by NS affected households was found to be a challenge partly because of poverty. As presented earlier, the poor socioeconomic situation of the Acholi is largely a result of marginalisation dating back to colonial times (Branch 2013). I spent months living with and among affected communities and so inasmuch as respondents spoke about their socioeconomic situation, I also personally witnessed the level of poverty under which they lived and reflexively describe it in the prologue and field setting sections of this thesis. The magnitude of poverty I report here affected this populations’ housing situation, nutrition, education, movement, and influenced the healthcare decisions that they made. This is in tandem with what Leatherman (2005) highlighted in his article on the relationship poverty and ill-health have with spaces of vulnerability in which he argued that decision making ought to be understood among other things, within material conditions. This living situation consequently impacted the way affected households experienced the illness. According to Kutalek (2012), illness experience is not only hinged upon the ethnic and cultural background of affected communities but on their socioeconomic situation as well.

We ought to recall that some NS victims were also epileptic while others had hunchbacks and opportunistic ailments which synergistically interacted with the effects of the poverty they suffered in what Singer and others call a syndemic (Singer 1996; Singer and Clair 2003; Singer, Bulled, and Ostrach 2013; Singer et al. 2017). According to Mendenhall et al. (2017), chronic socioeconomic problems are a crucial undergird for population health syndemics.

Victims, affected households, and communities suffered and collectively experienced the pain of NS in what Kleinman, Das, and Lock (1997) conceptualised as social suffering. As a concept it is used to communicate the impact on humans that adverse circumstances like war and civil conflict situations bring about including physical, emotional and economic violence, among others things (Scheper-Hughes and Bourgois 2003). In the results section of this thesis, I describe the physical and emotional impact victims and their primary caretakers suffered as a result of living with NS in a civil war context. War-related activities, the long time spent in the IDP camps together with the high poverty levels due to marginalisation and other socio-political process rendered the local population vulnerable to disease outbreaks. The NS situation is a reflection of what Kleinman (2010) posits that all social actions have unintended consequences some of which affect human health and may cause social suffering. It therefore is imperative that healthcare interventions are aimed at the population collectively rather than target individuals in an inequitable manner (Jansen et al. 2015).

The perception and illness experience of NS was found to have been impacted by conceptions of neglect by the government, high poverty levels, as well as the inequitable distribution of healthcare services. While poverty played a crucial role in healthcare access, the government was specifically blamed for laxity in the design and implementation of effective intervention services generally. Where they were existent to a given extent, they only were directed towards the victims of NS while the needs (especially psychosocial) of the caretakers in the home setting, for example were not bothered about. This is akin to Parker et al.'s (2016) submission that because of neglect, government priorities, social relations, and social behaviour are to blame for the pain affected populations endure in their illness experience. Das (2015) insightfully writes about the healthcare horizon as comprising ones family, professional healthcare providers, the state, and the market. She posits that care and neglect are spread among all these entities at one point or the other and elaborates how material lack and ongoing poverty very readily disintegrate into neglecting the ill on both familial and institutional levels. She goes ahead to show how this lack may yield violence akin to what is reported in the findings of this study.

8.5. Gender dimensions surrounding nodding syndrome: children as victims

Patriarchy and a gendered leadership system are seen to additionally influence and/or guide especially the rural Acholi population's lifestyle (Muyinda and Whyte 2011; Baines and

Rosenoff Gauvin 2014). Caregiving in Acholi culture is a prerogative of both the nuclear and extended family. Nonetheless, caregiving is considered primarily the responsibility of women and girls because of the patriarchal system in effect. Findings show that care was provided by members of the nuclear family with especially biological mothers as the primary caretakers. The mothers were in some cases complemented by fathers, siblings and other family members. It was not unusual, however, to find households where primary health care giving was done by female grandparents, siblings, aunts, and step mothers. It is important to note that the majority of primary caretakers were women who also expressed feelings of being burdened by their role. At this point, however, I hasten to add that despite the fact that the majority of primary caretakers were women, I conducted most caretaker interview sessions with men. This was the case because of the patriarchal system by which women are subordinate to men. The women often sat close by and made their contribution only after the men had spoken which conforms with what Kleinman (2012) says that sometimes voices of caregivers go unheard. Besides patriarchy, in some cases it seemed like men acted this way as a result of "rigid gender attitudes" as seen in Slegh and Richters' (2012:134) study of masculinity and violence in Rwanda.

According to Finnström (2008), female and male children have roles to play in the Acholi tradition and parents have expectations of each of their children which when sabotaged by an illness such as NS create a feeling of loss and confusion about what to do by the victims' family and the community within which one lives. Culturally and socioeconomically, family members together engage in food production and animal rearing to sustain the family's livelihood. Given the NS illness situation which required full time care for the victims, food reserves and in turn general nutrition were affected because the women could not afford to spend long hours doing garden work especially since several men within the same households spent most of their time consuming alcohol in local trading centres. In case of widowed caretakers, access to land for growing food was also a problem since customarily landownership was a privilege only for men. Custom has it that a clan occupies the land customarily passed down to descendants by the clan members' ancestors. The common practice is that portions of land are divided amongst the members according to family lines and it is upon this land that economic activities, mainly subsistence agriculture for the family's livelihood, take place. Given that the war claimed the lives of many men because of abduction and direct involvement as LRA soldiers, it was the women who faced the greatest challenges in land matters (Wilhelm-Solomon 2013). Acholi society is virilocal (with women

living in their husband's homes after marriage) and patrilineal (with property passed down to men). Many women whose husbands had died, or for whom formal marriage ceremonies were not complete were denied access to patrilineal land during the post conflict period but also no longer had rights on matrilineal land (Muyinda and Whyte 2011; Baines and Rosenoff Gauvin 2014).

