Mapping of Prevalence of Nodding Syndrome and Associated Epilepsy Reporting in Uganda: Spatial – Temporal Approach

Kizito Ongaya
Makerere University, School of Computing and Informatics Technology, Kampala, Uganda
kongaya@cis.mak.ac.ug

Benedict Oyo
Gulu University, Department of Computer Science, Gulu Uganda
b.oyo@gu.ac.ug

Paul Ssemaluulu
Makerere University, School of Computing and Informatics Technology, Kampala, Uganda
pssemaluulu@cit.ac.ug

Gilbert Maiga
Makerere University, School of Computing and Informatics Technology, Kampala, Uganda
gmaiga@cis.mak.ac.ug

Abstract

In recent years, transmission of diseases has exhibited new spatial and temporal patterns. Emerging diseases are being discovered more often. Some have unknown transmission patterns and mechanisms for diagnosis. This results to numerous hypothetical postulations just as in the case of nodding syndrome which has affected thousands of children in Uganda. Spatial-temporal analysis may provide a quick mechanism to establish comparative understanding of the various hypotheses ascribed to an emerging disease. This situation, is particularly seen in nodding syndrome where there is considerable suspicion that nodding syndrome is a form of epilepsy. Little literature is available on spatial-temporal comparison between incidences of these two ailments. The *aim* of this paper is to establish spatial-temporal relationships between ailments diagnosed as nodding syndrome and ailments diagnosed as epilepsy. We carried out an *exploratory* survey in three districts of Northern Uganda. Spatial data of health centres were recorded and ArcGIS was used for display. Our *findings* established that, there was significant spatial-temporal relationship of diagnosis reporting of nodding syndrome and epilepsy. The study *concludes* that the surveillance mechanisms for nodding syndrome established in 2012 are effective. At the same time, the study affirms that in the event of occurrence of an emerging disease, when there is no established clinical diagnosis, geographical information systems approach is an effective alternative investigation mechanism to establish relationships between hypothetically similar outbreaks.

Keywords: Nodding syndrome, Emerging diseases, Surveillance, Spatial-temporal, Geographic information system

1 Introduction

In recent years, transmission of diseases has exhibited new spatial and temporal patterns (Samphutthanon *et al.*, 2014). Emerging diseases like nodding syndrome with unknown transmission patterns and mechanisms for diagnosis are being discovered more often. There is therefore need to harness geographical information system (GIS) capabilities to establish insights into patterns of spatial transmission.

Nodding syndrome is an illness that has eluded surveillance models in Africa for over six decades since its discovery in the 1960's (Colebunders *et al*., 2014; Korevaar & Visser, 2013). There is hardly any surveillance model for investigating spatial diffusion and supporting geographical knowledge on how to intervene on the spreading of nodding syndrome outbreak. Many authors agree that its spatial diffusion patterns, and transmission models are not properly understood (Spencer *et al.*, 2016), the characteristics, risk factors as well as aetiological factors are also not well established (MoH, 2012; Spencer *et al.*, 2015; CDC, 2014) complicating surveillance efforts. Up to the year 2012, when the Ministry of Health Uganda recognised the ailment as a public health concern, it had affected estimated thousands of children in Northern Uganda (Idro *et al.*, 2016; CDC, 2014).

The surveillance form used for Integrated Disease Surveillance and Response lacked provision for nodding syndrome for all the years before 2012. The ailment became endemic in the population and the disease reached a threshold after over a decade to warrant public health concern. In many cases where the disease was prevalent, the low prevalent level made its data unavailable at the Ministry of Health because it was not considered a public health epidemic.

