

# The enigmatic nodding syndrome outbreak in northern Uganda: an analysis of the disease burden and national response strategies

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## Abstract

To date, the cause of nodding syndrome (NS) remains unknown; however, efforts continue to establish risk factors and optimal symptomatic treatments. We documented the burden and national response strategies including involvement of key stakeholders in the management of the NS epidemic in order to inform future interventions against epidemics of undetermined aetiology. Data were collected through semi-structured interviews with selected leaders in the affected districts and at the Ministry of Health, and through review of documents. We participated in and analysed the proceedings of the first international scientific conference on NS held in Kampala in August 2012. We then analysed the chronology of the NS notification and the steps undertaken in the response plan. Over 3000 children have been affected by NS in northern Uganda; with an estimated case fatality of 6.7%. The first cases of NS were reported in 1997 in internally displaced people's camps in Kitgum district; however, response efforts by the Ministry of Health and partners towards understanding the disorder and establish management only commenced in 2009. Key strategies in response to the NS epidemic have included formation of a national and district task forces, development of training manual on NS and training of primary healthcare professionals on case diagnosis and clinical management, establishment of treatment and rehabilitation centres, surveillance and promotion of researches to further inform management of the syndrome.

**Key words:** burden, epidemic response strategies, nodding syndrome, northern Uganda

## Key Messages

- The nodding syndrome was first recognized in Uganda in 1997; however, fully pledged national response program against the syndrome only commenced in March 2012.
- Over 3000 children have been affected by the nodding syndrome epidemic in northern Uganda, with an estimated case fatality rate of 6.7%.
- Key response interventions undertaken to manage nodding syndrome have included formation of a national and district task forces, development of health workers training manual and training of primary care health workers on management of the disease, establishment of treatment and rehabilitation centers for the provisions of symptomatic medical treatment, nutritional support and rehabilitation of the affected children, and implementation of researches towards understanding nodding syndrome.

## Introduction

Nodding syndrome (NS) is an emerging debilitating disorder of unknown aetiology. It is characterized in its early course by repetitive forward dropping of the head often in association with feeding and cold weather (Wadman 2011; CDC 2012; Sejvar *et al.* 2013) and later by epileptiform seizures, neurological and cognitive decline and stunted growth (Lacey 2003; Winkler *et al.* 2008; Nyungura *et al.* 2011; Wasswa 2012; Sejvar *et al.* 2013). A nodding syndrome-like disorder was first reported in Tanzania in the 1960's (Jilek 1964) and was later described in Liberia (Goudsmit and van der Waals, 1983), South Sudan (Lacey 2003; Nyungura *et al.* 2011) and more recently in Uganda (Kaiser *et al.* 2009; Donnelly 2012; Edwards 2012; Wasswa 2012; Williams 2012; Sejvar *et al.* 2013).

The aetiology of NS remains unknown (Wilmshurst *et al.* 2014) although the disorder has been associated with infections with *Onchocerca volvulus* (Ov) (Kaiser *et al.* 2009) because of the observed concurrence of heavy loads of infection with the nematode among cases of NS as compared with controls (Lacey 2003; Winkler *et al.* 2008; Kaiser *et al.* 2009; Nyungura *et al.* 2011). However, the pathophysiological mechanism by which the nematode may cause the apparently neurologic disorder is only speculative. The syndrome has also been associated with malnutrition, vitamin B6 deficiency (Makumbi 2011; Nyungura 2011; Donnelly 2012) and epilepsy (Kipp *et al.* 1996; Sejvar *et al.* 2013). The NS outbreak in Uganda has affected over 3000 children aged 5–15 years in the northern districts of Kitgum, Pader, Lamwo and Gulu (WHO & MOH 2012a; MOH 2012d).

The first report of the existence of the NS in Kitgum district dates back to 1997 (Iyengar *et al.* 2014; Wilmshurst *et al.* 2014). However, reports from the Uganda Ministry of Health (MOH) suggest that the syndrome was first detected in 2009 (Wadman 2011; MOH, 2012b; Wasswa 2012). Therefore, the actual point of recognition of the epidemic remains uncertain. The NS outbreak was initially reported in the three districts of Kitgum, Pader and Lamwo but later involved other districts in the northern region including Gulu, Amuru and Lira. The number of affected children increased steadily through the year 2000 to a peak about 2008–9 then started to decline. By end of 2013, there were no new cases of NS reported in all the listed affected districts in northern Uganda (MOH 2014). This sharp decline has been attributed to the aerial spray of black flies along the rivers in the affected region and the mass treatment of children with ivermectin to reduce the load of microfilariae of *Onchocerca volvulus* which are transmitted by the black flies (Coblunders *et al.* 2014).