The inequitable distribution of resources and roles propagated by unequal treatment of women also fed into the quality of caretaking victims received. The girls and women whose role it was to provide care for the ill expressed their exhaustion quickly adding that the sick should be taken out of their care and institutionalised instead. We ought to remember that these women also suffered the consequences of war including the loss of husbands which resulted into an increase of responsibilities for some. Trauma due to acts of violence during the war like rape and other forms of injustices also constituted these caretakers' reality. This is akin to what Richters and Kagoyire (2014) share regarding the impact of civil conflict on women and how their outlook on humankind is impacted. These expressions were also played out in a violent way going by the incidences of domestic violence against the children in their care as seen in the results section. In a similar way, some women were victims of violence from their partners perhaps because of a violent history but also because of male dominance perpetuated by patriarchy. This again resonates with Slegh and Richters' (2012) study in which they found that exposure to violence tends to give rise to violent behaviour and that it is natural for men to dominate women. Mothers to ill children were blamed for bearing ill children and often times were physically assaulted, verbally insulted as well as banished from their homes along with their ill children in order that the man could enjoy life with a new wife in the hope she would bear him healthy children free from NS. Violence was also economic in a sense that the men often did not provide for their families but instead sold off whatever they could; food and all, to sustain their alcohol consumption. The findings show that households that suffered domestic violence were those in which the men spent the entire day consuming alcohol. It was the same men who were at the forefront of my interviews with caretakers even though they did not participate in caretaking themselves which, as earlier mentioned most likely was because of their gender inequality attitudes as suggested by Slegh and Richters (2012).

The child victims themselves were not spared the physical and emotional violence all of which had an impact on how they experienced the illness. Considering that girls were perceived to be a source of wealth through dowry, when marriage seemed no longer possible for the girl child because of NS, feelings of displeasure sometimes set in and led to

abandonment and segregation of these children even from biological parents. This shows that there is a link between health and gender roles (Pike et al. 2010).

8.6. Influence of the media and past research activities on lay perceptions

I found it intriguing that several years down the road, the perceptions of local affected communities about the possible cause of NS remained more or less the same. This was despite progress in research that had ruled out some leads like the link to chemicals of war and munitions during the civil war period, contaminated domestic water sources and the pesticide coated seeds provided by humanitarian agencies that were washed and eaten by the people in IDP camps for lack of food (see appendix 1).

From the findings presented above, it is clear that the people's social reality at the time NS emerged played a role in influencing (or is it informing) their trend of thinking subsequently shaping their perceptions about its cause. I, however, also realised from their narratives that the information they were exposed and had access to from the media and research activities (past and ongoing) also had a tremendous impact on how the illness and what surrounds it, was perceived which perhaps partly accounts for the unchanging perceptions. "Ideas about how the body functions are dynamic. They change in response to public health messages, medical advertisements, and emergent analogical frameworks related to changing technology" (Nichter 2008:37). I say partly because this consistency in perceptions may point to something that has probably been missed or even ignored by the research community trying to establish the aetiology of NS.

Important to note also is that the perceptions respondents had and especially how they presented them may have also greatly been influenced by the numerous studies over the years from a number of perspectives on the subject. It was not uncommon for me to be told to ask the questions quickly as people had a lot else to do, reason being that they had been through this kind of exercise on number of occasions. I also was openly told that many researchers had been to these communities asking the very same questions and asked what difference my research would make when all they want is to know the cause of the illness and for the scientific community to find a cure for their dying children to be saved. This influence may have affected their conceptualisation of the syndrome and played into their narratives. Sillitoe (2016:6) shares an example of an Australian website of indigenous people who were in a similar situation. "We have been researched to death and there is nothing on the ground to show for it" was their exclamation.

The media, especially local radio stations within Gulu and Kitgum districts which most affected households had access to, was a source of information and constant updates about NS. I found that this too impacted the people's thinking regarding the emergence and persistence of the syndrome in northern Uganda. For example their conceptualisation of the illness as being politically engineered as well as the perception that GOU probably wanted to wipe out the Acholi ethnic group through NS may have likely been arrived at by the way the situation was depicted in local and national media. Indeed van Bemmel (2016:172) argues that "the media plays a large role in the conceptualisation of NS as a 'mysterious, political and deadly disease'" and fuels the fear that affected communities have regarding its communicability as seen in the next chapter. Local perceptions, as is observed by Benson et al. (2008) are dependent on past experiences, interaction with institutions as well as what comes out of the media.

During my stay in the field, I also found that there was a tendency for media platforms to speak critically of government emphasising their lack of concern for the NS affected masses in northern Uganda. In this rhetoric, radio/TV presenters and authors of newspaper articles for instance often mentioned historical factors that have seen the north as a neglected and marginalised region. This may have in one way or another informed the positions that affected communities took especially the hostility towards government regarding its failure to help alleviate their suffering. Exaggerations and misinformation from a human perspective (Stout, Villegas, and Jennings 2004:558) are reported to have often occurred and this certainly has the power to distort the people's reality by reinforcing certain aspects of their narratives rather than others.

Narratives from Acholi land – in much the same way as those obtained from Good and Good's (Good and Del Vecchio Good 1994:835) study in Turkey – maintain "multiple perspectives and the potential for multiple readings, suggesting alternative plots about source and outcome of illness, and they represent potency and the possibilities for healing through stories of encounters with the mysterious".

Finally, this project was aimed at exploring the local perceptions surrounding the emergence and experience of NS following an ethnographic study design. Specifically, the study set out to answer the following major questions:

a. What perceptions do NS affected communities have regarding the cause of NS?
b. How do affected communities experience this illness?

