NODDING SYNDROME IN POST CONFLICT NORTHERN UGANDA: A HUMAN SECURITY PERSPECTIVE

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"When you go to the family with nodding syndrome (NS) you will see that there is no happiness. Because this disease has brought a lot of problems…These are children who should have helped their parents in future but they have been wasted by the disease."

- *40 year old mother of three affected children*

INTRODUCTION

An increasing concern of public health is the relationship between health and human security in conflict and post-conflict settings.[1] Environments where conflicts have taken place are associated with the breakdown of public health infrastructure, massive displacement of people and disruption of livelihoods.[2,3,4] Thus the processes and outcomes of violent conflict have implications for health and well-being, including recovery processes in post-conflict settings. Violent conflict is also closely related to "structural violence", which broadly includes "violence of poverty, social and political marginalization, and other forms of structured inequalities and their effects on people's lives, health and agency."[5]

This underscores the need to understand how the health and well-being of people in post-conflict settings is influenced by violent conflict, antecedents to the conflict, or the complex intersection of both.[6] This complex relationship raises questions about the challenges of ensuring human security in post-conflict settings especially in developing countries where public service delivery systems, including health and health care delivery, are already constrained.

Human security in this paper is contextualized as the safety for people from both violent and non-violent threats. It is a state characterized by freedom from pervasive threats to people's rights, their safety, or even their lives.[7] At the core of the human security paradigm is the recognition that people and communities are fatally threatened by events well beyond their control, especially threats that come as a surprise.[8,9,10]

In Uganda, there is a growing health challenge, Nodding Syndrome (NS), which is threatening to reverse the progress of recovery in Northern Uganda, an area that was affected by a two decade civil war which displaced almost 90 percent of the population in the region. The paper discusses the epidemiology and consequences of NS, arguing that NS undermines essential human capabilities, triggering potential reversals in recovery from conflict for individuals and communities.

THE ARMED CONFLICT IN NORTHERN UGANDA

For more than two decades, Northern Uganda suffered a protracted and intractable violent conflict between the Lord's Resistance Army (LRA) and the Government of Uganda (GoU).[11,12] This violent conflict claimed thousands of lives, displaced over 1.8 million people and resulted in the abduction of over 20,000 children for forced conscription and sexual exploitation.[13,14,15] The conflict also left many people in the northern region of Acholi-land, particularly in the districts of Gulu, Kitgum, and Pader, prone to hunger, malnutrition, disease, psychological trauma, and the chronic effects of living displaced and disrupted lives.[16,17] The situation was characterized as one of the world's worst humanitarian crises.[18]

Since late 2006, relative peace has returned to Northern Uganda and there has been a dramatic improvement in security overall.[19] Security improvements have allowed many of the internally displaced persons (IDPs) to return to their ancestral homes and villages.[20,21] Nevertheless, in this fragile post-conflict environment, addressing the aftermath of war's devastation and displacement remains a significant challenge. The negative impact of the prolonged conflict on the economic, social and physical capital of the region continues to be evident.[22] The government and development partners are making significant efforts to restore basic social services and improve infrastructure although, overall, such services remain out of reach for residents in the majority of return areas —thereby exposing many people to multiple vulnerabilities. [23]

The Nodding Syndrome (NS)

The NS is a recent, little known illness that seems to primarily affect children between the ages of 5 and 15 years. In 2009 the Uganda Ministry of Health (MoH) observed that in the districts of Kitgum and Pader in Northern Uganda, there was a progressive disease characterized by head nodding, mental retardation and stunted growth. Earlier on, in 1992, a

similar ailment that had an association with epilepsy was reported in Kabarole district in western Uganda[24] in an area hyper endemic for river blindness among communities that had migrated to the area from southwestern Uganda in search of land to settle in.

In northern Uganda, this syndrome was reportedly noticed by the local populace for over five years before it was reported to MoH in 2009. The MoH therefore concluded that NS may have started as early as 2003 when most of the Northern Uganda population had moved to Internally Displaced People's (IDP) Camps. There was a gradual increase in the number of new cases over the years, particularly in 2008 (Kitgum district) and 2009 (Lamwo and Pader districts). The Uganda Ministry of Health estimates that by 2011, up to 3,000 children were affected in the 3 districts of Kitgum, Lamwo and Pader in northern Uganda.[25,26] Currently, the total number of cases of NS in the 3 districts of study is 1,876. The highest burden of the disease was in Labongo Akwang sub-county in Kitgum district with a prevalence of 1,305 per 100,000 population and Pader district with a prevalence of 519 per 100,000 population.

