

CONCEPTUALIZING ILLNESS: NODDING SYNDROME IN NORTHERN UGANDA¹

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This paper presents an ethnographic study of conceptualizations of nodding syndrome (NS) in Uganda. NS is a poorly understood condition characterized by repetitive nodding of the head, mental retardation and stunted growth, which affects thousands of children in northern Uganda, South Sudan and Tanzania. Although extensive research for causative agents has been conducted, no convincing single cause has been reported. This study establishes an understanding of different representations of NS and argues that the episodes of head nodding are related to the socio-political body in which they are manifested. Three interwoven approaches towards NS take main stage whereby the syndrome is presented as a biomedical, spiritual and/or political problem. The conceptualizations are linked to different notions of healing and affected families combine various forms of therapy. Through the examination of different narratives, this study disrupts the idea of a singular perspective on illness and pleads for a focus on motion and plurality.

KEY WORDS: NODDING SYNDROME, UGANDA, HEALTH, CONCEPTUALIZATION, ANTHROPOLOGY

Introduction

Nodding syndrome (NS) is a poorly understood condition characterized by repetitive episodes of nodding of the head in children with previously normal development between the ages of three to eighteen. The head nodding is often triggered by food and cold weather, and frequently combined with epileptic seizures, varying degrees of mental retardation, stunted growth and a failure to develop secondary sexual characteristics (Winkler et al., 2008; Sejvar et al., 2013; Idro et al., 2013; Van Bommel, Derluyn & Stroeken, 2014). Children living in the poorest conditions seem most susceptible to the syndrome and the majority of affected families experienced food shortages and have a history of internal displacement. Up to now, an estimated 10,000 children have been affected in Tanzania, South Sudan and Uganda (Idro et al., 2016) and calculations of the total number of patients in northern Uganda vary from 1687 (Iyengar et al., 2014) up to 3320 (Idro et al., 2016). Several researchers emphasise that the existence of NS should also be systematically investigated in other areas (Kaiser et al., 2015; Wamala et al., 2015; Föger et al., 2017). At least 170 deaths have been reported in Uganda, mostly

¹ This is the report of PhD research carried out at Ghent University, under the supervision of Koen Stroeken and Rijk van Dijk (Van Bommel, 2017a).

due to injuries after falling into fire or water during convulsions (WHO, 2012). In this paper, attention is paid to the circulation of various conceptualizations of nodding syndrome in northern Uganda.

Nodding syndrome

Reports of nodding syndrome in Uganda appeared around 1998, during two decades of violent conflict between the Lord's Resistance Army (LRA) and Ugandan government. During the course of this conflict, between 25,000 and 60,000 children were abducted to serve in the LRA (Betancourt et al., 2009; Derluyn et al., 2004) and an estimated 1.7 million people have been forcefully moved into internally displaced person (IDP) camps. The twenty years of conflict resulted in loss of lives, mass displacement, discontinuation of social services and destruction of infrastructure. In this situation, nodding syndrome proved to be yet another challenge for the northern region.

While the signs of epilepsy or *two lirlir* had been known in the area for a long time, the symptoms of nodding syndrome were considered to be something new (Van Bommel & Van Der Weegen, 2017). Cases increased annually beginning in 2001, with peaks in 2004 and 2008, followed by a decline towards present-day baseline levels (Landis, Palmer & Spencer, 2014: 2). In 2009, approximately three years after the return of relative peace to the northern region, the first epidemiological investigations into the head nodding symptoms in Kitgum district were carried out. Media reports on the emergence of a 'strange disease' emerged (e.g. *Daily Monitor*, 2009), but the topic soon disappeared from the national spotlight. This changed at the end of 2011, when local actors became concerned about what they considered to be a lack of action and demanded an adequate political response to the distressing symptoms. With discussions touching upon political and ethnical sentiment, politicians were forced to make clear-cut statements in public. In March 2012, the attention to nodding syndrome resulted in an official governmental response plan (MoH, 2012) and the opening of several nodding syndrome treatment centres in the northern districts of Uganda.

