

# The Quest for Treatment. The Violated Body of Nodding Syndrome in Northern Uganda

Karin van Bommel

*Department of African Languages and Cultures, Ghent University, Belgium*

## Abstract

Nodding syndrome is an unexplained affliction that affects thousands of children in northern Uganda. It is characterised by episodes of repetitive dropping forward of the head and often accompanied by convulsions. Symptoms were first reported in Uganda around 1998, during two decades of violent conflict between the Lord's Resistance Army and Ugandan government. Violence and politics have been assimilated into local narratives on nodding syndrome and illness experiences are connected to the trauma of past conflict. This paper provides insight into how narratives on nodding syndrome are affected by the experience of conflict and how they in turn shape responses to illness. Attention is paid to the complex politics of illness and healing in the context of a pluralistic medical system.

## Introduction

Her arms are adorned with bangles and two colourful necklaces decorate her neck. She carefully chooses her words while sharing knowledge on the poorly understood affliction that recently emerged in this area. 'During the past, it was not there. Nodding syndrome started happening during the era of the rebels. People were abducted and burned in their huts. They were killed for no reason. That is when this illness started coming'. The story of *ajwaka* Apira<sup>16</sup> resonates with the many narratives I heard while spending countless hours with affected family members at their homes, in health centres and during burial ceremonies. 'I know it's the war that has brought this illness', the mother of a young, shy-looking girl explains. 'A lot of guns were fired, the ground was shaking. And the people who died are now *cen*, evil spirits, attacking the [afflicted] children'. An elderly man softens his voice when speaking about his experiences with violence: 'During the period of war, people saw many different kinds of killing. Some people were slaughtered with *pangas*, some were beaten to death. Others were burned in the house and some were shot with guns'. In the surrounding area several memorial monuments show the names of numerous people who lost their lives during the twenty years of conflict in the northern part of Uganda.

---

<sup>16</sup> I am using pseudonyms throughout.

Based on fifteen months of qualitative fieldwork and ninety in-depth interviews with affected families, health workers, politicians and spiritual healers in Kitgum District (2012, 2013 and 2014), this paper aims to create insight into the conceptualisation of nodding syndrome (NS) in relation to conflict, politics and the quest for treatment. First, I focus on the context in which meaning-making takes place in order to explore the relationship between health, conflict and politics. Attention is paid to the political connotations of NS and responses from the Ministry of Health. In the second part, this paper discusses the quest for treatment and the different non-biomedical actors involved in this process, shedding light on illness management in the context of a pluralistic medical system. The narratives on nodding syndrome illustrate how illness experiences are affected by conflict and how these narratives in turn shape responses to illness.

## **Nodding Syndrome in a (Post-)Conflict Setting**

A variety of unknown symptoms were observed and mentioned for the first time in local discourse in northern Uganda around 1998. Nodding syndrome, as the illness has recently been labelled by biomedical actors, has affected thousands of children in post-conflict northern Uganda, South Sudan and in Tanzania (WHO 2012a). The syndrome mainly affects children aged between five and fifteen years old and is characterised by repetitive, involuntary nodding of the head, triggered by food and cold weather (Winkler *et al.* 2008; Sejvar *et al.* 2013); the children start nodding their heads when receiving food or—mostly in the morning hours—in response to feeling cold. The affliction can result in mental retardation and stunted growth, and many of the affected children also suffer from epileptic seizures. At least 170 deaths have been reported in Uganda, mostly due to injuries after falling into fire or water during convulsions (WHO 2012b). The number of affected children is not clear, but estimations have been made of 1,687 (Iyengar *et al.* 2014) up to 3,094 (DGHS 2012) children in Uganda and 5,000-10,000 afflicted children in East Africa (Idro *et al.* 2013).

From a biomedical perspective, NS is believed to be a new type of epilepsy. Epidemiological researchers have suggested links between the syndrome and a variety of factors: *Onchocerca volvulus* (Winkler *et al.* 2008), a novel neurotropic virus (Colebunders *et al.* 2014), mycotoxins and food (Spencer *et al.* 2013), post-traumatic stress disorder (Musisi *et al.* 2013) and a link with pediatric catatonia (Dhossche & Kakooza-Mwesige 2012) have all been mentioned in etiological hypotheses. Despite the fact that more than ten NS-investigations have been conducted by the World Health Organization (WHO), Centers for Disease Control and Prevention (CDC), various academic institutes and the Ugandan Ministry of Health (MoH), its cause and cure are still unknown.

The uncertainty of not knowing what nodding syndrome entails leaves much room for collective constructions of the affliction. Many ideas and speculations on the (various) cause(s) have been put forward as different actors try to make sense of the misfortune. Whereas academic discourse predominantly makes use of biomedical terms, in the local discourse nodding syndrome is mainly associated with social issues such as the trauma of past conflict and frustrations over neglect (Van Bommel *et al.* 2014). The majority of the affected families experienced food shortages and have a history of living in Internally Displaced Persons (IDP) camps during the war between the Lord's Resistance Army (LRA) and Ugandan government (WHO 2012a). It was in these camps that symptoms of nodding syndrome were first noticed. Since only children belonging to the Acholi community seem to be affected by the syndrome, suspicion arose over its cause, and anxieties emerged over whether it could be a planned attack

on the local population. Its limitation to a politically sensitive area—targeting people who have for decades been associated with suffering, political opposition and conflict—elicited a lot of political statements and (inter)national media attention (Van Bommel 2016).

The dominant idea in local discourse is that not enough has been done to address nodding syndrome and to assist the local community. Negative remarks mostly concentrate on a perceived lack of governmental response; the current leadership has been criticised for a lack of support and downplaying the prevalence and impact of the affliction. In addition, stories circulate in northern Uganda about the hypothetical role of governmental actors and chemical weapons in the etiology of NS. Rumours on the role of explosives, the use of weapons, and poisoned or rotten food distributions are prevalent, as are narratives on vengeful spirits as a result of countless deaths during the period of war.

