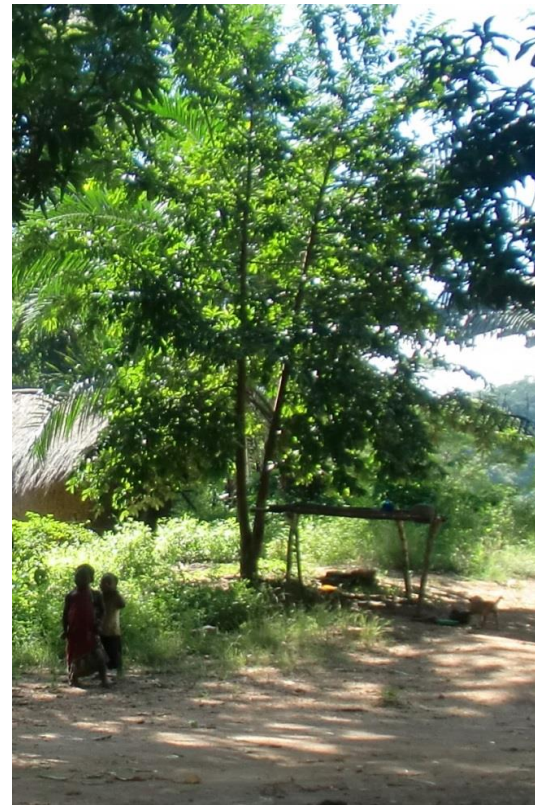


Shifting Meanings of Illness

An anthropological study of nodding syndrome in Tanzania

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1. Introduction

During the past decade reports started showing up in the media and scientific literature about a new mysterious illness turning children into zombies. The alarming reports were referring to nodding syndrome (NS), also known as nodding disease or head nodding. So far nodding syndrome has been found in South-Sudan, the north of Uganda and southern Tanzania. Nodding syndrome is medically defined as a seizure disorder affecting children that manifests itself in episodes of head nodding, combined with stunted growth, cognitive decline, and often development of generalized seizures (Dowell et al. 2013: 1374; Korevaar & Visser 2012: 1; Van Bommel et al. 2013: 2; Winkler et al. 2008: 2008). So far no definitive cause has been identified and little is known about the prevalence, course, and cure of this mysterious illness.

It is the sudden rise of alarming messages about NS that first caught my attention as an anthropologist. I wondered why this illness, that only occurs in three small areas in Africa and does not seem to be a great threat to public health, suddenly received so much attention from international media, international health organisations, and scientists all over the world. These initial questions formed the starting point of what would eventually become this anthropological study into nodding syndrome in Tanzania. The majority of the research that has been done into nodding syndrome focussed on Uganda and South Sudan, however not much is known about NS in Tanzania. This is remarkable since the symptoms were already reported fifty years ago in Tanzania by a Norwegian physician in her studies of epilepsy among the Pogoro tribe, located in the south of Tanzania. Symptoms of NS were not seen in the north of Uganda and South-Sudan until about fifteen years ago. Research in Tanzania specifically focussing on what is now known as nodding syndrome only started when symptoms were found in Uganda and South-Sudan. However the contexts in which NS occurs are quite different, it is important to take into account that the north of Uganda and South-Sudan are neighbouring areas with a recent history of war and internal displacement, as opposed to Tanzania. Van Bommel et al. (2013) show in their anthropological study of NS in Uganda that the history of war and internal displacement has a large influence on the conceptualization of NS. This makes studies of NS focussing on Uganda and South-Sudan less applicable to NS in Tanzania. Since not much is known about NS in Tanzania, it is highly relevant to find out how NS is affecting Tanzania and what specific contextual factors are at play there. The few biomedical studies into NS that have been done in Tanzania do not provide answers on the context of NS in Tanzania, so a different approach was needed. An anthropological study is capable of looking at illness in a holistic way by incorporating the individual, the social, the political, and the spiritual as factors that influence and are influenced by illness. This was the first anthropological study into nodding syndrome in

Tanzania and therefore provides a new and unique angle when it comes to understanding this mysterious illness.

1.1. A social constructionist approach to nodding syndrome

The majority of the scientific studies focussing on nodding syndrome are biomedical in character, focussing on the cause, course, and cure of the illness. Nodding syndrome is presented as a fact of nature within these biomedical studies, leaving little room for the context in which NS occurs. Consequently, the available scientific studies on NS reflect a rather one-sided image. Within anthropology illness is regarded as part of a social context, a social context that is made. This approach is called a social constructionist approach and shows a different perspective on illness. Since illness is not a fact of nature but embedded in social- and political processes, a social constructionist approach to nodding syndrome was applied in this study. As Conrad and Barker (2010: 67) state, a social constructionist approach does not take a phenomenon as a natural and universal event but takes into account the cultural and historic aspects that give meaning to a phenomenon. The meanings of phenomena do not inhere in them but are constructed through interaction in a social context. So people in a specific context produce their social reality. If we move away from the understanding of illness as a given biomedical fact, we are left with: '[...] a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux (Brown: 1995: 37).' When looking at nodding syndrome in a similar way we can state that nodding syndrome is being constructed in interactions between many different actors, discourses and practices, influenced by power relations. These interactions can also be seen as friction, a concept used by Tsing (2005). The friction that arises in heterogeneous and unequal encounters can lead to new arrangements of culture and power, according to Tsing (2005: 5). Therefore the aim of this study is to clarify how nodding syndrome is constructed in Tanzania through friction that arises in the encounters between different actors, discourses, and practices. This thesis shows that friction leads to continuous shifts in meaning of nodding syndrome in Tanzania. These shifts in meaning are particularly visible in the friction that arises in the encounters between actors constructing nodding syndrome internationally and the specific context of nodding syndrome in Tanzania.

Medical anthropologists and –sociologists using a social constructionist approach regularly make a conceptual distinction between disease and illness (Conrad & Barker 2010: 67). Disease can be understood as biological abnormalities in the structure or functions of the body, reinterpreted as objective symptoms by medical practitioners (Hanna & Kleinman 2013: 20; Young 1982: 264). Illness then refers to the subjective experience of certain socially disvalued states and the social meaning

attributed to them (Young 1982: 265; Conrad & Barker 2010: 67). Illness can therefore stretch beyond what is considered to be a disease according to the biomedical model (Young 1982: 265). Sickness is often added to the disease/illness distinction to refer to the way disease and illness are socialized and understood within a population, influenced by political, economic and institutional forces (Young 1982: 270; Brown 1995: 46). The distinction between disease, illness and sickness however is not as straight forward as it seems. Disease as a biological abnormality in the body implies that illness is a fact of nature waiting to be uncovered by scientists and doctors (Conrad & Barker 2010: 68). However, studies into the construction of medical knowledge show that determining what biological states are labelled as disease, is a complex process of social construction (Conrad & Barker 2010: 67-68). Besides the category of disease, the separate categories illness and sickness are also problematic. Young (1982: 279) states that within medical anthropology there seems to be a separation between the anthropology of illness and the anthropology of sickness. The anthropology of illness is being accused of not taking into account the social and economic determinants of illness, which led to the introduction of the anthropology of sickness. However illness and sickness cannot be seen separately. The individual experience of a socially disvalued state and the meaning attributed to that state, referred to as illness, is always determined by larger social and economic forces. So the social and economic forces referred to as sickness have to be taken into account when studying illness, making a separation impossible.

Since the conceptual distinction between disease, illness, and sickness is problematic, nodding syndrome will only be referred to as illness here. For the purposes of this thesis illness refers to the subjective experience of and meanings given to a socially disvalued state, following Young (1982: 265) and Conrad & Barker (2010: 67). Since the individual suffering from illness is influenced by its social environment and macro social forces, the social context is considered to be an integral part of illness in this study, instead of a separate category.

It is important to clarify that the focus of this research is on the construction of illness and not on medical knowledge. However, medical actors, discourses, and practices that are active in the construction of nodding syndrome will be taken into account. It is the medico-scientific community that has the most power in constructing knowledge about NS. These processes of (bio)power cannot be ignored. Despite these processes of power people do not blindly accept biomedical discourses and practices. Interaction and dialogue is always taking place in a specific context so it is not likely that anyone will explain and deal with their illness completely in biomedical terms. Since it is not only biomedicine that is of influence in the construction of illness, the illness experience has to be taken into account as well. The illness experience sheds light on the social context in which people, who are dealing with illness, are living, the meaning given to illness, and ways of adapting to life with illness (Conrad & Barker 2010: 71). The illness experience is therefore an integral part of the construction of

nodding syndrome. Following Reynolds Whyte (1997) a pragmatic approach to misfortune will be used to illustrate how people deal with nodding syndrome within the specific social- and historical context they live.

1.2. Context and population

Studying nodding syndrome means that globalization is one of the contextual factors one has to deal with. Nodding syndrome does not seem to be associated with globalization at first sight, but given the fact that it is being constructed on an international scale globalization has to be acknowledged. Important actors in the construction of NS are the World Health Organisation (WHO), Centres for Disease Control and prevention (CDC), national governments, and scientist from all over the world. These actors, amongst others, can be classified under the rubric of global health. Global health deals with the body, health, and illness worldwide, especially focussing on areas where health disparities are greatest. Since the countries where NS occurs are dealing with great health disparities, influences of global health are everywhere. It is not just the national governments that are dealing with health issues within their borders, an international collection of actors from different fields are involved just as much. The interaction taking place between all these different actors in the field of global health forms a large part of the construction of NS.

When linking the construction of NS in this global arena to theories about globalization a connection can be seen with Appadurai's (2008) view on globalization. Appadurai (2008) represents globalization as force producing flows of people, capital, images, ideas, and goods that turn the world into an interconnected and highly complicated place. According to this view globalization is a hegemonic and totalising framework of social change (Tsing 2008: 90). Global health can be seen as a force of globalization with many different actors working under the rubric of 'health for all,' striving to make health attainable worldwide according to a universal biomedical model. However, the world is not going to turn into an interconnected space where everything is the same according to Tsing's (2008) view on globalization. Instead the world should be seen as heterogeneous, open-ended, and multidirectional (Tsing 2008: 90). The study of multidirectional global connections and the friction that arises in these encounters, would be more productive according to Tsing (2005: 5). So looking at global health, it is not a hegemonic framework making health and illness the same everywhere according to the universal model of biomedicine. Friction causes health and illness to be different worldwide. Hence the focus on friction in this study of nodding syndrome. Langwick et al. (2012: 13) support the focus on friction when anthropologically studying health and illness in Africa, taking into account globalization. They state that: 'Health and illness are managed through the very ruptures, differences, and contestations that are mobilized and acted upon in the myriad attempts to enable,

control, and tame the universalizing flows of medicine, politics, economics, and science across national and continental borders' (Langwick et al. 2012: 13). So in reality health and illness are different in every context because they are continuously being co-produced through friction amongst different actors, discourses, and practices. It is the friction between the actors constructing nodding syndrome that leads to the unique and continuously changing meaning of NS in Tanzania.

