

# The rise and fall of nodding syndrome in public discourse: An analysis of newspaper coverage in Uganda

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## Abstract

Nodding syndrome is an unexplained affliction that has affected thousands of children in post-conflict northern Uganda, South Sudan and in Tanzania. This study focuses on the sudden rise of nodding syndrome in the Ugandan public discourse, based on 369 newspaper reports over a timespan of 4.5 years and interviews with journalists, politicians, caretakers and health workers during 15 months of fieldwork in Kitgum district. The news coverage of nodding syndrome follows a non-linear trajectory, increasing at the end of 2011 and declining a year later. Attention is paid to the conceptualization of nodding syndrome in media reports, linked to the formation of public opinion and management of the affliction. Different settings elicit different concepts and it is therefore necessary to contextualize illness and focus on processes of formation.

## Keywords

Uganda, Acholi, nodding syndrome, media discourse, content analysis, conceptualization, politics, conflict, illness

## Introduction

The story has been one pitying tale of an ignorant population caught unaware, fighting a mysterious illness that has sent many of their children to an early grave and a government caught napping as the unknown disease consumes the young people. (Newspaper *Daily Monitor* about nodding syndrome, 26 May 2012)

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In May 2012, two Members of Parliament move a motion asking the Ugandan government to declare ‘Acholi sub-region’ a humanitarian emergency area (PoU, 2012a). In this way, hope arises for the distribution of emergency relief after thousands of previously healthy children in northern Uganda, South Sudan and Tanzania are reportedly affected by nodding syndrome (NS). On a daily basis Ugandan news reports, weblogs and television-items about this unexplained illness appear throughout 2012, thereby often linking the syndrome to conflict, ethnic identities and politics, and using prefixes such as ‘mysterious’, ‘devastating’ and ‘deadly’ (e.g. see introductory quote).

According to the World Health Organization – that labels the syndrome a ‘mysterious disease condition’ – nodding syndrome is characterized by repetitive, involuntary nodding of the head, triggered by food and cold weather, mainly affecting children aged 5 to 15 years and resulting in mental retardation and stunted growth (WHO, 2012a; Winkler et al., 2008). Some children are unresponsive to commands and stare absently during nodding episodes, whereas for others the head nodding does not disrupt eating or the ability to follow commands (Tumwine et al., 2012: 244). Children living under the poorest conditions seem most susceptible to the syndrome (CDC, 2011) and the majority of the affected families experienced food shortages and have a history of living in internally displaced persons (IDPs) camps during war at the beginning of this century (WHO, 2012c). In local explanations the syndrome is often associated with conflict, since the affected areas have served for 20 years as a battleground for the war between Lord’s Resistance Army (LRA) and the Ugandan government. As a result, many ‘*cen*’ – the spirits of people suffering a violent death – are now said to roam the country, bringing sickness and accidents (Van Bommel et al., 2014). From a biomedical perspective, epidemiological studies have suggested a link between the syndrome and *Onchocerca volvulus* (e.g. Winkler et al., 2008), fungal contamination of food (Spencer et al., 2013), complex developmental trauma disorder (Musisi et al., 2013) and pediatric catatonia (Dhossche and Kakooza-Mwesige, 2012). Sejvar et al. recently associated the nodding spells with clinical and electrographic seizures including generalized tonic-clonic and absence seizures (2013). So far at least 170 deaths have been reported (WHO, 2012b) and more than 10 investigations on NS have been conducted, but the etiology, mode of transmission, pathogenesis and clinical course remain unknown (WHO, 2012c). In other words; up to now, there is no known cause or cure for the approximately 3000 children that suffer from the syndrome in northern Uganda.

Although similar symptoms have been described in the mid-1960s in Tanzania and were mentioned by caretakers in South Sudan and Uganda to have started about a decade ago (Bukuluki et al. 2012; Jilek and Jilek-Aall, 1970; Nyungura et al., 2011), it is only recently that reports on the syndrome appeared in media, thereby touching upon political and ethnical sentiments, such as the long standing north-south divide in the country and a perceived neglect of the northern region by the government. Since only children belonging to the Acholi ethnic group in Uganda seem to be affected by the syndrome, suspicion arose in the northern

area over the cause of NS and anxieties emerged over whether it could be a planned attack in order to ‘wipe out the next generation of Acholi’. Although government did not declare the affected areas to be emergency zones, NS *did* spark a public debate on issues of health and unity in Uganda. It became a hot topic in national public discourse, generating a lot of attention; over the past three years an international scientific conference on NS has been organized in Kampala, a response plan for ‘the control of the nodding disease in Acholi sub-region’ was developed (MoH, 2012), several governmental NS-treatment centers have been opened and two lawsuits blaming government negligence have been filed (2012). All along, the media has been reporting from the front row. As one biomedical investigator – somewhat agitated – tells me: ‘It has been a media circus’.

## Methodology

Practices of medicine are inextricably linked with wider political and social phenomena. In a previous paper, we detected the circulation of different NS-discourses with a clear divide between hegemonic biomedical accounts and counter-hegemonic social-issue analyses. Besides its biomedical importance, NS offers a model of social disharmony in which it is linked to conflict, poverty and frustrations over neglect (Van Bommel et al., 2014). The present article continues to emphasize the importance of contextualization, while analyzing media reports and exploring the sudden interest in the syndrome in national public discourse. Although NS was noticed by the local populace in northern Uganda around 2000 and officially reported by the Ugandan Ministry of Health in 2009 (Bukuluki et al., 2012), national and political interest only came at the end of 2011; resulting in more than 200 news reports in the major daily newspapers during the following year. This paper seeks to demonstrate the role of media in the conceptualization and management of illness and aims to analyze how certain perceptions of NS were formed. Previous studies examining images of (mental) illness in media, indicate that they are often misrepresented through exaggerations and misinformation (Stout et al., 2004: 558) and could contribute to stigma, inaccurate use of terms and unfavorable stereotypes (Wahl, 1995). Paying attention to the media-narratives of NS provides a fertile ground for investigating processes of conceptualization and the historical power relationships that put people in their current socio-geographical sphere (Blommaert and Bulcaen, 2000). Instead of focusing on the ‘product NS’, attention is shifted to processes of formation.

The nature of how media – the primary disseminator of information to citizen – portrays facts and expert opinion is crucial in understanding the nature of what informs people’s opinion (Shanahan et al., 2008), and media is likely a powerful shaper of public opinion (Swain, 2005 in Kiwanuka-Tondo et al., 2012). The analysis of the sudden media interest in NS reveals how the topic has been presented to the public over time and how it obtained – and lost – a central place in public discourse. This description is based upon 90 in-depth interviews with journalists, health workers, affected families and local politicians during 15 months of

qualitative fieldwork (2012, 2013 and 2014) in Kitgum district, an area in northern Uganda in which many cases of NS have been reported. Interviewees were asked about their knowledge, attitudes, perceptions and practices related to nodding syndrome, making use of semi-structured topic lists on explanatory models (Kleinman 1980: 105), expressions of disease, illness-management and media-attention. Snowball sampling was used and respondents were selected through different institutions, such as NS treatment centers, humanitarian organizations, religious institutes and community leaders. Interviews were conducted in English or, with help of a translation assistant, in *leb* Acholi. Each interview took between 30 and 90 minutes and was recorded with the respondents' consent. Analysis of the transcribed data was by thematic analysis whereby key concepts were identified in the interviews. Observations have been made at the homes of affected families, treatment centers, during outreaches and meetings. This article presents the findings on the media-conceptualization of NS.

An analysis of all articles about NS in two Ugandan national newspapers, *Daily Monitor* (DM) (203) and *New Vision* (70), and the regional online-newspaper *Acholi Times* (AT) (96) was conducted. The sample period ranges from August 2009 – when the first media report on NS appeared – until March 2014. The online-databases of the three newspapers were searched using 'nodding' as keyword. In addition, other Internet search-engines were used (Keywords: 'Daily Monitor AND nodding'; 'The Monitor AND nodding'; 'New Vision AND nodding'; 'Acholi Times AND nodding'). The articles obtained from this search were selected when they addressed 'nodding syndrome' or 'nodding disease'. An in-depth content analysis has been carried out of all news reports mentioning 'nodding' in the headline in DM (124), *New Vision* (37) and AT (73).<sup>1</sup> Content analysis is a method to systematically code media content according to pre-determined categories, enabling drawing inferences on media treatment of defined topics of interest. In the media accounts on NS, attention was paid to significant and recurrent segments, corresponding with often-mentioned topics during interviews. These key concepts were identified and synthesized into categories selected for coding. The developed coding scheme evaluated each news-report in terms of the length of the article in words, the quoted number of NS-affected children and mortality rate,<sup>2</sup> the mentioning of politics<sup>3</sup> and negative remarks concerning the political response to NS,<sup>4</sup> the description of social<sup>5</sup> and physical effects<sup>6</sup>, references made to the potentially deadly character<sup>7</sup> of NS and to mysterious elements,<sup>8</sup> such as an unknown cause or cure. In addition, all selected news-reports were coded on the presence of keywords 'victim', 'suffering' and 'Acholi'.