At the end of 2011, media houses and local politicians increased pressure on the Ugandan government to make firm statements about its role in handling NS. The topic was presented in hundreds of newspaper articles and discussed several times in parliament. During one of these meetings, member of parliament (MP) Hon. Dombo hinted at sensitive issues of political inclusion and exclusion in regard to NS: ‘Can you imagine what will happen if this House fails to relate with the plight of the people of northern Uganda? This (...) could have political ramifications and also make people think that as Parliament, we do not care about the people?’ (PoU 2012a). Shortly after this meeting, MP Hon. Anywar transported a group of afflicted children on a bus from Kitgum to Mulago hospital in Kampala, publically doubting the ability of an adequate governmental response. During a parliamentary meeting she stated: ‘The situation is so bad that we cannot just sit here and look on as Government dilly dallies over the emergency money. (...) It is a national disaster which needs attention’ (PoU 2012b).

In northern Uganda, the distrust of political leaders and ideas about the suffering status of Acholi people stretch back to earlier experiences, including a long standing north-south divide in the country, involvement of Acholi soldiers in the Ugandan Bush War, where they fought against the National Resistance Army (NRA), Alice Lakwena’s Holy Spirit Movement and the war between the LRA rebel movement and Ugandan government, in which both sides committed serious crimes against civilians. NS mainly generated a lot of attention because of its political connotations: the idea (according to local comments) that national leaders had failed to offer adequate protection to the (already perceived as *vulnerable*) Acholi people in the (*neglected*) northern region of Uganda. The affliction quickly obtained prominence at the level of policymakers, media and the public, whereby politicians and Acholi spokespersons dominated the national debate and played out political battles. The discussions highlighted dissatisfaction about unequal accessibility of health care and the neglected status of Acholi people in Uganda.

The frustration over a perceived lack of state support for the affected families resulted in a court case in which the government was accused of negligence and an inadequate response to NS. In this way, the syndrome became an instrument in a political struggle, highlighting perceived oppression from the government (Van Bommel *et al.* 2014). Through the references to structural causes of suffering in narratives on nodding syndrome, it came to represent suffering on a collective level.

## **Public Health Care and the Management of Nodding Syndrome**

The court case and accusations of governmental negligence touch upon pressing issues of health care accessibility and responsibility in Uganda. Questions arise about the role of the state and

other actors in relation to NS. Who has the responsibility to take care of the afflicted children? In which manner and to what extent?

It is clear that differences in health care provision and accessibility exist in Uganda. Far more people live below the poverty line in northern Uganda than in other regions of the country, and a direct relationship has been demonstrated between poverty and the prevalence of malaria, dysentery and diarrhoea (MoH 2010: 9). The lack of a comprehensive social security system makes the poor more vulnerable in terms of affordability and choice of health provider. In 2002, the population within a 5-kilometre radius of a health centre in Kitgum and Pader was 13.1 percent and in Gulu 32.6 percent (northern Uganda). In other regions such as Jinja, Tororo and Kampala, nearly 100 percent of the population was able to access health care within 5-kilometre distance (MoH 2005: 53). The distribution of human resources between the urban and rural areas is also disproportionate. In 2005, the density of nurses in or around Kampala was 13.4 times greater than in the rest of the country (Kigozi *et al.* 2010: 6). A variety of reasons can be mentioned for these regional differences—let us not forget that the long period of war affected the infrastructure in northern Uganda—but regardless of the involved factors, these differences can lead to angry feelings of being ‘left out’.

Over the past years the Ugandan government did address the issue of nodding syndrome in several ways. In 2012, the Ministry of Health developed a national response plan incorporating various activities focusing on the challenges of NS (WHO 2012a). A manual was developed on how to identify and effectively manage the affected children, and a selection of health workers was trained on the treatment guidelines (Idro *et al.* 2013). In March 2012, three NS treatment centres opened their doors and outreach services to the affected communities commenced. Forms for the detection of new NS cases were distributed among health centres and a ‘Medical Intervention Algorithm for Nodding Syndrome’ was developed in which ‘intervention packages I up to V’ were described, ranging from outpatient management to investigation with (unavailable) CT-Scan or MRI (MoH 2012: 78). Posters decorated with colourful drawings and written in the Acholi language urged caregivers to bring their sick children to the health centres. An aerial spraying program against flies associated with the syndrome was launched and an international conference on NS was organised in Kampala. The majority of afflicted children currently receive anti-epileptic drugs (AEDs), mainly Sodium Valproate, which are (irregularly) provided for free by the MoH. Although this medication does seem to alleviate the symptoms to some extent (Idro *et al.* 2014), the affected families are not satisfied with the results.

The nodding syndrome treatment centres that have been constructed at several hospitals in northern Uganda could be approached as ‘zones of exception’ (Prince 2014), illustrating novel spatial and temporal forms of government. The centres were opened in response to the earlier mentioned allegations and look great in humanitarian reports and (inter)national media publications. In reality, the centres are under-resourced; there is a lack of equipment and adequately trained staff. Outreaches take place irregularly, as does the payment of workers’ salaries. The patients in the main treatment centre have been shifted thrice and the children spend months, some of them years, in the ward waiting for a ‘miracle pill’ that is not available. And despite much justified critique on the provision of governmental health facilities in northern Uganda, the question is what *could* be done for these families when answers are simply not there? Without the miracles the NS-affected families long for, the special hospital ward has become a zone of exception, not only detached from the village community but also from the medical system.

## Help-Seeking and Social Wounds

In the absence of a well-functioning governmental treatment programme (or of resources for such programmes to be deployed) the quest for therapy continues, engaging a large group of different actors in a complex struggle for ownership of illness and treatment. This leaves the families of afflicted children navigating within a fragmented landscape of health promotion and dealing with inequality in access to (uncertain) treatment. So far we have looked at the socio-political context in which NS exists and macro structures at work concerning health care provision in Uganda. Let us now shift focus to the actors who have to navigate in the complex landscape of health care providers in a situation in which a definite cure is not available and current treatment efforts seem to fall short.