The more conclusive diagnosis of NS appeared therefore to coincide with the apparent end of violent armed conflict led by the Lord's Resistance Army. The more stable environment following the conflict led to a fairly stable health service delivery system which enabled systematic recognition and diagnosis of the condition. Most of the affected children are malnourished (stunted), disabled, have dropped out of school, and live in areas where *Onchocerciasis* (river blindness) is prevalent.[27,28]

The condition is characterized by head nodding episodes that consist of repetitive dropping forward of the head.[29] The nodding is sometimes precipitated by food or cold weather or may be spontaneous, and is often accompanied by other seizure-like activity such as convulsion or staring spells. During the episodes, the child stops feeding and appears nonresponsive, with or without loss of consciousness.[30] While the etiology and prognosis remains unknown, NS is very debilitating physically and mentally. The syndrome is associated with mental and growth retardation.[31] Reports from caregivers also indicate that affected children sometimes suffer serious injuries or death resulting from falls during seizure episodes.[32] The impact of NS can be viewed as negatively impacting daily productivity.

METHODS AND PROCEDURES

This article is based on research that utilized in-depth interviews and document review. Given that limited information is available about NS in post conflict settings, the design allowed for examining questions of subjective experience and situational of NS to caregivers of affected children.[33]

The study was conducted in Kitgum District located in the North central region of Uganda. Study participants[34] were selected because they were deemed to have relevant characteristics, experiences and knowledge to share about the research questions.[35] Eight caregivers of children suffering from NS were selected through snowball sampling and interviewed to understand their experiences with the NS. In addition, five key informants among policy and implementation units charged with response to NS were also selected for in-depth interviews. All in-depth interviews were conducted using unstructured research instruments with key themes, but participants were not limited to the themes while expressing their opinions and sharing their experiences. Finally, data collection also involved review of documents using a checklist to examine and compare data from interviews.

Thematic and content analysis techniques were used to draw emerging themes linked to the research issues.[36] Interviews were recorded, transcribed and translated and entered into MS Word software for editing as the first step to "formal" analysis. It was then categorized according to key themes that were emerging.

Informed consent was obtained from all respondents prior to the interviews. Study participants were informed about the purpose of the study and the scope of issues in the in-depth interview guides. Confidentiality was ensured in data management and only aggregate information without subject identifiers was reported. All data was secured in a safe location accessible only to the study team. Ethical review clearance was obtained from Makerere University School of Public Health, Higher Degrees, Research, and Ethics Committee (HDREC) and the Uganda National Council of Science and Technology prior to commencement of the study as part of the overall studies on *NS*.

SUMMARY OF RESULTS

Etiology of NS and Community Perceptions

The cause of the syndrome remains unknown. Nonetheless, previous epidemiological studies had suggested a possible link between the neurologic condition and infections with *Onchocerca volvulus*, a parasite that can cause river blindness. A high number of those with NS also have antibodies in their system for *Onchocerca*. In addition, most of the children affected by NS live in close proximity to the fast flowing rivers of Aswa and Pager, in which riversides abound with the black fly and are highly endemic for river blindness.[37] It is notable that study participants had similar perceptions about the etiology of NS being related to river blindness and the black fly as illustrated by the quote below:

> *The black fly that causes river blindness may also be responsible for this NS because these children exhibit symptom of river blindness such swollen eyes, skin rushes and swelling of the lower lips.*
>
> - *44 Year old male with 4 children affected by NS*

However, other signs thought to be characteristic of NS in northern Uganda, such as swollen lips may be the result of repeated injury that victims suffer during violent falls during convulsions, and this is not to be considered of etiologic significance.