The two daily newspapers were chosen for content analysis because they have the highest newspaper circulation. *New Vision* (NV) is established in 1986 and sells about 38,000 copies daily, reaching 304,000 readers, and the Ugandan state owns 53 percent share in its publishing house (African Media Barometer, 2012: 33). The non-governmental newspaper *The Monitor* is established in 1992 and relaunched as DM in 2005. The paper sells about 25,000 copies daily, reaching 254,034 readers (Kiwanuka-Tondo et al., 2012), and operates since 2000 as a subsidiary of the

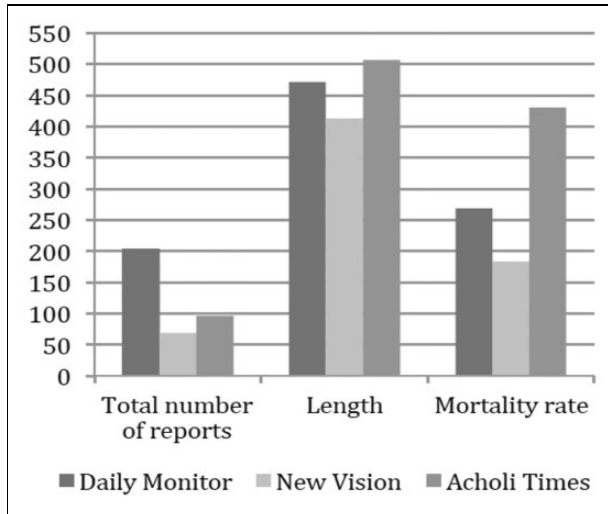
Nairobi-based Nation Media Group, which is present in Kenya, Uganda, Tanzania and Rwanda (NMG, 2013). According to their own statement, the private ownership of the paper 'guarantees the independence of its editors and journalists, free from influence of Government, shareholders or any political allegiance' (DM) 23 November 2009). In addition to the two national newspapers, AT has been chosen for a content analysis since it is a private owned news-source from the area in which NS is prevalent and reports from a regional perspective since 2010. It is published by Kumalo Entertainment – all contributors come from Acholi sub-region – and 'free from the influence of Government, shareholders or any political allegiance' (AT, 2014). On its website, AT is introduced as 'a voice of the suffering people of northern Uganda' and its mission described as 'an alternative to the pro people's suffering in Acholi and the international media who have instead turned to cheering and glossing over the neglect and abuse of the Acholi people'. The paper's political views are often opposing the current national leadership.

The combined use of quantitative and qualitative data on NS answers the need for contextualization of text and enables the linking of media reflections to data on events and local discourse in northern Uganda. Hereby, attention can be paid to power relations and the situatedness or construction of meaning of the analysed texts. Blommaert and Bulcaen (2000: 460) argue that discourse analysis could benefit from more attention to ethnography as a resource for contextualizing data and as a theory for its interpretation, so that attention is paid to social circumstances under which text is produced and consumed and what effects it has.

First, I start by looking into media ownership and the reflection of nodding syndrome and argue that media plays a large role in the conceptualization of NS as a 'mysterious, political and deadly illness'. I then demonstrate that images of the suffering – and political body often emerge in media accounts and suggest that earlier narratives of suffering and conflict are being reproduced and reinforced into media frames when discussing NS. In addition, several factors are identified that contribute to the media interest in NS and the sudden increase and gradual downfall of public attention. Finally, I will look into the relationship between media reports and illness-management, referring to the theory that actual language products stand in dialectic relation to social structure.

## **Media reflection**

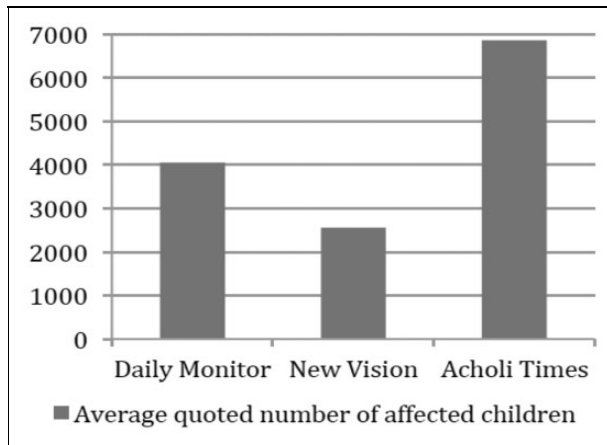
The sudden rise of national interest in nodding syndrome is illustrated by the coverage in Ugandan press. From our national newspaper-sample, the first articles mentioning NS appeared in 2009 when 'A strange disease strikes Kitgum children' (headline DM 21 December 2009), followed by fewer articles on NS in 2010 and an increasing number of reports at the end of 2011. A major jump in coverage took place in 2012 with more than 200 published articles, followed by a decline in media interest in 2013. The same pattern in coverage of NS can be seen in the regional online newspaper AT, which came into existence in 2010.



**Figure 1.** Number of reports mentioning NS in DM, NV, AT, August 2009 to March 2014. Average length of articles in words and average quoted mortality rate of NS in news-reports with 'nodding' in headline.

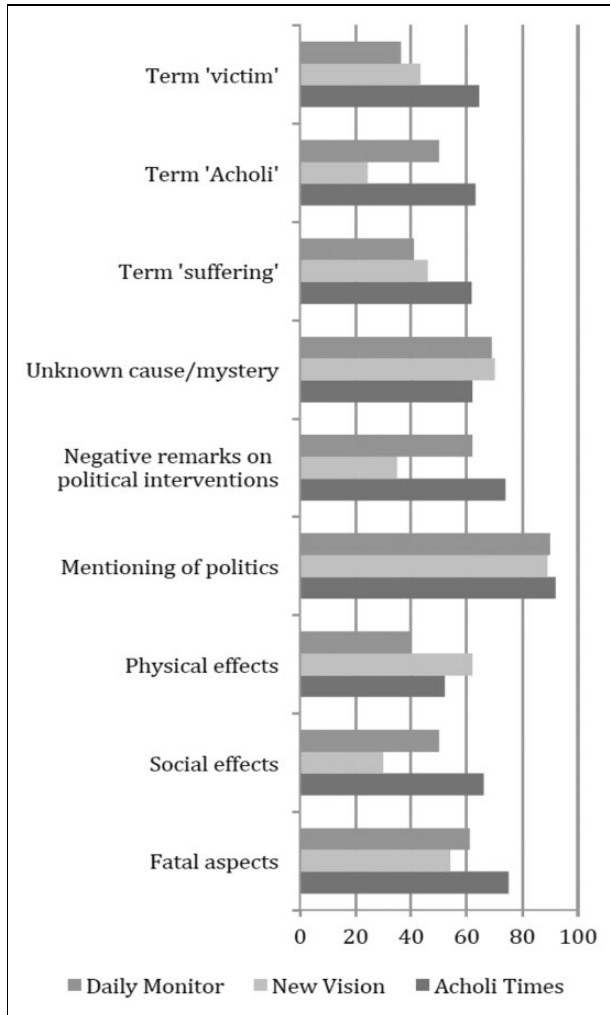
The relevant discourse-data question 'Why now?' (Blommaert and Bulcaen 2000: 461) – and the equally important question 'Why not anymore?' – will be addressed later in this article, but for now the fact that more than 200 news reports mention NS in 2012 points at the central place the affliction has obtained in public sphere over the past years. Through its mass appeal to audiences, media had the ability to bring NS to be a public matter. Besides playing a role in disseminating information, media – pushed by several actors – also played an important role in the development of interpretations. There is a strong correlation between the emphases that media place on certain issues and the importance attributed to these issues by mass audiences. Tversky and Kahneman (1973) state that judgement and attitude are directly related to the ease in which instances or associations could be brought to mind. By making some issues more salient in people's mind, mass media can shape the considerations that people take into account when making judgements or forming attitudes. Framing models assume that how an article is characterized in news reports can influence how it is understood by audiences.

When analyzing the content of newspaper articles on NS, narratives on mystery, suffering and politics are prominent (Figures 1 to 3), overlapping with local discourse in northern Uganda. Newspapers term the syndrome 'the death sentence that is slowly wiping out Acholi children' (AT 27 February 2012), 'a form of genocide' (AT 7 November 2012), 'the new terror in Acholi sub-region' (DM 31 January 2012) and 'mysterious killer disease' (DM 21 December 2012). DM uses



**Figure 2.** Average quoted number of children affected by NS in newspaper reports with ‘nodding’ in headline August 2009 to March 2014, DM (124), NV (37), AT (73).

the headline ‘Acholi sub-region desperate as children nod to their death’ (14 January 2012) and describes the situation as ‘sitting on a explosive that will detonate to destroy a whole generation’ (23 May 2012). The fact that not much is known about NS probably fuels the amount of media reports, suspicions and attempted explanations: e.g. ‘Northern disease still a mystery’ (NV 8 December 2010), ‘Are pharmaceutical trials to blame?’ (AT 9 April 2012) and ‘Acholi MPs link nodding disease to weapons used during the war’ (AT 21 May 2012). Although scientists assure that NS is not contagious, media reports feed the fear for contraction. An article from DM for example states that ‘more new cases are likely to continue emerging, more people will continue dying and, may be, the disease may spread to other areas so far not affected’ (5 March 2012) and AT reports that ‘officials are warning of a pandemonium and widespread deaths, which, if not adverted immediately, could easily wipe out a whole generation’ (7 November 2011). In short, the press reports seem to conceptualize the syndrome as a mysterious, fatal and Acholi (i.e. region- and ethnic-bounded) affliction, thereby often referring to politics, conflict and marginalization. The varying descriptions of NS illustrate how difficult it is to conceptualize an illness when so little is known about its etiology, symptoms, prevalence and treatment. In our media sample, the average reported number of people being affected by NS is 4637 (Figure 2), with figures shifting from ‘more than thousand’ (DM) to ‘ten thousand’ (AT). In general, the governmental newspaper *New Vision* reports lower mortality – and prevalence rates than DM, with AT reporting the highest average numbers of deaths and affected children. Deadly aspects of NS are mentioned in 65 percent of the articles (mostly in AT) and the mysterious character of the syndrome is emphasized in 67 percent



**Figure 3.** Topics mentioned (%) in newspaper reports with 'nodding' in headline August 2009 to March 2014, DM (124), NV (37), AT (73).