Nodding Syndrome is a childhood neurological disorder which affects communities in Northern Uganda (Kitara *et al.*, 2017). There is considerable suspicion that nodding syndrome is a form of epilepsy (Spencer *et al.*, 2016; Colebunders *et al*., 2014; Idro *et al.*, 2016). Much as these findings are of biological significance, there is limited literature on spatial models comparing spatial prevalence of nodding syndrome and associated epilepsy. The Ministry of Health of Uganda and partner organizations identified the gaps in knowledge of nodding syndrome that "the actual geographic coverage and distribution is not known, and that there is need for surveillance in other areas outside the current foci and the overlap of areas of distribution of nodding syndrome, etiological, potential risk factors and other information of interest (Ministry of Health Uganda, 2012). Also, the burden of nodding syndrome in the currently reported three foci and surrounding areas are also not known. The increasing

prevalence of nodding syndrome in northern Uganda has generated a wide range of speculations with respect to aetiology and natural history and best possible medical treatment for this mysterious seizure disorder. Despite in-depth investigations by the United States Centers for Disease Control and Prevention and the Ministry of Health in Uganda, agree that no clear causal factors have emerged (Mitchell *et al.*,2013).

The government of Uganda (GoU) and development partners are making significant efforts to restore basic social services and improvements in infrastructure in Northern Uganda, however, overall, such services remain out of reach for residents in the majority of places —thereby exposing many people to multiple vulnerabilities (Global Health Governance, 2012). Therefore, deliveries for intervention to curb disease outbreaks are usually delayed because of lack of knowledge on spatial and spatial temporal distributions.

Further, the spatial epidemiological prevalence of nodding syndrome particularly in Northern Uganda is inaccurately presented by different organizations (Bemmel, 2014). For instant, the independent charity organization; Kitgum District NGO Forum, which first announced the outbreak of nodding syndrome, estimates that as many as 5,000 children are infected by the disease in Kitgum alone, while government officials say; there are only 3,200 infected children, Other scholars put the total number of cases of nodding syndrome in the 3 districts of study at 1,876 (Global Health Governance, 2012). These news reports and some clinical scholarly research examined above, clearly lack systematic spatial and temporal analysis of nodding syndrome.

Furthermore, many scholars believe that "nodding syndrome is a form of epilepsy" (Idro, 2013), (Korevaar and Visser, 2013), (Gazda, S. Et al, 2015), (Suzanne, 2015) and (Kitara, 2015). However, these reports and researches hardly critically examined the distribution of the two diseases over time in-order to contrast them and make spatial correlation to deduce conclusion and intervention plans.

The compelling issues of this paper therefore are: i) The need to determine whether nodding syndrome is being reported by the different health facilities in Northern Uganda, ii) The spatial prevalence of nodding syndrome reporting and spatial relationship between nodding syndrome and epilepsy.

The Case for GIS in Epidemiological Surveillance

The importance of mapping, place, and time came in light more than 200-years ago when Dr. John Snow modelled a map of cholera deaths in relation to London's water pumps. This was one of the first, and perhaps the most celebrated, disease maps model. His history of disease mapping is filled with examples of maps that helped provide etiological clues to diseases from cholera to lung cancer. With the help of his famous map model, Snow was not only able to track the source of what he called "the most terrible outbreak of cholera which ever occurred in this kingdom," but he was able to convince authorities to take action against the disease (Snow, 1855). Space-time mapping and analysis of disease data has historically involved the search for patterns in aggregated data to identify how regions of high and low risk change through time (Meliker & Sloan, 2010). Mapping of space and time analysis of aggregated data has great value, but represents only a subset of space time epidemiologic applications. Technological advances for tracking and mapping individuals (e.g., global positioning systems) have introduced mobile populations as an important element in space time epidemiological modelling (Stevens & Pfeiffer, 2011). Analyzing and mapping spatial and temporal dynamics of infectious diseases features mathematical and spatial modeling approaches that integrate applications from various fields such as geo-computation and simulation, spatial analytics, mathematics, statistics, epidemiology, and health policy (Chen *et al.*, 2014) provides great insights to understanding disease outbreaks.

2.0 Method

This paper, compares spatial-temporal diagnosis of diseases identified as nodding syndrome and those that have been identified as epilepsy in three districts in Northern Uganda. Purposive sampling of health centres was used to identify facilities that are relevant for the study. Twelve (12) health centres were identified for the study based on Ministry of Health IDSR (Integrated Disease Surveillance and Reporting tool). These centres have evidence of providing care for nodding syndrome victims in their tool and out-patient registers. This was done with the support of district health officers and respective nodding syndrome focal persons.