This article analyses the burden and documents the processes of NS management including the genealogy of the outbreak in order to inform effective planning and management of the condition as well as guide response to future epidemics.

## Methods

### Study design

This was an observational and analytic study based on data collected through semi-structured interviews and secondary data analysis of documents pertaining to the recognition, notification, response and treatment of the NS.

### Data collection procedures

The study was conducted during August 2012 to December 2013. Data collection involved mainly use of qualitative techniques and

review of records. We attended various national and district task forces and planning meetings in Kampala at the MOH and the affected districts, respectively, and subsequently reviewed records of such meetings to extract data on NS recognition, notification and response strategies. Qualitative data were collected through semi-structured interviews with key stakeholders at the Ministry of Health and selected local political leaders and health officials in the affected districts of Kitgum and Pader. The key informants included the district local council five chairpersons, secretaries for health, and the district health and vector control/entomology officers of Kitgum and Pader districts. We participated in and carried out analysis of proceedings of the First International Scientific Conference on NS held in Kampala, Uganda in August 2012. We reviewed and analysed technical reports on NS recognition and management that were publicly available in key government departments, ministries, and non-governmental organizations including the district health departments, MOH and Uganda Red Cross Society respectively. We also searched and reviewed published and grey literature on NS in Uganda and other sub Saharan African countries.

### Data management and analysis

A database of relevant documents was formed and data were analysed manually using content analysis techniques. Themes and categories were derived and consensus reached through discussions among the authors. We documented the steps and processes of public health and clinical responses, and identified academic institutions and development partners that participated in the national response to the NS epidemic in northern Uganda from August 2009 to December 2013, inclusive. We abstracted information on the specific roles and resources provided by each stakeholders involved in the NS epidemic response.

## Results

### Burden of NS

The NS has affected more than 3000 children with over 200 deaths in the districts of Kitgum, Pader and Lamwo in northern Uganda (Table 1).

### Notification and confirmation of NS epidemic

Review of documents including minutes of meetings, technical reports at the MOH and published data, and discussion with officials in Kitgum, Pader and Lamwo districts revealed that the first cases of the syndrome were reported from Amida internally displaced persons (IDP) camp, in Kitgum district between 1997 and 2003 (Iyengar *et al.* 2014; Wilmshurst *et al.* 2014). Although the disorder was first reported in the 2009–10 Ministry of Health annual reports when up to 1876 children were already affected (MOH 2010), the steps towards characterization of the syndrome and search for

**Table 1.** Burden of nodding syndrome in northern Uganda

District	Number of new cases of Nodding Syndrome and deaths	
	Affected children, Number (percentages)	Death, Number (percentages)
Kitgum	1278 (41)	98 (58)
Lamwo	328 (11)	6 (4)
Pader	1488 (48)	66 (39)
Total	3094 (100)	170 (100)

Sources: MOH (2012d).

aetiology became apparent in 2009 (Table 2). The first investigation by the MOH and partners on the syndrome was in 2007 when a team of experts visited and assessed children in the villages of Alune, Panykel and Pajimo in Kitgum district. The team considered variants of epilepsy and or post-traumatic stress disorders (PTSD) as possible causes, and recommended further investigations to characterize the strange disease and establish its aetiology (MOH 2012d).

Further investigations by MOH and partners in March and August 2009 confirmed the existence of a new disorder and noted that the disease probably started in 2003 when most of the northern Uganda population had moved to IDP camps and that the disorder predominantly affected children aged 5–15 years and termed it a 'Progressive Cerebro-Musculo-Skeletal Epileptogenic Syndrome' of unknown aetiology (MOH 2012d).

### Key response interventions and strategies

The Government of Uganda adopted a multipronged and collaborative strategy to respond to the NS outbreak by formulating a structured response plan. The various stakeholders (Table 3) formed multi-sectoral teams at the national and district levels to investigate and characterize the disorder and mitigate its impact on individuals and communities in the affected districts.

