

HEALTH AND PEACE RECOVERY

SITUATION REPORT ON NODDING SYNDROME CASE MANAGEMENT

M.O.H
MINISTRY OF HEALTH



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FACTS ABOUT NODDING SYNDROME

Nodding syndrome (NS) is a neurological condition with unknown etiology. It was first documented in the United Republic of Tanzania in the 1960s, then later in the Republic of South Sudan in the 1990s and in northern Uganda in 2007. Typically, NS affects children between the ages of 5 and 15 years causing progressive cognitive dysfunction, neurological deterioration, stunted growth and a characteristic nodding of the head. Despite numerous and extensive investigations in all three countries that have experienced NS, very little is known about the disease and its cause¹.

In the meeting report of the International Scientific Meeting on Nodding Syndrome (2012), it is stated that although independent researchers and respective ministries of health of the affected countries have conducted over ten investigations on NS, etiology, mode of transmission, pathogenesis and clinical causes of the illness remain unknown.

The report further states that NS management is not standardized and therefore there is no established definitive treatment. Anti-epileptic drugs (phenobarbital and sodium valproate), which have had various outcomes with patients are the main drugs currently being used for treatment. Whereas suspected cases in Gulu were treated with supportive treatment of Carbamazepine Tablets, Phenytoin Tablets, Folic acid, Phenobarbital Tablets as per clinical diagnoses². Scientists recommend that a community – wide syndromic and holistic approach to NS case management focus on controlling seizures, nutritional supplement in malnourished children and psychosocial support for the affected children, families and communities. Cognitive, physical and or rehabilitation therapy was also identified as important treatment for long term case management.

As of 14 February 2012 about 3,094 suspected cases and 170 deaths were registered in Kitgum, Lamwo and Pader districts. By this date unverified cases were also reported in Gulu district. By March 2013, Nodding syndrome cases with symptoms of peculiar pendulous head nodding, fitting, alertness/consciousness, stunted growth, wasting and excoagulation skin conditions of rash and scaling had manifested in more than 230 cases in Lamola parish, Paloro sub county, Gulu district. In Aromwanglobo primary school, about 214 (102 females) pupils were reported to be suffering of Nodding syndrome. By April 27th 2012, there were 211 cases of NS screened and referred and 85 treated at Odek Health Centre III in Gulu District, and 7 new cases – 2 from Barlonyo in Lira district; whereas in Paloro Sub County there were 22 suspected cases screened and 3 were probable case, provided with symptomatic treatment³.

As of date, the community and the health personnel are yet concerned about what causes NS, its origin, why the disease affects children and not adults, which gender is mostly affected, and whether the disease is communicable or not.

¹ International Scientific Meeting on Nodding Syndrome. 2012. Meeting Report, August. Kampala Uganda.

² Nodding Disease Report. (2012). Gulu District Local Government.

³ Nodding Syndrome response plan. 2012. Gulu District –National Task Force Meeting

NODDING SYNDROME CASE MANAGEMENT ANALYSIS REPORT

"We have remained prisoners, we cannot do anything for ourselves while taking care of these kids, and the government should really support us" lamented a caretaker of a Nodding Syndrome Patient at Kitgum General Hospital.

1.0. INTRODUCTION

This report is a follow up on the developments associated with Nodding Syndrome (NS) in northern Uganda. It serves as a catalyst in advocacy for sufficient response to the plight of NS patients in post conflict northern Uganda. It calls for the establishment of conditions that can meet the basic needs and aspirations of the victims as was observed in the International Scientific Meeting on Nodding Syndrome in August 2012 in Kampala. Though the report is limited to developments associated with Nodding Syndrome disease in Kitgum district, it serves as a reminder to concerned stakeholders that the NS remains a challenge and needs an adequate response.

This report entails a summary of key issues, responses and challenges noted in the response to NS in the region. It draws on the case management progress reports compiled by Kitgum district local government which has been enriched by Refugee Law Project's continued engagement with the affected communities in Kitgum, Pader, Lamwo and Gulu districts in understanding the dynamics associated with the Nodding Syndrome and the recovery of the affected victims.