The health centres were identified with the help of District Health Officers and nodding syndrome focal persons of individual districts. In Gulu district, the following health centers were identified (Oroko, Labworomor, Paibona, Cwero and Omel) to be receiving nodding syndrome patients. In Omoro District we identified, Odek Health Centre, Lalogi Health Centre III and Hope for Humans health Centre. While in Kitgum District; Pajimo Health Centre II, Tumangu Health Centre II, Okidi health Centre II and Kitgum Hospital were identified.

2.1 Data Collection Tools

Two questionnaires were used for data collection with the first one designed for health workers interfacing with nodding syndrome patients. It was to elicit basic information on the gravity of nodding syndrome in the communities and also provide some statistical overview of patients attended to from a particular health centre. The second was designed for health centres and hospitals data managers. It was particularly tailored to examine the depth of information available from a particular health center identified as receiving nodding syndrome victims. Although attempt was made to capture information for a span of 10 years, only five years were adequately accessible from almost all the health centres. Global Positioning System (GPS) was used to plot positions of the health centers. This was to provide some approximation of at least 5-10 km radius where the patients receive treatments from the nearest health centre and was the basis for mapping.

2.2 Data Analysis

Environmental System Research Institute (ESRI) ArcView Software was used for analysis and display of the data on a map. Spreadsheet was used for trend analysis. Analysis was done consecutively for five years to establish the spatio-temporal aspects.

3.0 Findings

Following the recognition of nodding syndrome as a public health threat in 2012 by the Ministry of Health Uganda, some health centres like Figure 1: Kitgum Hospital, Lalogi, Cwero, Paibona and Labworomor health centres formally began reporting the cases of nodding syndrome diagnosed differently from epilepsy. The local NGO hope for humans have already long been advocating for the plight of nodding syndrome victims.

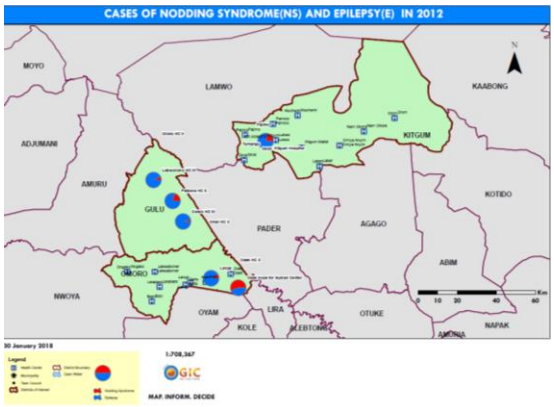

Figure 1: Map of Health Centres Reporting Nodding Syndrome and Epilepsy in 2012

In 2013, we can observe that more health centres, began as reporting on nodding syndrome patients incidences especially in West of Aswa river basin. We can observe Oroko, Omel and Okidi health centres beginning to receive the patients.

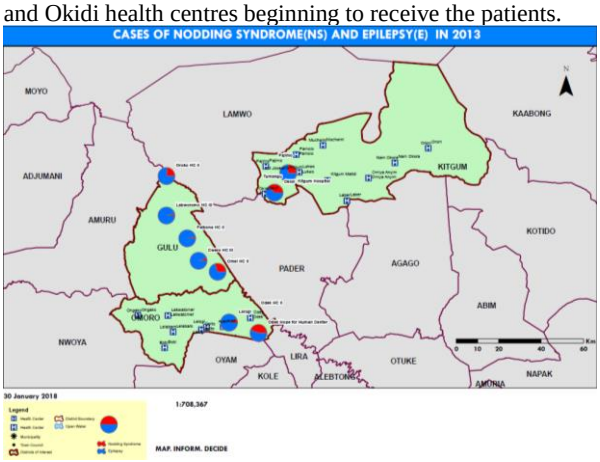

Figure 2: Map of Health Centres Reporting Nodding Syndrome and Epilepsy in 2013

Further so, we can observe reporting of nodding syndrome and epilepsy cases increasing in even more by different health centres in 2014 (figure 3.). With Tamangu and Pajimo in Kitgum District. Surprisingly, Odek Health Centre that was reporting previous year did not record any diagnosis as nodding syndrome. This was because, the patients were referred to Hope for Human Centre which was thought to have better facilities and specialization in treatment of nodding syndrome patients.