NS has also been associated with epilepsy. Quite a high number of NS cases have signs of epilepsy. Thus, NS appears to be an epidemic epileptic encephalopathy.[38] The nodding of the head is due to atonic seizures. The areas affected by NS are known to have high prevalence of both onchocerciasis and epilepsy, making the two conditions the most strongly associated with the syndrome. The syndrome has also been associated with malnourished children or young adults who have a vitamin B6 deficiency and other micronutrients (Vitamin A, Seleniun and Zinc).[39]

Disease outbreaks in a community, especially with previously unknown or unfamiliar characteristics, are likely to elicit community explanations based on societal attitudes, beliefs and practices. In absence of a known etiology, several lay perceptions have emerged. Given the recent violent conflict, the most common factor that participants associated with NS is the war and its consequences. Nearly all lay accounts, while varied in nature, reflected the significance of the war in explaining misfortune such as NS. To begin with, study participants perceived that the syndrome may

be related to evil spirits that arose from the massive death toll due to the conflict, as illustrated in the quotes below:

> *"I don't know the causes of NS, but I am thinking that could be, because of the war that was in northern Uganda which led to many people being killed and now their evil spirits are the ones attacking the children. I also think that it is caused by the black fly that causes river blindness since I am living near [River Pager] but as I mentioned before I don't know the real cause of the disease."*
>
> - *40 year old mother of three affected children*

"The time we produced these children was a time of turmoil and life was not easy. Rebels come from somewhere and kill people in your own compound which was not in the Acholi custom that you kill somebody and come with the body to another's compound. So I think it's the evil spirits of the people who were killed as a result of the war, which is disturbing the children. They kill them and leave behind their evil spirits then take away the good spirits in your home and that is the sole reason this disease is common among children than adults."

- *44 Year old father of four affected children*

> *"I sometimes think that it may have something to do with spirits of who died during the insurgency. When this child was making movements to places to gather sheer nuts she may have found a dead body that was killed long ago during the insurgency and the evil spirits of that dead person caught her. She could have also met things she does not know but that much we may not understand or tell because we have no idea. They are just imaginations.*
>
> - *36 year old single mother of a 14 year old girl affected by NS*

In post-conflict circumstances where an unknown or unfamiliar disease occurs in epidemic proportions, the likelihood of people associating it with misfortune is high. This triggers the process of questioning such misfortune in terms of the recent experiences related to the violent conflict. We noted from document review that conditions associated with NS were present in other regions of Uganda. However in those regions, NS cases have been seldom reported or not at all. As NS occurs in epidemic

proportions in Northern Uganda therefore, affected communities begin to question why their regions are not spared. As they search for explanations, they frequently resort to personalistic explanatory models of illness and draw from recent experiences of suffering and misfortune.

As noted by Kleinman, traditional illness explanatory models seem to fit squarely into the people's quest for illness explanations that are culture-bound.[40] In personalistic belief systems, misfortune and illness is perceived to be a result of unseen forces such as ancestors, spirits and enemies.[41] Within this line of argument, misfortune and illness is associated with one's relationship with people, especially relatives and friends, and ancestral spirits. Although misfortune and illness may have an immediate physical trigger, the true cause is in a number of cases linked to relationships with people and the spiritual world.[42,43,44] Many people associate misfortunes with the supernatural, such as witchcraft. This reasoning is an attempt to reestablish control in an otherwise uncertain world.[45]

Participants' narratives further reveal that NS is thought to be caused by wartime chemical exposure, including toxic residue of the munitions left over from the two-decade long conflict between the LRA and GoU. NS has also been linked to the seeds and relief food that were distributed by relief agencies and consumed by locals. Similarly, some participants perceived that NS was associated with the presence of vast uninhabited areas during the conflict (due to displacement) which could have led to the emergence of this strange disease. Moreover, such areas were perceived to have been contaminated by the massive numbers of dead bodies during the conflict. In effect, participants' narratives implied that the environment, including bodies of water and farmlands, were transformed into a wilderness which may explain the emergence of such diseases of unknown etiology. This is illustrated in the quotes below:

> *"I think our environment here is also partly causing the NS because in terms of our drinking water from the rivers and swamps or wells, you find that the bodies of the people who were killed and left in the bush decayed and the rain washed it to these water bodies and now humans go and drink the same water which to me means drinking soup of a dead person."*
>
> - *44 Year old father of four affected children*

NS as a Human Security Threat

Nodding Syndrome may affect the recovery and development process in Northern Uganda by leading to poor health and undermining livelihoods. Several documents and key interviews reveal that there Northern Ugandans are facing food insecurity, diminished productivity, and unemployment, all of which diminish human capital and lead to low productivity. Moreover, another consequence of NS is that affected children drop out of school or require special needs education, which is complex and expensive to deliver. At the same time social capital is diminished due to already-weakened social networks that result from stigma and discrimination. Ultimately affected children will fail to develop into independent adults, thus increasing the economic burden on the few healthy adults of the time.