Political, social, economic, cultural, and environmental/ecological (biological) factors are at the centre of the nodding syndrome in northern Uganda. In other words, NS is a manifestation of different aspects within the above mentioned categories and how they either mutually enhanced or singly affected individuals and eventually a population in form of this illness.

NS among the Acholi is a reflection of what a history of civil conflict, marginalisation and abject poverty does to an already vulnerable population. It is also evidence of the role culture plays in shaping local perceptions, experience and response to illness. The meanings respondents attached to their perceptions of the condition arose from interaction of bio-sociocultural factors within the spaces affected communities lived over a period of time. This context is what guided the perceptions they had about the origin and experience of NS.

These results are aligned with the anthropological perspectives on disease emergence and illness experience presented in the introduction of this thesis. With reference to the syndemics framework it is evident from the findings that NS emerged in a context characterised by political and social upheaval both of which play a significant role in raising the probability of disease emergence and exacerbating the rate at which diseases spread. Epilepsy was found to be rampant among NS affected communities and so is the closeness of affected communities to the fast flowing rivers in which river blindness causing black flies breed.

I also submit that poor disaster preparedness, corruption and the absence of political will affected the design, implementation, and evaluation of interventions to affected communities. The uptake of the few available healthcare services was compromised due to the high poverty levels people suffer, inadequate drug and personnel resources at the HC's as well as mistrust towards the government. Similarly, the inadequate effort put into the design and implementation of efficient and effective interventions to address the multi-faceted forms of suffering of NS affected communities impacted how affected communities perceived the origin and experienced NS. In addition to the structural forces alluded to in the discussion, suffering for this population has in many a way been reinforced by the attitude with which government of Uganda has reacted to NS. It is impossible not to believe that this suffering could have been mitigated by a fast and efficient response to those in need by those with the power and means.

9. POLICY AND PRACTICE IMPLICATIONS OF FINDINGS

Contextualising these findings within the aforementioned theoretical framework reveals implications for policy makers at both national and international level in light of new and re-emerging illnesses. This is especially true for countries of the global south which carry a very high burden of mortality from both communicable and NCDs (WHO 2018a). Structural factors are at the helm of the explanatory models NS affected communities have about the illness. Similarly, structural factors impact the way the illness is experienced. For this reason therefore, if change is to be realised, it should begin with changes in the social and structural fabric that gives rise to social problems emanating significantly from structural violence, among other things.

A better understanding of the pathogenesis of NS may lead to prevention and treatment opportunities (Korevaar and Visser 2013) and will help policy makers plan measures of intervention which will positively impact the livelihoods of the affected communities. In the meantime though, the need to tackle the problem as it is now through mitigation strategies cannot be over emphasised. One of the many challenges Uganda has been over the years faced with in almost all social sectors is the total lack of, inadequacy, and problematic implementation and/or enforcement of policies. This is attributed to a number of things with corruption being ranked very highly followed by nepotism which focuses on who gets employed where rather than whether or not they are qualified for the job. While corruption and nepotism should be sternly handled with the full force of the law, of more importance at the moment is to deal with the NS situation in line with the WHO 1999 position regarding ways of curbing the incidence of abuse that may occur as well as dealing with such incidences which may have already occurred to children in the environment they reside in. Specifically, enlisting the support of UNICEF towards the welfare of affected children would go a long way in improving their situation as it is now. Whatever is within the mandate of UNICEF to provide is without a doubt needed by these children. For example, the findings have revealed that even when HC were accessed by victims and there often were no drugs for them to receive. The private healthcare centre H4H which played a key role in child victim care was overwhelmed by the financial resources required to keep it running that the proprietors were forced to wind up their activities closing down the facility at the end of 2017. UNICEF working hand in hand with the government of Uganda would revive this institution which

local people spoke highly about regarding the professional care for NS victims in Odek sub-county.

Additionally, epidemiological evidence should be obtained in order that the true magnitude of the problem is known. Once this information is in place control and preventive measures would most likely have the intended impact realised rather than simply working on assumptions. Gathering this kind of evidence however requires plenty of resources and therefore calls for the support of the WHO through funding and personnel if results are to be realised fast.

Policy makers ought to inculcate in themselves discipline to ensure disaster preparedness and to engage in regular surveillance of areas that may be susceptible to outbreaks of this kind as a way of being pre-emptive. In line with Kleinman's (2010) submission, since social actions intended for good may carry undesirable consequences, prediction where possible ought to be done and mitigation measures enacted. In cases where the negative consequences outweigh the benefits then such social actions should completely be done away with or replaced with less harmful ones. This process would not only focus on human beings but also animal life including both domestic and wild because these may act as hosts for potentially dangerous vector transmitters of disease.

Inter-disciplinary collaboration in the prevention and treatment of diseases is just as important as the collaborative work that goes into understanding their causes and burden. In fact, the one World, one Health initiative was formed to deal with diseases from a high level by focusing on the grass root causes of emerging diseases (Khan 2008) through a multi-disciplinary approach. WHO (2018c) also advocates concerted and collective efforts on a global scale in tackling the mental health problem worldwide. It is therefore imperative for epidemiologists and anthropologists to additionally collaborate in guiding health planners and policy makers towards ensuring that the right policies are put in place and strategies engaged to not only treat but guard against the emergence of conditions such as NS. According to Willen et al. (2017), a combined human rights and syndemics approach to health intervention would go a long way in battling inequalities and enhancing positive outcomes on the policy and practice fronts. In as far as interventions are concerned, incorporate the local people's perceptions into their design and include their participation in having them implemented to ensure uptake which would in turn raise the probability of attaining the desired goal. According to Sillitoe (2016:225), "ignoring the voice of the people in such matters ends up as a very expensive

venture and an offensive intrusion into people's lives". Provision of health services ought, therefore, to be for all, inclusive, and multi-faceted because of the benefits it carries along which include adding value through its search for excellence, enhancing accountability as well as advancing institutional missions (McDougle, Lu, and Castro 2011).