The implementation of the response plan was structured into two phases (Table 4):

1. Phase one: The emergency phase (January–December 2012) involved screening and case detection, research into cause and effective medicines, nutritional assessments, setting up treatment centres and resource mobilizations. During this phase, strategic activities undertaken included:
  - Development of health workers manual for management of NS and training of primary healthcare workers in the early detection, surveillance, diagnosis and symptomatic management of NS was done for the districts of Kitgum, Pader and Lamwo and later for the health workers in the districts of Gulu, Amuru, Nwoya, Oyam and Lira.
  - Active surveillance by trained primary healthcare professionals to identify and record all suspected cases of NS. This was spearheaded by the World Health Organization and the Uganda Ministry of health.
  - Organization of the first international scientific conference on NS to share experience and harmonize key definitions and terms to aid research and management of the syndrome.
  - Formation of task forces and regular meetings of the national and district task forces to review progress, identify loopholes and forge way forward in mitigating impact of the disorder.
  - Community mobilization, health education on NS and psychosocial support to affected families by government, NGOs like Uganda Red Cross Society.
  - Establishment and opening the NS treatment and rehabilitation centers.
  - Implementation of several researches to aid understanding of the disorder and inform treatment and prevention.
2. Phase two: The post emergency phase (January 2013–December 2014), focused on consolidation of phase one achievements and rehabilitation. The main activities included:
  - Continued case management and psychosocial support,
  - Active surveillance and researches into causes and best practice management strategies,

- Biannual mass treatment with ivermectin and aerial spray of black flies along the main rivers in the affected districts,
- Social mobilization and health promotions,
- Initiation and support of livelihood improvement programs and setting up special needs schools and rehabilitation services.

Several research initiatives have been instituted and implemented by institutions including the Centres for Diseases Control and Prevention (CDC), World Health Organization (WHO), Gulu University, Makerere University, MOH and Mulago and Butabika national referral hospitals on various aspects of NS. These studies have included search for the aetiology and risk factors, community beliefs and knowledge, clinical presentations and staging of NS and nutritional assessments.

### Key stakeholders involved and their roles

The response to the NS epidemic has involved the participation of several key stakeholders that have contributed to the investigations and management of the outbreak including Uganda Ministry of Health, Office of the Prime Minister, World Health Organization (WHO), Centre for Disease Control (CDC) Atlanta, Georgia, USA, the National referral hospitals, public Universities and research institutions and the affected districts in the northern region (Table 3).

The MOH and WHO coordinated and engaged in epidemiologic surveillance and geographical positioning system (GPS) mapping of NS. Makerere University College of Health Sciences, Mulago and Butabika national referral hospitals were involved in the development of health professional training manual, training of health professionals on NS management and rehabilitation of the affected children.

The districts have been involved in community mobilization, case identification and reporting. Treatment and rehabilitation centres were established in the districts and involved in symptomatic treatment of NS and associated disorders, provision of nutritional support and rehabilitation of affected children and families (Table 4).

### Discussion

In this study, we document the case fatality of NS and the processes and interventions undertaken in the framework of the national response strategies to the NS epidemic in northern Uganda. The Uganda national response to the NS involved replicable structured approaches including recognition and reporting of a strange disease by community/primary healthcare workers and local leaders to the district health departments, notification of the ministry of health (MOH) by the districts, followed by a series of investigations carried out by the MOH and partners which culminated into confirming the presence of a novel disorder of public health importance. Subsequently, the MOH involved several and multi-sectoral stakeholders to form a national task force (NTF) and district task forces that formed the bedrock for the responses including planning, capacity building, mobilization of resources and implementations of clinical and public activities. It is anticipated that these processes can inform responses to future epidemics, thereby shortening response time and limit morbidity and mortality.

By end of 2013, the NS had affected over 3000 children aged 5–15 years in the northern Uganda districts of Kitgum, Pader and Lamwo *Iyengar et al. 2014*. The NS has claimed over 150 lives of children in northern Uganda (MOH 2012d) with an estimated case fatality rate (CFR) of 6.7% (WHO 2012b; MOH 2012c). Reasons