The Refugee Law Project has been on the forefront of articulating conflict issues associated with Nodding Syndrome in post conflict northern Uganda. The first highlight was on the 22nd of January, 2012 when the RLP team visited Tumangu village in Lamit Parish, Akwang Sub County Kitgum district. The briefing note that was produced influenced concerned stakeholders to act. This report draws on our recent visit, to Kitgum from the 12th to the 14th January, 2013. The visit aimed at analyzing progress already made in the fight against the Nodding Syndrome. During the visit, the team interacted with a total of 66 respondents (28 females). These included; a doctor in charge of Kitgum General Hospital, community members, village health teams, elders and the office of the Chairman LCV of Kitgum. The analysis in this report is complemented by data from Kitgum general hospital and Kitgum District Local Government.

Following the first International Scientific meeting on NS held between July-August 2012, in Kampala, Uganda several commitments were pledged by different stakeholders. Key recommendation was formation and activation of a National Task Force. This report sheds light on what has so far been done in response to the Nodding Syndrome as well as the current concerns of NS victims. Also this report helps policy makers to rethink and reframe policy responses in light of the Nodding Syndrome in conflict sensitive context. Undoubtedly, the health sector and the status of the health of post conflict constituents have a great correlation towards contributing to sustainable livelihood, peace recovery and a fight against poverty

reduction. The promotion of good health is strongly called for in the Millennium Development Goals (MDGs) and Uganda is a signatory to this commitment. Though there are recognizable efforts towards improving service delivery in the health sector and realization of the MDGs, NS is one of the factors threatening the attainment of MDGs in post conflict communities such as northern Uganda.

The Nodding Syndrome is largely recognized as a threat to families and households of affected victims in the districts of Pader, Kitgum, Lamwo and Gulu. In response to curb the ailment, the government of Uganda with support from development partners established treatment centres in Kitgum General Hospital, Atanga HC III and Gulu Regional Referral Hospital. The Ministry of health also carried out aerial spraying in a bid to get rid-of the black flies suspected of spreading or causing Onchocerciasis. The health Ministry has been relying on epilepsy drugs to control and manage the conditions associated with NS. Through the Office of the Prime Minister (OPM), patients have been feeding on fortified foods which are said to have helped in boosting their immunity.

Despite the above commitments by the Government of Uganda in responding to the problem of Nodding Syndrome, there are still challenges being faced. As a result, critics have condemned government for its slow and sluggish response to the disease. Regardless of the numerous and extensive investigations, the cause of NS is yet to be known – implying that the patients will have to remain on treatment and monitoring for unknown period of time. This has instilled anxiety and feeling of hopelessness in the affected children and their families.

2.0. NODDING SYNDROME CASE MANAGEMENT: KITGUM LOCAL GOVERNMENT, (AUGUST - DECEMBER 2012).

Aligned to the national task force on NS, Kitgum district task force and functional committees have been established to enhance response to the NS epidemic under the coordination of the Ministry of Health and OPM, through which valuable support (medicine and food) is channeled. The case management team conducts community outreaches three times a week in the affected areas of Tumangu, Okidi and Kitgum Matidi. During outreaches, services such as; health education, counseling, general assessment of conditions of NS patients and food distribution for therapeutic and supplementary feeding are offered. The outreach sites provide the opportunity for the case management team to follow up on clients' progress and their response to treatment.

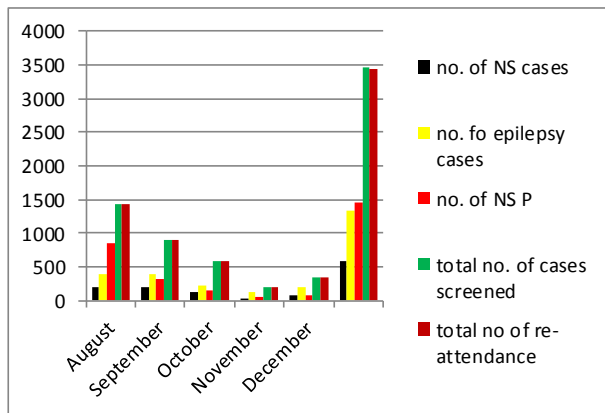
Transport equipment has been availed in the different treatment centers in the north. In Kitgum for example, the medical unit has one motorcycle and 2 ambulances. However, transport challenges still suffice thus preventing effectual response and management of the syndrome. At the time of the visit, the response team had run out of fuel. The fuel was being offered by the Lutheran World Federation-an NGO operating in the region. As such, the district response team could not adequately undertake sufficient field visits and monitoring of the NS patients. Also, the food distribution schedule to the patients was hampered. *"We are supposed to distribute food to*