(mostly in AT and DM) of newspaper reports with 'nodding' in the headline (Figure 3). Discrepancy between reported mortality – and victim rates is visible between the newspapers and the Ugandan Ministry of Health and World Health Organization, who report that 3094 children have been affected (DGHS, 2012) and estimate that 170 deaths occurred due to the syndrome in Uganda (WHO, 2012b). Unfortunately, there is no doubt that several affected children indeed have died (the author witnessed six cases of death during fieldwork), but there is no indication

that the syndrome itself is deadly or contagious –as often misrepresented in newspaper articles. So far, the reported cases of death are due to secondary causes such as drowning and falling into fire during seizures (Donnelly, 2012, Van Bommel et al., 2014).

## Ownership

It should be noticed that the government-owned *New Vision* newspaper and the private news sources DM and AT differ greatly on the amount of negative remarks being made on political interventions regarding NS (Figure 3). In Uganda, an adequate response to nodding syndrome has largely been seen as a government responsibility, and the current leadership has been criticized for a lack of support and downplaying the prevalence and impact of nodding syndrome (e.g. ‘Minister of Health downplays number of victims affected by nodding disease’ AT 6 August 2012). In addition, rumors circulate in northern Uganda about the hypothetical role of government actors or chemical weapons in the etiology of NS. In local discourse, feelings of political distrust are often mentioned, stretching back to a long existing north-south divide in the country and experiences of conflict and frustration over neglect (Van Bommel et al., 2014). This is reflected in narratives on NS. During a parliamentary meeting, the Kitgum MP for example made – and later withdrew – an allegation about distributed food-aid for NS-affected families; ‘I was informed by the sick people, that when the food was distributed (by government), they found metallic cans (...) labeled ‘poison’ (PoU, 2012b).

These stories find their way to media representatives, and mediatized narratives of suffering have the potential to mobilize popular sentiment and collective action (Kleinman et al., 1997). Who owns the news-organization may impact the way in which information is presented and what information is presented about NS. DM is part of the multinational Nation Media Group, the largest independent media house in East and Central Africa and operating since 1959, and therefore not tied to a specific political program in Uganda. *New Vision*, however, has to think about its majority stakeholder when it comes to articles it publishes, since some critical stories –such as mentioned above – might damage government programs (African Media Barometer, 2012: 34). To some extent the newspaper serves ‘as a mouthpiece for government policies and strategies’ (Kiwauka-Tondo et al., 2012: 369). The sensitivity of press reports was visible when the office of newspaper DM was closed for more than a week by authorities after publishing a critical report on the Ugandan president in May 2013. Acayo and Mnjama (2004) wrote about the state of press freedom in Uganda: ‘The publication of information deemed to be contrary to the government’s view may result in warnings, arrest, harassment, assault, court proceedings and even imprisonment by the government’. During interviews with journalists in northern Uganda, fear was regularly expressed for punitive measures after writing about politically sensitive topics.

Whereas the private-owned papers express a critical view on the results and approach concerning NS so far (e.g. ‘Nodding: Parents cry as government makes

slow move to save kids' DM 11 January 2012 and 'Lack of government support increasing desperation among parents of nodding syndrome victims' AT 16 December 2013), the reports in *New Vision* frequently emphasize achieved success and contributions of government programs ('Government to open nodding disease treatment centers' NV 7 March 2012 and 'Nodding disease children improve' NV 14 March 2012). More and lengthier articles on NS are covered in the private newspapers (Figure 1) and these employ a political frame more often than the government-owned newspaper. Whereas *New Vision* puts more emphasis on the physical effects of the syndrome and its unknown cause, the other newspapers mention more negative comments on political intervention, quote a higher number of affected children and mortality rate, describe more social effects of NS and use the term 'Acholi' significantly more often in connection to the syndrome (Figure 3), thereby creating a link between the syndrome and – highly politicized – ethnicity. Narratives heard during fieldwork in Kitgum mostly resemble the private news accounts, linking NS to questions of political marginalization and frustrations over neglect. The influence of media ownership has been clearly described by Kiwanuka-Tondo et al. (2012) in an article on HIV/AIDS coverage by Ugandan press. Their results show that private newspaper DM published more features and lengthier articles on HIV and utilized action, tragedy and victim frames more often than the government-owned *New Vision*, corresponding with our findings on NS reports. In conclusion: the story depends in part on news organization ownership.

## Victimhood and media

A prominent and frequently used tragedy-frame is the 'victimization' or devastating portrayal of NS-affected children, who have been termed 'Uganda's walking dead' (AT 28 May 2012) and 'half-human' (DM 17 February 2012) in news reports. According to Kleinman et al. (1997: 1) suffering is 'a master subject of our mediated times'. Perhaps the fact that NS afflicts children, arguably the weakest, voiceless components of society, adds to the eagerness of media and other spokespersons to speak on their behalf. A published letter in one of the newspapers states that: 'Children, unlike adults, are innocent beings and I believe these children wished they could help themselves' (DM 31 January 2012). While describing an award-winning picture of a little girl collapsing from hunger in Sudan, Kleinman points out that the child is depicted as a 'lone individual' (existing free of local people and worlds) and the picture assumes that 'they must be protected, as well as represented, by others' (...) 'Something must be done, but *from outside* of the local setting' (1997: 7). In almost all news reports on nodding syndrome, children are reduced to the status of passive, helpless victims and in 46 percent of the articles the term 'victim' – which could be perceived as an image of innocence and passivity (Kleinman et al., 1997: 10) – is literally being used. Distress is emphasized and more than half of the articles report social effects of the syndrome, mostly mentioning children dropping out of school due to the symptoms, parents not being able to

work on the field because of taking care of their children, stigma, cases of rape resulting in pregnancies and in some occasions parents are mentioned who ‘tie children onto trees’ (DM 17 February 2012) in order to prevent them from wandering away. Physical effects from NS, such as stunted growth, mental retardation and saliva drooling, are mentioned in 47 percent of the articles (Figure 3). An example of the devastating portrayal of affected children is the following description of a girl with NS:

Her skin peels off like that of a snake. Occasionally, big chunks of her skin falls off reveal(ing) the red part of her inner skin. Adong must keep alert all the time to keep flies away from sucking on her daughters fresh skin. (...) Two (children) are almost mad and very violent. They walk around naked. When given clothes, they tear them off their bodies (DM 31 January 2012).

In addition, a reporter from the AT writes: ‘Half naked, pale, looking tired and with her legs tied together (...). Her hands are scarred and rotting away from burns she obtained after she fell into a fire during an attack’ (27 February 2012) and *New Vision* states that: ‘In some cases, instead of the children eating chicken, you find the chicken pecking on their wounds’ (18 May 2012).

It is worth noting that the private- and government-owned media have a different approach to victimhood. As mentioned before, the private media puts more emphasis on the social effects on the lives of affected families, whereas the government newspaper pays more attention to the physical effects of nodding syndrome (Figure 3). By writing about social – arguably more subjective – aspects of NS, the syndrome is being ‘personalized’; evoking empathy from the reader and arousing critique on the current situation. Thereby, the stories perhaps encourage readers to blame certain actors for not putting enough effort to support the affected families and minimize the (partly preventable?) secondary effects of NS. I’d like to argue that the victimization of nodding syndrome in media and local discourse is linked to the political and social status of Acholi in Uganda, whereby the suffering, victimized status of NS children is used in political statements about the perceived marginalization of Acholi people and as a way to criticize current leadership. I will elaborate on this later, when I discuss the political body of NS. Contrary to the private media, the government-owned newspaper focuses more on physical – bio-medical – effects of NS; although these images certainly evoke empathy, direct finger-pointing cannot take place over the existence of (more or less) objective symptoms such as seizures, stunted growth and saliva drooling – and thus less politics are involved.

During a discussion with a Ugandan (opposition) politician about my intentions of writing a report on NS, he suggests to entitle the document ‘Terrible, Mysterious, Killer, Nodding Syndrome’, as a way to attract attention. Although I obviously opted for a different title for this paper, his suggestion would probably have attracted more readers. Disaster brings attention. When searching for ‘nodding disease’ in the search engine of the popular video-sharing website YouTube,

thousands of videos come up. One of the video clips shows a CNN news report on NS that has been posted twice: one clip is posted by the official CNN news channel (in March 2012) and has been viewed 9622 times (May 2014), while the other is posted by someone called 'wshDAY17' (in March 2012) and has been viewed almost 15 times more often (143,023, May 2014). The content is the same, the only difference being the title of the video-clip. CNN named its news-coverage 'Mysterious disease devastating families' while the other clip is entitled: 'Mysterious "Zombie" Illness Strikes Uganda (Turns Children Into Violent "Zombies")'. Sensationalizing seems to work in order to receive attention: viewership increases by using spectacular headlines. There is a market for suffering: victimhood is commodified (Kleinman et al., 1997: xi) and voyeurism is an outcome of construing suffering at a safe distance, without the social responsibility of real engagement (Kleinman et al., xviii).