Respondents revealed that caring for the affected children was time-consuming, drawing them away from production of food and other basic needs. As a coping strategy, some parents are forced to tie their children on poles of their huts or trees or lock them inside the house in order to be able to do garden work. Parents argue that this is the only way they can guarantee the safety of their children from burns, drowning in open water sources such as dug-out wells and other accidents when they are out there in the gardens and in the case of girls, rape and defilement with the complications of pregnancy and sexually transmitted diseases.

> *"The challenges that the family and children are facing is problem of food, money because I cannot go to the garden frequently since there is no one to help me look after the children and if I am to go away, then I lock them inside the house without anything dangerous like fire or water. There are also financial needs. I cannot go to work so as to get money because my children need constant monitoring. If I live them alone at home I will fine them in fire or water but if the worst comes to the worst, I lock them inside the house for example when you came, I was not around because I had gone to quarry stones such that I get money for buying food. So the chairman came and told me about you and I came."*
>
> - *40 year old mother of three affected children)*

"The families with NS need to be given ox-ploughs for digging because if you observe well, almost all the homes with this disease have a lot of problem of getting food. This is because every time you need to look after this child and you will not have time to go to the garden. So if the ox-plough is there, I will request anybody to help me dig or I lock them in the house while I go to garden 'but if I have big person who can look after the child then I can live them out to prevent them from fire and water."

- *72 Year old Parent of 16 year-old affected child*

"I try to engage in agriculture, I harvest and sell then use the money to buy what is required but all those are seasonal crops and sometime unreliable. The child on a good day when the disease is not disturbing can help with light weeding of crops as a family we depend on the crop cultivation for our survival. I also have a blind brother much as I have oxen but he can't dig because he is blind. This year I don't know how I am going to survives because even this child who has been helping is now sick am going starve because of famine. I go together with her to the garden and stay with her, support her when she is not on attacks."

- *36 year old single mother of a 14 year old girls affected by NS*

Our discussions with caregivers revealed that the mental health of children suffering from NS makes them prone to accidents causing injuries and death. Some of the children run away from home when attacked and can easily end up in springs or fireplaces, and could fall in and die if not saved by their parents. The victims also suffer drastically stunted growth and are unable to feed because they often suffer attacks when they see food; those who have reached their youth still look like infants. Study participants identified the direct damage to the brain, injuries during seizures, and malnutrition due to difficulty in eating as the main causes of death in affected children.

The impact of NS can be viewed as both having acute and long-term effects on productivity. The last two decades had already witnessed a decline in productivity due to the civil unrest caused by the armed conflict between the GoU and the Lord's Resistance Army. Indeed, the gap in food production was supplemented almost entirely by food supply from the

World Food Programme and NGOs as part of emergency relief for those living in IDP camps. Once resettlement commenced after the war, there arose a need to revamp food production from farming. Such food production was mostly subsistence farming, small scale in nature, and dependent on household members for labor. But with the outbreak of NS, the combination of time spent away from farming to take care of sick children as well as the inability to call on sick older teenage children to help in the farms, led to an additional decline in productivity. When families have no time to tend to their crops, there are acute shortages in food security when survival is dependent on daily farming.

In addition, qualitative findings show that one of the impacts of NS is reduced food consumption reflected in terms of both quantity and quality. This was particularly reflected in reductions in the size of herd, diminishing area of land cropped, the planting of fewer crop varieties, and in some cases the abandonment of certain activities and crops. Long periods of forced displacement in northern Uganda have already seriously disrupted agricultural productivity in the region. Affected populations are impoverished, already having experienced a history of severe shortages of food as a result of conflict and being displaced. And while recent security improvements have allowed a number of farmers to return home and resume normal cultivation, NS is disrupting livelihoods. This dual context breeds an environment that constitutes a threat to human security. It undermines livelihoods through creating food insecurity, diminished productivity, and unemployment.