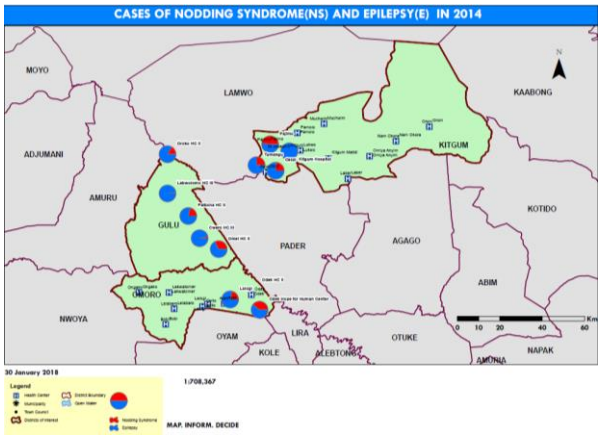

Figure 3: Map of Health Centres Reporting Nodding Syndrome and Epilepsy in 2014

In 2015, numerous health facilities recorded low turnout of patients with nodding syndrome. Most health facilities however, were still recording epileptic patients across the region. In fact health facilities like Omel,Oroko, Labworomor, Odek did not receive patients with nodding syndrome (figure 4). However, it appears nodding syndrome victims were seeking for better facilities in referral hospitals and specialised health centres like Hope for Humans in Odek because the referral hospitals recorded 1,720 patients in this year. This was because, there was a specialized unit set up to provide special care for the victims in Kitgum. The year 2015, also coincided with the year massive Campaign by politicians in the Northern part of Uganda and as such, nodding syndrome patients were gathered in referral hosptals especially Kitgum district.

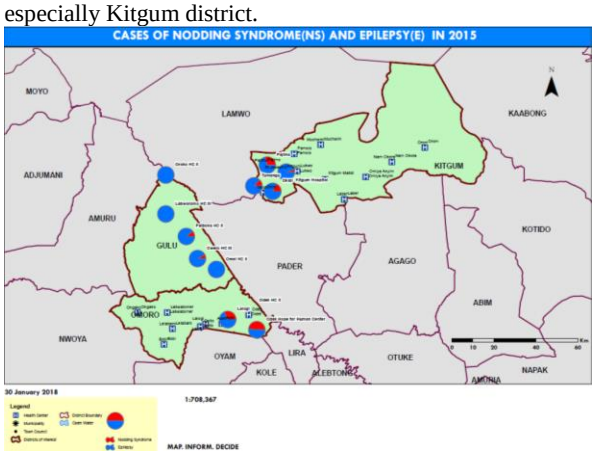

Figure 4: Map of Health Centres Reporting Nodding Syndrome and Epilepsy in 2015.

The Campaign for the plight of nodding syndrome patients yielded 4,540 patients with associated epilepsy in Kitgum Referral Hospital. However, specific diagnosis of nodding syndrome were lowly recorded across the region. It appears that, epileptic patients that results to nodding were mostly reported to the facilities.

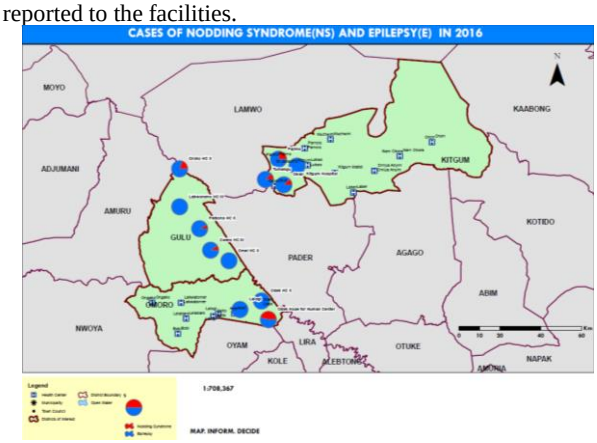

Figure 5: Map of Health Centres Reporting Nodding Syndrome and Epilepsy in 2016.