Although the children and their families are certainly burdened by this illness and encounter many difficulties, reductionist portrayals of them as merely passive victims are not representative for all children afflicted with NS. In the mediated experiences of suffering, the 'sufferers' are often isolated from their local context. But even while suffering, people remain actively involved in life tasks. During fieldwork in Uganda, I encountered NS-afflicted children under different circumstances; some of them were in terrible condition, malnourished, not able to walk or talk and no doubt desperately in need for help. Others, however, were coping well with the symptoms and able to go to school, participate in daily activities, such as washing clothes and play with age mates – though often put on daily mediation. The nature of how media portrays facts is crucial in understanding the nature of what informs people's opinion (Shanahan et al., 2008: 117) and we should challenge dominant images that focus exclusively on their status as victims, since labelling has important consequences for those identified (Good, 1994: 34) and to be deemed 'sick' can have restrictive consequences (Gardner et al., 2011). Caretakers in Kitgum complain for example about social stigma and report that their children are at times not allowed to play or sit in class with other children out of fear for transmission. Although the acknowledgement of distress caused by NS should be encouraged, caution should be used when creating (unrealistic) media-images, since they could complicate screening activities and help-seeking behaviour and lead to social stigma, in the end harming the affected children.

At this 'age of the picture' cultural technologies exist that can fashion the 'real' in accord with the interests of power (Kleinman et al., 1997: xiii). It seems that their perceived helplessness and vulnerability makes the NS-affected children ideal 'mascots' in order to attract humanitarian funding and play out political battles –perhaps without necessarily taking account of the children's interest. Last year, for example, a fight took place between two opposing politicians in front of affected families, accusing each other of 'eating the money meant for nodding syndrome'. Later on, during a meeting on NS, the appointed chairman desperately sighed; 'Political leaders are using nodding syndrome. They are destroying our children for

their political games'. On both national and international level this could easily lead to well-known images of 'the suffering African child': the image of poor, suffering children coming from a politically and economically marginalized post-conflict area seems to be easily digested in media and on weblogs (e.g. a news-item recently shown in Belgium and the Netherlands compared the NS-affected children to 'zombies' (literally dehumanizing them) and stated that 'ten thousands already died and 15,000 victims are dying at this moment'). Thereby some aspects of NS become expressible, while others are wrapped in silence. How we picture suffering in media, becomes that experience and 'what is not pictured is not real' (Kleinman et al., 1997: xiii).

The most well-known photo in relation to NS depicts a child being tied to a tree, her fingers covered in bloody wounds. After this photo was published in a Ugandan newspaper, women tied themselves to trees in Kampala as a way to show solidarity with mothers whose children are suffering from the syndrome (and in the meantime criticize the slow response of government), illustrative for the way media can trigger forms of social mobilization. During a meeting with a group of non-governmental organizations some months later, the members decided to visit some of the affected children, expressing the idea that 'If it drops some tears in your eyes, you are ready to start a plan'. According to this view emotions are deemed as a necessary base for actions, being able to speak a 'language of suffering'. Another example occurred when a foreign investigator recently visited a hospital in northern Uganda and took multiple pictures of a severely malnourished girl covered in burns after falling into fire. She admitted finding it difficult to do and looked uncomfortable while using her camera, but explains that 'in order to receive funding in the future' she needs this kind of coverage. In this way, the suffering, neglected child is being seen as the archetype of the NS-victim in 'disease ridden Africa'. Portraying the syndrome in its most devastating form is perceived as a way to receive attention and funding. Perhaps this is telling us more about the needs and expectations of potential donors and indicates that showing images fitting into a *charity frame* (Darnton and Kirk, 2011) is the most successful way to engage this economically powerful group. Images of victims are frequently commercialized and taken up into 'processes of global marketing and business competition'. Experiences are hereby used as a commodity, and through the representation of suffering, the experience is being 'remade, thinned out, and distorted' (Kleinman et al., 1997: 2). Mass-mediated reports of disease in Africa have a signal impact on Western constructions of 'third world peoples' as abject, intractable and doomed (Comaroff, 2010: 25), representing the Constitutive Other. The way Comaroff (2010: 31) describes a third world HIV/AIDS sufferer as *homo sacer* (citing Agamben, 1998) is also applicable to the image of NS-affected children: 'A scarcely human being condemned, in an age of humanitarian empathy, to callous exclusion, to death without meaning or sacrificial value; a being left untreated in an era of pharmacological salvation'. Suffering children coming out of a 20-year during war seem to fit well into this kind of framework and it is precisely this image that is emphasized in media-conceptualizations of NS.

Like war, this media frame strips the human of all meaning, so as to rebuild in reference to a consumable model.

### The suffering body

The discourse surrounding NS seems to point at a broader discussion – we could even argue that the children afflicted with NS are only portrayed on the sidelines. Not only the medical healthcare system is at stake, but the syndrome stands as a symbol for political, social and economical marginalization, since it targets an area and people that have for decades been associated with suffering, opposition and conflict. This view is expressed in often-heard comments during fieldwork, stating that the deaths which occurred due to NS can be ‘blamed upon a general lack of interest (of current leadership) in supporting Acholi’ and that, when looking at the response to NS, ‘cows in western Uganda seem to be more important than people in Acholi’ (DM 8 March 2012).

The portrayal of Acholi-people as ‘victims’ is not a new phenomenon, but can be traced back to narratives on ‘a wandering people’, raids by slave traders in the 19th century, colonialism and a north-south division, cattle raids, forced displacements and IDP-camps, Ebola, Cholera and a lot of conflict: for example Acholi involvement in the Uganda bushwar (1981–1986), Alice Lakwena’s Holy Spirit Movement (1986–1987) and the war between the LRA and Ugandan government (1987–2006) (for a short historical context of violence and war in Acholiland, see for example Branch, 2012). During the course of the recent insurgency, it is estimated that between 25,000 and 60,000 children have been abducted to serve in the LRA and an estimated 1.7 million people have moved into IDP camps (Derluyn et al., 2004; Harlacher, 2009). For decades the Acholi people have been associated with hardship and distress. Whitmore (2011: 192) writes about the perception of Acholi people in Uganda; ‘The Acholi are not only on the whole darker-skinned than most southern Ugandans, they are often described as less modern and more ‘backwards’ by others in the country’. Opira Morise Kato, a well-known singer and *adungu*-player in Kitgum district, describes the continuous hardship in Acholiland in his song ‘Can lobo’ (poverty of the world):

We have suffered in this world. In World War II, during the British era (...), even during the Mau Mau rebellion (...), our cows were all taken by Karamojong (...), Kony also finished us (...), HIV/AIDS (...), Nodding disease wants us also (...), We have suffered, our children (Opira Morise Kato, 2014)

Can we perhaps, when looking at the conceptualization of NS in media and local discourse, detect continuity in the way Acholi political, cultural and historical region-bound identity is being negotiated (or perhaps victimized)? As *Daily Monitor* writes in one of its newspaper-reports: ‘For a region that has endured two decades of war, the nodding disease presents another bereavement: the death of their future, which is their children. But for how long should Acholi land remain

Uganda's heart of despair?' (30 January 2012). In many ways these earlier narratives of suffering and conflict are reproduced and reinforced in the media frame, whereby the syndrome represents the return of well-known misery to the area. NS is being labeled 'a fresh distress to the already suffering region' (DM 16 July 2012) and is described in similar terms as earlier conflict. President Museveni is for example quoted in DM (26 March 2012) saying that he would 'defeat the nodding disease syndrome just as he did with the elusive LRA leader Joseph Kony' and that he will 'return to command war against it' and AT argues that the syndrome 'presents a form of bereavement that has come to finish what the war has left behind: the death of Acholi future' (28 May 2012).

It is interesting to note that the (homogenized stereotype of) suffering in these reports is often applied to the Acholi ethnic group instead of the affected individuals. This points to the relationship between media and the local history, whereby a reductionist image of Acholi-identity is displayed with descriptions of a unified, homogeneous group, bounded to the so-called 'Acholi sub-region', and frequently linked to conflict and politics. But this image is not only prevalent in media accounts. A local politician in Kitgum district mentioned for example during an interview: 'If one eye hurts, then the whole body suffers', emphasizing the perceived oneness of Acholi and how NS is affecting the whole community. This illustrates that health is a social process and human suffering can be at the same time collective and individual (Kleinman et al., 1997). The narratives yield traces of past relationships between political, cognitive, and ideological hegemonies and patterns of resistance (Blommaert and Bulcaen, 2000).

### **The political body**

Besides linking the media-conceptualization of NS to a long-existing association between Acholi people and conflict or suffering, I argue that NS is also used as a symbol of marginalization in political struggles. Concerns are not only with the physical body and experiences of physical pain and fragility, but also with social and symbolic aspects (Jenkins et al., 2005). Politics seems to be a main issue in the conceptualization of NS; in nearly all conversations during fieldwork in northern Uganda and in most newspaper reports political aspects are mentioned (Figure 3). Scheper-Hughes and Lock (1987) describe the concept of 'body politic' as an artifact of social and political control and mention that bodies can be regulated by government and external influences during conflict. It is interesting to note that respondents in northern Uganda perceive the time when their bodies were 'damaged by NS' to coincide with the period in which over 90 percent of the population were driven from their homes into IPD camps by government forces (Harlacher, 2009); when the control over their bodies was externalized. During a meeting in Kitgum a local leader cried out: 'This syndrome (and thereby the body in sickness) is highly politicized!'