Insofar as healthcare services are concerned, adequacy, equitability and quality are key factors (Kutalek 2012; Jansen et al. 2015). The example of sociotherapy (Richters 2015; see also, among others, Richters and Sarabwe 2014; and Richters 2010) in post-genocide Rwanda could actually be adopted to benefit this community as well while the population deals with the trauma of the war and nor the NS challenge. Undeniably, the level of expertise of the service provider and awareness of the cultural setting in which the illness is experienced is equally important. The need for a skills and competence based approach towards training of health personnel in Uganda cannot be over emphasised if public health problems are to adequately and expeditiously be dealt with before they get to epidemic levels and wreck the very existence of the people of the nation through otherwise preventable loss of life which consequently affects other sectors and areas of livelihood. Children are one of the things that people hold in high esteem and once interventions target them, then susceptibility to and spread of disease will have been tackled at its root (Trostle 2005). They are an important category in as far as interventions are concerned (Desai 2010). This training ought to be focused on all areas affecting the child including proper health and feeding practices, child care, child neglect and abuse, protection and generally what the child is entitled to as a basic human right. Child protection requires urgent address in terms of building evidence based cases of violence and neglect against children as well as strengthening the dialectical "restorative and retributive" (Bukuluki et al. 2017:201) justice system in northern Uganda for victims to obtain justice.

Capacity building programmes for caregivers in the family and clinical setting should pay attention to the way caregivers interact with patients by advocating for "presence" as advanced by Kleinman (2017a:2458). The state of affairs at most public HCs in my study area warranted that adequate staff recruitment is done to curb the problem of long waiting hours for patients and keep healthcare givers well motivated. With regard to social suffering, healthcare planning ought to be cognisant of the fact that ailments that are chronic, psychosocial in nature and lead to mental capacity degeneration such as NS put a lot of physical and emotional strain on especially primary health caregivers in the home setting

which necessitates that intervention programmes for this category as well be catered for in the design of interventions.

There also ought to be better communication channels for all stakeholders to have access to information regarding the health of children and community members in general. Like Korevaar and Visser (2013) indicate in their publication about availability of information on NS, many a researcher has been to affected areas in a bid to generate information which would then shed more light on this new and unsettling phenomenon but "good data" still eludes the common man. My realisation is that channels and mechanisms through which the public is informed and updated about what is going on are either lacking or inefficient in the case of Uganda. Furthermore, findings from these numerous studies are either not published or they, for one reason or another take ages to get published so the masses are affected by way of an information gap. This too is actually one of the complaints that kept coming up from respondents saying that many a researcher has been to their villages and homes asking questions about the syndrome but once they are gone, the community never gets to hear from them regarding their findings and the status of the problem. The CDC was particularly cited as one of the culprits when they took samples from victims and flew some to Atlanta but no formal feedback was obtained thereafter.

Healthcare practitioners in the popular and professional sectors lie at the helm of care provision to the ill (Kleinman 1980). As a moral requirement and experience, the caregiver provides a priceless gift out of love to the one in their care. The proximity shared between the patient and caregiver yields knowledge that can only be shared once the caregiver has an opportunity to be heard (Kleinman 1999; Kleinman 2017b).

Furthermore, to foster healing therefore caregivers and patients are better off speaking a 'common' language with either one understanding the other. This can easily be fostered if they share the same "cultural and language background" (Kutalek 2012:1). It is important for practitioners to appreciate the cultural and social diversity of their patients and how they negotiate healthcare. The ability to for instance acknowledge how health seeking decisions are made and the meanings attached to what the patients say and how they behave would be a step in the right direction towards fostering effective communication in the healing process. According to Kleinman and Benson (2006:1673), culture ought to be taken seriously enough to evaluate "the cost-effectiveness of culturally informed therapeutic practices…"

While medical anthropology is increasingly and steadily becoming very popular as a branch of anthropology, there is need for greater collaboration between anthropologists, medical and public health researchers. An interdisciplinary and holistic approach to public health problems would fetch more in terms of success stories and improved livelihoods compared to a disjointed approach.

According to Dowell of the CDC (Dowell et al. 2013), diseases such as NS take time to figure out. Nonetheless, Nichter (2008) calls for continued research into communicable and vector-borne diseases but emphasises the need for new studies to be designed for purposes of investigating behavioural tendencies of NCDs and chronic ailments. Given that NS has both been classified as chronic and non-communicable by the scientific community and yet it is seen as probably communicable sections of affected communities, I recommend that this particular aspect is further investigated. This recommendation is also because inasmuch as I have substantially read published and unpublished literature on NS, I have found extremely little written about the infectiousness (or not) of NS, which in my opinion raises several questions.

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APPENDICES

Appendix 1: Aetiological factors and data conclusions

Factors evaluated	Conclusions based on results	Investigations and references*
<u>Helminths</u> *Onchocerca volvulus*	Further investigations needed	URT 2005 (case series, Winkler et al. (2008)) -South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) -South Sudan 2011 (case control, case series, NS meeting presentation, Riek et al. (2011)) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012) Sejvar et al. (2012) presentation, Foltz et al. (2012) Sejvar et al. (2012))
Mansonella *streptocerca*	Further investigations needed	-Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Mansonella perstans	Further investigations needed	-South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012)