In 2017 (figure 6), it appears that diagnosis of nodding syndrome were very low across the region, however, the associated epilepsy were distributed across. However, the Referral Hospital in Kitgum and Hope for Human Centre had high number of diagnosis of epilepsy.

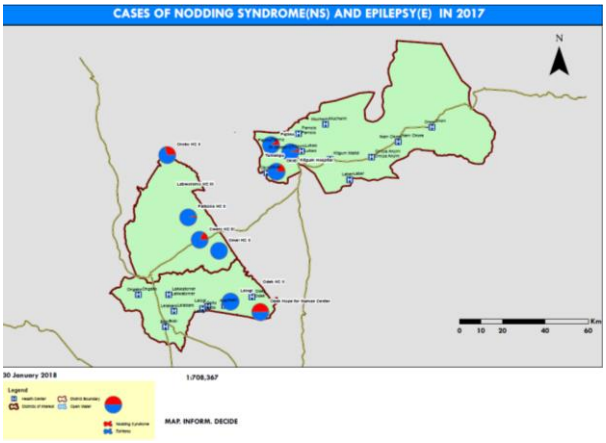

Figure 6: Map of Health Centres Reporting Nodding Syndrome and Epilepsy in 2017.

4.0 Discussion

As shown in figures 1-6, the number of health centres reporting of nodding syndrome were rising and yet the diagnosis prescribed as nodding syndrome were decreasing and remained well below 2000 patients over the last five years in the three districts Gulu, Omoro and Kitgum. This could be due to the fact that there no new cases being reported, but rather the health centres were treating cases that had contracted the disease earlier and discharging them in out patient departments. However, this also raises a very fundamental aetiological questions such as; when did the patients contract the disease? Where were they during time they contracted? Were contracted from one source? And if the aetiological factor in the transmission is blackfly, how spatially distributed were the cases showing up? These are hypothetical questions that needs to be investigated in later studies to establish exact aetiological factor and transmission patterns.

	Reporting of NS and Epilepsy by Health Centres in Northern Uganda from 2012-2017		
Period	**Nodding Syndrome**	**Epilepsy**	**No. of Health Centres Reporting**
2012	1782	5364	6
2013	1789	5648	9
2014	1247	4985	11
2015	761	4081	11
2016	564	7725	12
2017	435	3132	9

Table 1: Nodding syndrome & associated epilepsy reporting

However, epilepsy diagnosis were well above 5,000 patients in the three districts with the peaks in 2006 following political campaign for the plight of nodding syndrome in the region.

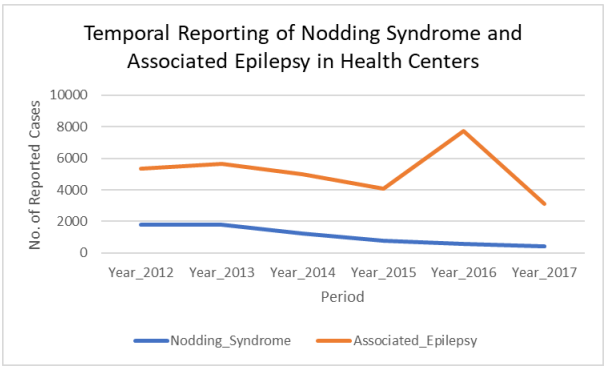

Figure 7: Temporal Graph showing Nodding syndrome & associated epilepsy reporting

We can observe that the spatial-temporal prevalence of nodding syndrome and associated epilepsy were mimicking one another for the period of 2012 following recognition of the plight as a public health disaster by Ministry of Health through to 2014. The period between 2015 and 2017 is special in that there was massive campaign for support to nodding syndrome victims.