Since the reports from the media, scientists, and international health organisations formed my initial frame of reference starting this research into NS, global health could be seen as my first field site. Since global health is a conceptual field that is not clearly demarcated I had to turn global health into a physical fieldsite. The literal field in terms of space became the city of Dar es Salaam, and more specifically the offices of global health actors located in Dar es Salaam. Employees from the WHO, CDC, the ministry of health, national newspapers, and scientists studying NS formed the population in the first phase of this study. At the WHO, CDC, and ministry of health I was able to interview the heads of the departments involved with NS. In addition I interviewed three scientists involved in studies of NS, one of them affiliated with Muhimbili University and others affiliated with CDC and the ministry of health. I was also able to visit the archives of two of the biggest publishing companies of newspapers in Tanzania, both companies publish several English and Swahili newspapers. To get a better understanding of global health in Tanzania I also interviewed several employees from international NGO's active in Tanzania. Even though the research population in Dar es Salaam is a small population as opposed to the people directly dealing with NS in the south of Tanzania, the people in this small group have a powerful voice in constructing NS in Tanzania and on an international scale.

Even though the actors from the context of global health hold the most power in constructing NS internationally, the actors dealing more directly with NS are just as important in constructing NS. So the area where NS actually occurs in Tanzania is another important part of the context in which the construction of NS takes place. Therefore the second fieldsite was the Vigoi division in the Ulanga district, located in the south-central part of Tanzania. The Mahenge Epilepsy Clinic was the starting point of this second part of the research. The nurses from the clinic became important informants during this phase of fieldwork. Through the nurses at the clinic I was able to contact patients suffering from nodding syndrome and their families. I was able to speak to twelve patients and their families at their homes in the Vigoi division. This population of twelve was largely chosen based on location, age, and gender. Some patients however were found unexpectedly while visiting villages, selection criteria were not applicable in those cases. In addition I spoke to a small population of four traditional healers, found through the snowball method. To get a better understanding of the context in which NS occurs I also spoke to twenty patients suffering from epilepsy at shelters belonging to the catholic mission, at a work project by an NGO, and unexpectedly

while visiting NS patients. A smaller part of the population was made up out of community health workers, catholic priests, village leaders, and other members of local communities.

1.3. Methodology

What distinguishes anthropology from other disciplines in terms of research methods is its use of extensive ethnographic fieldwork to gather data. Ethnographic fieldwork is characterised by the researchers' prolonged residence among the research population, participation and observations in the field in order to understand the inside view of the research population and to get a holistic view of the subject that is being studied (Sluka & Robben 2012: 7). When studying the construction of nodding syndrome this approach to fieldwork becomes slightly problematic. Nodding syndrome in Tanzania is being constructed in the interaction between many actors spread out, not only across Tanzania, but also across the rest of the world. The actors therefore determined the field, a field that could not be limited to one geographically circumscribed area. So due to the fact that this research covers multiple sites it can be referred to as multi-sited fieldwork. Marcus (1995) described multi-sited ethnography as, ethnography in the world system. 'Multi-sited fieldwork is designed around chains, paths, threads, conjunctions, or juxtapositions of locations in which the ethnographer establishes some form of literal, physical presence [...]' (Marcus 1995: 105). At the centre of these chains, paths, and threads is the object of study, in this case nodding syndrome. It means following nodding syndrome located within a world system. However, it is the focus on a world system that makes Marcus' (1995) approach problematic in this study. Cook et al. (2009: 54) criticize the implicit holism that much multi-sited fieldwork is hiding. By studying multiple sites researchers implicitly try to uncover a system, a larger hidden social reality like a 'world system' for instance. As stated before, there is no framework in the form of a world system, there are only multidirectional global connections (Tsing 2008). As it turned out during the course of this research, there is no system or coherent whole to uncover when it comes to nodding syndrome. Even nodding syndrome itself, as focus of this study, is a collection of associations, explanations, and connections. So I would refer to this research as multi-sited in the sense that it was composed of multiple sites organised around multidirectional connections. The chosen fieldsites however, were not already determined by the nature of a larger system (Cook et al. 2009: 55) but created by the researcher with a research question in mind.

The main techniques for data collection used during fieldwork were participant observation, semi-structured interviewing, and informal interviewing. During my stay in Dar es Salaam semi-structured expert-interviews were held with employees from organisations involved with either nodding syndrome or health care in general and scientists studying nodding syndrome. A translator

was not needed since this group of informants spoke English. Participant observation combined with informal interviewing was the technique used in the epilepsy clinic. I spent quite a few mornings at the clinic during consultations. Since the patients spoke Pogoro or Swahili, the nurses served as translators. Through the clinic I met many patients with epilepsy and several with nodding syndrome. Since patients with nodding syndrome live far apart and spread out over a big area I visited about twelve patients at their homes, some of them more than once. The technique I used was semi-structured interviewing and observation. I worked with a translator since the interviews were in either Pogoro or Swahili. When visiting a patient with nodding syndrome the interview usually took place with one or more family members. Patients were often too shy to talk or were unable to answer my questions due to cognitive impairments. With the help of a translator I also conducted semi-structured interviews with several traditional healers. During my visits to shelters lead by the catholic mission and during my visit to a work project for epilepsy patients spontaneous focus group interviews arose, providing valuable insights in the context of epilepsy in Ulanga. All interviews took place after receiving verbal informed consent. The data were anonymised as much as possible by using pseudonyms and leaving out the names of villages in the thesis.

Data triangulation was applied by using different data sources and research methods. Semi structured interviews took place with different actors involved in constructing nodding syndrome. Part of the interviews took on the form of expert-interviews and spontaneous focus group interviews. Participant observation and informal interviewing took place in the epilepsy clinic. In addition, observations in all settings enabled me to compare verbal data collected in interviews with actual actions and practices. During the course of the research I collected reports, news articles and documents concerning nodding syndrome, epilepsy, and health care in general which were analysed during the research and afterwards.

The topic of this research, nodding syndrome, presented itself in a fragmented, ambiguous, and incoherent manner, making me often wonder what exactly I was studying. Unconsciously I was looking for coherent explanations of what I thought nodding syndrome might be, largely based on my own Western biomedical background. Inspired by Pool (1989; 1994) I realised I needed to see my data in a different light and accept that fragmentation is an integral part of ethnography. As an anthropologist I am not studying the construction of nodding syndrome as mere observer, I am a part of it. Following Pool (1989: 24) I am interpreting and not representing my participants' knowledge about nodding syndrome within this ethnographic process. I am part of the production of that knowledge, knowledge that is fragmented, incoherent, and ambiguous. The continuous dialogue taking place between all the actors constructing nodding syndrome, including myself, dialogue that leads to continuous shifts in meaning, is visible throughout this thesis.

1.4. Structure of the thesis

The thesis is divided into five chapters, of which chapter two to four each mark a phase of this study. Of course these phases were not entirely separate since all actors, discourses, and practices surrounding NS are somehow connected. The phases mark the shifting meaning of NS, from the order of the predominantly biomedical nodding syndrome to the much more fragmented reality of NS in the south of Tanzania. Chapter two marks the first phase in this research into NS and focusses on global health and the international construction of NS. It turned out that the internationally developed biomedical definitions and case descriptions were difficult to reconcile with the specific context of NS in Tanzania. This led to doubts among global health actors in Tanzania. The friction between global health actors and the specific context of NS in Tanzania consequently causes shifts in meaning of NS in Tanzania. The third chapter of the thesis shows the transition from global health into the specific context of NS. The context of NS largely influences the construction of nodding syndrome in Tanzania. The history and accompanied stigma of epilepsy is intertwined with NS and its construction. However, global health influences and biomedical explanations of NS slowly reach the Ulanga district causing friction in encounters with local actors, discourses, and practices. This transition into the specifics of nodding syndrome leads to chapter four that focusses on the illness experience. The illness experience shows the shifts in meaning of NS through the different and seemingly contradictory discourses and practices that are used interchangeably when dealing with NS. The illness experience is characterised by the pragmatic approach to illness in which curing is central. Biomedical, traditional, and religious discourses and practices are all used in the search for a cure or explanation, these different discourses and practices are continuously changing through friction and are not mutually exclusive. The thesis ends with a conclusion in chapter five in which all arguments are brought together.

2. An illness called nodding syndrome

Starting this research into nodding syndrome the only sources of information available were biomedical descriptions and alarming media reports about NS. The focus of this research has always been on the construction of illness stretching beyond biomedical explanations, but starting out from a biomedical point of view was the only possible option in this case. In order to understand how nodding syndrome is being constructed in Tanzania it is vital to pay attention to the construction of nodding syndrome on an international scale. It is the construction of nodding syndrome internationally that caused a shift in meaning of what was considered to be a type of epilepsy to a distinct medical condition called nodding syndrome. The actors involved in the construction of nodding syndrome on an international scale are mainly international health organisations, scientists, and politicians active in the arena of global health. Their voices, using the universal language of biomedicine, are most powerful in defining nodding syndrome. This chapter clarifies the biomedical discourses surrounding nodding syndrome and the power going out from the actors using these discourses on an international scale. But, as this chapter will also show, the reconciliation between internationally constructed biomedical definitions and the specific situation of nodding syndrome in Tanzania is not straight forward.

2.1. Nodding syndrome, the biomedical discourse

Nodding syndrome is a seizure disorder affecting children in South-Sudan, the north of Uganda, and the south of Tanzania. It is unknown how many people are suffering from NS, reports from South-Sudan and Uganda vary from hundreds of cases to thousands of cases. In Tanzania 62 cases are confirmed by researchers (Dowell et al. 2013: 1373). The main symptom of NS, the involuntary and repetitive dropping of the head, was first described by dr. Louise Jilek-Aall in Tanzania about fifty years ago. The symptoms were described in studies focussing on epilepsy among the Pogoro tribe in the remote Ulanga district in the south of Tanzania (Spencer et al. 2013: 176). It was not until the beginning of the 21 century, after the discovery of similar symptoms in South Sudan and the north of Uganda, that scientific studies specifically focussing on NS as a distinct medical condition were being published. It is still not clear whether NS is the same in all areas where it occurs. The presentation of the actual head nodding episode seems to be the same in all areas but other symptoms seem to differ slightly, especially between Tanzania and the two other areas in South-Sudan and Uganda (Winker et al. 2014: 92). The prevalence of NS in Tanzania seems to be consistent over time as

opposed to South-Sudan and Uganda. Consequently Winkler et al. (2014: 90) state that NS in Tanzania might be endemic in character and more epidemic in character in South-Sudan and Uganda.