When people are distressed they frequently turn for help to family members or others around them. Kinship groups are implicated in the diagnosis and treatment choice, and often function as well-structured social support nets for illness management (Muela *et al.* 2000). The process of diagnosing illness, selecting therapies and evaluating treatment is not an isolated phenomenon (Janzen 1978: 7). Cultural factors and popular perceptions of what is appropriate care influence therapy management, as well as previous experiences with healing, socio-demographic criteria, accessibility, availability and flexibility of payment terms (Muela *et al.* 2000; Abbo *et al.* 2008). The functioning and cohesion of support networks can be affected by the experience of conflict, since the scars of excessive violence remain entrenched within the social fabric of society (Hollander & Gill 2014: 217). In northern Uganda, the violent past has resulted in the breakdown of traditional kinship relationships. Numerous people disappeared during the period of war and many fathers of NS-affected children are no longer around. Mothers often take care of the children by themselves and at the same time deal with the visible and invisible scars of war. De Jong (2007: 350) asserts that family disruption, parental illness and death can affect attachment, bonding, separation and socialisation. During fieldwork in Kitgum, mental health issues and memories of traumatic experiences often came up. Feelings of sadness, fear and despair were frequently mentioned, as well as alcohol abuse and interference with social and livelihood activities.

Apart from looking for social support from family and neighbours, the affected children and their caregivers seek treatment within a landscape of medical pluralism. Given that biomedical practice has often been uncertain, inadequate, and sometimes counter-productive, its superiority over other medical practices and forms of healing is fragile (Prince 2014: 6). The majority of nodding children undergoes repeated efforts to find healing using medical systems in combination. In addition to the biomedical doctors at the hospital, traditional healers are appreciated as key sources of care and knowledge on illness. According to the Health Sector Strategic Plan, approximately sixty percent of Uganda's population seeks care from traditional and complementary medicine practitioners before visiting the 'formal sector' (MoH 2010: 8). Abbo and colleagues (2008) argue that consultation of traditional healers is more likely to produce an illness identity that matches the patient's perceptions. Traditional healers have the advantage over biomedical healthcare providers in that they spend more time and maintain a close personal relationship with their patients. As a result, patients usually feel secure enough to disclose their experiences, including family matters (Galabuzi *et al.* 2010: 15).

Even if biomedical treatment has some effect, it does not address social wounds. Health is not only located inside but also beyond the biological body, and sickness can be seen as a form of communication through which nature, society, and culture speak simultaneously (Scheper-Hughes & Lock 1987: 31). An important question in many northern Ugandan minds is: who is

going to heal the afflicted children? Since ‘nothing can be found in the blood’ despite the efforts of biomedical doctors, who is going to offer meaningful treatment? In the search for answers, many of the NS-afflicted families turn to non-biomedical authorities.

## **The Quest for Treatment**

In a small mosque in Kitgum town, Islamic sheiks promote Quran treatment with anointed water. Nearby, *ajwaki* also concentrate on the questions that the poorly understood affliction poses, while addressing vengeful spirits of murdered people. Herbal healers sell powerful products that the affected children need to smear, drink and inhale, and in the boardroom of a neighbouring school Christian leaders organise a prayer event to chase away the devils thought to cause the mysterious symptoms.

Healers, patients and their significant others all participate in negotiating and constructing meanings of illness. They are engaged in the quest for a cure, by ‘imagining alternative outcomes, evaluating the potential meanings of the past, and seeking treatment’ (Good & Del Vecchio Good 1994: 838). Whereas the case description of nodding syndrome designed by the Ministry of Health mentions a range of biomedical symptoms (e.g. regression in growth, mental retardation), other signs and symptoms are added in its local definition. The *lucluc* (head-nodding) children are said to ‘wander around’, attacks come ‘when the moon comes out’ and ‘shouting and noise are following them’. A mother describes how the eyes of her son ‘become yellow, like the eyes of someone who is dead’ and an elderly lady mentions that her granddaughter’s eyes ‘turn red’ during an attack. Caregivers call their afflicted children ‘confused’ and sometimes ‘aggressive’, they can ‘suddenly run away, as a mad one’. Many of the children see things that are invisible to others; often these visions are related to war. A caregiver talks about the behaviour of her daughter: ‘She shouts that she is seeing a group of soldiers, clothed in uniform and armed with their rifles, advancing towards her. And nobody sees the soldiers’.

Among the affected families, ideas about NS and healing other than the biomedical circulate. The majority mentions that nodding syndrome comes as a result of war and spiritual actors are often part of their explanatory models. Mass political violence aggravates the severity of harmful spirit possessions, according to Igreja and colleagues (2010: 597). The body as an integrated aspect of self and social relations can be vulnerable to feelings, wishes and actions of others, including spirits or dead ancestors (Scheper Hughes & Lock 1987: 21). When illness may arise from the acts of evil beings that can harm humans, it is necessary to investigate alternative ways of negotiating illness and look beyond its biomedical importance. In what follows, focus is put on several non-biomedical actors involved in treating the NS-affected population.

## ***Ajwaki*, *Cen* and Herbal Treatment**

A respected elder in Kitgum explains that different kinds of illness exist: ‘Some things are medical, some things are spiritual. (...) It [NS] has defeated the medics. People forgot how to differentiate sickness of bad spirits and scientific ways of illness.’ Like many others in this area, the *mzee* is convinced that NS is related to conflict and caused by revengeful spirits. ‘Twenty years of war brought bad spirits, many people died and were not buried. Their bodies were rotting in the bushes and no ceremonies were being held. The spirits became annoyed. When the

spirits are unhappy, they can cause bad sickness. (...) The only way of stopping nodding syndrome is by chasing away the bad spirits’.