**Table 2.** Notification and reporting of nodding syndrome

Event Date	Event	Source of information	Findings		Recommendations; actions taken
			Age affected	Features in affected population	
1997	First cases recognized in Kitgum	Kitgum district leaders, minutes of meetings	3–18 years	Excessive sleepiness on sight of food	Amida, Akwang District health department to investigate and then inform MOH
March 2005	First cases observed and reported to MOH	Foltz, 2013; Dowell, 2013 Documents review and discussions with Kitgum district leaders in March 2012	Children aged 3–18 years	Excessive sleepiness when presented with food; stereotypical forward movement of heads; small for age; stunted	Amida IDP; Kitgum district Report strange disease to MOH
March 2008	High Prevalence of epilepsy in Northern Uganda reported by MOH	MOH <sup>a</sup>			Kitgum, Pader, Lamwo Investigate and manage epilepsy
February 2009	Disease surveillance by MOH and partners	MOH <sup>a</sup>	3–18 years	Narcolepsy in children	National task force to investigate narcolepsy in children
March 2009	First team of experts from MOH to investigate strange disease	Document review, proceedings of NTF meetings and minutes, technical field reports at MOH <sup>b</sup>	Children age 5–15 years	post-traumatic stress disorder	Amida; Kitgum district Over 300 children in Kitgum district affected; MOH to intervene further in terms of investigations and management
August 2009	Official reporting to MOH by DHO Kitgum	MOH <sup>a</sup>	Children 5–15 years		
August 23rd–28th 2009	Second team of experts from MOH to investigate nodding disease	Document review, proceedings of NTF meetings and minutes, technical field reports at MOH <sup>b</sup>	Children <20 years; 260 children affected	Excessive sleepiness, head drooping, physical/mental retardation, stunting, seizures; probable Progressive Cerebral Muscular–Skeletal Epileptogenic Syndrome	Amida, Akwang, Alune, Panykel, Pajimo; Kitgum district and palabek gem in Lamwo district Developed working surveillance diagnosis for identification, and management plan; train health workers; further investigations and researches

DHO = District Health Officer, IDP = Internally Displaced Persons Camp, MOH = Ministry of Health, NTF = National Task Force.

Sources: <sup>a</sup> MOH (2012e); <sup>b</sup> MOH (2009).

**Table 3.** Key stakeholders involved and their roles

Stakeholder	Key roles
Ministries Ministry of Health (MOH)	Planning, investigations, resource mobilization, coordination, supervisions, training, quality control, research; formed the national task force (NTF), surveillance, establishment of treatment centres for nodding syndrome Aerial spray of black flies along rivers, biannual mass treatment of children with ivermectin
Office of Prime Minister (OPM)	Planning, resource mobilization, advocacy and coordination
Local Governments Kitgum district, Pader district, Lamwo district, Gulu district, Amuru district	Formed district task forces, implementation of action plans, surveillance and case definitions, treatment, rehabilitation, advocacy, nutritional support, treatment outreaches
Multilateral organizations/United Nations World Health Organization (WHO)	Planning, research, advocacy, funding research and scientific meetings, surveillance
CDC	Research, planning, advocacy, funding research and scientific meetings
DFID/UKaid	Planning, funding scientific meetings
Academic and Training Institutions Makerere University (College of Health Sciences, Institute for Social Research, Agriculture, Food Sciences and Technology, School of Veterinary Medicine) Gulu University Kyambogo University	Planning, training, researches, advocacy
National and Regional referral hospitals Mulago and Butabika national referral hospitals	Clinical investigations, diagnosis, and management of patients; rehabilitation; training of health workers
Gulu and Lira regional referral hospitals	Clinical care, rehabilitation, training and support supervisions of lower health units
Civil Society and Research Organizations AFENET	Research and epidemiological investigations
Uganda Red Cross Society	Advocacy, distributions of food and household supplies
Others (Members of Parliament, Media, Individual advocates and politicians)	Advocacy, mobilizations

for death have included drowning in water and getting burnt with cooking fire (Wadman 2011). The disease burden has been far greater than the epidemic reported in South Sudan in 2002 (Nyungura *et al.* 2011; Lacey 2003). The burden of NS on the affected communities includes the unrelenting and progressive nature of the disorder that ultimately leads to mental and physical retardation and often death if not treated. Further, the disease makes the affected households economically bankrupt owing to devoting long time caring for the sick child with limited time left for economic productivity/farming.

Although an earlier case series study in Uganda showed no durable improvement in children with NS (Sejvar *et al.* 2013), a more recent larger observational study done at the specialized NS treatment centers showed that NS children respond well and regain functional abilities when treated with anticonvulsants including sodium valproate (Idro *et al.* 2014). Similarly, durable improvements were also demonstrated with anticonvulsant treatment including carbamazepine and phenobarbitone in Tanzania (Winkler *et al.* 2014). NS may therefore be a condition that can be managed.