In more than 60 percent of the articles with 'nodding' in the headline, negative remarks about the governmental approach to NS are being mentioned, as expected

more often in the private – than government-owned newspapers (DM 62% and AT 74% versus NV 35%). These negative remarks mostly concentrate on a perceived lack of government response. As mentioned earlier, the dominant idea in local discourse is that Ugandan government has not done enough to assist the affected community. In 2012, two civil suits have been filed against the Attorney General, accusing the government of negligence and inadequate response to NS, violating ‘the right to life, education, freedom from discrimination, freedom from cruel and inhumane treatment’ (NV 29 May 2012). In 2013, media reports appeared about a group of Members of Parliament (MPs) from northern Uganda calling for the region to break away and form an independent country: ‘The lawmakers (...) accused the government of discriminating the people of northern Uganda, whom they said had suffered a lot in the last 30 years’. The MP women of Kitgum is quoted saying in terms not concealing ethnic strife: ‘The nodding disease syndrome hasn’t ended and it is high time we broke away and formed our own government or continue to be marginalized’ (DM 21 February 2013). On another occasion opposition politician Besigye went to visit affected children at the hospital and expressed the need for change of government, stating that: ‘The current one is not sensitive to issues affecting citizens such as nodding disease’ (DM 12 March 2012). These examples show that NS is not only related to the affected children but is linked to broader long-standing social issues and used as an instrument in political debates. In particular, members of opposition parties make sure that their voices are heard when NS is being discussed, thereby playing a big role in politicizing the conceptualization of NS in media. During a parliamentary meeting in Kampala, the Aruu county MP cries out for more help in the struggle against the syndrome: ‘Come and explain what is happening, because we are also Ugandans. We are tired of complaining every day. We also want to be treated like other people’ (PoU, 2012b).

In addition, narratives of (political) violence and conflict automatically come up when discussing NS. Symptoms first appeared during the insurgency in northern Uganda and many local explanations emphasize a link between NS and war, bombs, chemical weapons or spirits of murdered people (Van Bommel et al., 2014). Also in media accounts on NS, the war is frequently mentioned (e.g. 21 May 2012 AT). In this way, addressing NS enables talking about experiences and atrocities that took place during wartime. In Kitgum, mothers led me to big craters next to their huts, pointing out where bombs exploded and sharing their thoughts about how this could have caused NS. One concerned respondent showed me a list of places in northern Uganda where he suspects that chemical weapons have been used. While discussing NS, a number of caretakers talked about the abduction of their children by LRA rebels – after which they started noting the nodding symptoms – or described the difficulties they encountered when living in IDP-camps, where stories about NS first came up. And *ajwakas* (spirit mediums/traditional healers) mentioned the role of unhappy spirits of murdered people in causing NS, due to the difficult circumstances under which they died. It seems that by talking about NS, a range of social and political issues are being addressed.

The media and public discourse on NS illustrate how social and political issues intersect as people try to give meaning to experiences they have. In addition, it illustrates how the syndrome is being used to – vice versa – give meaning to political and social situations. We cannot understand the experience of suffering and health without paying attention to the context in which negotiation and meaning-making takes place. Discussions concerning NS could be seen in a broader attempt to negotiate what it means to be Acholi. The ‘afflictive history’<sup>9</sup> that surfaces in many narratives on Acholi, as discussed in the previous section, influences the conceptualization of this ‘mysterious syndrome’ whereby NS can be seen as symbol of political marginalization. This ‘afflictive history’ also creates a community of suffering. We could argue that this combined suffering is a uniting factor and perhaps leads to combined efforts in finding healing and peace (e.g. therapeutic community?).

### **Nodding syndrome’s popularity**

So far, we can conclude that NS has been a hot topic in media and public discourse over the past years. We could question *why* NS has attracted so much attention in the first place, since the narratives of suffering concerning NS resemble other well-known stories about inefficient health care systems. As a matter of fact, there are many illnesses in northern Uganda that affect a larger number of people. So why has this large amount of (media) attention been given to this particular affliction and at this particular moment?

I start by suggesting that the recent amount of interest in NS has to do with the mystery surrounding the syndrome. When faced with crisis people seek a sense of control, especially when they are not sure what they are dealing with. Sickness poses questions about our very sense of existence and how to deal with uncertainties of living (Jenkins et al., 2005). In the case of NS a great amount of fear is involved as well, since the mode of transmission, prognosis and cure are unknown. Perhaps we could speak about the public representation of NS in terms of a ‘moral panic’, defined by Krinsky (2013: 1) as ‘an episode, often triggered by alarming media stories and reinforced by reactive laws and public policy, of exaggerated or misdirected public concern, anxiety, fear, or anger over a perceived threat to social order (e.g. see Van Dijk (2001) about ‘voodoo’ in the Netherlands or La Fontaine (1998) about ‘satanic abuse’ in England). Moral panics gain momentum as politicians and other moral crusaders join forces with media (ibid: 5) and the action or actors involved are pictured in a highly stereotyped way (Cohen, 2002). According to DM ‘frustration and fear has continued to dominate the nodding disease debate’ (27 February 2012) and ‘sooner than later it may spread like wildfire and doom the entire country’ (6 February 2012). The fear that potentially anyone could be affected enables easy identification with the victims and causes anxiety, like Canetti (1984: 15) states: ‘there is nothing that man fears more than the touch of the unknown. He wants to see what is reaching towards him, and to be able to classify it’. Almost seventy percent of the news-reports refer to mysterious aspects

of NS, emphasising for example the fact that there is no known cause or cure (Figure 3). In response to this state of uncertainty, people look for information. Media deals with these lingering questions as it seeks to represent society and depends on public interest in order to exist. Perhaps the mystery also calls for detective-like initiatives to try solving the ‘nodding disease puzzle’ (DM 12 January 2012), ‘medical mystery’ (CNN 6 June 2011) or nodding syndrome ‘riddle’ (Scott Dowells in Edwards, 2012). This could be seen as part of a competitive battle to ‘own NS’; the person finding the cause and – even better – the cure for NS is sure to get instant fame (and fortune?). Since so far no results came up everyone is still ‘in the race’.

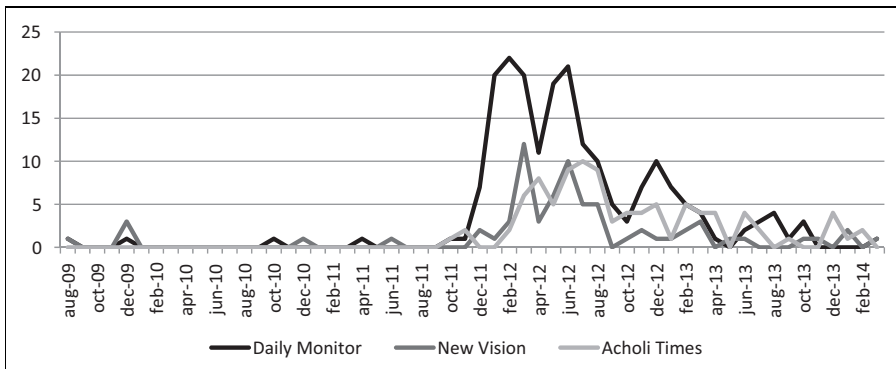
It seems plausible that mystery, uncertainty, personal identification and fear are factors contributing to the national interest in NS. Empathy should also be mentioned, since many people sympathize with the affected families. In addition, human beings seem to have a fascination for topics related to suffering. Contemporary society increasingly consumes both real and commodified death and suffering through audio-visual representations, popular culture and media (Stone and Sharpley 2008: 580). Watching and reading about suffering has become a form of entertainment (Kleinman et al., 1997: 8). In a study on tourist-attraction of sites associated with death and suffering, Dann (1998) argues that people like to ‘dance with the death’ and that it might heighten their own sense of mortality. Spectacular forms of suffering can also ‘deflect attention from routinized misery at home’, Kleinman points out (1997: 11).

Another explanation for the syndrome’s popularity in media is its boundedness to a political sensitive area, therefore eliciting a lot of political statements and interest. Also, the fact that only children are afflicted by NS adds to the eagerness of others to talk on their behalf and, as mentioned before, makes them ideal humanitarian mascots, ‘turning children affected with nodding disease into a money making venture’ (AT 16 June 2012). Attracting financial means to the northern region is especially important since many NGO’s closed their offices after years have passed by in relative peace. Reasons related to funding-issues were given for the call to declare Acholi sub-region a humanitarian emergency area, referred to in the introduction of this paper, since only then ‘the disease will receive the world attention it deserves and put pressure on stakeholders concerned, to act as they are expected to’ (DM 23 May 2012). This illustrates how media is able to place NS in the spotlight and can thereby put pressure on stakeholders to act accordingly.

According to Critcher (2002) three arenas are crucial in shaping the prominence of social issues; it must assume prominence at the level of policy makers, media and the public. As illustrated above, all elements are present in the NS narratives.