The spirits of people who have died a bad death are said to become *cen* and are considered to be extremely evil, vengeful and dangerous (Behrend 1999: 27). Since numerous people were killed during the conflict between LRA rebels and the Ugandan army, many *cen* are now believed to roam northern Uganda. During the war, it was often not possible to carry out rituals of purification and the spirits of those who were killed remain unreconciled, inflicting different kinds of misfortune. Dealing with these spiritual actors is not easy and a visit to the hospital will have no results. ‘They sent samples to America and looked at it in a complicated laboratory’, an elderly lady narrates. ‘They were testing A, B, C (...) and did not find anything. It is the evil spirit of the dead disturbing these children. You cannot treat this syndrome with drugs. (...) They should perform rituals to get cured’.

When looking for treatment, some caretakers decide to bring their children to an *ajwaka*, the medium of a spirit. The spirit helps him or her to divine and investigate the *cen*. One of the *ajwaki* treating nodding syndrome is Apira, operating from a grass-thatched hut at the edge of town. The spirits have accompanied her for a long time, but she only recently started to offer her services. During the insurgency it was dangerous to do this kind of work and she feared that rebels would kill her. The spirits ‘found’ Apira when she was twelve years old and currently more than ten spirits accompany her. One of the spirits is a young government soldier who was killed in the bush during the war. When he is present Apira wears a camouflage army cap. Her sister-in-law Acomo also works as *ajwaka*, as well as her son Opio. He was very young when he started having seizures and a large number of spirits came to him.

During a consultation, the *ajwaka* first needs to identify the spirit that is disturbing the client. In order to summon the spirits he/she shakes a gourd rattle (*ajaa*). Apira: ‘Then it [the spirit] starts talking. (...) It will say, I am the one who died at such and such a place, I was killed, that’s why I’ve come at this moment’. She also communicates with the spirits by using numerous cowry shells (*gagi*) and other objects, such as a large shell and stones. The spirits speak through the objects: ‘I can see what is wrong. The *gagi* make me understand if a person is sick’. A dialogue starts between her own spirit(s) and the evil spirit (*cen*) that is disturbing her client.

All three *ajwaki* are convinced that nodding syndrome is a new disease that is caused by ‘mostly young people, who were killed during the insurgency’. Apira explains: ‘The spirit of someone who died, who was killed when the rebels were killing seriously, it’s that spirit coming back to attack’. Young people were greatly affected by the violent conflict, since abduction of children was the main method of recruitment of the LRA (Derluyn *et al.* 2004: 861). By possessing the nodding children, the spirits wreak havoc and re-enact the wrongs that have been done to them. The head nodding often occurs at the sight of food and, according to local comments, this is connected to the experience of food shortage during the insurgency. The suffering that was inflicted on the war victims due to hunger is now preventing the nodding children to eat: ‘When you bring food for the child to eat, it immediately throws the child down, it stops the child from eating. (...) The spirits are saying that they died without eating food, so the children should also die without eating’.

*Cen* needs to be appeased, otherwise the afflicted person is doomed to suffer. The spiritual mediums treated several children by calling the vengeful spirits and satisfying their needs. Apira talks about the spirit affecting a girl with NS who was recently brought to her:

*The rebels abducted and killed him in the bush. When he was killed, he was not brought back home, like Acholi tradition says the*

*spirit should be summoned back. (...) Even a funeral was not organised, now it [the spirit] has come back to disturb this child. (...) During the time when we called and it spoke, the spirit said that it is sorrow that made it come back to disturb that child. (...) Its desire is that since it was abducted and died, it should also kill. People should also die like it, because there's no happiness in its heart. The spirit says that it was abducted and killed without reason before its time to die had reached.*

*Cen* can be seen as polluting forces violating the bodies of their victims. Past experiences with violence are transferred to the nodding children, whereby NS becomes an intergenerational issue affecting more than the individual body. The violated body incorporates collective narratives on conflict, and discussing NS therefore enables talking about experiences that took place during wartime.

After the spirit is identified and asked for its wishes, preparations start in order to send the spirit away from the suffering person. *Ajwaka Acomo* explains how she removes *cen* from the afflicted children:

*For lucluc we found cen, this needs a sheep to remove it. (...) The sheep is placed upside down on the anthill. We hold the knife together with the mother of the person with the illness and then we pierce the stomach of the sheep and open it. Then we cut off the head separately and first pull out the intestines and put them back. The sheep is then laid in the anthill like a dead person to be buried. You now summon the spirit that has been removed from that person and it will speak from inside the anthill. Then you put back the head of the sheep and then it is buried like a dead body so that the person doesn't die. The spirit will now go with the sheep instead of the person with the illness.*

It is the sheep that 'collects the unhappy spirits'. The spirit is summoned with the gourd rattle, which is put on the head of the sheep while the *ajwaka* tells it to 'stay on the sheep'.

In addition to this ceremony, the afflicted children receive herbal medicine. One of the *ajwaki* uses two types of plants. She grinds them to a powder which the children need to inhale and she mixes them with water to 'drop three times' in the nose. Others talk about herbal medication that the children need to drink, eat or rub under their nose. An older lady explains that she had a dream in which the medicine was shown to her: 'They showed me the picture while I was dreaming. When it was dawn I woke up and saw that medication right in front of the house'. She now sells the roots of this plant to the affected families, who smear it on the bodies of the children and mix it with their food.

Some community members point out that NS could be seen as revenge for 'all the sins the Acholi people committed in the past', thereby not only referring to events that took place during the insurgency, but also to plundering and murdering acts of Acholi soldiers during the Ugandan Bush War. Besides the role of the many killings during wartime, elders mention that NS exists as a result of a lack of traditional ceremonies. The places of worship where the ancestral spirits (*jogi*) were being honoured have been 'tormented during war and are no longer clean'. This evokes ideas about the moral order associated with (romanticised) notions on how

things were done before the political upheavals (Allen & Storm 2012: 25). When the ancestral spirits feel neglected, they become angry and can start war and illness. ‘Right now, people don’t follow the right procedures’, according to an elderly lady who is well known in the area for her traditional knowledge. ‘People don’t bury their loved ones in the proper traditional way. (...) Most people also don’t have an *abila* [ancestral shrine] anymore. You have to please the spirits, otherwise they will become angry. That is what has happened now’.