One of the first prevalence study on NS based on the WHO diagnostic criteria was carried out in March 2013 and showed a prevalence of 6.8 probable cases of NS per 1000 children (Iyengar *et al.* 2014). However, recent data from the Uganda MOH showed that there have been no documented new cases of NS throughout 2013 (MOH 2014). The lack of new cases of NS has been attributed to the mass treatment of children with ivermectin to reduce the human carriage of the microfilaria of *Onchocerca volvulus* and the aerial spray

of the black flies (that are vectors of the *Onchocerca volvulus*) along the main rivers in the affected districts (Colebunders *et al.* 2014).

In Uganda, the actual point in time when NS was first recognized remains unknown. Available published data suggest that the first cases were recognized in 1997 (Iyengar *et al.* 2014; Wilmshurst *et al.* 2014). Data from the MOH also show that the syndrome could have started to affect the children in the northern districts of Kitgum and Pader way back in 2003–4 when the population of these districts were still living in IDP camps and depending on food rations from the World Food Program (WFP) and other agencies (MOH 2012a; MOH 2012b). However, the MOH recognized NS as a national problem of public health importance only by about August 2009. NS apparently evolves slowly. This slow pattern of evolution could have contributed to the delayed recognition and reporting of the syndrome in Uganda. Similarly, recognition of the NS as a unique entity of public health importance in South Sudan also took quite some time (Lacey 2003, Nyungura *et al.* 2011; CDC 2012). Delay in outbreak recognition may also arise from a lack of case definition of the disorder either due to the novelty of the disorder or a missed opportunity by public health and epidemiology departments of nations where such disorders have earlier occurred to document diagnostic criteria and surveillance case definitions to allow rapid recognition of cases for routine reporting. To minimize circumstances of delayed reporting, a system of syndromic surveillance (Uscher-Pines *et al.* 2009) has been proposed where nations may use pre-diagnostic data and statistical algorithms to detect epidemics earlier than traditional surveillance would allow (May *et al.*

**Table 4.** Response interventions

Period	Response interventions	Achievements/tasks	Stakeholders
February–December 2012	Established diagnostic criteria for nodding syndrome	Screening, case definitions, surveillance	MOH, WHO, Makerere CHS, Mulago and Butabika hospitals
February–December 2012	Establishment of the national task force	Develop response plan, oversee implementation, coordinate response	MOH, WHO, OPM
January–December 2012 January–December 2012	Implementation of national response plan Phase 1: Emergency response phase	Case definition, epidemiologic surveillance and mapping affected regions, determination of disease burden, case detection and management, research (Risk factors or causes, community beliefs and knowledge, treatment), development of training manual and schedules, training of health workers, setting up NS treatment centres, nutritional and rehabilitation supports	MOH, WHO, CDC, Makerere CHS, Mulago and Butabika hospitals, Gulu University
January–February 2012	Development of health professionals training manual	Draft health professionals' training manual developed	Makerere University College of Health Sciences, Mulago hospital, Butabika hospital
March 2012	First training of health professionals, Kitgum district	60 health professionals at primary healthcare facilities trained on nodding syndrome and management	MOH, Makerere CHS, Mulago hospital, Butabika hospital, Gulu University
May 2012	Setting up treatment and rehabilitation centres for nodding syndrome patients	Three treatment and rehabilitation centres set up and officially opened by president of Uganda (Kitgum hospital, Atanga HC III, Padibe HC IV and Odek HC III)	MOH, OPM
2nd August 2012	First International Scientific Conference on nodding syndrome	Scientific Meeting held in Kampala. Nodding syndrome name harmonized, research agenda harmonized for Uganda, Tanzania and South Sudan	Organized and sponsored by MOH, CDC, WHO, DFID
10th September 2012	Second training of health professionals, Gulu district	60 health professionals trained on nodding syndrome and management	MOH, Makerere CHS, Mulago and Butabika hospitals
2013 January–2014 December	Phase 2: Post emergency response phase	Continue longitudinal researches, Rehabilitation and reintegration of affected families, initiation and support of livelihood improvement programs, setting up and operationalizing special needs schools and vocational centres	MOH, OPM, WHO, CDC

Keys: HC = Health Centre, OPM = Office of the Prime Minister, CDC = Centre for Disease Control and Prevention, Atlanta, Georgia, WHO = World Health Organization, CHS = College of Health Sciences, DFID = Department for International Development – United Kingdom.

2009). Uganda and other nations may in future use such systems to help detect outbreaks early and institute appropriate management.