Loa loa	Ruled out based on lack of Loa loa endemicity	-South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002))
Wuchereria bancrofti	Ruled out based on case-control study	-South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)
Other infections Human African Trypanosomiasis (HAT)	Ruled out based on lack of co-endemicity in URT, Pader/Kitgum in northern Uganda, rate of infection in case control study in Mundri County in South Sudan, serological testing in Uganda	South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) - Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
African Swine Fever (ASF)	Unlikely, based upon inconsistent epidemiology (ASF is not known to be a human pathogen), and failure to detect nucleic acid sequences of ASF on PCR	- Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012) Sejvar et al.(2012))

Hepatitis E	Ruled out based upon inconsistent epidemiology, and failure of laboratory testing to demonstrate a preponderance of infection among NS children	-Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Cysticercosis	Not consistent with current data	-URT 2005 (case series, Winkler et al. (2008)) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Malaria	Unlikely since the presentation is inconsistent with cerebral malaria, and there was no difference in the presence of parasites on blood smears between cases and controls	-Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Meningitis	Unlikely since no consistent history of signs and symptoms suggestive of viral or bacterial meningitis could be elicited from cases	- Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))

Measles	Unlikely based on lower frequency of history of measles among cases compared to controls and biological plausibility	- South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Prion disease	Unlikely based on incompatible clinical presentation, and uncharacteristic EEG and MRI findings. Histopathology, however, would be required to definitively exclude this possible aetiology.	-URT 2005 (case series, Winkler et al. (2008)) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Nutritional factors Bush meat, river fish, Monkey brain and meat.	Ruled out based on comparison of data for cases and controls	--South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Relief food, seeds for planting	Ruled out based on case control study	- South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))

Urinary thiocyanates	Ruled out based on case control studies and inconsistency of clinical presentation with characteristics of bitter cassava toxicity	-Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012)) -South Sudan 2011 (case control, case series, NS meeting presentation, Riek et al. (2011))
B12, A, Selenium	Ruled out based on case control studies	-Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012)) -For B12: Also South Sudan 2011 (case control, case series, NS meeting presentation)
"Local" foods (red and unripe sorghum, cassava)	Unlikely based on comparison of data for cases and controls	- South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al (2002)) -South Sudan 2011 (case control, case series, NS meeting presentation)
Vitamin B6	Further investigations needed	-South Sudan 2011 (case control, case series, NS meeting presentation)
Early malnutrition	Further investigations needed	-South Sudan 2011 (case control, case series, NS meeting presentation) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Fungal contamination of local food	Further investigations needed	South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002))

Toxic/Environmental factors Crushed roots (Herbal / traditional medicinal remedies)	Unlikely based on case control studies	-South Sudan 2011 (case control, case series, NS meeting presentation) -Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Exposure to ammunitions	Unlikely based on the lack of data to support use of chemical weapons and lack of biological plausibility for exposure to other types of ammunition	-South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002) -South Sudan 2011 (case control, case series, NS meeting presentation, Riek et al. (2011))
Domestic water sources	Ruled out	-Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Mercury, Arsenic, Lead, Copper	Ruled out based on laboratory data	-South Sudan 2011 (case control, case series, NS meeting presentation) - Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))
Pesticides	Ruled out based on case control study	-South Sudan 2011 (case control, case series, NS meeting presentation) Uganda 2009-2010 (case control, case series, NS meeting presentation, Foltz et al. (2012), Sejvar et al. (2012))

Other environmental toxins	Further investigations needed	-South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002))
Other causes Genetic	Further investigations needed	-URT 2005 (case series, Winkler et al. (2008)) -South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) -South Sudan 2011 (case control, case series, NS meeting
Psychogenic	Further investigations needed	-Musisi, NS meeting presentation: -Neuropsychiatric aspects of NS in Uganda: a possible role of psycho trauma
Population displacement, poverty	Further investigations needed	-South Sudan 2001-2002 (case control, case series, NS meeting presentation, Anker et al. (2002)) -South Sudan 2011 (case control, case series, NS meeting presentation)

Source: (WHO et al. 2012:7–10)

Appendix 2: Summary of conclusions of the 2015 NS international conference

Disease nosology	• Clear distinction between Uganda's Nakalanga syndrome and NS still lacking • Inasmuch as NS in Uganda has been associated with *O.volvulus* evidence shows that this is not true for all cases in Uganda which indicates that it is not the primary cause at least in as far as Uganda is concerned • Deficiency of biotinidase in blood and urine samples of children at Odek H4H care centre
Risk factors	• IDP camp environment, black flies, munitions, contaminated food, evil spirits • Poverty and un-purified drinking water
Clinical findings	• Cases found to have psychiatric disorders including episodic major depression, current post traumatic stress disorder, generalised anxiety disorder, and pervasive developmental disorder
Treatment	• Correcting malnutrition, anti-seizure medication, special needs education, high level of personal care and attention, local music and dance therapy
Seizure types and course	• Tonic, atonic and HN seizures seen whose course ranged from daily to once a year • Generalised tonic-clonic seizures that started in children 0-17 years old after onset of nodding seizures • No more seizures for some cases on antiepileptic treatment
Disease concepts	• NS may possibly be a post-measles brain disease • NS could be a mitochondrial disorder with metabolic acidosis association

- NS maybe a form of late on-set autism
- “NS is part of a spectrum of different types of seizures in *O.volvulus*-endemic areas and several of the different types of epilepsy most likely have a related aetiology as a direct and/or indirect (potentially immune mediated) consequence of *O.volvulus* infection” (Spencer et al. 2016:82)

Source: (Spencer et al. 2016)