Although there is still much uncertainty surrounding NS, scientists overall agree that NS is a seizure disorder that affects children between the ages of five and fifteen. The illness starts with occasional episodes of head nodding but often episodes increase in number and last longer as time goes by, episodes of NS can be triggered by food and cold weather. In many cases the patient eventually develops more complex partial and generalized seizures (Winkler et al. 2008-9: 2013). NS can therefore be divided into NS and NS plus, NS plus means the presence of epileptic seizures apart from the symptoms of NS (Winkler et al. 2008: 2009-2010). It is not clear how the disease develops exactly, but in many cases children quickly get weaker once the symptoms start. Stunted growth and cognitive decline resulting in mental retardation, were often reported. It is unclear whether NS is lethal, but patients have died due to accidents during seizures that led to drowning or burning (Korevaar & Visser 2012: 2).

Definitive answers on the cause of NS are not available so far. Different possible causes have been studied and are still being studied. The possible relationship between NS and *Onchocerca Volvulus* is mentioned in most studies as possible cause. The filarial worm *Onchocerca Volvulus* is transmitted by the black fly (*Simulium*), breeding near fast-flowing rivers. This worm is known for causing *Onchocerciasis* or Riverblindness. Many of the areas where NS occurs are highly infested with *Onchocerca Volvulus* (Winkler et al. 2008: 2008-9). So far scientists have not been able to confirm *Onchocerca Volvulus* as the cause of NS. Another factor possibly related to the cause of NS is vitamin B deficiency, found in many patients (Dowell et al. 2013: 1379). Winkler et al. (2014: 92) state that there is also the possibility that NS is a genetic syndrome, given the positive family history with epilepsy in patients with NS found in Tanzania. Other possible causes such as toxics in food, environmental factors, and several infectious diseases were ruled out (Korevaar & Visser 2012: 2).

The course of NS on the long term is still unknown, as well as prognosis and optimal treatment. Currently NS patients are treated with anti-epileptic drugs to control the seizure activity. Different types of anti-epileptic drugs are being used and there is no clarity about which drug is most effective (Dowell et al. 2013: 1383). Besides the lack of clarity regarding treatment it has also proven to be difficult to diagnose NS, according to Van Bemmelen et al. (2013: 8-9). There is a lack of classification, guidelines, tools, and medical technologies, making it difficult to confirm NS and to distinguish it from other medical conditions.

Big international health organisations such as the World Health Organisation (WHO) and Centres for Disease Control and prevention (CDC) got involved with NS when it seemed to be spreading in South-Sudan and Uganda. Both WHO and CDC are doing research into NS, working together with ministries of health from the affected countries and scientists from all over the world.

From July 30th until August 1st 2012 the International Scientific Meeting on Nodding Syndrome was held in Kampala, Uganda. The meeting was organised by the WHO, CDC, and the ministry of health from Uganda. Scientists, politicians, and NGO's involved in the medical field were invited from the three affected areas in Africa and many other parts of the world. The WHO meeting report (2012: 1) reports that the participants evaluated the knowledge from scientific research and ruled out certain possible causes of NS. Also plans were made for further investigations and collaborative actions. Since different names were used to refer to the same illness, it was decided that nodding syndrome would be the most appropriate name to be used from then on. The name was considered appropriate because of the presentation of the illness and what is currently known about it (WHO 2012: 2). The participants also came up with a case definition that was to be used from then on to ensure consistency in identification of cases and comparable research results (WHO 2012: 20). From Tanzania representatives from the WHO, CDC, the ministry of health and social welfare, and Muhimbili University attended the international scientific meeting on Nodding syndrome. These are also the only organisations dealing with nodding syndrome in Tanzania. Before this meeting there was not much focus on NS in Tanzania. All that was known came from the studies done by Winkler et al. (2008; 2010; 2014). In 2012 an epidemiological study was initiated by the ministry of health and social welfare together with CDC, this study is still in progress. The WHO monitors and studies NS internationally and advises and assists the ministry of health and social welfare in Tanzania when necessary. The international scientific meeting on nodding syndrome and the actors involved exemplify how NS is being constructed on an international scale. Together the actors had the power to define what nodding syndrome is and what the proper name should be. The next paragraph focusses more on the actors constructing NS internationally in an arena called global health.

2.2. A local illness constructed on a global scale

In order to clarify how NS is being constructed in Tanzania, it is important to take into account the construction of NS on an international scale. The arena in which NS is being constructed internationally, the arena where all the actors dealing with NS interact, can be referred to as global health. Global health deals with health and illness worldwide and focusses especially on areas with great health disparities, this makes global health unavoidable when studying health and illness on the African continent.

Global health started taking shape when international organisations such as the World Health Organisation (WHO) started coordinating international health initiatives (Biehl and Petryna 2013: 6). In its constitution the WHO states that attaining the highest attainable standard of health is one of the fundamental rights of every human being, thereby defining health as: '[...] a state of

complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO 1948: 1). In the early stages of global health, nation states were the main source of authority in terms of setting priorities and allocating resources, but according to Biehl and Petryna (2013: 6) this changed after the United Nations' Millennium Development Goals made health one of its focus points for development. From then on many different actors with different motives and backgrounds jumped on board under the banner of humanitarianism, development and security. Global health therefore is not only the terrain of medical disciplines involved in the practice of health care, but also the terrain of: politics, power, knowledge, social organisation, and economics (Langwick et al. 2012: 1). When it comes to the international construction of nodding syndrome many different processes of power are at play. For the purpose of this thesis, the power processes related to the construction of knowledge on nodding syndrome are most relevant.

In the complex arena called global health, the close connection between knowledge and power becomes evident. Knowledge according to Berger and Luckmann is: '[...] the certainty that phenomena are real and that they possess specific characteristics' (1966: 13). However what passes as knowledge in a society is a complex process highly dependent on power. In their account of the social construction of illness, Conrad and Barker (2010: 69) pay attention to Foucault's notion of knowledge/power. Foucault stated that expert knowledge on what is normal and abnormal in humans is the principle form of power in modern society. So having knowledge about the body gives someone the power to govern over the self and others, referred to as biopolitics (Fassin 2011: 185; Scheper-Hughes & Lock 1987: 27). With more and more actors entering the arena of global health, it is not just the state that has the power to govern its population. National medical institutions, private medical institutions, NGO's, pharmaceutical companies, and national governments are now all possessors of what is called biopower. Fassin defines *biopower* as a: '[...] normalizing power over life' (2011: 185). Global health actors use biological, medical, economic and demographic knowledge to define, count, and classify individuals and populations. Knowledge about the body gives them the (bio)power to decide on the distribution and access to healthcare, medicine, and financial aid (Hanna & Kleinman 2013: 26), ultimately deciding on the worth of people's lives. Medical discourse constructs knowledge about the body and influences how people behave towards their bodies in illness and in health (Conrad & Barker 2010: 69). So getting the label nodding syndrome changes the ways people perceive themselves and how others perceive them, being labelled ill has major influence on people's lives. However the individual does not have a say in the actual labelling, it is the medical professional possessing the knowledge and ultimately the power to decide on the life of the patient.

Looking at the international construction of nodding syndrome it is the biomedical discourse that is most prevalent. It is not only the ability to define health and illness that makes global health

actors powerful in the construction of nodding syndrome, it is also the universal character of biomedical knowledge that generates power. That health and illness are universal in character for many global health actors, becomes evident in their utopian vision of 'health for all,' focussing on the equitable access and distribution of health and health care worldwide. Global health thus refers to health as a universal theme. However, a universal, according to Tsing (2005: 7) is not the confirmation of a pre-formed law but an always unfinished achievement. So health might be something that people worldwide aspire to, but because health has different meanings in different contexts, achieving 'health for all' will always remain an unfinished endeavour. This study looks at health and illness as socially constructed, making them cultural phenomena. According to Tsing cultures are continuously being co-produced in interaction she calls 'friction,' referring to: '[...] the awkward, unequal, unstable, and creative qualities of interconnection across difference' (2005: 4). This means that health and illness are being co-produced in the interactions between the different actors involved. Universals are powerful because they are both spread through interaction and used in interaction, however universals will never be the same everywhere also because of this very same interaction (Tsing 2005: 10). So to understand the construction of nodding syndrome, this study looks at the intersections of the 'universalising logic' of illness and health and the particular cases of illness and health, following Tsing (2005: 5). The international construction of a biomedical nodding syndrome is filled with the 'universalising logic' that Tsing (2005: 5) speaks about. There is power in the universal language of biomedicine which is used to define nodding syndrome. But when looking at the intersections between the universalising logic of biomedicine and the particular case of nodding syndrome in Tanzania, defining nodding syndrome becomes much more complicated.

2.3. Becoming embroiled in specifics

To understand nodding syndrome and its construction in Tanzania I had to become '[...] embroiled in specific situations,' following Tsing (2005: 1-2). The first place where I hoped to find out more about the specifics of NS in Tanzania was the city of Dar es Salaam. Dar es Salaam is the biggest city in Tanzania and the entry point into the country for most visitors of Tanzania. This automatically made Dar es Salaam the starting point of my research into nodding syndrome. The paralysing heat and humidity of the economical capital of Tanzania was the backdrop of the first phase of this research. Dar es Salaam is one of the fastest growing cities in the world, situated in a country that is among the poorest of the world. Consequently Dar es Salaam is a city full of development agencies from all over the world. Due to the great health disparities and the failing health care system Tanzania is dealing with, many international health organisations found their way into the country. Starting out with the general biomedical descriptions of nodding syndrome from the arena of global health, I was led to

the offices of international health organisations and researchers dealing with nodding syndrome in Tanzania. Their quiet and cold air-conditioned offices, situated in the best parts of town were in great contrast with the hot, busy, unorganised, and impoverished cityscape where millions of people are trying to make a living.