the patients after every two weeks, and we have been unable to do this because we lack fuel”⁴. The food ration for each patient is about 20 kilograms of maize flour and 6 kilograms of beans. The food is provided to boost the immune systems and fight malnutrition which is also a common disease amongst NS patients. Though the food is said to be available in store, there is an outcry in delay in the distribution due to some unresolved challenges. According to Doreen a mother of a NS patient, this is what she had to say;

“Some of us have stayed for long in the hospital and not done any farming, we cook by ourselves. There is food, we see it, but we don’t know why it is not being distributed”

Accordingly, this similar sentiment arose in Tumangu village. Residents of Tumangu village stated that the last food distribution took place on the 10th of December 2012. By 12th January 2013 there should have been at least two distributions made in between, but this had not happened. The residents also refuted the food rations. They stated that it was not true that each patient is often given 20 kilos of maize flour and 6 kilos of beans. Instead, they are provided with 7 cups of beans and 4 cups of maize flour.

Graph 1: General summary of patients seen at the various outreach centers in Tumangu, Okidi and Kitgum Maditi

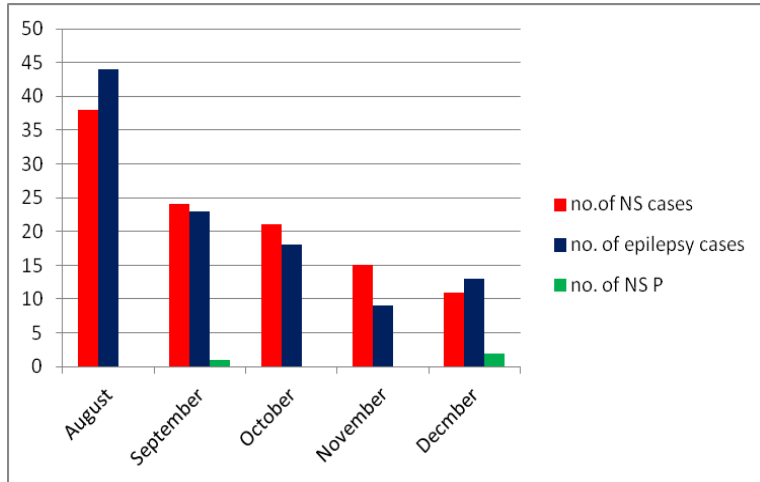


From the various outreach centers, it was documented that there were a total of 17 new cases and 3 reported deaths. According to the Graph 1 aside, there was a general decline in the number of children with Nodding Syndrome cases from August to December 2012. This trend was also experienced with the number of children diagnosed with Epilepsy and those diagnosed as Nodding Syndrome plus (NSP). The reason for the decline in the number of the NSP is not clearly

understood. To some individuals and medical personnel the decline is attributed to the probability of either the drugs or food supplements provided as being effective. The decline in the number of the new cases also defies the assumption that the syndrome is communicable or can be transferred from one person to another. However, what remains a puzzle to the community is the failure to ascertain why one family ends up having more than one victim or patient of NS. To many, this casts doubts on the reports that NS is non-communicable.