Appendix 3: The sample

Interview code - **Victims**	Gender of study participant	Age	Location of study participant	Reason for inclusion
V1	Female	14	Akoyo	Host family and seriously scarred
V2	Male	16	Akoyo	Eldest of eight and only victim
V3	Male	18	Akoyo	Host family member in secondary school
V4	Female	16	Akoyo	Approached me for help to get into H4H
V5	Male	15	Akoyo	Physically deformed victim long term patient used a face of NS to the public
V6	Male	16	Odek	Patient at Odek HCIII
V7	Female	16	Akoyo	Physically scarred
V8	Male	17	Akoyo	Family abandoned be father
V9	Female	14	Tumangur	Home for victims' prayer meetings
V10	Male	24	Tumangur	Oldest victim in Tumangur
V11	Female	20	Tumangur	Young adult victim
V12	Male	18	Tumangur	Victim married to another victim
V13	Female	38	Odek	Outside 5-15 year age bracket
V14	Female	18	Tumangur	Five victims in family with 24 children
V15	Male	13	Tumangur	Five victims in family with 24 children
V16	Female	8	Odek	Sought healthcare on her own

V17	Male	11	Akoyo	Victim of domestic violence
Caretakers	**Gender/Relationship**	**Age**	**Location**	**Reason for inclusion**
C1	Grandmother	56	Akoyo	Host family
C2	Father	48	Akoyo	Hands-on caregiver and VHT member
C3	Female/ Employee	27	Akoyo	Exposure to many victims as caretaker
C4	Mother	32	Akoyo	Abandoned by husband
C5	Mother	30	Akoyo	Leader of victim caretaker self-help group
C6	Father	35	Akoyo	Hands-on male caretaker
C7	Aunt	50	Akoyo	Extended family member as primary caretaker and her adult son abandoned his family with two child victims
C8	Male	56	Tumangur	Son died at 19 and VHT senior member
C9	Female	42	Tumangur	Mother to 24 year old victim
C10	Father	43	Tumangur	All three victim children dead
C11	Father	42	Tumangur	Father of five victims
C12	Sister	17	Tumangur	Primary caregiver to ill brother
C13	Brother	25	Tumangur	Medical care university student with ill brother

C14	Male	32	Akoyo	Male institutional caretaker
C15	Father	30	Akoyo	Child neglect, substance abuse, sexual crimes against victims
C16	Father/ Neighbour	46	Odek	Long distance walk for health care
C17	Father	39	Akoyo	Four victims in family with domestic violence record
C18	Grandmother	64	Tumangur	Elderly caretaker who provided land free of charge for health centre construction
C19	Male	38	Tumangur	Father of suicidal victim
Public health workers	**Gender**	**Age**	**Location**	**Position**
PH 1	Male	41	Odek	Local government NS task force member
PH2	Male	32	Odek	Senior clinical officer
PH3	Male	28	Odek	Public health practitioner with VSO
PH4	Male	30	Odek	Senior clinical officer
PH5	Female	32	Odek	Nurse
PH6	Female	35	Akoyo	Nurse
PH7	Male	40	Tumangur	Senior clinical officer

Key informants	**Gender**	**Age**	**Location**	**Reason for inclusion**
K1	Male	78	Akoyo	Community elder
K2	Male	35	Odek	Community elder
K3	Female	34	Akoyo	Special needs teacher and community elder
K4	Male	39	Tumangur	Gate keeper and NS task force member
K5	Female	41	Akoyo	Community member

DATA COLLECTION INSTRUMENTS

Appendix 4: FGD guide for children aged 14-17 years

Introduction

I am carrying out a study on the local perceptions of NS in northern Uganda and their implications for interventions.

The level of response towards NS in the socially and economically unstable communities of northern Uganda contributes to a lot of frustration to individual households.

While several researchers continue to investigate what the possible cause(s) of NS is and what treatment(s) would be effective, equally important is the need to address – in greater detail, the local perceptions towards the syndrome and the meanings attached to them. In so doing, a better understanding of the syndrome will be achieved which, it is envisaged, will help bridge the now existent information gap for instance about risk factors and what intervention measures ought to target which in turn will positively impact the families and communities affected by NS.

The purpose of this study therefore is to primarily generate information on the syndrome by bringing to light conceptions of the Acholi surrounding the experiences of children and young adults affected by NS and the meanings attached to them. As secondary information, it will also highlight what challenges from a first-hand account perspective these families face.

You have been selected to participate in this study because you are a caretaker of a child identified for inclusion in this study. I am requesting that you participate in the study voluntarily which participation will call for your involvement in informal conversations, in-depth interviews or group discussions with the researcher(s). In some instances, the information you give will be recorded on audio tapes so that it is captured exactly as you say it. Your identity will be concealed throughout this study unless written consent is obtained.

It is anticipated that the information you will share shall help us gain a better understanding of the plight of children and families affected by NS and subsequently enable us inform the interventions design process ultimately for the improvement of the livelihood of especially those directly affected.

Background

- Kindly tell us about yourself; your age, your siblings (if any), if you go to school or not, where, in which class you are and anything else you would like to say about yourself.
- How would you describe your life so far?

Perception about the illness

- What do you think about your health?
- What do you call your illness? What name does it have?
- What do you think caused the illness?
- Why and when did it start?
- What do you think about how it is spread?
- How severe is it in your opinion?
- Will it have a short or long course?
- What do you think the illness does? How does it progress?
- What kind of treatment do you think the patient should receive?
- What are the most important results you hope your patient(s) receives from this treatment?

Experience of the illness

- Please tell me about how you experience this illness (Symptoms, physical and/ or emotional pain).
- What affects you most about the illness?
- Are any other persons in your family also directly affected by the illness? (Probe: What are their ages?)
- Are your symptoms similar or different? (Probe: In which way?)
- How is your relationship with the other members of your family affected or not? (Probe: Acceptance, support, et cetera)
- How is your relationship with other members of the community; both affected and not? (Probe: Acceptance, support, stigmatisation et cetera)

Healthcare seeking behaviour

- Have you or your guardians sought health care for this illness?
- From where has this healthcare been sought?
- What kind of treatment was/is provided at this facility?
- What effect has it had on your health?
- Have you observed other children in your situation seeking healthcare at these same facilities?
- What is your opinion about the frequency and consistency of healthcare seeking behaviour for affected children and families?
- What effect has it had on the affected children's wellbeing?