Before arriving in Tanzania all I knew about NS was the information from scientific articles and media reports. The majority of this information was based on the situation in Uganda and South-Sudan. I expected to find out more about the specific situation of NS in Tanzania from national- and international health organisations, whose offices are based in Dar es Salaam. And since NS received media attention all over the world there had to be some information in Tanzanian media archives. Soon after arrival I got a first reality check, telling random people I met about the topic of my research I did not get the recognition I was hoping for. In fact, every person I told about my research, besides the people directly dealing with NS, had never even heard of the illness. I faced another disillusion searching through both physical and online media archives. I only managed to find two articles about NS in Tanzanian media, one in a Swahili newspaper and one in an English newspaper. However, both focussed on NS in Uganda and the possible risk of the illness spreading to Tanzania. The fact that media in Tanzania have not picked up the topic of NS in Tanzania and the fact that random people I spoke to never heard of it made me question what it was that I was looking for. I contacted the few organisations and people dealing with NS located in Dar es Salaam, hoping to get more answers about NS in Tanzania.

I ended up talking to informants from the WHO, CDC, ministry of health, and scientists studying NS in Tanzania. All of these informants take part in the international construction of nodding syndrome. The scene in each of their offices was pretty much the same, cold air-conditioned rooms in buildings in the best parts of town and a large desk in the middle, usually stacked with files and papers. Even the character of the conversations was the same. After introducing myself and my research I asked what they could tell me about NS in Tanzania. Their answers always reflected the biomedical case definition that was agreed upon during the international scientific meeting on nodding syndrome in 2012. A meeting in which most of these informants, as global health actors, participated. But even though they used the internationally agreed upon case definition, there were still many doubts surrounding NS in Tanzania that came to the fore in all conversations. I was told by informants from the WHO, CDC, ministry of health, and scientists that they were unsure if NS in Tanzania was the same as in Uganda and South-Sudan. It was stated that, other than the episodes of head nodding, symptoms seemed to develop somewhat differently and that the populations suffering from NS differed in Tanzania. There was never any need for alarm or specific actions targeting NS in Tanzania since there was nothing new happening. Now, led by the forces from Uganda and South-Sudan, NS is being constructed in an international arena as a distinct medical

condition. Remarkably, it was only after the discovery of nodding syndrome in Uganda that global health actors from Tanzania got involved with nodding syndrome. Suddenly NS became a new illness, classified as a neglected tropical disease due to the possible link with *Onchocerciasis*. Since they were now dealing with a potentially new infectious illness, actions were expected from Tanzania. One of the most dominant statements in conversations with global health actors in Tanzania was that more research was necessary. Collecting information about the burden of disease was especially important to them in order to determine further actions. Currently no official reports or action plans are available concerning NS. Much remains unknown about NS in Tanzania so the main objective of global health actors in Tanzania is to get more clarity about the whole situation. Any piece of information is welcome. This was also reflected in the fact that all of these actors I spoke to clearly reminded me to send them the report of my research findings. The doubts, reflected in the statements of global health actors based in Tanzania, show the friction in the interaction with other actors dealing with nodding syndrome. There is friction between the universalising logic of the biomedical definition they rely on and the specifics of nodding syndrome in Tanzania. Reconciling the two seems difficult at this point, global health actors in Tanzania therefore seemed unsure about how to view NS and what actions to take.

2.4. Conclusion

What is clear at this point is that the international construction of nodding syndrome in biomedical terms has great impact on the construction of nodding syndrome in Tanzania. The powerful actors, discourses, and practices from the arena of global health caused a shift in meaning of NS in Tanzania, a shift from type of epilepsy to distinct medical condition and possibly infectious illness. However, the biomedical definition of nodding syndrome, developed internationally, does not completely fit the specific context in Tanzania. It is the friction between the universalising logic of biomedicine and the specific context of nodding syndrome in Tanzania that causes NS to be constructed in a distinct way. So to clarify the specific construction of nodding syndrome in Tanzania I had to become further embroiled in the specific, the next chapter marks that transition.

3. The Transition

After an exhausting 12 hour bus ride I finally arrived at the Kilombero river, the natural border separating the Ulanga district from the rest of the country. After crossing the river by ferry the journey continued on the dirt road heading further south into the district. The old and tiny *dala dala* bus was packed full of people and goods. The bus was clearly not built for the roads we were on, so we stranded after passing only a few villages. We already covered a large part of the low lands and I was told it was still a few hours up to the mountains of Mahenge, my final destination. It was getting dark and it did not take long for people to notice that there was a white person on the bus. Surrounded by a growing crowd of children from the village I attempted to call my hosts asking for them to pick me up. With barely any reception I finally managed to reach them. I could not be happier to see my hosts a few hours later and late in the evening I finally reached Mahenge, my temporary home.

Mahenge is a small town situated on top of a mountain. It is the main town of the Ulanga district, situated in the Morogoro region in the south-central part of Tanzania. Mahenge has all the amenities you would expect in a small town, it houses the district council, government hospital, police station, prison, a post office, banks, a petrol station, a large catholic mission, schools, a market and plenty of small shops and bars. But still it was hard not to feel cut off from the rest of the world. A few weeks into my stay a heavy rainy season hit Tanzania, literally cutting Ulanga off from the rest of the country. The Kilombero river flooded and the ferry was out of use, meaning that no vehicles could get in or out of Ulanga. On top of it all the dirt roads connecting villages to each other and the outside world were practically impassable.

Life is tough for the population of Ulanga, the majority of which belong to the Pogoro tribe. Most people are forced to live off their small plots of land since there are barely any opportunities for employment. The crops people grow are mostly for their own consumption and during the dry season this often means great food shortages. During the time I was there people were already dreading the upcoming dry season, knowing that their harvest would be bad due to the heavy rains. Most people live in small red mud brick houses and are not connected to electricity. The few people that are connected to electricity face power cuts every day. Days going by without any electricity are no exception. Information reaches Ulanga with difficulty, however more and more people manage to get access to mobile phone technology.

My arrival in the Ulanga district marked a transition in this research into NS on many points. A transition from the city to a rural district, a transition from English to Swahili, a transition from biomedical discourse to a fluid collection of discourses, and a transition from actors dealing with NS from a distance to actors directly dealing with nodding syndrome. After a first glimpse of the

interaction between the universalising logic of the biomedical nodding syndrome and the specifics of nodding syndrome in Tanzania, I now had to dive further into the specifics. Besides the biomedical discourses and practices, there are specific contextual factors in the Ulanga district that are of great influence on how nodding syndrome is constructed and experienced. So before focussing on the actual illness experience, as part of the construction of nodding syndrome, it is vital to understand the specific context in which NS occurs.

3.1. The Mahenge Epilepsy Clinic

The Mahenge Epilepsy Clinic is a first important contextual factor in the construction and experience of nodding syndrome. It is also the clinic that marked the transition into the second fieldsite. The epilepsy clinic is located on the property of the government hospital in Mahenge and was founded by Louise Jilek-Aall. During her work as a medical doctor in the Ulanga district, Jilek-Aall discovered the high prevalence of epilepsy among the Pogoro tribe and set up an outpatient clinic to treat and monitor them. The clinic serves as district mental health clinic and epilepsy clinic which means that both people suffering from psychiatric conditions and epilepsy patients are treated there. Since epilepsy in Tanzania is classified as a mental health problem this is not an unusual combination. Nodding syndrome is also treated at the clinic because it is locally classified as epilepsy.

The epilepsy clinic is a small room situated at the back of the government hospital property. In front of the room is an outdoor waiting area covered by a sheet metal roof. The clinic employs two nurses who are in charge of diagnosing, treating, monitoring and evaluating patients with psychiatric conditions and epilepsy. Most patients visiting the clinic are from the Vigoi division, the division in which the clinic is also situated. The Vigoi division covers a big mountainous part of the district so people often walk for hours to reach the clinic. Most patients receive treatment for free since they are suffering from chronic mental illnesses, epilepsy and NS are considered to be chronic mental health problems. Patients come to the clinic once a month to collect their medication and report on their progress, a consultation usually only lasts a few minutes.

In order to learn more about nodding syndrome in the Ulanga district I started observing at the epilepsy clinic. Since Nodding Syndrome is not as common as epilepsy, finding people who suffer from NS is hard to do by randomly asking around. The epilepsy clinic was the centre of several earlier studies into NS and therefore seemed the most logical place to start this phase of the research. It is the place where most of the knowledge on NS locally is concentrated and where there is a known group of NS patients receiving treatment. Working together with the epilepsy clinic, Winkler et al. (2008: 2010) confirmed 62 cases in their earlier research on nodding syndrome. Searching through the registers from recent years I found about 20 registered NS cases. It turns out the clinic uses

international WHO codes to register their patients' diagnoses. All patients with nodding syndrome received the code 'E' referring to epilepsy. I found two register books in which '+NS' was added to the existing 'E.' It turned out that was around the time research into NS was conducted at the clinic. In the current registers there is no differentiation between epilepsy and NS. Besides the registers the diagnosis can also be found in the small notebooks that serve as patients' files. However, if a patient later develops generalised seizures the diagnosis changes into epilepsy. On top of that patients regularly stop their treatment at the clinic temporarily or for good. All these factors make it difficult to determine how many patients with nodding syndrome the clinic actually treats.

The interaction taking place between the many different actors constructing nodding syndrome becomes evident at the clinic. There is interaction with researchers from the medical field, between the nurses and patients, between the nurses and local communities, and there is interaction between the nurses and me as a researcher. Locally there is not much known about the global health discourses that, for a large part, construct NS. Occasionally the nurses at the clinic and local communities come into contact with global health actors in the form of researchers studying nodding syndrome, those are the moments when information is shared. However, besides a document about NS given to them by dr. Jilek-Aall, there have no documentation about NS at the clinic. Contact between global health actors and local actors is sporadic and fragmented, nonetheless there is still friction taking place in these encounters that lead to shifts in meaning of NS.