## **The rise and fall of an affliction**

The results in Figure 4 indicate that the news coverage of NS follows a non-linear trajectory; the interest in NS as a media-topic suddenly emerges at the end of 2011



**Figure 4.** Number of articles mentioning nodding syndrome in DM, New Vision and AT, August 2009–March 2014.

and decreases a year later. As Blommaert and Bulcaen (2000: 461) state, the contextualization of discourse data is important and ‘Why now?’ is a relevant question in analysis. Why did attention for NS come up at this moment, while symptoms have already been noticed more than a decade ago? Or: why didn’t media-attention arise earlier?

An obvious reason is that the area in which the syndrome is prevalent was until recently involved in a war; people had other priorities related to conflict and survival (e.g. food, shelter and safety). The symptoms of head nodding were being discussed in IDP camps, but not picked up by media or politicians. Mobility and communication means were restricted and the area was difficult to access. The more conclusive diagnosis of NS therefore appeared to coincide with the apparent end of the war. A more stable environment following the conflict led to a fairly stable health delivery system, which enabled systematic recognition and diagnosis of the condition (Bukuluki et al., 2012). However, relative peace returned to the area in late 2006 and the first sporadic NS-reports came up in media in 2009. Then why did NS only spark a public debate at the end of 2011? In the years after the conflict had ended, people were moving from IDP camps to their original homes and perhaps the overall magnitude of NS was not clear yet. Also, after decennia of receiving news reports on northern Uganda in relation to conflict, the national public and media-houses might have been tired of hearing about (new) tragedies in this area. ‘Compassion fatigue’ describes the scenario in which people who are constantly facing stories of suffering become desensitised to these stories over time (Kiwanku-Tondo et al., 2012). Media-consumers can be ‘overwhelmed by the sheer number of atrocities’, producing ‘moral fatigue, exhaustion of empathy, and political despair’ (Kleinman et al., 1997: 9). In addition, the violent past and the breakdown of traditional kinship networks had resulted in the erosion of social trust and a lack of togetherness in the northern region (Angucia 2010; Baines 2010), complicating the united demand for media- and political attention. During

interviews in Kitgum district, people would mention a perceived lack of interest in northern Uganda as a reason for the delayed national attention to the syndrome. Others link it to rumours that chemical weapons were used during the war and might now be causing NS, describing it as ‘part of war machinery that the Museveni government is using as part of the genocide project to eliminate Acholi as a community’ (AT 27 August 2012). Some respondents accused leaders that they are now trying to cover this up and purposely keep quiet about the syndrome. During a conversation with a political activist, she wonders out loud: ‘Could there have been any attempt to not bring this disease to light?’.

When the frequency of media reports on NS increased at the end of 2011, people found themselves in a more stable environment. A better infrastructure had come into existence to disseminate information to the public and to ventilate (critical) opinions; there was more space to talk about NS and to think about the position of the Acholi within Uganda. An important factor is that regional media-houses were much stronger during this time; Kitgum radio-station *Mighty Fire* was for example established in 2008 and the regional newspaper *AT* came into existence in 2010. This is illustrative of how form and content go hand in hand; how networks grow out of ideas and matter. According to respondents in Kitgum, media played a large role in drawing attention to NS and many claim that local media-houses were the first to initiate action for the affected families. A media-representative in Kitgum mentions that attention to the syndrome increased after a local radio station invited a group of parliament members in September 2011 to visit the affected area. Another radio show on NS was also aired in Kitgum during the same month. While explaining the purpose of this show, the presenter tells his audience; ‘We think it is important to come here today to share what suffering is inflicting your homes (...) so that the whole world can hear’. Later on in the show an interviewed local leader states; ‘*Mighty Fire* should voice our concern out there, so that people with this disease start receiving help (...). Voicing our concerns should be the number one issue’ (*Mighty Fire* FM, 30 November 2011).

This local attention indeed coincides with the onset of increased media attention to NS on a national level. Thereby the Women MP of Kitgum (member of an opposition party) plays an important role as strong vocal person. She is cited in many newspaper articles on NS and gained a lot of media attention when she decided to transport a group of children with nodding symptoms from Kitgum district to the national referral hospital in Kampala, because ‘she was not convinced that enough studies had been done’ (NV 7 March 2012). Respondents in northern Uganda refer to this event as the time the syndrome came into the (inter)national spotlight. Although it is difficult to pinpoint the exact reasons why NS rose up as a media topic in late 2011, improved infrastructure, the development of more powerful media houses, a strong vocal person and increased stability after the war are likely contributing factors.

Figure 4 shows that after a peak in mid-2012 the media-interest in NS seems to decrease. Cohen (2002: 1) argues that the object of a moral panic can be quite novel and suddenly appear in the (media) limelight, after which the panic sometimes

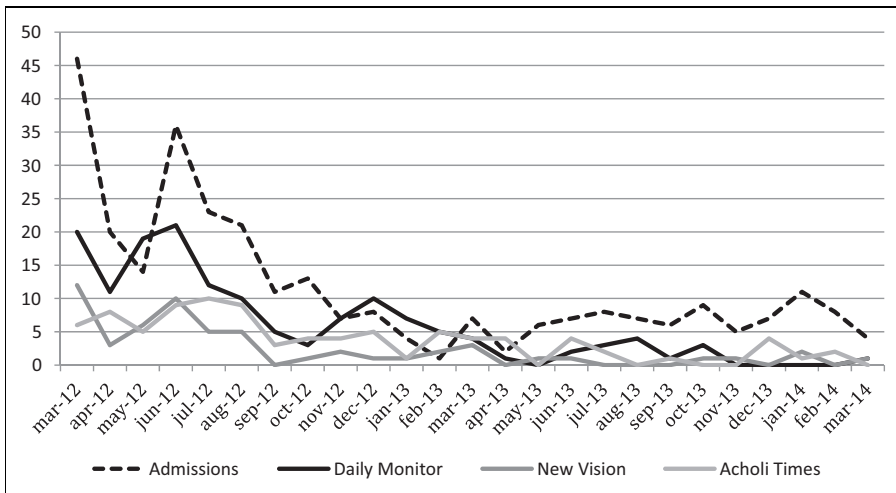
'passes over and is forgotten, except in (...) collective memory'. Although the topic of NS did not totally disappear from newspaper reports, the amount of articles mentioning the syndrome went down and people in northern Uganda are not heard talking about NS as often as before. Perhaps this can be explained by the fact that no new insights into the cause or cure have been gained over the past years. New cases of NS continue to be reported by the community, but seem rare and some doubt exists over whether these reflect truly new cases. In addition, anxiety over the illness has calmed, since it doesn't spread as fast as people initially feared and scientist are convinced that it's not contagious. Especially for people living in other parts of the country, fear of catching NS has diminished and thereby identification possibilities with its victims also decreased. Another explanation for the decrease in media attention came up during interviews in northern Uganda; affected families and health workers were reportedly told not to share information on the syndrome with journalists (see also: 'Mulago, police block media accessing patients' DM 5 March 2012). Secrecy and silence feed suspicion. Some respondents complained about political pressure and feared punitive measures when talking about NS. During an interview, a government employee mentioned that indeed only certain spokespersons were appointed to give out information about NS, in order to prevent false information, exaggeration and politicking (thereby automatically making it more difficult to make (negative) statements about government's role in NS). The respondent suggested that some people might have misinterpreted this initiative and completely banned -or even punished - talking about the syndrome in public. According to a report from Human Rights Network for Journalists-Uganda, local leaders in Kitgum district 'forced journalists out of a meeting that was discussing the nodding disease' and there was pressure to 'suspend two journalists from the radio' in September 2012 (HRNJ-Uganda, 2013: 30). After this incident a local radio station and journalists were accused by the district of 'hosting political discussions or campaigns (...), by creating incitement (...) civil unrest, causing alarm and despondency among the general population of Kitgum district to the extend of courting urban terrorism' (AT 24 September 2012). In response to these allegations the Kitgum District Media Practitioners' Association (KIMEPA) decided to suspend any coverage of the district chairperson for his alleged persistent attacks on the media. This action illustrates the sensitive relationship between media, politics and NS, arguably because the syndrome is linked to a region that is often associated with political opposition, marginalization and conflict. As stated before, narratives on NS often include narratives on conflict and a perceived lack of political support.

All in all, national interest in the syndrome is going down. Other news-items have entered the stage, now receiving media-attention and thereby pushing NS into the background. Newspaper DM reports: 'While a few months back it was a national issue, today it's been relegated to the bottom of our priorities, only resurrecting when it claims life' (6 May 2012). The media-narrative of NS illustrates the sudden rise and fall of illness in public discourse.

## The power of media

It's an early morning in 2013 when the usual stream of patients arrive at the NS treatment centre, this time encountering an empty out-patient department and no medical doctor to see them. The attending nurse is careful in her moves. She tells me that she wants to inform the patients that there is no doctor available at the moment. On the other hand she emphasises the need for sensitivity and the role of media as a powerful platform for complaints. She argues: 'In two or three days they can go to the radio. You have to be very careful with them!', thereby referring to previous occasions when the hospital was shown in a bad light in media reports related to NS. This incident illustrates the controlling factor of media and its connection to power; i.e. its ability to influence behaviour or events. Media can create as well as reflect reality (Le Roux, 2002). Language products stand in dialectic relation to social structure and linguistic-communicative events can be formative for larger social processes or structures (Blommaert and Bulcaen, 2000: 452). For example, a group of Islamic sheiks decided to travel all the way from Kampala to Kitgum (8-hour bus ride) after hearing about NS in news-reports, in an attempt to heal the children with Islamic doctrine. Another occasion in which the power of media was addressed, occurred during a meeting of Christian leaders. While organizing a NS prayer event, one of the invited guests remarked that it would be good to have recording devices on the days of prayer, because 'that is how you make the world aware of what is taking place'. After heart-breaking pictures appeared in newspapers, women in Kampala – as mentioned earlier – tied themselves to trees (DM 8 March 2012). Media can be used to control, to punish and reward and work as a watchdog of community wellbeing.