## Sheikhs and *Jinn*

A group of other spiritual authorities entered Kitgum town at the beginning of 2012. Their ‘adventure’—as one of the Islamic sheikhs termed it—started when alarming reports of nodding syndrome appeared in the media. Soon after the first (quite sensational) stories were published, the four sheikhs from Kampala went on ‘expedition’ to the small northern Ugandan town, in order to treat children with the notorious syndrome. Their appearance in this area is striking, since only a very small minority of Kitgum’s local population is considered to be Muslim. The decision to travel was made after previous efforts to heal the afflicted children ‘succumbed to timorous and perpetual failure’ and they concluded that ‘the disease is not scientific but explicitly devilish’ (Report compiled by Sheikh K. in 2012). According to the sheikhs, the children with nodding syndrome are being haunted by *jinn*.

The primary written sources of Islam refer to the existence of *jinn*, which are attributed characteristics close to those of humans. A duality of living worlds is indicated: a human world and a *jinn* world. Although they can have good and bad qualities, the Quranic meaning of the word *jinn* is rather negative and many Muslims fear their unpredictable powers (Mackenrodt 2006: 5). Some types can be sent by a spirit practitioner to afflict a selected victim; others come on their own. They manifest themselves through illness and misfortune, and treatment requires the services of ritual specialists (Giles 1995: 90).

Unlike *cen*, *jinn* are conceived of not as spirits of dead humans but as a separate form of creation. Whereas the sheikhs from Kampala are not familiar with the concept of *cen*, for the local Imam *jinn* and *cen* are both part of his spiritual surroundings. He states: ‘*Jinn* come here too much, because of killings. They like where blood splattered. (...) Those who died, their shadows [*cen*] are moving anyhow with those *jinn* now, in the area. They are together’. The combining of *cen* and *jinn* in Imam’s narrative on NS illustrates how his Acholi background mixes with an Islamic discourse on spiritual actors. Although *cen* and *jinn* are perceived to be different kinds of spiritual beings, both violate the bodies of nodding children in relation to past conflict.

According to Sheikh K., one of the identified *jinni* (Limakaabir) in Kitgum can be seen as a ‘symbol of atrocities’. He mentions: ‘When you kill me, that *jinni* comes to your family, like punishment. (...) The Kony war, what happened here was unimaginable, like cutting someone’s lips and nose. If you do something like that, a creature [*jinni*] can watch you because it is invisible. And Kony was using a lot of ghosts during his war. Even [Alice] Lakwena, she was using a lot of ghosts.’ Sheikh J. explains that when rebel leader Joseph Kony left the region after many years of fighting ‘the devils separated with him’ and they ‘mixed with the devils in the villages, so it became a bigger problem to fight’.

There are many different types of *jinn* and it needs careful examination to detect which one is disturbing a person. The team of sheikhs identified several types that they believe to be involved in nodding syndrome. In their press release report (2013), we read on page 3:

*The prevalence of a Jinni (Devil) known as (Khadimu lilhammaamu) residing in toilets and dirty unhygienic places. Common signs of its presence: This type is very dangerous, it orders the possessed to commit suicide, fall in the river, crash with vehicle or drink poison (...) Swarms of flies buzz around the patient (...) Consistent trembling of the body. (...) Jinni Limakaabir. This type resides in cemeteries, grave, shades or under trees in and around cemeteries. Its signs: (...) dreaming of dead people and sitting among corpses and within graves. (...) Constant dizziness and weakness. When it attacks: (...) Nodding the head timorously. Denies one food and drinks. (...) The patient sees a silhouette that compels him to run away fearfully. Other types detected are Ashiku and Khadimu Sihiru but are not rampant.*

According to the sheikhs, human bodies are enjoyable to *jinn*. When they ‘invade’ the human body, they come in ‘hundreds, thousands and millions’ and they multiply rapidly. The moment they have entered the body, they don’t want to leave and need to forcefully be ‘flushed out’. After identification of the type of *jinn*, a personal treatment programme is made. All patients are registered and receive an ‘Iraaju form’, containing a file-number, diagnosis, ‘detected cause’ and the ‘dosage to be applied’, as in the following example:

*O. (15) is suffering from the deadly nodding syndrome for 9 years now. It started by falling down and [he] remained unconscious from evening until the next day by almost noon. From then he has been having the epileptic condition once monthly. He dreams [about] people attacking him with spears, when he tries to run is when he falls down. He eats well. Constant headache. Detected cause: Khadimu Ssihiru. Dosages to be applied: (verses) Surat Al Bakara. Al Hiriku, Surat Swaffaatu x 7, Surat Qafu x7, Adhau x7. (Iraaju form from patient O., March 2013).*

The sheikhs treat their patients by means of reciting the Quran and the application of anointed water. The treatment should consist of ‘seven consecutive treatment sessions’, after which the patient needs to come once every week for ‘checking and counselling on preventive measures’ (Press release report 2013).

During the recitation of the Quran, the patient sits in front of the sheikh(s) and verses are recited close to his/her ears. Surat Swaffaatu is for example used to ‘burn the devils in the body’. After recitation, treatment continues with the application of Ruqyatu Maa'iyat, water that is anointed with Quran verses. The patient sits or lies down on the floor of the mosque and water is thrown at him or her. Sheikh K. explains: ‘We are targeting different body parts. When the water hits the *jinn* it hurts them very much, they will cry and scream. (...) Sometimes they pretend to be strong, but it feels like iron is hitting them’. Some of the dosages applied to the patients are ‘responded by the devils running out of the bodies’. According to the sheikhs: ‘The moment they get out of the body, the patient starts feeling okay’.

## Devils and Healing from Above

It is a quiet Sunday afternoon at the nodding syndrome ward in Kitgum hospital when five women, dressed in brightly colored *gomesi*, gather around the hospital bed of teenage girl Aber. She was admitted to the hospital several months ago after she fell into fire while having a seizure. Both her feet are currently wrapped in white bandage, but the women assure her that she will be healed and that she 'should then praise and worship God'.