Still being led by the biomedical explanations of nodding syndrome that this research started with, I asked if the nurses recognised symptoms of cognitive decline and mental retardation in their patients in addition to the episodes of head nodding. They stated multiple times that they never saw that in any of the cases of NS they came across. When asking for their definitions of NS they both could not come up with one. One of the nurses therefore started to search for a definition of nodding syndrome using the search engine Google on his phone. On different occasions the nurses also mentioned that they sometimes search for information on the internet about the illnesses they treat. Since little up-to-date biomedical information is available to the nurses, they rely on practical experience for a large part. They do use biomedical knowledge, including biomedical knowledge about NS and other illnesses that came to them through global health actors, to diagnose and treat patients. However their knowledge is more mixed with practical experience and local discourses, coming from the interaction with their patients and communities. This friction between biomedical explanations coming from global health actors and the local context was reflected in the statement one of the nurses made when I asked about the criteria for diagnosing NS. For the diagnosis of NS a patient or relative of the patient had to describe the episode of head nodding with a loss of consciousness, usually happening during breakfast or lunch. Sleeping in school could also be a sign of NS. The age of onset was usually between the age of 7 and 10 and often progression into epilepsy

was also considered characteristic for NS. The nurse used the biomedical definition when referring to the episode of head nodding, usually happening while eating and with an onset in childhood or adolescence. However he modified the biomedical definition based on his own experiences from interactions with patients. He narrowed down the age of onset, specified the time of the seizures by stating they usually happen during breakfast and lunch, and referred to sleeping in school as a sign.

Besides the occasional differentiation between epilepsy and NS, and use of both biomedical and practical knowledge, there is something else that shows the interaction between the nurses and global health actors. One of the nurses mentioned that when researchers came to study nodding syndrome, a Swahili term had to be developed to refer to NS in contact with the patients. The nurse said that he came up with the term *kifafa cha kusinzia*. *Kifafa* is the Swahili word for epilepsy and *kusinzia* refers to the nodding of the head as if someone is falling asleep. Before this name was adopted, NS was just referred to as *kifafa* according to him. *Amesinzia kichwa* is a term used as well and means nodding the head, however this term is usually only used to describe the symptom of head nodding. The transition from *kifafa* to *kifafa cha kusinzia* shows the shift in meaning of NS in Tanzania, a transition taking place in interaction with actors from outside. Although still seen as a form of epilepsy, nodding syndrome now has its own name in Swahili. The specific name of epilepsy with generalized seizures is *kifafa kuanguka*, meaning epilepsy and falling down. *Kifafa cha kusinzia* is considered to be the harbinger of *kifafa kuanguka*. *Kifafa kuanguka* usually raises more fear and is seen as more dangerous as the next paragraph will show.

3.2. The stigma of *kifafa*

As the name *kifafa cha kusinzia* shows, *kifafa* is an integral part of the construction of NS in Tanzania. The Pogoro tribe of the Ulanga district has a long history of epilepsy, the Swahili word for epilepsy, *kifafa*, means little death. *Kifafa* is associated with generalised seizures characterised by a person falling on the ground in an unconscious state combined with jerking, frothing, and incontinence. Other types of involuntary movements of the body and psychiatric illness can also be associated with *kifafa*.

In her study on epilepsy in Africa Jilek-Aall (1997) describes the history of epilepsy in the south of Tanzania. Epilepsy has been associated with supernatural powers in many parts of the world including the African continent. In Western Europe these associations have diminished due to the influence of biomedicine but are still present today. According to Jilek-Aall et al. (1997: 783) views towards epilepsy in Africa are remarkably similar throughout the continent and shaped by both ancient European views towards epilepsy and indigenous beliefs. By the Pogoro, *Kifafa* is often related to witchcraft and spirit possession leading to fear and exclusion of the person suffering from

kifafa. Although views towards epilepsy are slowly changing, fear remains present. People are often afraid that *kifafa* is contagious when coming into contact with bodily excretions of the sufferer. It is not uncommon that people abandon a person having a seizure out of fear that the evil spirit would leap over to them (Jilek-Aall et al., 1997: 784). This causes extra risks for the person suffering from *kifafa*, especially when seizures happen near water or fire. I met many patients at the clinic and outside with severe burns that led to amputation or deformations. People with *kifafa* can develop psychiatric problems, making them behave inappropriately, have violent outbursts, or suffer from psychosis. Besides that, people can suffer from psychological and social trauma due to the isolation they face within their families and communities (Jilek-Aall et al. 1997: 783-4). On different occasions I witnessed people suffering from *kifafa* being referred to as crazy, I was told that you should be careful in communication with them because they would easily get angry or aggressive.

Since the Mahenge Epilepsy Clinic started treating epilepsy with anti-epileptic drugs and people saw the effects of that, trust in the biomedical treatment and explanation grew according to Jilek-Aall et al. (1997: 789). Treatment, together with education of communities about biomedical explanations of epilepsy, improved the attitude towards people with epilepsy in Mahenge. The quality of life of people with *kifafa* continues to improve but the stigma remains.

Conrad and Barker (2010: 69) state that studies into illness, using a social constructionist approach, are able to show how some illnesses have particular social or cultural meanings attributed to them. This means that some illnesses can become stigmatised while others do not. Stigma influences the way illness is experienced, depicted, responded to, and treated policy wise. However there is nothing inherent about a condition that makes it stigmatizing, stigma comes about by the social response to the condition, its manifestation, or the people who suffer from it (Conrad and Barker 2010: 69). Research into epilepsy has shown that the stigma can sometimes be more difficult to manage than the actual seizures according to Conrad and Barker (2010: 69). The Swahili word for nodding syndrome, *kifafa cha kusinzia*, already showed the close connection between nodding syndrome and epilepsy in the Ulunga district. This means that the stigma surrounding *kifafa* is also affecting people with nodding syndrome.

All of the people I met with *kifafa* or *kifafa cha kusinzia* never went to school or had to quit due to their illness. Sometimes they were literally sent away out of fear, but often they were advised by their teachers to quit because they experienced difficulties learning. Parents themselves also tend to keep their children at home. Parents were afraid that seizures would happen on the way to school on a potentially dangerous place. Also parents stated that they did not think their child would be able to pay attention in class or able to understand what was expected from him or her. The future of people suffering from *kifafa* or *kifafa cha kusinzia* is insecure. Their chances of finding employment are close to zero and without any education their chances are even smaller. On top of the stigma of

kifafa is the general belief that people who are ill or disabled cannot participate in society. People believe that they cannot work and should be taken care of. Children growing up with an illness or disability are often shielded by their families and are brought up dependent. Many of the children and adolescents with *kifafa* or *kifafa cha kusinzia* I saw spend their days at home, occasionally doing some small chores. In villages nearby Mahenge the catholic mission runs two shelters for people who are not able to provide for themselves, some of the people who stay there suffer from *kifafa*. The shelters are called camps by the people in Ulanga. The people living in the shelter are seen as *maskini*, referring to a person that cannot provide for himself. Most of the people in the shelter ended up there because they did not have family that could or wanted to take care of them. About the history of the camps I was told that a long time ago people with *kifafa* from all over the country were sent there. Many people suspect that the high prevalence of *kifafa* in Ulanga is because the people from the camp mixed with the local population, spreading *kifafa* through their children.

3.3. Conclusion

The ultimate transition that this point in the research marks, is the transition from nodding syndrome to *kifafa cha kusinzia*. *Kifafa cha kusinzia* brings together the biomedical knowledge about nodding syndrome and knowledge from the local context in which NS occurs. Since the biomedical definition of nodding syndrome is difficult to reconcile with what is referred to as NS in Tanzania, the term *kifafa cha kusinzia* leaves more room for the actual illness experience. The next chapter will move deeper into context in which NS occurs, focussing on the illness experience.

4. An illness called *Kifafa cha kusinzia*

Just as any other illness, NS is for a large part constructed at the experiential level. This chapter focusses on the illness experience as part of the construction of NS, looking at how people understand NS and how they live with it (Conrad & Barker 2010: 1). The illness experience sheds light on the meaning given to illness, the social organisation of the environment the sufferer lives in, and the strategies used to adapt to life with illness (Conrad & Barker 2010: 71). As this chapter will show, the illness experience does not just take place on an individual level but takes place in a social context, in interaction with different actors, discourses, and practices. As already stated before, the experience of NS is largely affected by the cultural meaning of epilepsy as a stigmatised illness. However the illness experience also shows how the meanings of epilepsy and NS are shifting as a result of dialogue, and the friction taking place within those dialogues, amongst different actors using different discourses and practices.

When it comes to the illness experience, the people in the Ulanga district do not use or relate to the term nodding syndrome. *Kifafa cha kusinzia* is used to refer to the symptoms of NS. The local name has wider associations than nodding syndrome and takes in account the local context, therefore *kifafa cha kusinzia* is the term used in this chapter. Speaking to people directly dealing with *kifafa cha kusinzia*, it becomes clear that defining *kifafa cha kusinzia*, or NS for that matter, is impossible. Its meaning is in flux. People use different discourses and practices interchangeably concerning *kifafa cha kusinzia*. Biomedical discourses, discourses regarding witchcraft, and religious discourses are used both separately and mixed together. What discourse the emphasis is put on is different per person and situation. People interact with each other and the context they live in, so there is constant negotiation about the meaning of *kifafa cha kusinzia*.

4.1. A holistic approach to the body and illness

Within this study of nodding syndrome, a holistic approach of the body is applied to be able to come to a better understanding of NS in Tanzania. Hanna & Kleinman (2013: 17) state that a biosocial approach is needed in the study of illness and health worldwide. According to them: 'A biosocial approach posits that [...] biologic[al] and clinical processes are inflected by society, political economy, history, and culture and are thus best understood as interactions of biological and social processes' (Hanna & Kleinman 2013: 17). Since biological and social processes influence each other, both have to be taken into account when studying health and illness. However the biosocial approach falls into the trap of the Cartesian dualism by implying that the biological and the social are two different entities. Cartesian dualism is prevalent in western biomedicine, viewing the biological and the social,

the body and the mind as separate entities (Sharp 2000: 289-290). Scheper-Hughes and Lock (1987: 7) state that scholars studying the body in illness or in health should move away from the dualism separating body and mind, the biological and the social, the visible and the invisible, the natural and the supernatural, the rational and irrational, and the real and unreal. The body is intertwined with the context in which it is situated, making it physical and symbolic, naturally and culturally produced, all at the same time without a clear distinction. According to Scheper-Hughes and Lock (1987: 7-10) illness is therefore not just a pathology situated in individual bodies, instead a body in illness can be seen as a model of social disbalance, conflict, and disintegration of society as a whole. Illness should therefore not be medicalized and individualised but politicised and collectivised.