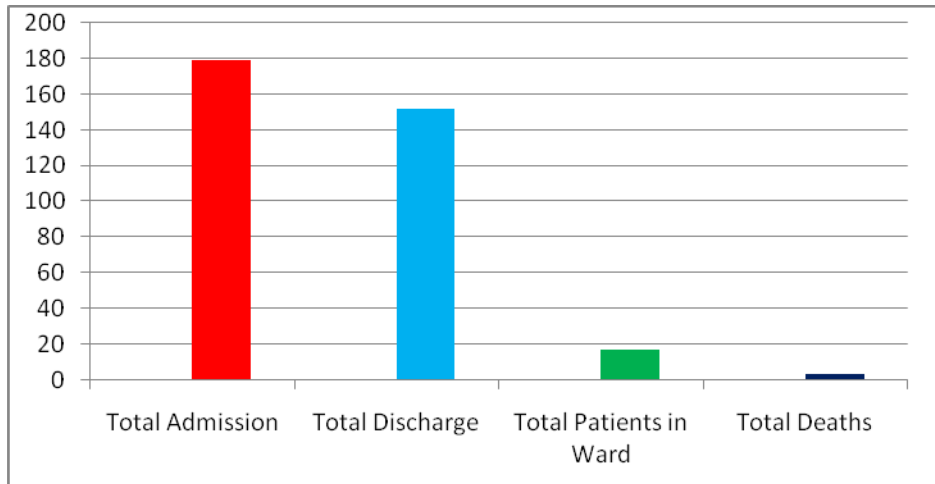
⁴ Interview with medical personnel. 12th January, 2013. Kitgum Hospital.

Graph 2: Summary of patients managed at the out-patient department (OPD) at Kitgum General Hospital treatment center.



From August to December, 2012, a total of 109 cases of NS were recorded and managed at Kitgum General Hospital, 107 epilepsy cases and 03 Nodding Syndrome Plus case with one recorded in the month of September and the other two in December. As the year progressed NS case kept declining from a high rate of 38 suspected cases in August to barely 11 cases in December.

Graph 3: Summary of patients admitted at Kitgum General Hospital Nodding Syndrome ward (in-patient).



A total of 179 patients were admitted, 152 discharged, 17 were handled in the in-ward, and three were reported dead. The statistical abstract from the in-patient ward indicates that there are about 73 males and 106

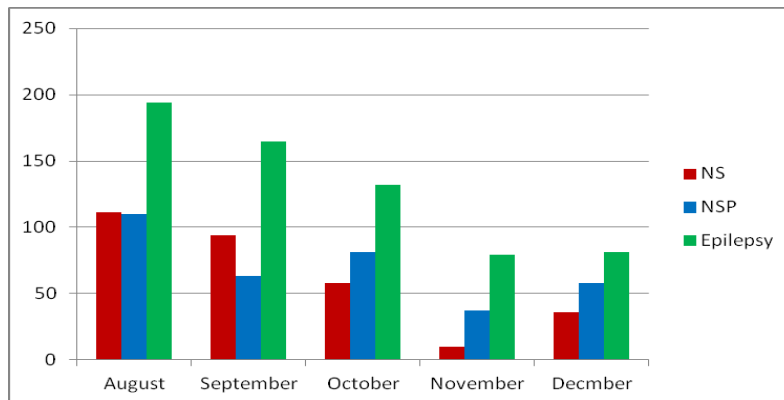
females attended at the in-patient department.

Graph 2 and 3 indicate the variance in admittance at the out-patient and in-patient department at Kitgum hospital. Whereas the out-patient graph recorded monthly admittance (from August to December 2012), the in-patient associated with the dynamics relating to the handling of NS in entirety.

2.1. Nodding Syndrome Case Management in Okidi Health Centre III

The graphs below draws on a comparative analysis of different cases documented at Okidi Health Centre III in Amida Sub County, from the months of August to December, 2012.

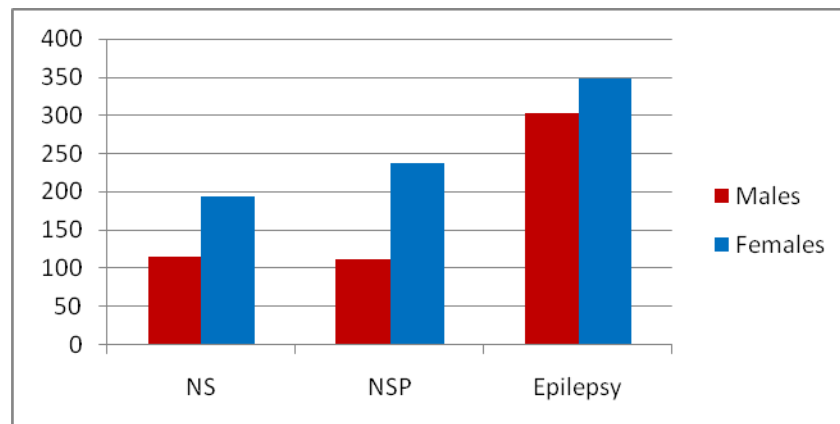
Graph 4: Summary of NS case Management in Okidi Health Centre III from August to December 2012.