The group of women visits the nodding patients every Sunday at the hospital. They stand in a circle around the bed and lift their open hands. One of the ladies puts a hand on Aber's head and then the praying starts:

*Lord at this moment we lift Aber and put her in Your hands. For the pain she is feeling, we ask You to be the doctor for that thing. You heal her, send to her the Holy Spirit. (...) You created and gave us many good gifts. But our enemy comes and refuses and spoils the gifts You gave us. Right now in the name of Jesus Christ of Nazareth, we want You to return the gifts which You gave Aber in the beginning Lord. Return the gifts the devil stole from her Lord. (...) In the name of Jesus with the power that You gave us, we remove all the spirits and bad things that are disturbing her. (...) Protect her with Your precious blood and protect us also. Heal her, cleanse her bed with Your blood, the bed of each patient with Your blood. We cover the hospital with Your precious blood that doesn't dry up Lord Jesus. Send Your Holy Spirit and angels to protect the patients and everyone in this hospital. (...) Let Him stretch His right hand and touch them, so that they receive the healing that comes from You. We pray in the name of your Son Jesus Christ our Lord. Amen.*

The women end the prayer with a song, in which they sing: 'Lord we are waiting for Your power from above (...), for Your Spirit from above (...), for Your healing from above'. Afterwards, they shake hands with Aber and move to the patient next to her.

Although the patients in the hospital are advised not to use herbal treatment and to stay away from *ajwaki* and Islamic healers, there is no problem when representatives of Christian churches visit the children. Most of the reports written in the NS-hospital record book teem with biomedical terms, but now and then a spiritual entity slips into the writing. For example, in one of the night reports a nurse describes the status of an 18-year old patient: 'She is not sleeping well during night hours, because the devil is disturbing her frequently'. The attending nurses often mention their personal Christian background and the affected families are encouraged to pray frequently.

In a quiet part of Kitgum town a group of religious leaders gathers at a primary school. The topic of their meeting is 'Intensive prayer for children affected with lucluc/NS', as indicated at the top of the distributed agenda. Several Christian churches are represented. 'All the denominations should join hands', an Evangelical lady emphasises, since NS does not discriminate and 'comes in every household'.

Bernard is the organiser and chairman of the meeting. Supported by a charity organisation from UK, his church developed a programme to support the NS-affected families in

three communities. Home visits are regularly made and the families receive oxen, ploughs and seeds. An important aspect of the programme is conducting prayers for the sick children. The project officer puts it this way: 'Most parents said that the cause of this disease is demonic. We can only chase away those devils through prayer. We can talk about oxen and farming tools, but it is important to start with praying to restore hope in parents'. According to a young man attending the meeting: 'It is only God who can help. If you look at the blood, you don't see anything. (...) The children present the disease as the devil attacking them and they need prayer to chase away the devil'. A Pentecostal pastor agrees that 'there is nothing like any medicine or drugs that can cure [NS], except from praying'.

At the end of the meeting, the priest of a catholic church explains why he believes that nodding syndrome is targeting this area:

*The community of Acholi, we should accept that we are very vulnerable. Our vulnerability comes as a result of the long war we had. (...) All these problems come as a result of Satan, to distract the lives of the people. (...) When we had hepatitis A, which is like nodding syndrome, praying was helping. They confessed that they were healed by praying. (...) We should not be surprised if it [NS] might spread over the whole Acholi area. Let's pray for the people of Acholi. There are a lot of devils in this part of the country and they are fighting our people.*

Here, as in the explanatory models of the *ajwaki* and Islamic sheikhs, the causes of NS are situated in a violent past. An Evangelical pastor adds: 'As Acholi, we might have been paid for the wrongdoing our ancestors have done'. All attendees agree with him that 'it is faith from a person that can set you out of pain. (...) If the community has faith, they will be healed'.

It seems that NS has currently joined the category of incurables such as HIV. In one of the affected areas, the church leader organises three days of prayer addressing both NS and HIV in every first weekend of the month. A delegation from another church has spent a week in the NS-affected communities to pray. Recently, a visiting Catholic leader also held special prayers for the nodding children, in order 'to provide spiritual healing and hope' (Komakech 2015).

However, fighting the devil takes a long time. A representative from a Catholic church in Kitgum concludes: 'This is just the beginning. These prayers may even take more than one, two or three years. If there is a war, commit yourself to fight until the war is over'. It seems that even when the actual guns become silent, violent actors remain present and continue to affect the local population for an extensive period of time.

## Conclusion

This paper shows how narratives on nodding syndrome are affected by the experience of conflict and how they in turn shape responses to illness. Although NS is considered to be a new affliction, long-existing notions of suffering, political negligence and the role of spiritual actors are reproduced in its conceptualisation. In explanatory models the causes of NS are mostly situated in a violent past. Vengeful actors are present during healing ceremonies and enable discussions about experiences that took place during wartime. Nodding syndrome hereby represents the continuity of well-known misery to the area; it allows for a simultaneously

embodied language for the afflicted individuals as well as collective experiences of distress. The intertwining of NS and narratives on conflict facilitates the expression of both individual and collective suffering during the search for relief.

The unknown cause of nodding syndrome elicits diverse explanatory models suggesting a variety of etiological factors, ranging from onchocerca volvulus to the role of evil spirits. These models are linked to different notions of healing. In their pragmatic quest for treatment, affected families combine elements from various forms of therapy: e.g. several (non-Muslim) children interrupted hospital admission in order to attend Islamic healing sessions; a lady well-known for distributing herbal medicine spent weeks at the nodding ward with her bedridden daughter; and the majority of AEDs-taking children have visited a healing ceremony addressing *cen*. In addition, different forms of treatment overlap: Islamic sheiks borrow forms from biomedicine, nurses urge prayer, *cen* and *jinn* are considered to occasionally combine forces, and *ajwaki*, sheiks and Christian prayer groups all attempt to expel evil spirits. Although various therapies have been suggested and eagerly tried out, the current treatment efforts seem to fall short. Just as illness understandings may change through time, the content of treatment services and the available options also change as events unfold. Subjunctivising elements of conditionality, doubt and hope (e.g. Good & Del Vecchio Good 1994; Whyte 2005) in the narratives on nodding syndrome allow the affected families to justify continued care seeking.