Politicizing and collectivising illness in resource poor contexts, often leads to studies focussing on illness as structural violence. Structural violence is the embodiment of social, political, and economic forces as health and illness (Farmer et al. 2013: 9). Structural violence is seen as a form of social suffering, referring to the results of what political, economic, and institutional power does to people (Hanna & Kleinman 2013: 30). According to Hanna and Kleinman (2013: 31) structural violence should be taken into account when studying illness in order not to overestimate agency and underestimate constraint. Of course it is true that people in resource poor contexts are more exposed to risks and effects of illness and other types of misfortune, studying NS this cannot be ignored. However Langwick et al. (2012: 2) criticize studies of illness in resource poor contexts for focussing too much on social suffering and structural violence, they call for study that: “[...] resists being another ‘derivative’ of African suffering” (Langwick et al. 2012: 2). Despite the afflictions that people deal with, they are still looking for meaning and control of their bodies. What illness does to people and what meaning it has, is more complicated than a story of suffering.

Another outcome of politicising and collectivising illness is the focus on illness used as a political instrument. Studies by Ticktin (2011) and Fassin (2007), amongst others, show that illness can give access to resources and power that otherwise would not have been accessible to people, in the form of e.g.: residency permits, medical care, and disability grants. Illness can therefore lead to therapeutic citizenship. Especially in resource poor settings illness can give opportunities that people otherwise would not have had. Van Bommel et al. (2013) describe how Nodding Syndrome in northern Uganda provided new opportunities. Due to NS, resources were made available by the government and NGO’s that otherwise would not be made available. Besides that, NS provided a region feeling abandoned and marginalized with an opportunity to let its voice be heard, not just nationally but internationally.

When looking at NS in Tanzania, politicizing and collectivising illness is not a fruitful approach. Collectivising and politicising NS by stating that its sufferers are the helpless victims of macro political processes, or on the other hand politicizing NS by stating that it is used as a political

instrument does not do justice to the experience of NS in Tanzania. Although illness, power, and politics are closely related, illness does not always represent protest against for example social inequality. Misfortune should therefore be recognised as an etiological category (Lock 1993: 143-4).

By viewing illness as misfortune this study of NS intends to show how people deal with NS within their social contexts, leaving room for agency and meaning. Reynolds Whyte (1997: 3) studied how people deal with uncertainty when misfortune strikes. Uncertainty is an aspect of social experience and studies of uncertainty: '[...] remind us that the discourses and narratives we human actors use are partial, incommensurate with one another, and often incapable of convincing us fully' (Reynolds Whyte 1997: 225). According to Reynolds Whyte (1997: 3) people enquire about what is happening and what is to be done when misfortune strikes. Using a pragmatic approach to misfortune Reynolds Whyte (1997: 3-4) describes how experiences of uncertainty and ways of dealing with it are socially mediated and how the process of limiting uncertainty are filled with doubt, trial, and error.

4.2. The reality of fieldwork in Ulanga

After spending some time in the epilepsy clinic to get a feel of the local context, I started visiting patients suffering from *kifafa cha kusinzia* and traditional healers in several villages in the Vigoi division. I got the names from patients and the villages they lived in, from the registers at the clinic. I got the names of healers through the snowball method. I travelled to the villages with a translator since the local population only speaks Swahili and Pogoro. The trips to patients and healers were usually an adventure for both myself and my translator. We never knew where we would end up that day, who we were going to meet, and what we were going to experience. The villages bordering Mahenge were usually relatively easy to reach since the main roads through Mahenge were paved. Going off the main road was challenging since the rainy season was on full force, and there was often no certainty that we would actually reach our destination. On most occasions we could not contact people to announce our visit. When we reached a village we usually asked the village leader or village health worker to guide us to the people we wanted to visit. On other occasions we would just ask around to find them. Especially in more remote villages it was not always easy to locate people since many people live in the hills far from the village centres and main roads. On many occasions a neighbour or family member would lead us on foot to people's homes. This usually meant a walk through a maze of narrow paths, leading through rice fields and forested hills, with small houses and huts scattered here and there. After seeing how remote people lived I understood why many patients often do not show up for their check-ups at the clinic. For a while the clinic visited remote villages once a month to dispense medication but there is no longer a vehicle available to do this.

We were able to visit 12 patients suffering from *kifafa cha kusinzia*, however two of them did not suffer from the symptom of head nodding. It turned out that *kifafa cha kusinzia* has wider associations. Two of the patients we spoke to and some healers as well, referred to *kifafa cha kusinzia* when they described symptoms sounding like narcolepsy whereby someone suffers from 'sleeping attacks.' Since *kusinzia* refers to nodding the head as if someone is falling asleep this is not a strange association. All of the 12 patients we spoke to were above the age of 16, and most of them even above the age of 18. The clinic did not treat children suffering from *kifafa cha kusinzia* at the time, and in fact had not seen any new cases for a while. The classic case description states that children get the illness between the age of five and fifteen and it is unsure how it develops when children reach adulthood. Starting out this research from a biomedical point of view I was surprised to see so many adolescents and adults with NS. Only few of the patients I met had cognitive impairments and most of them only suffered from head nodding and not from generalized seizures that *kifafa cha kusinzia* usually develops into. This is also different from the case descriptions in scientific literature. This was the point where I really had to let go of biomedical definitions and assumptions that were familiar to me. The reality of *kifafa cha kusinzia* was much more fragmented, inconsistent, and indeterminate in character than biomedical explanations. According to Pool (1994: 25) fragmentation, inconsistency, and indeterminacy are the normal state of affairs in ethnography, not just because people's beliefs are fragmentary but because the praxis in which ethnography is constituted is itself fragmentary. Pool (1994) cites Tyler, who speaks about post-modern ethnography, when clarifying this point:

'A post-modern ethnography is fragmentary because it cannot be otherwise. Life in the field is itself fragmentary, not at all organized around familiar ethnological categories such as kinship, economy, and religion, [...] nor do particular experiences present themselves, even to the most hardened sociologist, as conveniently labelled synecdoches, microcosms, or allegories of wholes, cultural or theoretical. At best, we make do with a collection of indexical anecdotes or telling particulars with which to portend that larger unity beyond explicit textualization. It is not just that we cannot see the forest for the trees, but that we have come to feel that there are no forests where the trees are too far apart, just as patches make quilts only if the spaces between them are small enough' (Pool 1994: 25).

There is no coherent system of beliefs concerning *kifafa cha kusinzia* that could be represented here. I can only interpret the dialogue taking place between research population, their social- and historical context, and myself as a researcher. So in the end all I can show is that illness is constructed

through interaction and dialogue, I cannot give a definitive answer to the question of what *kifafa cha kusinzia* is, nor could my informants.

The conversations I had when visiting people's homes, were usually with one of the patient's parents. We would often find the patient home alone, parents were usually working on the land and brothers and sisters were either on the land as well or in school. The patient or a neighbour would go and get the parents if the land was not too far from the house. Most of the patients were too shy to talk to us or not able to understand or answer questions due to cognitive impairments. The fact that we would often find patients home alone shows how protected and shielded they are by their families. On one occasion we walked up to a small mud brick house and found a young man named Philippe, sitting on the porch. It was late in the afternoon and there was no one else around, his parents were working on the land down the hill. Philippe was busy shaving himself. On the ground I found a notebook with child-like drawings in it. Philippe said he made the drawings that afternoon. David was shy and did not seem to know what to make of our presence, eventually he went down the hill to call his parents.

4.3. A pragmatic approach to misfortune

High on the slope of a hill, in the middle of a forested area we arrived at Lucas' house. The house was a small mud brick house with a thatched roof, as most of the houses in the area. A small area in front of the house was cleared of trees in order to cultivate some crops. At the house we found Lucas and his brother preparing boiled cassava for lunch. We were able to speak to Lucas. He was not as shy as some of the other patients we had met and seemed to have no cognitive impairment preventing him from answering questions. In fact he seemed to do quite well.

Lucas is 18 years old and started suffering from *kifafa cha kusinzia* when he was about 14. He usually got episodes of head nodding during lunch or dinner. He was in his final years of primary school when the problem '*kusinzia*' started and said that he got trouble seeing and understanding what was being said. He therefore stopped going to school. He then lived with his father in another village and he took him to the local dispensary where he received medication. Because the medication did not work they went to a traditional healer which did not help either. He then ended up at the Mahenge Epilepsy clinic and started using medication again. Since he still suffered from occasional episodes of head nodding he stopped the medication and went to a different traditional healer last year. For a while he used medication from the traditional healer, it was the bark of a tree which had to be grinded and mixed with porridge once a day. Since going to this healer he is no longer suffering from episodes of head nodding. Lucas explained that when he was still sick, he felt weak, his arms were too weak to do any heavy work. As a safety precaution he was also not allowed

to go near the cooking fire or near water. Now, he said, he feels much stronger. Lucas now works on the land and even goes swimming, he is not so scared anymore. He is still not sure whether the problem is entirely gone, he is still afraid that it might come back. Lucas said he does not know anything about his illness, he does not know what caused it but believes it might be witchcraft because he was completely healthy before. Lucas is unsure about his future because he did not finish his education. He now works on the land a lot because he does not want to become a *maskini*.

Central in the story of Lucas is his search for relief. Relief for him was not the diminishing of the episodes of head nodding but entirely stopping the episodes and accompanied weakness. There was involvement of the whole family, and the interaction between people and continuous evaluation of results led him to different options. They first consulted a nearby medical facility but the medication did not bring relief, so the family went to a healer. When the healer did not bring relief they went to the Mahenge Epilepsy Clinic, far from where they lived. The medicine from the clinic also did not bring him enough relief, which led the family to a different healer that finally brought the relief they were looking for. Lucas was cured even though he is still not sure if it will last. Remarkably the suspicion of witchcraft as possible cause did not exclude biomedical treatment, showing that different practices and discourses are used interchangeably. Witchcraft and biomedicine are not mutually exclusive, anything that can bring relief is used. The story of Lucas can be best understood in terms of a pragmatic approach to misfortune. His illness experience does not reflect a story of suffering and neither can the illness be seen as a political tool in this instance. Lucas and his family are simply dealing with the misfortune that comes to them in pragmatic way. They are negotiating about the best possible treatment options, trying those options, and reflecting on them. All patients and families dealing with *kifafa cha kusinzia* that I have met had this approach. This pragmatic approach to misfortune does not just come about in the interaction between the patient and his/her illness but maybe even more in interaction with their families, communities, health workers, traditional healers, religious leaders, and even the occasional researcher or doctor passing by. I was also regularly asked for an explanation of symptoms or asked if I knew of any medication that would completely cure the illness.