In the years following the opening of these centres, NS emerged as an important public health issue and much speculation arose about its causes; e.g. an experiment gone wrong, relief food poisoned with chemical preservatives, the after effect of exposure to munitions during war, psychological consequences of the conflict, the lack of ancestral ceremonies, revengeful spirits, or a deliberate attempt to harm the Acholi population (Van Bommel, 2016a, 2016b, 2017b). 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: a novel neurotropic virus (Colebunders et al., 2014), mycotoxins and food (Spencer et al., 2013), post-traumatic stress disorder (Musisi et al., 2013), a link with paediatric catatonia (Dhossche & Kakooza-Mwesige, 2012) and an auto-immune disorder initiated by a parasitic infection with *Onchocerca volvulus* (Johnson et al., 2017) have all been mentioned in aetiological hypotheses. Although extensive research on NS for biological and environmental causative agents has taken place over the past decades, no convincing single cause has so far been reported. And even though

affected children seem to improve substantially with symptomatic treatment (Idro et al., 2014), no proven effective treatment is as yet available.

Conceptualizations of illness

The focus of this study is on the processes in which nodding syndrome is selected, labelled and recognized as a distinct category and the consequences this has on ways of dealing with the symptoms (Van Bommel, 2017a). The act of head nodding in children has obtained special meaning related to the socio-political context in which it exists. Scattered traits of behaviour and disparate explanations that had not previously been thought of as constituting one system came to be considered as part of the same NS phenomenon. Subsequently, the acquired meaning of the nodding episodes initiated certain social (re)actions, and stands in direct relation to the syndrome's management. The central thesis of this study is that we can learn more about afflictions and their management by looking at formative processes through which illness is conceptualized. Hence we focus on the various and distinct discourses that express the search for insight into nodding syndrome and thus constitute its conceptualization (Van Bommel, 2017a). Currently, emphasis lies on how meanings of phenomena do not necessarily inhere in the phenomena themselves but develop through interaction in a social context: i.e. how actors contribute to producing perceived social reality and knowledge (Conrad & Barker, 2010: 68).

The lack of knowledge of causative agents of NS has consequences; not-knowing constitutes a major part of the meaning that has accrued around the syndrome and can be seen as a resource for political, spiritual and biomedical action (Van Bommel, 2017a). First, this study explores the fields of meaning in which terms associated with nodding syndrome are embedded and the way they relate to each other in people's discourse. Insight is gained into conceptualizations of head nodding episodes by focusing on how they are represented: which elements are emphasised, why and by whom? Once insight is gained into various concepts of nodding syndrome, the focus shifts to how they are acted upon and, in turn, facilitate action.

Methods

The study is based on 15 months of qualitative fieldwork in Uganda, spread over four periods in 2012, 2013 and 2014. Fieldwork was conducted in an area known as 'Acholi sub-region', which refers to the districts in northern Uganda that are traditionally inhabited by Acholi people. Reports of nodding syndrome mainly appeared along the riverbanks of the northern districts of Kitgum, Pader and Lamwo (Landis, Palmer & Spencer, 2014). Data collection for this study predominantly took place in Kitgum, a district with a population of 204,048 (UBOS, 2016: 51). In 2012, the number of nodding syndrome affected people in Kitgum district was estimated to be 1278 (Nduhuura, 2012; MoH, 2012).