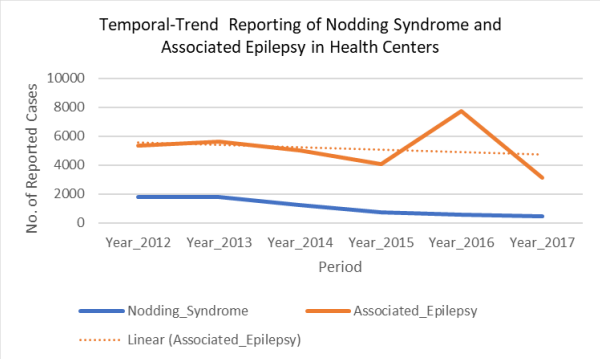

Figure 8: Temporal Graph with line of best-fit showing Nodding syndrome & associated epilepsy reporting.

Since nodding syndrome manifests with epilepsy, the turn up of patients diagnosed as epilepsy other than nodding syndrome were exceedingly high with the peak of 7,725 patients. This also explains the anomaly in the reporting figures for nodding syndrome by the different organization partnering to provide health services in Northern Uganda. As we observed in literature, for instant, the independent charity organization; Kitgum District NGO Forum, which first announced the outbreak of nodding syndrome, estimates that as many as 5,000 children are infected by the disease in Kitgum alone, while government officials say; there are only 3,200 infected children, while other scholars put the total number of cases of nodding syndrome in the 3 districts of study at 1,876 (Global Health Governance, 2012). We can observe that these reporting are in the range of the figures established. However, this particular paper is a preliminary retrospective investigation excluding two key districts of Pader and Lamwo which have been reportedly having nodding syndrome too. The overall total population study will be concluded if Pader and Lamwo are also included in the study.

5.0 Conclusion

From this preliminary investigation, we have established that reporting on nodding syndrome by the different health facilities started in the year 2012 following recognition as a public health threat. Beyond 2012, no record exists in the reporting tools provided by Ministry of Health Uganda especially in the Integrated Disease Surveillance and Response (IDSR) form. In fact, there was no provision in the IDSR form beyond 2012.

As we can observe, the trend of prevalence of nodding syndrome and epilepsy over the period of four years were very much the similar. However, there was exceptional peak trend in associated epilepsy between 2015-2016 due to mass political assertion to intervene on the outbreak. Also, because nodding syndrome usually first manifests as epileptic conditions, the diagnosis and reporting in health facilities were not upright nodding syndrome, but rather epilepsy in the reporting tools provided by the Ministry of Health Uganda.

When we insert line of best fit, we can observe that the trends of both nodding syndrome are very much similar to epilepsy trend. From the spatial-temporal analysis of diagnosis and reporting by the different health facilities, the study confirms that spatial-temporal distribution nodding syndrome is associated with spatial-temporal distribution of epileptic condition. This is also in line with other scientific establishment such as (Idro *et al*., 2015; Spencer *et al.*, 2016; Colebunders *et al*., 2014 and Gazda *et al*., 2015) through clinical studies which established that nodding syndrome is a form of epilepsy. Therefore, we can affirm that the established surveillance mechanisms for nodding syndrome established in 2012 are effective. At the same time, we can also affirm that in the event of occurrence of emerging disease, when there is no established clinical diagnosis, GIS approaches can be effective alternative investigation mechanisms to establish relationships between hypothetically similar outbreaks.

6.0 Reference

Bemmel, K. V. (2014). The rise and fall of nodding syndrome in public discourse: An analysis of newspaper coverage in Uganda. Critique of Anthropology 2016, Vol. 36(2) 168–196. *Sage publication.* DOI: 10.1177/0308275X15614635. Availbles: http://coa.sagepub.com (Accessed on 13th May 2016)

Bemmel, K. V Derluyn I, Stroeken K. (2014). Nodding syndrome or disease? On the conceptualization of an illness-in-the-making. Ethn Health 2014;19:100–18.

Center for Disease Control –CDC, (2013). Nodding syndrome. *Emerging Infectious Diseases* • www.cdc.gov/eid • Vol. 19, No. 9, September 2013. DOI: http://dx.doi.org/10.3201/eid1909.130401 . (Accessed on 18th August 2017)

Center for Disease Control (CDC), (2010).Technical Guidelines for Integrated Disease Surveillance and Response in the African Region. 2nd ed. Center for Global Health Division of Public Health Systems and Atlanta, Georgia, USA.