The response by Uganda government involved a multifaceted approach including formation of a national task force to plan and coordinate activities of the various stakeholders involved in the epidemic investigations and control, as well as promote and commission researches into the causes, course and management modalities of the NS. The multilateral and United Nations partners have been instrumental in the investigations, surveillance and management of the syndrome while the academic and research institutions have contributed human resource and technical expertise to investigate the syndrome and help train health professionals on the syndrome and its management. This was an innovative approach that helped to harness resources and maximize output from the different actors. In addition, district task forces (DTF) for Kitgum, Lamwo and Pader were formed between January and March 2012. The DTF and collaborating partners at the district levels were responsible for the direct implementations of activities, including community mobilization and health promotion, risks mitigation, and evaluation of progress and challenges (MOH 2012b). Although CDC and WHO were also involved in the investigations and management of the outbreak in South Sudan (Lacey 2003; CDC 2012), we have not found any publicly available documentations of structured systems of management including involvement of academic, multilateral and UN stakeholders as has been the case in Uganda.

Formation of task forces at multiple levels, including at the national and district levels, and involvement of various key stakeholders in management of epidemics has been successfully implemented in Uganda before (Okware *et al.* 2002). Much earlier, task forces have also been used by the WHO to aid timely and effective multifaceted responses to epidemic diseases including the response to and containment of a sexually transmitted disease epidemic in eastern Europe and central Asia (Vaugh 1999). In that STD epidemic, the main responsibilities of the task force were to solicit, coordinate and ensure timely availability of external support to the affected region, mobilization of national and international resources and thirdly, developing local capacity to respond to the sexually transmitted disease epidemics (Vaugh 1999).

Several key stakeholders and institutions were involved in the response to NS epidemic in Uganda. For example, the academic and training institutions, mainly Makerere University and Gulu University involved in researches into the cause, and local beliefs on NS (WHO & MOH 2012; WHO 2012c; Idro *et al.* 2013; Mutamba *et al.* 2014) and jointly developed a health professional training manual with a team of experts from World Health Organization, Mulago and Butabika national referral hospitals through a process of literature review, sharing experiences, and consensus building on key management goals. The manual has been used to train primary healthcare professionals in the affected districts on various aspects of NS including case definitions, clinical assessments, medical, nutritional and rehabilitative management of the affected children.

Collaborations between various institutions in epidemic response and control allow synergy of skills and experiences which may lead to more effective management of the epidemic. CDC, DFID and WHO supported the organization and as well funded the First International Scientific Conference on Nodding Syndrome during which the disorder was named 'Nodding Syndrome'. In the same conference, the diagnostic criteria were harmonized and research agenda were streamlined across affected countries (WHO 2012a; WHO 2012b).

When faced with outbreaks, especially of novel epidemics, nations need to urgently fund basic and operational researches that may provide valuable empirical data and empower health professionals to

provide culturally-sensitive care especially in outbreaks of unknown aetiologies such as NS. The Uganda government has funded more than four research areas on NS including assessment of clinical features and appropriate treatment regimes and a large community based anthropological study to systematically understand community explanatory model for NS in the broader context of the affected regions so as to guide continued efforts in the disease control and preparation for the aftermaths of the outbreak. This is in accordance with the WHO technical guidelines for responding to Ebola haemorrhagic fever (EHF) which strongly recommends that special attention be paid to the actual perception of the outbreak by the community including specific cultural elements and beliefs (WHO 1997). This recommendation is not limited to Ebola but may apply to all outbreak investigations especially novel epidemics.

### Lessons learnt

This study reveals that:

1. Notifications and confirmation of outbreaks and epidemics of unfamiliar disorders, e.g. NS may take longer than usual especially when death may not be attributable directly to the new disorder.
2. Several key stakeholders with a committed central organizing and coordinating committee for example the national task force is essential to prompt effective response to outbreak management.
3. Training and empowering frontline healthcare professionals based on actual situational analysis and available literature are invaluable in the management of novel disease outbreaks.

### Conclusions

The NS epidemic in northern Uganda has affected over 3000 children with a case fatality of 6.7%. Although the initial response to the NS was apparently delayed, the Uganda government adopted an effective response strategy that involved collaboration between several key stakeholders coordinated by the Ministry of Health. NS still remains enigmatic in its aetiology, pathophysiology and curative management. However, several hypotheses have recently been generated to guide further researches to unravel the disease.

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*Conflict of interest statement.* None declared.

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