The significance of nodding syndrome for individuals and collectives is determined by their positioning in relation to its various elements. The phenomenon of head nodding is for example situated in the context of laboratories and biomedical instruments, but it is also seen as a humanitarian crisis, a spirit-related or a political phenomenon. In order

to touch upon these different layers of meaning, the study includes narratives from actors positioned in different geographical and thematic areas, and follows them in various settings (e.g. affected households, hospitals, NGO offices). The study population includes affected children and their caregivers/support networks, biomedical health workers, *ajwaki* (spiritual mediums), herbal- and faith healers, humanitarian organizations (e.g. Red Cross, AVSI, Hope for Humans, MSF), journalists, politicians, policymakers, academic researchers and institutions dealing with NS (e.g. CDC, WHO, NS treatment centres, Ugandan Ministry of Health). Informed verbal consent was obtained from all respondents and they did not receive any form of payment, compensation or reimbursement for their participation. Interviews were conducted in leb Acholi, a Nilo-Saharan/Luo language, and in English. Data has been tape-recorded whenever possible and is supplemented with field notes. Four research assistants were recruited to help with translation during interviews, introduction in the field and transcription of interviews. They were trained on the study protocol, informed consent process and confidentiality (Van Bommel, 2017a).

In addition to countless conversations about NS at the market, in church, on the back seat of *bodaboda* taxis and in other informal settings, the following research methods have been used: ninety in-depth interviews; focus group discussions; the documentation of illness narratives; participant observation; analysis of communication patterns; and comparative analysis. With these research methods information was gathered about the personal world of health and suffering, in order to gain insight into conceptualizations of illness. Additionally, a 38-minute documentary was made during fieldwork, in cooperation with local actors involved in nodding syndrome (Van Bommel & Aalten, 2017). The film contributes to an embodied anthropological study by making the body audibly, visibly and viscerally present (Bates, 2013: 29). According to Lorimer (2010: 242), moving images can be used as a means of witnessing various forms of knowledge, skills and embodied practice that can escape text- and talk-based approaches. Therefore, video techniques are a powerful supplement to existing repertoires of representational methodologies, moving beyond the limits of text with the incorporation of sound, voice, colour, movement and narratives when representing the body. Furthermore, showing audio-visual data is an effective way of sharing research results with people in the field (and with non-scientific audiences), who often experience difficulties with accessing scientific texts².

Nodding syndrome as biomedical, spiritual and political problem

Throughout the analyses of data, three interwoven approaches towards the aetiology of NS take main stage whereby the syndrome is presented as a biomedical, spiritual and/or political problem. These different representations emphasise that the episodes of head nodding are related to the socio-political body in which they are manifested.

Nodding syndrome as a biomedical problem came to life in medical workshops. Here the

² The documentary, entitled 'Nodding Syndrome: an illness in the making', is available via the following link: www.vimeo.com/noddingsyndrome/docu (Van Bommel & Aalten, 2017).

phenomenon of head nodding is frequently detached from the social body by researchers who look for a medical system that explains the specific type of head movements. Biomedical actors display expert knowledge about the constructed boundaries in the functioning of the physical, whereby uncontrolled head nodding is considered to be abnormal behaviour and NS is presented as a bodily failure or unexplained neurological condition. The construction of NS as a disease entity is the product of social interactions, medical investigations and power relationships. Through conversations, academic publications and a shared medical education these actors use a similar discourse when discussing NS, consisting of specialized terms for which its audience needs some form of medical background. Their conceptualizations are grounded in the biology of disease and the nodding episodes are interpreted within a particular nomenclature. The actors base their theories on biomedical studies, in which they make use of physical examinations and simplified questionnaires. In addition, skin snips and other body samples have been taken to laboratories for investigation. In a biomedical definition, nodding syndrome is located beneath the skin and characterized by the presence and actions of human cells and micro-organisms. A biomedical case of NS has to meet certain conditions in order to be acknowledged: it is here that the construction of NS as a diagnostic entity takes place. Among the afflicted population, ideas about nodding syndrome (termed *lucluc* in *leb Acholi*) that are quite different to the biomedical circulate. Here NS is mainly perceived as a spiritual problem pointing to social disharmony in society. The majority of affected families argue that it came as a result of war and spiritual actors are often part of explanatory models. The nodding children are affected by harmful acts from non-human actors, which are connected to previous encounters with conflict. The most frequently identified aetiological agents are *cen*; vengeful spirits of people who have died untimely and often violent deaths. Rituals of purification were irregularly carried out during the twenty years of conflict, and the spirits of those who were killed remain unreconciled and are able to inflict misfortune. Criteria for the diagnosis of *lucluc* are based on knowledge from experiences with the afflicted children and knowledge on the local cosmology and shared values in the affected community. Underlying causes such as sins committed by Acholi during times of war, negligence of ancestors through the disregard of rituals and the demolition of places of worship are frequently mentioned. This conceptualization of *lucluc* is grounded in the spiritual world: it is mainly characterized by actions beyond the surface of the skin. The nodding episodes are interpreted within a particular set of terms, whereby a specific vocabulary is used for which knowledge on the local cosmology is needed. Previous experiences with violence are transferred to the nodding children by spiritual actors, whereby *lucluc* becomes an inter-generational issue affecting more than the individual body. Nodding syndrome as spiritual problem is therefore more closely connected to local histories than its biomedical construction.