The graph indicates that there has been a steady decline in the number of children diagnosed as epileptic patients. In the month of August, there were 194 epileptic children and this declined to 81 in November. There was correlation between epileptic cases and NS cases. The higher the epileptic cases the higher the

NS case. However, this correlation could only statistically be determined and not scientifically.

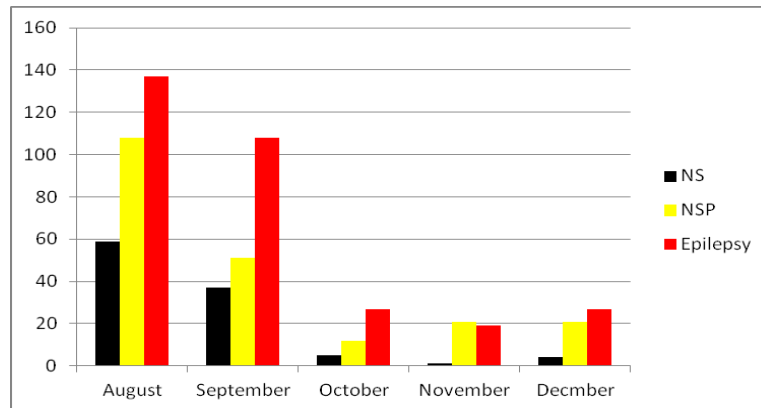
Graph 5: The Gender Dynamic of the N/S, NPS and Epilepsy in Okidi HCIII (August – December, 2012)



At large, the documented records in Okidi health centre –III, in Amida sub county indicates that: of all the cases registered including victims, individuals with Nodding Syndrome, Nodding Syndrome Plus and Epilepsy, females where the majority affected. Why females are more vulnerable or affected remains a matter of concern which requires a deeper inquiry.

2.2. Nodding Syndrome Case Management in Tumangu village in Akwang Sub County August to December 2012.

Graph 6: Summary of Case Management in Tumangu Village, Akwang Sub County.



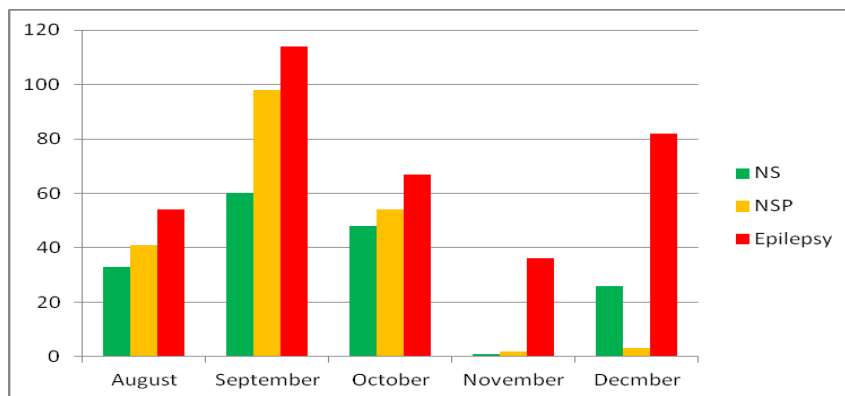
Between the month of August and September 2012, there was a decrease in the number of patients admitted and diagnosed to be having Nodding Syndrome. In the month of August, there were 59 cases, compared to 37 cases registered in September. Similarly, there was a decline in Nodding Syndrome Plus cases from 108 to 59 cases. However, the common trend is that many females were affected than males. From the month of October and November, Tumangu registered a decline in the number of individuals diagnosed with Nodding Syndrome. The figure varied from 5 cases to one case respectively. Where as individuals diagnosed to be having Nodding Syndrome plus, increased from 12 to 21 cases respectively from October to November 2012.