Challenges faced as a victim of this illness

- Have you faced any challenges as a result of this ailment? (Probe: Which ones are they?)
- Do your caretakers and guardians face any challenges in taking care of you? (Probe: Which ones are they?)

Strategies used to handle challenges faced as a result of the illness

- What strategies do you employ in dealing with these challenges?
- What strategies do your caregivers undertake in dealing with the challenges they face as they take care of you?

Community attitudes and perceptions towards children affected by the illness

- Which places have you normally gone to since you became affected by this illness?
- Have you ever felt any discomfort in going to any of these places after you fell ill? Why?
- What do you think is the community's perception of you?

Suggestions for interventions

What do you think ought to be done by whoever is concerned (parents/ guardians, healthcare facilities, the affected children themselves, those not affected, community members, local

leaders, political heads, the international community et cetera) in order that the problems arising from the illness are completely solved or at least mitigated in the short term?

Appendix 3: FGD guide for caretakers

Introduction

We are carrying out a study on the local perceptions of NS in northern Uganda and their implications for interventions.

The level of response towards NS in the socially and economically unstable communities of northern Uganda contributes to a lot of frustration to individual households.

While several researchers continue to investigate what the possible cause(s) of NS is and what treatment(s) would be effective, equally important is the need to address in greater detail the local perceptions towards the syndrome and the meanings attached to them. In so doing, a better understanding of the syndrome will be achieved which, it is envisaged, will help bridge the now existent information gap for instance about risk factors and what intervention measures ought to target which in turn will positively impact the families and communities affected by NS.

The purpose of this study therefore is to primarily generate information on the syndrome by bringing to light conceptions of the Acholi surrounding the experiences of children and young adults affected by NS and the meanings attached to them. As secondary information, it will also highlight what challenges from a first-hand account perspective these families face.

You have been selected to participate in this study because you are a caretaker of a child identified for inclusion in this study. I am requesting that you participate in the study voluntarily which participation will call for your involvement in informal conversations, in-depth interviews or group discussions with the researcher(s). In some instances, the information you give will be recorded on audio tapes so that it is captured exactly as you say it. Your identity will be concealed throughout this study unless written consent is obtained.

It is anticipated that the information you will share shall help us gain a better understanding of the plight of children and families affected by NS and subsequently enable us inform the interventions design process ultimately for the improvement of the livelihood of especially those directly affected.

Background

- Kindly tell us about yourself; your age, your relationship to the affected child, the size of your family, how many affected children are under your care, your marital status,

level of income, level of education and anything else you would like to say about yourself.

- How would you describe your life so far?
- How do you describe the life of the child (ren) under your care so far?

Perception about the illness

- What do you think about your child (ren's) health?
- What do you call their illness? What name does it have?
- What do you think caused the illness?
- Why and when did it start?
- What do you think about how it is spread?
- How severe is it in your opinion?
- Will it have a short or long course?
- What do you think the illness does? How does it progress?
- What kind of treatment do you think your patient should receive?
- What are the most important results you hope your child (ren) receives from this treatment?

Experience of the illness

- How many children in your family are affected by the illness? (Probe: What are their ages?)
- How many caretakers are there to watch over these children? (Probe: What is their relationship to the affected children?)
- Please tell me about how your child (ren) experiences this illness (Symptoms, physical and/ or emotional pain).
- What affects the child (ren) most about the illness?
- What affects you most about your child (ren's) illness?
- Are their symptoms similar or different? (Probe: In which way?)
- How do you describe the effect of this illness on the family member's relationship with each other? (Probe: Acceptance, supportiveness, et cetera)
- How do you describe the relationship of other members of the community; both affected and not towards you and your family? (Probe: Acceptance, support, stigmatisation et cetera)

Healthcare seeking behaviour

- Have you sought health care treatment for this illness for your child (ren)?
- From where has this healthcare treatment been sought?
- What kind of treatment was/is provided at this facility?
- What effect has it had on your child (ren's) health?
- Have you observed other children in your own child (ren's) situation seeking healthcare at these same facilities?
- What is your opinion about the frequency and consistency of healthcare seeking behaviour for affected children and families?
- What effect has it had on the affected children's wellbeing?

Challenges faced as a caretaker of a victim(s) of this illness

- Have you faced any challenges during the course of taking care of the affected child (ren) under your care? (Probe: Which ones are they?)
- Does your child (ren) face any challenges as a result of this illness? (Probe: Which ones are they?)

Strategies adopted to handle challenges faced as a result of the caretaking role?

- What strategies do you employ in dealing with the challenges you face as a caretaker?
- What strategies do your children undertake in dealing with the challenges they face as they experience the illness?

Community attitudes and perceptions towards children affected by the illness

- Which places have you and your children normally gone to since they became affected by this illness?
- Have you or your children ever felt any discomfort in going to any of these places after they fell ill? Why?
- What do you think is the community's perception of you and your children?

Experience of the illness

- Approximately how many affected children have you observed in your community? (Probe: What are their ages?)