The strand of discourse on nodding syndrome that is built around political themes is a particularly strong variety. The emergence of NS during war and its ability to address painful social issues meant that the condition quickly became presented as a 'political problem'. It mainly gained momentum because of its political connotations; the idea that

national leaders had ‘again’ failed to offer adequate protection to the ‘already vulnerable’ Acholi people. Thereby, the depicted suffering and political body of NS has been used in media and local discourse to discuss other important social and political issues, such as a perceived lack of political will to support the northern region and atrocities that occurred during war. Thus by linking the suffering of affected children to the suffering of an ethnic group, narratives on nodding syndrome were able to expose structural tensions of the Acholi in post-war society and facilitate the expression of both individual- and collective suffering. NS is for example frequently linked to worries about the complete annihilation of the Acholi as ethnic group, illustrating a deeply rooted fear for (revenge of) governmental actors which stretches back to earlier events. Local actors occasionally address a politically motivated cause of NS, by mentioning the use of poison or chemical weapons. So, although nodding syndrome is considered to be a new affliction, long-existing notions of suffering and political negligence play a prominent role in its conceptualizations. The political body of NS shows that the affliction is more than an isolated event, and that it can also be seen as an instrument in a political struggle or as a symbol of the marginalization of a region. Unlike the biomedical importance of this syndrome, it offers a model of social disharmony, linking NS to traumas of past conflict, to poverty and to (region-bound) frustration over neglect (Van Bommel, 2017a).

Nodding syndrome management

With the extensive media coverage, NS became an increasingly public experience, which led to the creation of social movements and demands for governmental action. The appearance of the head nodding symptoms – combined with heated debates in parliament – resulted in the creation of a parallel healthcare system for children afflicted by NS. Several NS treatment centres were opened and an outreach program was launched to supply affected children with anti-epileptic medication. Although the governmental response resulted in the acknowledgement of the burden of NS, dissatisfaction is frequently expressed about a lack of accountability, coordination and connectivity between multiple actors. The government is perceived as an important actor in the delivery of healthcare, but is also subject to much distrust that has built up over the past decades in northern Uganda. The response to NS has raised questions on the status of Acholi as citizens of Uganda and reveals feelings of detachment from the national healthcare system. In the northern region, in particular, the current leadership has been criticized for its lack of support and tendency to down-play the prevalence and impact of the syndrome. The political body of nodding syndrome is for example visible in the filing of a negligence lawsuit against the Ugandan government, in its frequent mention during parliamentary debates, in the protests by women groups and in the transport of affected children from Kitgum to the far-away Mulago hospital by an opposition member of parliament. Within northern Uganda, the concept of NS is strongly associated with the disadvantaged status of the Acholi population, given that its existence is bound to a region and community that have a complex relationship with current power holders.