Traditional healers are often the first person people go to when they get ill. During the course of the research it turned out that traditional healers also use mixed discourses and practices when it comes to *kifafa cha kusinzia* which sometimes seemed inconsistent. I regularly heard from patients that traditional healers actually referred them to the epilepsy clinic to treat the illness, showing once again that traditional and biomedical treatments are not two opposites. According to the healers I spoke to, *kifafa cha kusinzia* is not always caused by witchcraft but can also be hereditary, which seems to be a more biomedical explanation. However the knowledge about the cause comes to them through God. One of the healers actually mentioned that he spoke to

researchers in the past who told him that *kifafa cha kusinzia* is caused by an insect called *Vifuna*, referring to the possible link with the filarial worm that causes *onchocerciasis*. The conversations with traditional healers clearly showed the interaction taking place between actors dealing with *kifafa cha kusinzia*, especially in their use of both biomedical and spiritual discourses. As for the patients, curing is central in the pragmatic approach of healers.

Another example of the pragmatic way in which *kifafa cha kusinzia* is dealt with can be found in the case of David. In a village an hour away by car from Mahenge, we met with David and his father in the centre of the village. It turned out there was a funeral taking place there and many villagers came to the town centre. David and his father still insisted to talk to us so we found ourselves a more quiet place to sit on the roots of large tree. David is 21 years old and got *kifafa cha kusinzia* when he was about 15. He usually gets episodes of head nodding while eating. David's father described it as falling asleep and being unconscious. He also fell down once and remained unconscious for hours. After that event he started getting episodes of head nodding more often, not only during meals. David appeared to be very shy and let his father do the talking. David was still going to school when the problem started but he soon started to forget his books or lose them on the way without remembering. He was sent away from school because of fear of contagion. When the *kifafa cha kusinzia* started the family first took him to a traditional healer but that treatment did not work, the healer also could not tell them what caused the illness. The father believes it is witchcraft because David was very smart before. When his problem started he was not doing well in school anymore. After they went to a healer they consulted their local dispensary and started the anti-epileptic drugs he still uses. With this medication he still gets about four episodes of head nodding a month. They worry about how the illness progresses since it cannot be cured. They are afraid that he will one day fall down on the road or near the water.

David's father tells that they are facing discrimination and isolation because of the illness. Sometimes people stay away from the family out of fear of contagion and call David names on the street. They call him '*kifafa*' or '*maskini*.' David feels sad about the discrimination and the things he cannot do anymore like swimming or riding a bicycle. He spends most of his days at home doing nothing. Sometimes he works on the land but he gets a headache when he works hard. David and his father are unsure about his future, they stated that it is up to God. God regularly returned in conversations I had with people. Even though people actively look for a cure and explanation, they rely on God to cope with the situation on a day-to-day basis. Whatever misfortune comes to them and how it affects the future is God's plan.

In the mean while a group of women joined us, they turned out to be mothers of children with *kifafa* who heard about my presence in the village. I talked to them and David's father about *kifafa* in general. David's father says that it is because of an insect called *Vifuna* that there is so much

kifafa in the area. It is an insect that lives near water and stings like a mosquito. It was discovered a few years ago by researchers visiting the area according to David's father. Since recently they receive treatment once a year for 'Flaria,' Swahili for *onchocerciasis*. Once a year they have to take a few tablets during one day. Because of this there will be less *kifafa* in the future according to him.

In the attempts of David's father to explain *kifafa cha kusinzia* he uses biomedical, Christian, and traditional discourses. He thinks it is caused by witchcraft because his son was very smart before and they therefore visited a traditional healer. When there was no relief he continued with biomedical treatment but still believes the cause is witchcraft. With biomedical treatment there is relief but not a cure, forcing him to trust on God when it comes to the future. At the end of the conversation he refers to his interaction with researchers who stated that *kifafa* is caused by an insect. The yearly treatment for *onchocerciasis*, leads to the belief that there will be less *kifafa* in the future. All in all the statements made by David's father were inconsistent and fragmentary, as was the character of most conversations I had with people dealing with *kifafa cha kusinzia*. There is not one explanation people in Ulanga use for *kifafa cha kusinzia*, they use multiple explanations based on different discourses. There is also not one way of dealing with *kifafa cha kusinzia* in Ulanga, whatever practice or discourse people turn to can vary depending on the person, time, or situation. People dealing with *kifafa cha kusinzia* continuously look for a cure and explanations for their misfortune through dialogue.

4.4. Conclusion

The illness experience is an important part of the construction of nodding syndrome and is able to show the intersections of the universalising logic of NS in biomedical terms and the particular context of NS. The illness experience of people dealing with *kifafa cha kusinzia* shows that a pragmatic approach is used to deal with the illness. People enquire about ways to explain and deal with *kifafa cha kusinzia* through dialogue. Through interaction with family members, their communities, church, traditional healers, health workers, and researchers, different discourses and practices are employed in a search for relief. Consequently, the meaning of *kifafa cha kusinzia* is constantly shifting.

5. Conclusion & Reflection

Moving away from solely medical explanations of nodding syndrome this research went from nodding syndrome to the more fluid *kifafa cha kusinzia*. Nodding syndrome, as any other illness, has not always been there the way we know and conceptualize it now, nor will it stay that way. Illnesses are continuously changing in meaning on different levels and among different people. The construction of nodding syndrome in Tanzania is a complex process in which many different actors, discourses, and practices interact. Consequently the aim of this thesis was to show how nodding syndrome is constructed in Tanzania through the friction that arises in the encounters between different actors, discourses, and practices. The concept of friction, first used by Tsing (2005), was helpful to clarify the construction of NS. It is the interaction that Tsing (2005) calls friction, in which nodding syndrome is being co-produced. Throughout the thesis it became evident that, especially the friction between actors constructing nodding syndrome internationally and the specific context of nodding syndrome in Tanzania causes continuous shifts in meaning of NS. The importance of context when trying to understand illness is a recurrent theme throughout this thesis.

Starting out from a biomedical point of view, I entered the international arena of global health during the first phase of my research into nodding syndrome. Global health is the arena where international health organisations, medical professionals, scientists, and politicians construct NS on an international scale. The name and case description they agreed upon in an international meeting is now applied to all affected areas by global health actors involved in the construction of NS. It is the universalising logic of the biomedical case description that gives global health actors power in constructing NS internationally. Important global health actors in both the international construction of NS and the construction of NS in Tanzania are the WHO, CDC, the Tanzanian ministry of health, and scientists studying nodding syndrome. During my conversations with these global health actors located in Dar es Salaam, doubts prevailed. Trying to reconcile the universal biomedical case definition with the specifics of NS in Tanzania proved to be challenging. NS in Tanzania is not considered to be a new illness, the symptoms were already known for decades as a specific type of epilepsy and treated as such. The friction between the universalising logic of biomedicine that global health actors use and the context of NS in Tanzania in which they are situated, causes shifts in meaning of NS in Tanzania. Symptoms that were known for decades suddenly got the name nodding syndrome and were classified as potential infectious illness apart from epilepsy. These shifts were mainly led by forces from outside of Tanzania. Global health actors based in Tanzania are waiting for research to provide them with answers about NS in Tanzania before developing policy to deal with

this newly constructed illness. The friction among all actors, discourses, and practices that leads to shifts in the meaning of NS also became evident in the specific context where NS occurs.

The second phase of this research into nodding syndrome was marked by my transition from Dar es Salaam to the remote Ulanga district. Learning more about the specific context of NS in Tanzania was essential to understand how NS is being constructed. The long history of epilepsy, called *kifafa* in Swahili, largely affects how NS is viewed and treated in the Ulanga district. For a long time the local epilepsy clinic treats people with epilepsy. Since NS is regarded as a form of epilepsy it is treated in the same way by the clinic. After the discovery of symptoms of head nodding in Uganda and South-Sudan researchers and international health organisations started to visit the Ulanga district, focussing specifically on nodding syndrome. Through the interaction with these global health actors and their biomedical explanations the meaning of NS also changed in the Ulanga district. A separate name was developed for symptoms of head nodding, *kifafa cha kusinzia*, still showing the connection with epilepsy. Also more and more biomedical explanations about the possible cause, course, and treatment of NS started mixing with practical, traditional, and religious discourses and practices regarding NS.

In order to understand how NS is constructed in Tanzania I had to embroil myself in the specific context in which NS occurs. The final part of the research therefore focussed on the illness experience, studying the personal and social meanings of nodding syndrome. Friction between all the different actors became visible in the pragmatic approach people had to illness. Within this pragmatic approach different practices and discourses, that sometimes seemed contradictory, were used interchangeably in a search for a cure and explanation. Dialogue is central in this pragmatic approach. Nodding syndrome is continuously being co-produced in interaction with family members, the community, church, traditional healers, health workers, and researchers.

Growing up with the discourses and practices of Western biomedicine in which illness is presented as a fact of nature, this was my only point of reference when starting this research into nodding syndrome. I was trying to explain nodding syndrome based on biomedical assumptions. During the course of this research, these assumptions were continuously being challenged. I later came to the conclusion that this study was not about uncovering larger hidden systems of truth about nodding syndrome, because there simply is no such thing. This study came about through dialogue, it was made in interaction with the very same actors, discourses, and practices I was studying. There were no pre-existing facts to uncover since facts are always made, according to Rabinow (2007: 150), so the facts that the anthropologist interprets are made and remade. This is a process characterised by fluctuation, fragmentation, and indeterminacy as Pool (1989: 239) states.

'Fluctuation, fragmentation and indeterminacy are only a problem as long as we continue to accept positivistic assumptions about the prior existence of an external objective reality or an underlying order which can gradually be revealed by applying the proper research methodology or analytical techniques, and then authentically represented in the final monograph. [...] Once we accept that 'real' native culture does not exist out there in a pure and pristine form waiting to be discovered and represented by the ethnographer, but that ethnography is above all shared praxis, dialogue, production, in which communication is often not complete and unambiguous but indeterminate and fragmentary, then the problem appears in another light' (Pool 1989: 239).

NS could not be explained in a complete and unambiguous way because its meaning is continuously being co-produced and shifting through interaction. The only option was to embrace the indeterminate and fragmentary character of the data I collected. So in the end I could not define NS in Tanzania, however I was able to show the interaction in which NS is continuously being co-produced and the meaning NS had at a particular moment in time through the interactions I had with the actors, discourses, and practices surrounding NS.