Compared to the month of November, December registered a high number of Nodding Syndrome, Nodding Syndrome Plus and Epilepsy. Similarly, females remain the most affected. The change in trend makes it difficult to understand the changes relating to infection and transmission of the disease. It is known that the disease and rate of seizures is more prominent during cold periods, however in this instance –December being warm/hot more cases of seizures were registered than previous months. This complicates the layman’s understanding of the syndrome.

2.3. Nodding Syndrome Case Management in Kitgum Matidi (August—December 2012)

Like other treatment centers, the accumulated data for outreach relating to the documented cases of Nodding Syndrome, Nodding Syndrome Plus and Epilepsy cases in Kitgum Matidi from the month of August and December 2012, reinforcing the same trend and argument.

Graph 7: Summary of Case Management in Kitgum Matidi.



There was a general increase in the number of diagnosed cases in Kitgum Matidi. The statistical representation indicate that in the month of August there were a total of 128 cases registered and 272 cases registered in September resulting in to marginal difference of 144 cases. Of all the cases registered, epileptic cases were the highest in August and September as well.

Key for all the above graphs above:

NS—Nodding Syndrome cases

NSP—Nodding Syndrome Plus (cases with nodding syndrome, epilepsy and other conditions)

EP—Epilepsy cases

3.0. DEALING WITH NODDING SYNDROME: ACHIEVEMENTS, CHALLENGES, PERCEPTIONS AND RECOMMENDATIONS

Following an inter-ministerial visit to the affected parts of Acholi, government has since shown commitment to respond to the worrying NS. Some tangible achievements have been registered. However, the response team has encountered numerous challenges. Similarly perceptions about the syndrome have continued to characterize the evolving events including conflict of interest between leaders.

3.1. Achievements

The creation of a formal district task force has led to the establishment of a functioning treatment center with a great response to treatment and good adherence to drugs administered. Most of the cases have been identified with referrals of severe cases done by the working team of staffs in place. Also the affected children are able to attend school. Though, the medical practitioners confirmed that some of the Nodding Syndrome patients have gone back to school to study, their parents do not see any relevance of the kids attending school due to the negative effect of the disease on their mental growth and associated stigma. A participant said, *“It is very good to say*

these kids have gone back to school, going back to school is one thing, and performance is another thing. These kids are doing nothing”⁵.



Residents of Tumangu village in a dialogue about Nodding Syndrome

The health team have also been able to dialogue with patients and community on drug adherence, this is said to have resulted into significant improvement. Some care takers of Nodding Syndrome patients at Kitgum General Hospital stated that the medication provided to the victims is helping; however-it takes long for the victims to recover. Contrarily, a number of locals in Tumangu village refute that there is any improvement on the Nodding Syndrome patients. According to Christine this is what she had to say;

“These kids still suffer tremendously, and it is not proper for anyone to say that their health condition has improved, because it is difficult to determine the level of improvement. One or two days they are normal, the third day they are back to the same state. What we only see is that some of them have gained some weight”⁶.

On a positive note, identification and referral of severe cases has been made possible with the help of the available transport (van) and active participation of the staff both at health centre and Kitgum General Hospital.

⁵ Interview with male resident on 13th January, 2013 in Tumangu village

⁶ Interview with female resident. 13th January, 2013. Tumangu village

3.2. Challenges

Various challenges have been registered. In summary these include; malnutrition, limited human resource, increasing operational costs and poor accommodation facilities for the Nodding Syndrome Patients. A medical person at Kitgum General Hospital confirmed that, other than the Nodding Syndrome, malnutrition is another serious disease affecting the patients. This affects their body immune system and the potential to absorb treatment.

“This room was where the former IDP’s used to sleep; now it is a ward. It is very cold and there is need for renovation. At night, the victims are seriously affected by the cold weather – thus leading to seizures”⁷.



Ward for NS Patients in Kitgum Hospital



Inside the ward (NS patients caretakers)

Additionally, the cold weather due to poor accommodation facility is associated with increased seizures. Others challenges include; lack of recreational and psychotherapy materials, delay in the establishment of the proposed nutrition rehabilitation center to fight malnutrition and delay in procurement of equipment especially for therapeutic feeding. Similarly, the periodic drug shortage, lack of proper drug storage, high rates of child abuse and withdraw of volunteers has affected operations.