Affected households often shift from labor-intensive crops like millet and ground nuts cultivation to low labor-input crops and activities. This was perceived to lead to changes in livelihood, reflected in decreased income and increased vulnerability to food insecurity. Informal conversations with service providers and community leaders revealed that households find it difficult to adopt or even sustain recommended agronomic practices that may boost production. Because of reduced incomes from subsistence agriculture, affected families also tend to have less money to invest in farm inputs. Interviews with caregivers of children with NS revealed that the burden of care for affected children leaves them with less time to carry out food production. Consequently, they tend to rely on hired labor as a coping mechanism but quintessentially, this requires 'substantial' resources because it needs to be paid for.

Additionally, households with children suffering from NS tend to have increased needs for food amidst the vulnerability to food shortage.

Caregivers' narratives revealed that when these children are not attacked by the syndrome they eat on average about three times more than usual. This is reflected in the voices below:

> *"It is as if it is the illness (NS) eating but not the child."*
> - *Mother of child affected with NS)*

> *"According to me you find that this child with NS eats too much and when she is satisfied she can at least stay like for a day without being disturbed. But when she is not satisfied you will see how the child will be disturbed by the disease; so all in all, I as the immediate caretaker, I look after her and try as much as possible to provide for her the basic needs she requires, show her love and care…I am requesting that if the government or NGO's within could be in position to help, they should come and help test the brain of the child so that they get the right medication because you find that the condition of these child is not good and most time I can't move her to the hospital because of her condition. Furthermore, the government should find a way of supporting me through distributing food to us and other families affected with NS because you find that these children with the syndrome need a lot of food to eat. The worst bit is that the child needs to be looked at every time of which it has stopped me from going to the garden. If you live her alone at home she may get burnt.*
> - *72 Year old Parent of 16 year-old NS victim*

There is therefore a perception based on the experiences of caregivers that children with NS eat too much. In effect, families with these children cannot cope with their food requirements unaided. This is compounded by the context-specific reality that since all families in the community are struggling with resettlement after the two-decade war that ravaged the region, it is not easy for these affected families to get food supply from others. This suggests that in returning communities, the level of resilience is limited.

NS' Effect on Education

Human capital is considered essential for upward social and income mobility. Education is central to human capital formation and is one of the principle determinants for gainful employment and earning.[46,47] Northern

Uganda is recovering from decades of violent conflict that had serious implications with respect to access to education. During the conflict, children grew up without adequate and consistent access to quality education. This is reflected in the remarks below of a 20 year old returnee:

> *"I lived in Pabbo camp during the war. I was staying with my parents in the camp. But in 2003 rebels came to attack the camp and killed my father. I had problems after that. I couldn't go to school, because without my father we had no money. We became orphans. The rebels attacked the camp and killed my brothers, the following day…"*
>
> - *20-year-old returnee*[48]

Efforts by the government to improve access to education through Universal Primary Education and Universal Secondary Education initiatives notwithstanding, families that are returning home from Internally Displaced Persons (IDP) camps continue to face difficulties accessing quality education.[49]As a result of the violent conflict, it has been observed that "two generations of children – those who were displaced and those now growing up in return areas – have been left without an education and without the tools they might need to help rebuild their communities."[50] This is happening in light of the common understanding that education is a crucial component for successful recovery, given that "it gives people the tools they need to rebuild their communities."[51] Given that the region is emerging from conflict the role of education in building their human capital base cannot be over emphasized.

The above situation has been aggravated by the emergency of the high prevalence of NS among children aged 5 to 18 years in Northern Uganda.