- How many caretakers are there to watch over these children? (Probe: what is their relationship to the affected children?)
- Please tell me about how this child (ren) experiences this illness in your opinion. (Symptoms, physical and/ or emotional pain).
- What affects the child (ren) most about the illness?
- What affects you most about your child (ren's) illness?
- Are their symptoms similar or different? (Probe: In which way?)
- How do you describe the effect of this illness on the family member´s relationship with each other? (Probe: acceptance, supportiveness, et cetera)
- How do you describe the relationship of other members of the community; both affected and not towards you and your family? (Probe: acceptance, support, stigmatisation et cetera)

Health seeking behaviour

- Have you sought health care treatment for this illness for your child (ren)?
- From where has this healthcare treatment been sought?
- What kind of treatment was/is provided at this facility?
- What effect has it had on your child (ren's) health?
- Have you observed other children in your own child (ren's) situation seeking health care at these same facilities?
- What is your opinion about the frequency and consistency of healthcare seeking behaviour for affected children and families?
- What effect has it had on the affected children's wellbeing?

Challenges faced as a caretaker of an NS victim(s)

- Have you faced any challenges during the course of taking care of the affected child (ren) under your care? (Probe: Which ones are they?)
- Does your child (ren) face any challenges as a result of this illness? (Probe: Which ones are they?)

Strategies adopted to handle challenges faced as a result of the caretaking role?

- What strategies do you employ in dealing with the challenges you face as a caretaker?

- What strategies do your children undertake in dealing with the challenges they face as they experience the illness?

Community attitudes and perceptions towards children affected by the illness

- Which places have you and your children normally gone to since they became affected by this illness?
- Have you or your children ever felt any discomfort in going to any of these places after they fell ill? Why?
- What do you think is the community's perception of you and your children?

Suggestions for interventions

What do you think ought to be done by whoever is concerned (parents/ guardians, healthcare facilities, the affected children themselves, those not affected, community members, local leaders, political heads, the international community et cetera) in order that the problems arising from the illness are completely solved or at least mitigated in the short term?

Appendix 5: KII guide for healthcare practitioners, policy officials, local leaders, and non-government institutional staff

Introduction

We are carrying out a study on the local perceptions of NS in northern Uganda and their implications for interventions.

The level of response towards NS in the socially and economically unstable communities of northern Uganda contributes to a lot of frustration to individual households.

While several researchers continue to investigate what the possible cause(s) of NS is and what treatment(s) would be effective, equally important is the need to address in greater detail the local perceptions towards the syndrome and the meanings attached to them. In so doing, a better understanding of the syndrome will be achieved which, it is envisaged, will help bridge the now existent information gap for instance about risk factors and what intervention measures ought to target which in turn will positively impact the families and communities affected by NS.

The purpose of this study therefore is to primarily generate information on the syndrome by bringing to light conceptions of the Acholi surrounding the experiences of children and young adults affected by NS and the meanings attached to them. As secondary information, it will also highlight what challenges from a first-hand account perspective these families face.

You have been selected to participate in this study because you are a caretaker of a child identified for inclusion in this study. I am requesting that you participate in the study voluntarily which participation will call for your involvement in informal conversations, in-depth interviews or group discussions with the researcher(s). In some instances, the information you give will be recorded on audio tapes so that it is captured exactly as you say it. Your identity will be concealed throughout this study unless written consent is obtained.

It is anticipated that the information you will share shall help us gain a better understanding of the plight of children and families affected by NS and subsequently enable us inform the interventions design process ultimately for the improvement of the livelihood of especially those directly affected.

Background

- Kindly tell us about yourself; your age, where you hail from, how prevalent families affected by NS are in your area of residence, if you have any affected children under your care, your marital status, level of income, level of education and anything else you would like to say about yourself.
- How do you describe the lives of families affected by NS in your community?
- How do you describe the lives of the child (ren) affected by NS in your community?

Perception about the illness of the affected children

- What do you think about these children's health?
- What do you call their illness? What name does it have?
- What do you think caused the illness?
- Why and when did it start?
- What do you think about how it is spread?
- How severe is it in your opinion?
- Will it have a short or long course?
- What do you think the illness does? How does it progress?
- What kind of treatment do you think your patient should receive?
- What are the most important results you hope these children receives from this treatment?

Experience of the illness

- Approximately how many affected children have you observed in your community? (Probe: What are their ages?)
- How many caretakers are there to watch over these children? (Probe: What is their relationship to the affected children?)
- Please tell me about how this child (ren) experiences this illness in your opinion. (Symptoms, physical and/ or emotional pain).
- What affects the children most about the illness?
- What affects you most about these children's illness?
- Are their symptoms similar or different? (Probe: In which way?)
- How do you describe the effect of this illness on the family member´s relationship with each other? (Probe: Acceptance, supportiveness, et cetera)

- How do you describe the relationship of other members of the community; both affected and not towards the affected children and families? (Probe: Acceptance, support, stigmatisation et cetera)

Healthcare seeking behaviour

- How would you describe the health seeking behaviour by the affected families?
- From where is this health care treatment often sought?
- What kind of treatment is provided at these facilities?
- What effect does it have on these children's health?
- What is your opinion about the frequency and consistency of health seeking behaviour for affected children and families?
- What effect has this frequency and consistency had on the affected children's wellbeing?

Challenges faced by the caretakers of NS victims

- Are there challenges by the caretakers during the process of taking care of the affected children under their care? (Probe: Which ones are they?)
- Does the affected child (ren) face any challenges as a result of this illness? (Probe: Which ones are they?)

Strategies adopted to handle challenges faced as a result of the caretaking role?

- What strategies have you observed caretakers employ in dealing with the challenges they face in this role?
- What strategies have you observed the affected children undertake in dealing with the challenges they face as they experience the illness?

Community attitudes and perceptions towards children affected by NS

- Which places do the affected families normally visit since they became affected by this illness?
- What do you think is the community's perception of families?

Suggestions for interventions

What do you think ought to be done by whoever is concerned (parents/ guardians, healthcare facilities, the affected children themselves, those not affected, community members, local leaders, political heads, the international community et cetera) in order that the problems arising from the illness are completely solved or at least mitigated in the short term?