Over the past few years, media sent out critical reports on the lack of involvement of national leaders in response to the syndrome, thereby putting pressure on stakeholders (Ministry of Health in particular) to act in a more visible way. Critique from opposition politicians also frequently appeared in the newspapers. While discussing NS during a parliamentary meeting, MP Byabagambi states; 'We (politicians) hold a lot of power. When we talk in public, the public tends to believe what we say because of the power we hold (. . .) When we talk, whether on radio or to the press, it is very serious because of the power we hold' (PoM, 2012b). Kleinman et al. argue that 'what we represent and how we represent it prefigure what we will, or will not, do to intervene' (1997: xiii), thereby emphasising the way in which media can shape behaviour. The policy agenda must react to the prominence of issues in the media and public agendas. Sometimes the conditions of extreme public emotion can cause shifts in the views of opinion-leaders and policymakers (Cricher, 2002). Immediately after NS appeared into the (inter)national limelight – years after the symptoms were noticed for the first time – changes became visible in northern Uganda. In February 2012 – after a first peak in NS media reports – a NS governmental response plan was developed, followed by the construction of three NS-treatment centres in northern Uganda in March. In May 2012 – during a second peak in media reports – two lawsuits were filed blaming



**Figure 5.** Monthly number of admissions at the NS-ward since its opening in Kitgum hospital and number of articles mentioning nodding syndrome in three newspapers, March 2012–March 2014.

government negligence. In July the first international conference on NS was organized in Kampala and in November 2012 the launch took place of a governmental aerial spraying program against flies associated with the syndrome. The upcoming of NS as a topic in media indeed precluded the large-scale undertaking of action regarding NS, illustrating the relationship between language, power and social action. Figure 5 presents the monthly number of new admissions at the NS-treatment centre in Kitgum town since its opening in March 2012<sup>10</sup> and the amount of newspaper articles mentioning NS in the three different newspapers.

The graph shows that both media attention and the number of monthly admissions at the treatment centre declined over time and follow a similar pattern. It is plausible that the decline in media-coverage has affected help-seeking behaviour or vice versa. The consistent cries for help and attention in media reports (using moral sentiment to mobilize support for social action) encouraged different actors to respond to the NS situation – among other things to prevent a bad reputation. At the height of media attention in 2012, a nodding diagnosis often involved aid-distribution (food, blankets, etc.) by government and NGO's. This might have encouraged some people to seek out the 're-imaging of their condition so that they can obtain the moral as well as the financial benefits of being ill' (Kleinman et al., 1997: 10). Health workers in northern Uganda recount that many parents claimed to have NS-afflicted children at the beginning of the media-attention -and peak of humanitarian aid-, although medical investigations often didn't verify the syndrome. Currently less media-attention and (consequently?) less aid-items are being given to affected families, which is perhaps reflected in the decreased number of admissions at the NS treatment center.<sup>11</sup>

It seems clear that a relationship exists between media coverage on NS and illness-management: media reports encouraged healers (and international researchers!) to travel to the affected areas, media put pressure on politicians and NGO's to undertake action, media spread information about the syndrome and treatment possibilities and motivated local families to look for help. Media reports could either be written in reaction to events taking place (e.g. more admissions at the NS-treatment centers elicit more media reports) or the other way around (e.g. more patients seek help at the centers after the occurrence of media reports on NS). Either way, it points to the connection between language and social structure and emphasizes the importance of looking at social circumstances under which a text or discourse is produced and consumed.

## Conclusion

Nodding syndrome has been a hot topic in public discourse over the past four years in Uganda. Although complaints about inadequate illness-management on the African continent are not new and the narratives of suffering concerning NS resemble other stories about illness, the symptoms attracted a lot of attention and 'the body in sickness' became linked to political issues of marginalization, power asymmetries and conflict.

In 2011 – more than a decennium after the symptoms had first been reported – local media houses in Acholi sub-region started spreading information on NS, in response to concerns among the local public and dissatisfaction about perceived negligence. Pressure groups and politicians became involved and required a response from the government. Thereby they attracted a wide public and the issue started being discussed on a national level. In this paper I have argued that NS mainly gained momentum because of the political connotations of the affliction; the idea that national leaders had – again – failed to offer adequate protection to the – already vulnerable – Acholi people. Within a short time, politicians and Acholi-spokespersons dominated the debate on NS (this 'politicizing' often frustrating affected families) and sentiment was used in moving the public, playing out political battles and putting pressure to change policy. Thereby NS was presented in a stylized and stereotypical fashion. It seems that not only the affliction itself was at stake, but the relationship between government and other institutions and groups; both the perceived neglected and suffering status of Acholi, and the dissatisfaction about the national policy of (dis)unity in Uganda played a large role. While discussing NS as a health threat, the other two issues were constantly present – and arguably even more important in the debate. The components of the discussion included more than issues of health; violence, inequality and neglect were being incorporated into narratives on NS and the topic assumed prominence at the level of policy makers, media and the public. This resulted in the call for measures to deal with the problem, to which parliament responded by putting up programs targeting NS. After months passed by without new input, media attention to NS declined. In northern Uganda,

people also don't talk about the syndrome as often as before. Perhaps the aims of the 'media hype' have been achieved; the acknowledgement of the affliction, venting critique on current leadership, gaining attention for the neglected and suffering status of Acholi, and the implementation of programs regarding NS. Nevertheless; much-wanted answers to questions about its cause and cure have not come up.

In this article I aimed to reconstruct the media-frame of NS as it appeared in Ugandan newspapers by exploring how different networks come together to act as a whole in the conceptualization of NS. I have illustrated how the establishment of new media institutions, news ownership, (the ending of) conflict, perceived political negligence, strong vocal persons, physically ill-looking children, the absence of a known cause or cure, donor expectations and mediums such as YouTube and newspapers can all be seen as related elements in a network surrounding NS. Thereby not only the role of human beings is important, but also the ability of (media) technologies and other non-human actors. The narratives on NS illustrate the rise and fall of an affliction in public discourse and demonstrate the role of media – influenced by social and cultural context – in negotiating which narrative is being accessed. 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 might have happened during war. Hence, instead of paying attention to the 'product' nodding syndrome, it is important to focus on processes of creation, in which media – among a variety of other actors – plays an active and important role.

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### **Notes**

1. Three *New Vision*, one DM and four AT articles are excluded because they are not available for analysis (NV), focus solely on cases in South Sudan (DM) or are a duplication of reports from other news-sources such as CNN and IRIN (AT).

2. NS prevalence rate is mentioned in 47 percent and mortality rate in 41 percent of the selected articles. Only reports mentioning the total affected number of people in Uganda were taken into account in this analysis and when several amounts were mentioned in the same article, the highest quoted number was used.
3. Article contains at least one (neutral, positive or negative) remark about politics in relation to NS, e.g. Ministry of Health opens treatment centres.
4. Article contains at least one negative remark about politics in relation to NS, e.g. government has neglected nodding syndrome.
5. Article contains at least one remark about social effects of NS, e.g. children dropping out of school due to the symptoms, parents not being able to work on the field because of taking care of their children.
6. Article contains at least one remark about physical effects of NS, e.g. stunted growth, seizures, mental retardation, saliva drooling.
7. Article contains at least one remark about deaths resulting from NS, e.g. describing NS as a 'fatal illness'.
8. Article contains at least one remark about NS being a mystery, e.g. mentioning the unexplained cause or cure.
9. Affliction as a condition of great distress or suffering
10. Data based on hospital report
11. Other plausible reasons for this decline should also be mentioned, such as; a decrease in anxiety over transmission; no new medical insights into cause and cure; more children receiving biomedical treatment (anticonvulsants); no new reported cases; and a perceived lack of medical personnel and dedicated care at the hospital ward.

## References

- Acayo C and Mnjama N (2004) The print media and conflict resolution in Northern Uganda. *African Journal on Conflict Resolution* 4(1): 27–43.
- Acholi Times (AT) (2014) About us. Available from: [www.acholitimes.com/cultureacholi/index.php/about-us](http://www.acholitimes.com/cultureacholi/index.php/about-us) (accessed 5 June 2014).
- African Media Barometer (2012) *The First Home Grown Analysis of the Media Landscape in Africa. Uganda 2012*. Windhoek: Friedrich-Ebert-Stiftung.
- Agamben G (1998) *Homo sacer, translated by Daniel Heller-Roazen*. Stanford, Calif.: Stanford University Press.
- Angucia M (2010) *Broken citizenship. Formerly abducted children and their reintegration in northern Uganda*. PhD Thesis, University of Groningen, the Netherlands.
- Baines E (2010) Spirits and social reconstruction after mass violence: rethinking transitional justice. *African Affairs* 109(436): 409–430.
- Blommaert and Bulcaen C (2000) Critical Discourse Analysis. *Annual Review of Anthropology* 29: 447–466.
- Branch A (2012) How civilians became targets: a short history of the war in Northern Uganda. In: Taub (ed.) *Beyond Kony 2012: Atrocity, Awareness, & Activism in the Internet Age*. Online: Leanpub. Available at: <https://leanpub.com/beyondkony2012> (accessed 5 June 2014).
- Bukuluki P, Ddumba-Nyanzi I, Kisuule JD, et al. (2012) Nodding Syndrome in post conflict northern Uganda: a human security perspective. *Global Health Governance* VI(1): 1–17.
- Canetti E (1984) *Crowds & Power*. New York: Macmillan FSG.