Viruses, bacteria, instruments of war, *cen*, *jinn* and devils can all be seen as polluting forces violating the bodies of the nodding children. Whether afflicted by biomedical, political or spiritual actors, the body can be seen as a place where battles of the past and present are played out. Since definite answers on cause and cure remain lacking, NS-affected families keep on being exposed to existential uncertainty and the quest for treatment continues.

## Acknowledgements

This study is funded by the BOF/Special Research Fund Ghent University, Belgium. Approval was obtained from the Uganda National Council for Science and Technology. I particularly want to thank the people in northern Uganda who participated in this study.

## References

- Abbo, C.; Ekblad, S.; Waako, P.; Okello, E.; Muhwezi, W. & S. Musisi (2008). 'Psychological Distress and Associated Factors among the Attendees of Traditional Healing Practices in Jinja and Iganga Districts, Eastern Uganda: a Cross-sectional Study'. *International Journal of Mental Health Systems* 2: 16.
- Allen, T. & L. Storm (2012). 'Quest for Therapy in Northern Uganda: Healing at Laropi Revisited'. *Journal of Eastern African Studies* 6(1): 22-46.
- Behrend, H. (1999). *Alice Lakwena and the Holy Spirits. War in Northern Uganda 1986-97*. Oxford: James Currey Ltd.
- Colebunders, R.; Hendy, A.; Nanyunja, M.; Wamala, J.F. & M. van Oijen (2014). 'Nodding syndrome—A New Hypothesis and New Direction for Research'. *International Journal of Infectious Diseases* 27: 74-77.

- De Jong, J. (2007). 'Traumascape: an Ecological-cultural-historical Model for Extreme Stress'. In Bhugra, D. & K. Bhui (eds.). *Textbook of Cultural Psychiatry*. Cambridge: Cambridge University Press: 347-364.
- Derluyn, I.; Broekaert, E.; Schuyten, G. & E. De Temmerman (2004). 'Post-traumatic Stress in Former Ugandan Child Soldiers'. *The Lancet* 262: 861-863.
- Dhossche, D. & A. Kakooza-Mwesige (2012). 'Nodding Syndrome in Ugandan Children and Adolescents: Ménage à Trois of Epilepsy, Autism, and Pediatric Catatonia'. *Autism* 2: 3.
- Director General of Health Services Uganda (DGHS) Dr. J.R. Aceng (2012). *Uganda hosts first International Scientific Conference on Nodding Syndrome*. Press Release. Kampala, 30 July 2012.
- Galabuzi, C.; Agea, J.G.; Fungo, B.L. & R.M.N. Kamoga (2010). 'Traditional Medicine as an Alternative Form of Health Care System: a Preliminary Case Study of Nangabo Sub-county, Central Uganda'. *African Journal of Traditional, Complementary and Alternative Medicines* 7(1): 11-16.
- Giles, L.L. (1995). 'Sociocultural Change and Spirit Possession on the Swahili Coast of East Africa'. *Anthropological Quarterly* 68(2): 89-106.
- Good B.J. & M.J. Del Vecchio Good (1994). 'In the Subjunctive Mode: Epilepsy Narratives in Turkey'. *Social Science & Medicine* 38(6): 835-842.
- Hollander, T. & B. Gill (2014). 'Every Day the War Continues in My Body: Examining the Marked Body in Postconflict Northern Uganda'. *International Journal of Transitional Justice* 8(2): 217-234.
- Idro, R.; Musubire, K.A.; Mutamba, B.B.; Namusoke H.; Muron, J.; Abbo, C.; Oriyabuzu, R.; Ssekyewa, J.; Okot, C.; Mwaka, D.; Ssebadduka, P.; Makumba, I.; Opar, B.; Aceng, J.R. & A.K. Mbonye (2013). 'Proposed Guidelines for the Management of Nodding Syndrome'. *African Health Sciences* 13(2): 219-323.
- Idro, R.; Namusoke, H.; Abbo, C.; Mutamba, B.B.; Kakooza-Mwesige, A.; Opoka, R.O.; Musubire, A.K.; Mwaka, A.D. & B.T. Opar (2014). 'Patients with Nodding Syndrome in Uganda improve with Symptomatic Treatment: a Cross-sectional Study. *BMJ Open* 4: 1-8.
- Igreja, V.; Dias-Lambranca, B.; Hershey, D.A.; Racin, L.; Richters, A. & R. Reis (2010). 'The Epidemiology of Spirit Possession in the Aftermath of Mass Political Violence in Mozambique'. *Social Science & Medicine* 71: 592-599.
- Iyengar, P.J.; Wamala, J.; Ratto, J.; Blanton, C.; Malimbo, M.; Lukwago, L.; Becknell, S.; Downing, R.; Bunga, S.; Sejvar, J. & I. Makumbi (2014). 'Prevalence of Nodding Syndrome—Uganda 2012-2013'. *Morbidity and Mortality Weekly Report (CDC)* 63(28): 603-606.
- Janzen, J.M. (1978). *The Quest for Therapy: Medical Pluralism in Lower Zaire*. Berkely: University of California Press.
- Kigozi, F.; Ssebunnya, J.; Kizza, D.; Cooper, S. & S. Ndyabangi (2010). 'An Overview of Uganda's Mental Health Care System: Results from an Assessment using the World Health Organization's Assessment Instrument for Mental Health Systems (WHO-AIMS). *International Journal of Mental Health Systems* 4:1.
- Komakech, D.M. (2015). 'Church prays for Nodding Children and Families in Kitgum'. *Daily Monitor*, 1 April 2015. Accessed June 30, 2015. [www.monitor.co.ug/News/National/Church-prays-for-nodding-children-and-families-in-Kitgum/-/688334/2671892/-/11fly1j/-/index.html](http://www.monitor.co.ug/News/National/Church-prays-for-nodding-children-and-families-in-Kitgum/-/688334/2671892/-/11fly1j/-/index.html).