The outreach sites have limited medical staffs and lack basic equipment for conducting outreach activities. There is a shortage of fuel and thus, the increase in number of the sites has caused constraints on the available resources. Also, communities do not provide appropriate information on time. Some are not adhering to the prescribed use of drugs while some families with many sick children find it hard to transport all of them to outreach sites.

Apparently, the focus is more on addressing or managing the direct effect of Nodding Syndrome on the patients/victims especially providing medication, food supplies, and counseling. Thus more work needs to be done to resolve the prevailing economic and livelihood needs of the

⁷ Interview with medical personnel. 12th January, 2013. Kitgum General Hospital.

victims' families who spend most of their time taking care of the patients in the hospitals. This will help resolve immediate feelings of deprivation, hatred and frustrations amongst communities.

3.3. Recommendations

- The Ministry of Health together with the affected District Local Governments need to increase on the number of medical personnel and other human resource to supplement the available ones for better case management– including counselling and therapy.
- There is need to effectively manage the procurement of equipment and food items. Focus should be on procuring good quality food items, and timely delivery and distribution to help in handling the nutritional deficiency and malnutrition cases.
- The Central Government should improve on the conditions of the health facilities especially wards meant for the NS patients.
- There is need for regular supply of drugs and soliciting of funds for the continuation of the outreach programs. Home visits should frequently be carried out by case management team and volunteers to follow up and monitor the NS patients.
- Local community leaders, government and development partners should ensure that there is respect and protection of the rights of victims of NS some of whom have become prone to rape and unwanted pregnancies.
- The Office of the Prime Minister (OPM) and development partners need to provide sufficient financial support to ease operations and management of cases. The financing should also address other operational costs like fuel costs, vehicle maintenance and facilitation for village health teams to ease their work with communities.
- In Tumangu village – the locals specifically demand that the OPM fulfills its earlier promises made of establishing a fully operational Health Centre II in the area. This is to broadly improve on the delivery of health services and not only manage NS. The locals also request that a bore hole be drilled in nearby communities to ease access to clean and safe drinking water.
- Individual households affected by NS appeal to the Central Government to strengthen the livelihood component of those affected through agricultural projects, provision of farm implements – oxen, ploughs, and seedlings.

CONCLUSION

There is good motive and objectivity towards eliminating the Nodding Syndrome from post conflict northern Uganda. This has been evidenced through the various initiatives such as the establishment of Nodding Syndrome case management centers and the aerial spraying of the breeding grounds of black flies-associated to Onchocerciasis. However, there have been challenges and some degree of negligence from various key stakeholders in the fight against NS from both local to the national levels. Thus, the level of response towards the NS in this socially, and economically unstable communities of northern Uganda contributes to a lot of frustration to individual households. Consequently, the state is seen to be inconsiderate of the plight of the NS victims as desperation continues. The failure for the government to fulfill her promises to the NS households in some places has resulted into hostility and rejection of state representatives including local councilors. Thus, a further genuine course in the fight against NS is lost as the local's loss hope and confidence on the state.

About Refugee Law Project (RLP)

The Refugee Law Project (RLP) seeks to ensure fundamental human rights for all, including; asylum seekers, refugees, and internally displaced persons within Uganda. RLP envision a country that treats all people within its borders with the same standards of respect and social justice.

About Advisory Consortium on Conflict Sensitivity (ACCS)

The Advisory Consortium on Conflict Sensitivity (ACCS) is a three member consortium that brings together Refugee Law Project, International Alert and Saferworld. The overall aim of ACCS is assisting DFID and partners in strengthening the potential of the Post Conflict Development Programme (PCDP) and recovery process to address the causes of conflict and contribute to sustainable peace and stability. Under the ACCS, RLP is leading on contextual analysis of the overall recovery process (focusing on conflict indicators, issues and dynamics), and early warning as and when necessary.

Acknowledgement

This report is authored for strategic advocacy purposes and early warning in regards to the dangers that Nodding Syndrome disease poses to the recovery of the communities in Northern Uganda. The report was written by Denis Barnabas Otim (Project Officer) and Jackson Odong (Research and Advocacy Officer), with valuable input from Tabitha Avola (ACCS Intern), Stephen Oola (Programme Manger) and Dr. Chris Dolan (Director) . The report was made possible by UK-DFID financial support.



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