Chen, D., Moulin, B., and Wu, J. (2014). Analyzing and modeling spatial and temporal dynamics of infectious diseases, D. Chen, B. Moulin, J. Wu (Eds.), Wiley (2014). 496 pp. ISBN: 978-1-118-62993-2

Colebunders, R. (2015). Prevalence and distribution of river epilepsy in the Orientale Province in the Democratic Republic of the Congo (DRC). *2nd International conference on nodding syndrome*. July 26th-31, 2015. Gulu University.

Colebunders, R., Hendy, A., Mokili, J.L., *et al.* (2016). Nodding syndrome and epilepsy in onchocerciasis endemic regions: comparing preliminary observations from South Sudan and the Democratic Republic of the Congo with data from Uganda. *BMC Research Notes20169:182* DOI 10.1186/s13104-016-1993-7 Available through: www.sciencedirect.com
Gazda, S. (2016).

Hope for humans, caring for children with nodding syndrome. Available at: http://hopeforhumans.org/our-history/ Accessed on 21st September 2017.

Global Health Governance, Volume Vi, Issue 1 (Fall 2012) http://www.ghgj.org

Idro, R., Opar, B., Wamala, J., Abbo, C., Onzivua S., Mwaka, D. A., Kakooza-Mwesige, A.,Mbonye, A., Aceng, J.R. (2015).. Nodding syndrome; a new (infectious?) disease entity of the CNS in Eastern Africa. *Journal of the Neurological Sciences 333 (2013) e1–e64* doi:10.1016/j.jns.2013.07.184.

Idro, R. (2015). Proposed guidelines for the management of nodding syndrome. 2nd International conference on nodding syndrome. July 26th-31, 2015. Gulu University.

Kitara, D.L. (2015). History and the distribution of nodding syndrome in Uganda. 2nd International conference on nodding syndrome. July 26th-31, 2015. Gulu University.

Kitara, D.L. (2017). Nodding syndrome (NS) and Onchocerca Volvulus (OV) in Northern Uganda. Pan African Medical Journal. 2017; 28:1 doi:10.11604/pamj.2017.28.1.13554 http://www.panafrican-med-journal.com/content/article/28/1/full/

Korevaar D.A. & Visser B.J. (2013). Reviewing the evidence on nodding syndrome, a mysterious tropical disorder. *International Journal of Infectious Diseases* 17 (2013) e149–e152. journal home page: http://www.elsevier.com /locate/ijid

Ministry of Health-MoH, (2016). About Uganda Ministry of Health. http://health.go.ug/about-us/about-ministry-health

Meliker, J.R.& Sloan, C.D. (2010). Spatio-temporal epidemiology: Principles and opportunities. *Science direct. Elsevier*. Volume 2, Issue 1, March 2011, Pages 1-9 https://doi.org/10.1016/j.sste.2010.10.001 Accessed on: 30th January 2018.

Snow J. (1855). On the Mode of Communication of Cholera. London:John Churchill, 1855.

Spencer, P.S. Palmer, V.S. and Jilek-Aall, L. (2015). Nodding syndrome: origins and natural history of a longstanding epileptic disorder in Sub-Saharan Africa.

Stevens, K.B. & Pfeiffer, D.U. (2011). Spatial modelling of disease using data- and knowledge-driven approaches. *Pubmed.* 2011 Sep;2(3):125-33. doi: 10.1016/j.sste.2011.07.007. Epub 2011 Jul 19. Accessed on 30th January 2018.

Samphutthanon, R., Tripathi, N.T., Ninsawat, S., & Duboz, R.(2014). Spatio-Temporal Distribution and Hotspots of Hand, Foot and Mouth Disease (HFMD) in Northern Thailand. *International Journal of Environmental Research and Public Health ISSN 1660-4601 Int. J. Environ. Res. Public Health 2014, 11, 312-336; doi:10.3390/ijerph110100312* www.mdpi.com/journal/ijerph Accessed on 31st January 2018.