- Centers for Disease Control and Prevention (CDC) (2011) *Coordinated campaign against nodding syndrome in Uganda*. Available from: [www.cdc.gov/globalhealth/stories/noddingssyndrome.html](http://www.cdc.gov/globalhealth/stories/noddingssyndrome.html) (accessed 21 March 2012).
- Cohen S (2002) *Folk Devils and Moral Panics: The Creation of the Mods and Rockers*, 3rd ed. London: Routledge.
- Comaroff J (2010) *Beyond Bare Life: AIDS, (Bio)Politics, and the Neoliberal Order*. In: *Morality, Hope and Grief. Anthropologies of AIDS in Africa*. New York: Berghahn Books.
- Critcher C (2002) Media, Government and Moral Panic: the politics of paedophilia in Britain 2000-1. *Journalism Studies* 3(4): 521–535.
- Dann G (1998) *The Dark Side of Tourism*. Etudes et Rapports, Série L, Vol. 14. Aix-en-Provence: Centre International de Recherches et d'Etudes Touristiques.
- Darnton and Kirk (2011) *Finding Frames: New ways to engage the UK public in global poverty*. London: Bond for international development.
- Derluyn I, Broekaert E, Schuyten G, et al. (2004) Post-traumatic stress in former Ugandan child soldiers. *Lancet* 363: 861–863.
- Dhossche D and Kakooza-Mwesige A (2012) Nodding syndrome in Ugandan children and adolescents: ménage a trois of epilepsy, (Late-Onset) 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.
- Donnelly J (2012) CDC planning trial for mysterious nodding syndrome. *The Lancet* 379: 299.
- Edwards J (2012) Nodding disease confounds clinicians. *Canadian Medical Association Journal* 184(11): 558–559.
- Gardner, Dew, Stubbe, et al. (2011) Patchwork diagnoses: The production of coherence, uncertainty, and manageable bodies. *Social Science & Medicine* 73: 843–850.
- Good BJ (1994) *Medicine, rationality, and experience. An anthropological perspective*. Cambridge: Cambridge University Press.
- Harlacher T (2009) *Traditional ways of coping with consequences of traumatic stress in Acholiland*. PhD Thesis, University of Freiburg, Switzerland.
- Human Rights Network for Journalists-Uganda (HRNJ Uganda) (2013) *Press Freedom Index Uganda 2012. No Gains. Press Freedom still Fragile*. Kampala: HRNJ Uganda with support from Open Society Initiative for Eastern Africa (OSIEA).
- Jenkins J, Jessen H and Steffen V (2005) Matters of life and death. The control of uncertainty and the uncertainty of control. In: Steffen, Jenkins and Jessen (eds) *Managing Uncertainty. Ethnographic Studies of Illness, Risk and the Struggle for Control*. Copenhagen: Museum Tusulanum Press.
- Jilek WG and Jilek-Aall LM (1970) *The problem of epilepsy in rural Africa: 'Kifafa' in a Tanzanian tribe*. Paper presented at the Colloque de l'Épidémiologie de l'Épilepsie en Afrique, Marseille, 3 September 1968. *Transcultural Psychiatry* 7: 43–48.
- Kiwanuka-Tondo J, Albada KF and Payton FC (2012) Media ownership and news framing: an analysis of HIV/AIDS coverage by Ugandan press. *African Journal of AIDS Research* 11(4): 361–371.
- Kleinman A (1980) *Patients and healers in the context of culture: An exploration of the borderland between anthropology, medicine, and psychiatry*. Berkeley: University of California Press.

- Kleinman A, Das V and Lock M (eds) (1997) *Social suffering*. California: University of California Press.
- Krinsky C (2013) Introduction: The Moral Panic Concept. In: Krinsky (ed.) *The Ashgate Research Companion to Moral Panics*. Farnham: Ashgate Pub Co.
- La Fontaine J (1998) *Speak of the Devil: Tales of Satanic Abuse in Contemporary England*. Cambridge: Cambridge University Press.
- Le Roux (2002) Unsung heroines: Media reflections of the social conflict in South Africa. *African and Asian Studies* 1(4): 349–366.
- Ministry of Health Uganda (2012) (MoH) *Integrated Response Plan for the Control of the Nodding Disease Syndrome in Acholi Sub-region, Uganda. January 2012 to December 2014*. Kampala: Ministry of Health.
- Musisi S, Akena D, Nakimuli-Mpungu E, et al. (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.
- Nation Media Group (NMG) (2013) *Annual report & financial statements*. Nairobi: Nation Media Group Limited.
- Nyungura JL, Akim T, Lako A, et al. (2011) Investigation into the Nodding syndrome in Witto Payam, Western Equatoria State, 2010. *Southern Sudan Medical Journal* 4(1): 3–6.
- Opira Morise Kato (2014) Song: ‘Can lobo’. Available from: [www.ugandanrecordings.com/opira-morise-kato-can-lobo/](http://www.ugandanrecordings.com/opira-morise-kato-can-lobo/) (accessed 10 July 2014).
- Parliament of Uganda (PoU) (2012a) eNewsletter May 14, 2012–May 18, 2012. Vol 5, No 30. Available from: [www.parliament.go.ug/enewsletter/index.php/home/view/133](http://www.parliament.go.ug/enewsletter/index.php/home/view/133) (accessed 21 April 2013).
- Parliament of Uganda (PoU) (2012b) Parliament meeting Tuesday, 8 May 2012. 2.35 p.m. in Parliament House, Kampala. Available from: [www.parliament.go.ug/hansard/hans\\_view\\_date.jsp?dateYYYY=2012&dateMM=05&dateDD=08](http://www.parliament.go.ug/hansard/hans_view_date.jsp?dateYYYY=2012&dateMM=05&dateDD=08) (accessed 5 June 2014).
- Scheper-Hughes M and Lock MM (1987) The mindful body: A prolegomenon to future work in medical anthropology. *Medical Anthropology Quarterly* 1(1): 6–41.
- Sejvar JJ, Kakooza AM, Foltz JL, et al. (2013) Clinical, neurological, and electrophysiological features of nodding syndrome in Kitgum, Uganda: an observational case series. *Lancet Neurol* 12: 166–174.
- Shanahan EA, McBeth MK, Hathaway PL, et al. (2008) Conduit or contributor? The role of media in policy change theory. *Policy Science* 41: 115–138.
- Spencer PS, Vandemaële K, Richer M, et al. (2013) Nodding Syndrome in Mundri county, South Sudan: environmental, nutritional and infectious factors. *African Health Sciences* 13(2): 183–204.
- Stone P and Sharpley D (2008) Consuming dark tourism: a thanatological perspective. *Annals of Tourism Research* 35(2): 574–595.
- Stout PA, Villegas J and Jennings NA (2004) Images of mental illness in the media: Identifying gaps in the research. *Schizophrenia Bulletin* 30(3): 543–561.
- Tumwine, Vandemaële, Chungong, et al. (2012) Clinical and epidemiological characteristics of nodding syndrome in Mundri County, southern Sudan. *African Health Sciences* 12(3): 242–248.
- Tversky A and Kahneman D (1973) Availability – Heuristic for judging frequency and probability. *Cognitive Psychology* 5: 207–232.

- Van Bommel K, Derluyn I and Stroeken K (2014) Nodding Syndrome or Disease? On the conceptualization of an Illness-in-the-making. *Ethnicity & Health* 19(1): 100–118.
- Van Dijk R (2001) 'Voodoo' on the doorstep: Young Nigerian prostitutes and magic policing in the Netherlands. *Africa* 71(4): 558–586.
- Wahl OF (1995) *Media Madness: Public Images of Mental Illness*. New Brunswick, NJ: Rutgers University Press.
- Whitmore (2011) Whiteness made visible: A theo-critical ethnography in Acoliland. In: Scharen and Vigen (eds) *Ethnography as Christian Theology and Ethics*. London: Continuum International Publishing Group.
- Winkler AS, Friedrich K, König R, et al. (2008) The head nodding syndrome – Clinical classification and possible causes. *Epilepsia* 49(12): 2008–2015.
- World Health Organization (2012a) (WHO) *Uganda: Nodding disease. Situation as of 14 February*. Available from: [www.afro.who.int/en/clusters-a-programmes/dpc/epidemic-a-pandemic-alert-and-response/outbreak-news/3548-uganda-nodding-disease-situation-as-of-14-february-2012.html](http://www.afro.who.int/en/clusters-a-programmes/dpc/epidemic-a-pandemic-alert-and-response/outbreak-news/3548-uganda-nodding-disease-situation-as-of-14-february-2012.html) (accessed 21 March 2012).
- World Health Organization (2012b) (WHO) *Uganda adopts a multi-sectoral response to nodding syndrome*. Press Release No 1/2012, Kampala 2 March 2012.
- World Health Organization (2012c) (WHO) *International Scientific Meeting on Nodding Syndrome. Meeting Report*. UKaid, CDC, The Republic of Uganda, WHO, Kampala 30 July–1 August 2012.

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