- Mackenrodt, L. (2006). 'The Jinn fly on Friday. On Spiritual Healing Practices of the Swahili Coastal People in Contemporary Tanzania'. *Kölner Afrikawissenschaftliche Nachwuchstagung*. Accessed June 30, 2015. [http://www.uni-koeln.de/phil-fak/afrikanistik/kant/data/ML1\\_kant1.pdf](http://www.uni-koeln.de/phil-fak/afrikanistik/kant/data/ML1_kant1.pdf).
- Ministry of Health (2005). *Health Sector Strategic Plan II 2005/06–2009/2010. Volume I*. Kampala: The Republic of Uganda.
- Ministry of Health (2010). *Health Sector Strategic Plan III 2010/11–2014/15*. Kampala: The Republic of Uganda.
- Ministry of Health (2012). *Nodding Syndrome. Health Workers' Training Manual*. Revised edition: August 2012. Kampala: The Republic of Uganda.
- Muela, S.H.; Mushi, A.K. & J.M. Ribera (2000). 'The Paradox of Cost and Affordability of Traditional and Government Health Services in Tanzania'. *Health Policy and Planning* 15(3): 296-302.
- Musisi, S.; Akena, D.; Nakimuli-Mpungu, E.; Abbo, C. & J. Okello (2013). 'Neuropsychiatric perspectives on Nodding Syndrome in Northern Uganda: a Case Series Study and a Review of the Literature'. *African Health Sciences* 13(2): 205-218.
- Parliament of Uganda (2012a). *Parliament Meeting, 28 February 2012. 2.35 p.m. in Parliament House, Kampala*. Accessible via [www.parliament.go.ug/new/index.php/documents-and-reports/daily-hansard](http://www.parliament.go.ug/new/index.php/documents-and-reports/daily-hansard).
- Parliament of Uganda (2012b). *Parliament Meeting, Tuesday, 8 May 2012. 2.35 p.m. in Parliament House, Kampala*. Accessible via [www.parliament.go.ug/new/index.php/documents-and-reports/daily-hansard](http://www.parliament.go.ug/new/index.php/documents-and-reports/daily-hansard).
- Prince, R.J. (2014). 'Situating Health and the Public in Africa. Historical and Anthropological Perspectives'. In Prince & Marsland (eds.). *Making and Unmaking Public Health in Africa*. Ohio: Ohio University Press: 1-51.
- Scheper-Hughes, N. & M.M. Lock (1987). 'The Mindful Body: A Prolegomenon to Future Work in Medical Anthropology'. *Medical Anthropology Quarterly* 1(1): 6-41.
- Sejvar, J.J.; Kakooza, A.M.; Foltz, J.L.; Makumbi, I.; Atai-Omoruto, A.D.; Malimbo, M.; Ndyomugenyi, R.; Alexander, L.N.; Abang, B.; Downing, R.G.; Ehrenberg, A.; Guilliams, K.; Helmers, S.; Melstrom, P.; Olara, D.; Perlman, S.; Ratto, J.; Trevathan, E.; Winkler, A.S.; Dowell, S.F. & D. Lwamafa (2013). 'Clinical, Neurological, and Electrophysiological Features of Nodding Syndrome in Kitgum, Uganda: an Observational Case Series'. *Lancet Neurol* 12(2): 166-174.
- Sheikh Katongole (2012). *Research as per the Nodding Disease prevalent in Acholi Sub-region*. GULFA, Kampala.
- Sheikh Katongole (2013). *Press Release on GULFA's Treatment of Nodding Syndrome from 18<sup>th</sup> Mar-15<sup>th</sup> at Lulojo Mosque*. GULFA, Kampala.
- Spencer, P.S.; Vandemaele, K.; Richer, M.; Palmer, V.S.; Chungong, S.; Anker, M.; Ayana, Y.; Opoka, M.L.; Klauke, B.N.; Quarello, A. & J.K. Tumwine (2013). 'Nodding Syndrome in Mundri County, South Sudan: Environmental, Nutritional and Infectious Factors'. *African Health Sciences* 13(2): 183-204.
- Van Bommel, K.; Derluyn, I. & K. Stroeken (2014). 'Nodding Syndrome or Disease? On the Conceptualization of an Illness-in-the-making'. *Ethnicity & Health* 19(1): 100-118.
- Van Bommel, K. (2016, in press). 'The Rise and Fall of Nodding Syndrome in Public Discourse: an Analysis of Newspaper Coverage in Uganda'. *Critique of Anthropology* 36(2), June 2016.

- Whyte, S.R. (2005). 'Uncertain Undertakings: Practicing Health Care in the Subjunctive Mood'. In Steffen, V.; Jenkins, R. & H. Jessen (eds.). *Managing Uncertainty. Ethnographic Studies of Illness, Risk and the Struggle for Control*. Copenhagen:Museum Tusulanum Press: 245-264.
- Winkler, A.S.; Friedrich K.; König R.; Meindl M.; Helbok R.; Unterberger I.; Gotwald T.; Dharsee J.; Velicheti S.; Kidunda A.; Jilek-Aal L.; Matuja W. & E. Schmutzhard (2008). 'The Head Nodding Syndrome—Clinical Classification and Possible Causes'. *Epilepsia* 49(12): 2008-2015.
- World Health Organization (2012a). *International Scientific Meeting on Nodding Syndrome. Meeting Report*. UKaid, CDC, The Republic of Uganda & WHO, Kampala, 30 July-1 August.
- World Health Organization (2012b). *Uganda adopts a Multi-sectoral Response to Nodding Syndrome*. Press Release No 1/2012. Kampala, March 2.