The narratives on NS are affected by the experience of conflict and this shapes responses

to illness and the search for relief. Explanatory models are linked to different notions of healing and affected families combine various forms of therapy. In addition to biomedical treatment, the affected families enter into negotiations with spiritual actors. Spirits are not time-and-space bound and require specific measures to be dealt with. In Kitgum, a number of afflicted children are brought to *ajwaki*, spiritual mediums. Here, dialogues commence between spirits of the *ajwaka* and the spirit causing mischief, in which it reveals its motives and wishes. Subsequently, preparations are made in order to send the spirit away, often involving the killing of an animal. Islamic sheikhs are also involved in removing harmful spirits. Through the use of anointed water and recitations of the Quran, *jinn* are sent out of the bodies of suffering children. Furthermore, Christian faith healers organise praying events in order to send away devils that are believed to cause the children's condition. The affected families follow different – and often combined – therapeutic trajectories in the context of a pluralistic medical system. Since definite answers on cause and cure remain lacking, negotiation of the meaning of nodding syndrome continues (Van Bommel, 2017a).

Conclusion

The imaginary construct of a definite concept of nodding syndrome is a product of a specific history, consisting of certain actors, shared ideas, power struggles and available resources. Rather than the fictitious qualities of NS as a reified phenomenon in itself, it is the (re)production and (re)interpretation of knowledge on NS that has taken centre stage in this study, following different processes of adaptation, transformation and replacement in society.

The explored concepts consist of what exists in the mind as a representation of the 'phenomenon NS'. Scattered attitudes, behaviour and explanations that had not previously been thought of as constituting one system were brought together and recognized as being part of the same phenomenon. However, different actors visualize different – uncertain but real – products, whose contents continue to be negotiated. Thereby, boundaries are established, observed, transformed and transcended, and actors are both consciously and unconsciously adopting and adapting ideas, or seek to influence and change policies. Although the boundaries are arbitrary and depend on the creating actor, the established concepts do have important explanatory and decision-making power. Through the formation of NS -either as a biomedical, spiritual and/or political problem- it became something real upon which action is based (Van Bommel, 2017a).

In the attempt to analyse NS we could use the analogy of a prism: while it separates light into different colours, no single colour is dominant in determining what we experience as white light. The same applies to the different (e.g. biomedical, spiritual and political) discourses on nodding syndrome. Instead of perceiving NS as the product of a static box, we could view the nodding episodes as a prism from which different discourses emerge. Through the examination of these different narratives, this study disrupts the idea of a singular (universal) perspective on illness and pleads for a focus on motion and plurality. It allows us to move away from the notion that all discourses need to come together in

one static model of analysis. NS cannot simply be seen as the sum of all gathered narratives in this paper. Nodding syndrome is located both *beneath* and *beyond* the skin; it is connected to the *present* and *past*; and it is both *individually* and *collectively* experienced (Van Bommel, 2017a). There is no doubt that different discourses of NS profoundly influence each other and that some similar processes are at work in all discourses. But we should move away from the supposition that ‘what is seen from those different vantage points, though apparently diverse, is all really part of the same coherent, integrated phenomenon’ (Cook, Laidlaw & Mair on multi-sited research, 2009: 47).

The concepts of NS need to be understood as tentative and evolving – rather than certain and unchanging – and without the assumption that the different elements construct one comprehensive, unified whole when put together. A valid ethnographic account does not need to correspond to an integrated whole or claim to understand how things ‘fit together’. In contrast, the value of anthropology lies in its ability to explore and describe a diversity of interpretations and fields of knowledge, without the necessity of integrating them into one overarching and unifying framework. Through the exploration of NS, this study has offered a way to recognize and facilitate different discourses that do not fit the criteria of a static model. Over the course of this study, the static black box transformed into a more dynamic representation of NS, containing both the actual and the potential, the visible and invisible, the limits and infinity of the body (Van Bommel, 2017a).

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