Following Pool (1994: 25), I was negotiating the meaning of NS with the people I spoke to by confronting them with the topic and questions reflecting my associations with NS. This made people think and speak about phenomena and connections they would maybe otherwise not think of. The other way around the same thing happened to me. However it is important to take into account the power processes involved in the relationship between my informants and me as a researcher from Western Europe. Especially the people in the remote Ulanga district looked up to me as a white Western researcher. Often I was confused for a doctor, hoping that I could help them either financially or by providing a cure for the illness. The unequal relationship influenced the conversations I had with people. People were often not interested in me as a person but interested in the opportunities I could bring to them, mostly financial. Small talk or attempts to participate in day-to-day activities were always difficult since informants did not see me as a person that could relate to them. They felt guilty if I did chores with them and did not seem to understand why a white person from Europe would be interested in how they spend their days. Informants were often shy during conversations, they would wait for me to ask a question, answer dutifully, and then silently wait for the next. Because this research was conducted under a time constraint, I unfortunately did not have the chance to find out if people would be more comfortable around me if I had spent more time with them. People were also not used to talking about their illness or misfortune in much depth. They had no trouble telling about how it started and what their symptoms were, but questions relating to hardships, emotions, or coping mostly remained unanswered. The collected data were

therefore less in-depth than I initially hoped for but still rich enough for a first anthropological exploration of nodding syndrome.

Since this was a first anthropological exploration of nodding syndrome in Tanzania, this study showed for the first time how nodding syndrome is conceptualized and dealt with on different levels. This study therefore provides a broader perspective on nodding syndrome than the biomedical studies that are currently available. However future social scientific study, in which the researcher stays among the informants for a prolonged period of time, would definitely be necessary to understand nodding syndrome more in-depth. Using a social constructionist approach to illness, this study was able to shed a different light on nodding syndrome in Tanzania. While in itself nothing is wrong with biomedical studies of nodding syndrome, they do paint a rather one-sided picture of NS, a picture that cannot always be reconciled with the complex reality in which NS occurs. A more holistic approach was needed to understand how NS is conceptualized and dealt with on different levels. According to a social constructionist approach illness is not just situated in an individual body but is shaped by social interactions, cultural traditions, shifting frameworks of knowledge, and relations of power (Conrad & Barker 2010: 69). This approach provides a more holistic image of illness. Since little was known about NS in Tanzania and given the fact that this was the first social scientific study into NS in Tanzania, this study was exploratory in character. The different actors, discourses, and practices involved, were brought together for the first time in this anthropological study into NS. This study was therefore able to show a glimpse of the construction and conceptualization of NS in Tanzania on different levels, creating a stepping stone for future research into nodding syndrome.

Bibliography

Appadurai, Arjun

2008 Disjuncture and Difference in the Global Cultural Economy. *In: The Anthropology of Globalization: A Reader*. 2nd edition. Jonathan Xavier Inda & Renato Rosaldo, eds. pp. 47-65. Malden: Blackwell Publishing.

Bemmel, Karin, van., Derluyn, Ilse & Stroeken, Koen

2013 Nodding syndrome or disease? On the conceptualization of an illness-in-the making. *Ethnicity & Health* 2013: 1-19.

Berger, Peter L. & Luckmann, Thomas

1966 *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. London: Penguin Books.

Biehl, Joao & Petryna, Adriana

2013 Critical Global Health. *In: When people come first: Critical studies in Global Health*. Joao Biehl & Adriana Petryna, eds. pp. 1-20. Princeton: Princeton University Press.

Brown, Phil

1995 Naming and Framing: The Social Construction of Diagnosis and Illness. Extra Issue, 'Forty Years of Medical Sociology: The State of the Art and Directions for the Future,' *Journal of Health and Social Behavior* 35: 34-52.

Conrad, Peter & Barker, Kristin, K.

2010 The Social Construction of Illness: Key Insights and Policy Implications. Extra Issue, 'What Do We Know? Key Findings from 50 Years of Medical Sociology,' *Journal of Health and Social Behavior*. 51: S67-S79.

Cook, Joanna, Laidlaw, James & Mair, Jonathan

2009 What if There is No Elephant? Towards a Conception of an Un-sited Field. *In: Multi-Sited Ethnography: Theory, Praxis and Locality in Contemporary Research*. Mark-Anthony Falzon ed. pp. 47-72. Farnham: Ashgate Publishing.

Dowell, Scott F., Sejvar, James J., Riek, Lul, Vandemaele, Katelijjn A.H., Lamunu, Margaret, Kuesel, Annette C., Schmutzhard, Erich, Matuja, William, Bunga, Sudhir, Foltz, Jennifer, Nutman, Thomas B., Winkler, Andrea S., Mbonye, Anthony K.

2013 Nodding Syndrome. *Emerging Infectious Diseases*. 19(9): 1374-1384.

Farmer, Paul, Kim, Jim Yong, Kleinman, Arthur, Basilio, Matthew

2013 Introduction: A Biosocial Approach to Global Health. *In: Reimagining Global Health: An Introduction*. Paul Farmer et al., eds. pp. 1-14. Berkeley: University of California Press.

Fassin, Didier

- 2011 *Coming Back to Life: An Anthropological Reassessment of Biopolitics and Governmentality.*
In: Governmentality: Current Issues and Future Challenges. Ulrich Bröckling, Susanne Krasmann &
 Thomas Lemke, eds. pp 165-184. New York: Routledge.
- Fassin, Didier
 2007 *When Bodies Remember: Experiences and Politics of Aids in South Africa.*
 Berkeley: University of California Press.
- Hanna, Bridget & Kleinman, Arthur
 2013 *Unpacking Global Health: Theory and Critique.* *In: Reimagining Global Health: An
 Introduction.* Paul Farmer et al., eds. pp. 15-32. Berkeley: University of California Press.
- Jilek-Aall, Louise, Jilek, Martica, Kaaya, John, Mkombachepa, Lilian, Hillary, Kalister
 1997 *Psychosocial Study of Epilepsy in Africa.* *Social Science & Medicine.* 45(5): 783-795.
- Korevaar, Daniel Arnoldus & Visser, Benjamin Jelle
 2012 *Reviewing the evidence on nodding syndrome, a mysterious tropical disorder.*
International Journal of Infectious Diseases. pp. 1-4.
- Langwick, Stacey A., Dilger, Hansjörg & Kane, Abdoulaye
 2012 *Introduction: Transnational Medicine, Mobile Experts.* *In: Global Africa: Transnational Health
 and Healing.* Hansjörg Dilger et al., eds. pp. 1-27. Bloomington: Indiana University Press.
- Marcus, G.E.
 1995 *Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography.*
Annual review of anthropology. 24(1): 95-117.
- Mitchell, Katrina B., Kornfeld, Julie, Adiam, Joseph, Mugenyi, Andrew, Schmutzhard, Erich, Ovuga,
 Emilio, Kamstra, Jesse, Winkler, Andrea S.
 2013 *Nodding Syndrome in Northern Uganda: Overview and Community Perspectives.*
Epilepsy & Behavior. 26(1): 22-24.
- Pool, Robert
 1994 *Dialogue and The Interpretation of Illness: Conversations in a Cameroon Village.*
 Oxford: Berg Publishers.
- Pool, Robert
 1989 *There must have been something...: Interpretations of Illness and Misfortune in a Cameroon
 Village.* Ph.D. dissertation, University of Amsterdam.
- Rabinow, Paul
 2007[1977] *Reflections on Fieldwork in Morocco.* Berkeley: University of California Press.
- Reynolds Whyte, Susan
 1997 *Questioning Misfortune: The Pragmatics of Uncertainty in Eastern Uganda.* Cambridge Studies

in *Medical Anthropology*, 4. Cambridge: Cambridge University Press.

Scheper-Hughes, Nancy & Lock, Margaret M.

1987 *The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology*.
Medical Anthropology Quarterly: New series. 1(1): 6-41.

Sharp, Lesley, A.

2000 *The Commodification of the Body and its Parts*. *Annual Review of Anthropology*. 29: 287-328.

Sluka, Jeffrey A. & Robben, Antonius C.G.M.

2012 *Fieldwork in Cultural Anthropology: An Introduction*. In: *Ethnographic Fieldwork: An Anthropological Reader*. 2nd edition. Antonius C.G.M. Robben & Jeffrey A. Sluka, eds. pp. 1-47.
Hoboken: John Wiley & Sons Inc.

Spencer, P.S., Palmer, V.S. & Jilek-Aall, L

2013 *Nodding Syndrome: Origins and Natural History of a Longstanding Epileptic Disorder in Sub-Saharan Africa*. *African Health Sciences*. 13(2): 176-182.

Ticktin, Miriam

2011 *Casualties of Care: Immigration and the Politics of Humanitarianism in France*.
Berkeley: University of California Press.

Tsing, Anna

2008 *The Global Situation*. In: *The Anthropology of Globalization: A Reader*. 2nd edition.
Jonathan Xavier Inda & Renato Rosaldo, eds. pp. 66-98. Malden: Blackwell Publishing.

Tsing, Anna

2005 *Friction: An Ethnography of Global connection*. Princeton: Princeton University Press.

WHO

2012 *International Scientific Meeting on Nodding Syndrome*. Electronic document,
http://www.who.int/neglected_diseases/diseases/Nodding_syndrom_Kampala_Report_2012.pdf,
accessed May 21, 2014.

WHO

1948 *Constitution of the World Health Organisation*. Electronic document,
<http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf>, accessed July 6, 2014.

Winkler, Andrea S., Wallner, Bernd, Friedrich, Katrin, Pfausler, Bettina, Unterberger, Iris,
Matuja, William, Jilek-Aall, Louise, Schmutzhard, Erich

2014 *A longitudinal study on nodding syndrome: A new African epilepsy disorder*.
Epilepsia. 55(1): 86-93.

Winkler, Andrea S., Friedrich, Katrin, Meindl, Michael, Kidunda, Aslam, Nassri, Amir, Jilek-Aall, Louise,
Matuja, William, Schmutzhard, Erich

2010 Clinical characteristics of people with head nodding in southern Tanzania.
Tropical Doctor. 40(3): 173-175.

Winkler, Andrea S., Friedrich, Katrin, König, Rebekka, Meindl, Michael, Helbok, Raimund,
Unterberger, Iris, Gotwald, Thaddaeus, Dharsee, Jaffer, Velicheti, Sandeep, Kidunda, Aslam,
Jilek- Aall, Louise, Matuja, William, Schmutzhard, Erich
2008 The head nodding syndrome: Clinical classification and possible causes.
Epilepsia. 49(12): 2008–2015.

Young, Allan

1982 The Anthropologies of Illness and Sickness. *Annual Review of Anthropology*. 11: 257-285.