One of the challenges is increased absenteeism, as noted by one head teacher:

> *"In my class I have 14 cases whom I know very well and even when they absent themselves from school, I do not give them any form of punishment because I know that it is the disease that could have made him/her not come to school so that is what I am seeing happening to children suffering from nodding disease."*
>
> - *A Head Teacher, Primary school in Kitgum District*

Similarly, the slow pace of learning coupled with stigma and discrimination were mentioned as other challenges that children affected

by NS faced during their education. The quotes below illustrate these concerns:

> *"The majority of these children are slow in class unlike other children. They even do not want to sit in the middle and even when I give them a test or exercise to do they may not answer it. They also do not collect their books when given an exercise for marking."*
>
> - *A Head Teacher, Primary school in Kitgum District*

Our interviews suggest that many stakeholders, especially parents or guardians of these children, are concerned about the effect that NS has on the ability of their children to benefit from Universal Primary Education and Universal Secondary policies and programs. Parents and guardians of children affected by NS often stated that their children had dropped out of school, while others did not attend regularly. They believed that, with time, they are likely to drop out. It was noted that sometimes, the reason for the affected children's dropping out was not only NS but also stigma and discrimination from other children in school.

> *"Other children do not want to sit with them and have fear being close to them. They think that this disease is contagious and might also catch them for example yesterday I was counseling one girl who said her friend was having ns and did not want to sit close to her for fear of contracting the condition as well."*
>
> - *A Head Teacher, Primary school in Kitgum District*

> *"The biggest challenge so far I have seen here at school is that the other healthy children do not want to mix up and sit with them (children suffering from NS) thinking that the condition will catch them too so they have to sit in their separate places. When they go to their friends, they run away from them. Even when it comes to playing, other children do not want to play with them telling others that don't play with that one he/she is sick and their disease will also catch you so that makes them separate from other children."*
>
> - *A Head Teacher, Primary school in Kitgum District*

CONCLUSIONS AND PROGRAMMATIC IMPLICATIONS

Nodding Syndrome (NS) has emerged as a threat to socio-economic development and human survival in post-conflict Northern Uganda. NS remains a pervasive threat to livelihoods as it undermines productivity of affected households, and contributes to food insecurity. While disruption of food production is occurring, affected children appear to have an increased need for food. Families are therefore entrapped by the need to produce more amid increased demands placed on their time due to the need to care for children affected by NS. Consequently, families with affected children continue to experience vulnerability to poverty.

NS is also a threat to human capital development. For almost two decades, children in Northern Uganda had inadequate access to education due to the conflict. This affected the knowledge and skills base among youth in the region. As communities were beginning to recover from the conflict by improving children's access to education, NS appears to have disrupted this process by causing absenteeism and affecting the ability of affected children to concentrate in school. This disruption is happening in a situation where the service delivery system and infrastructure were already weakened by the violent conflict. Currently, to reverse the situation, children affected by NS require special needs education which is expensive and requires special training and equipment.

Our findings reveal that NS appears to be increasing at a time when the social networks that used to support families and communities to cope with misfortune had been weakened by the violent conflict and its associated consequences. Findings reveal that households affected by NS experience stigma and discrimination that weakens their social networks. Additionally, the burden of care for affected children reduces time available for caregivers to participate in social and economic activities that build and strengthen social capital. Thus, these families increasingly become isolated, forcing some of them to adopt radical coping strategies such as keeping the affected children bound by rope to create time for engagement in social and economic activities.

Similarly, our findings seem to suggest that awareness and knowledge of NS remains low. As an emerging disease with little known about its etiology and pathogenesis, there is limited public health knowledge about NS. This may explain why affected families and communities tend to resort to lay explanatory models to understand and cope with NS. Such explanatory models affect the health-seeking behavior of affected families

and communities which may be detrimental to the control and management of NS.

Given the above, NS should be considered a critical and pervasive threat to human security in the affected communities in Northern Uganda because it exacerbates vulnerability of people in the process of recovering from violent conflict. One of the effects of the conflict in Northern Uganda was the marginalization and breakdown of social structures that impeded implementation of public health programs. Priorities for NS control should include improving surveillance to monitor the number of cases and their geographic distribution and continuing to undertake collaborative and multidisciplinary research to determine the etiology and socioeconomic impact of the syndrome.

Specifically, programmatic efforts should focus on: providing psychosocial support to affected children and caregivers; enhancing nutrition to sick and affected families; and providing alternative basic education that takes into account the special needs of affected children. In addition, advocacy and community sensitization in the affected region should be a priority. It should be noted that this was an exploratory study and its findings may not be conclusive. However, the findings provide critical insights in NS as a human security threat. There is therefore a need for an in-depth qualitative and ethnographic study to further investigate the contextual, socio-economic and socio-cultural impact of NS from a global health and human security perspective.

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