

Improving the care and the treatment outcomes of children and adolescents with Nodding Syndrome and other Epilepsies through training, support supervision, research, and collaborations in Uganda

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Outline Of Presentation

- ▶ Background
- ▶ Activities
- ▶ Lessons learnt
- ▶ Way forward



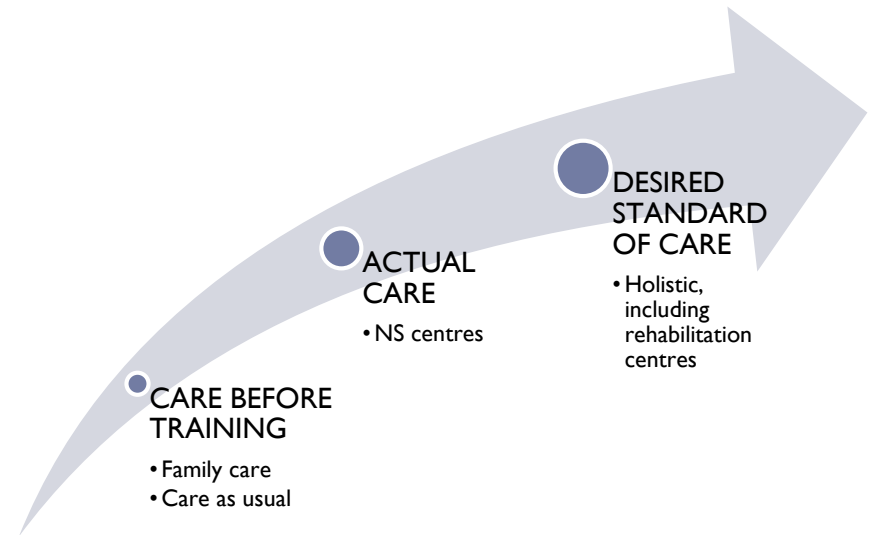
Background.

- ▶ In 2012, The Ugandan Government declared an epidemic of Nodding Syndrome (NS)
- ▶ In the Northern districts of Lamwo, Pader and Kitgum.
- ▶ This region also has a very high burden of other forms of epilepsy.
- ▶ Guidelines were developed and treatment centres established.



Background-The Gap

- ▶ The gap between the desired standards of services available and the services rendered to patients is wide



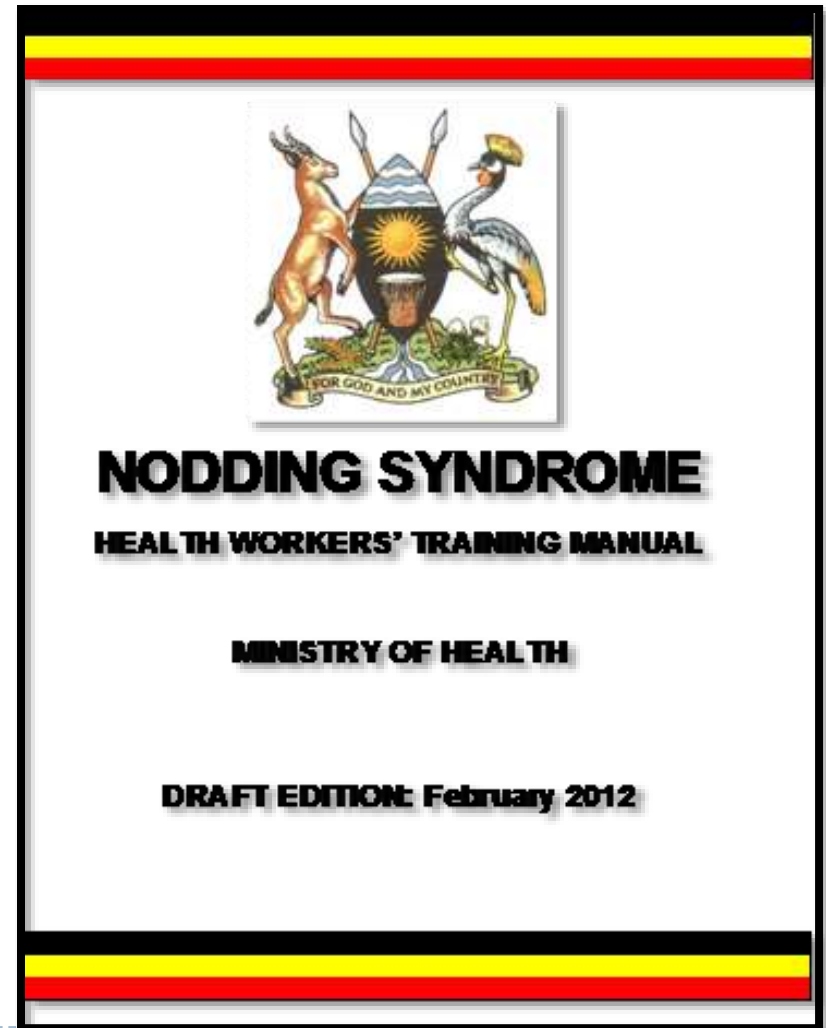
Activity-1: Planning Meetings.

- ▶ To narrow this gap, a series of planning meetings with the Ministry of Health (MOH), academicians, clinicians in relevant fields and development partners took place.
- ▶ National Task Force was formed
- ▶ several key activities were identified by the national task force to respond to the epidemic.



Activity- 2-Development of Training Manual..

- ▶ As NS is far from being a purely a health condition
- ▶ MOH set up a multidisciplinary team of clinicians, nurses and therapists
- ▶ Developed a training manual which was later used to train health workers in the syndromic management of NS and other epilepsies.



Activity-3: Setting up of Treatment Centres...

- ▶ Treatment centers were set up in all the NS affected districts



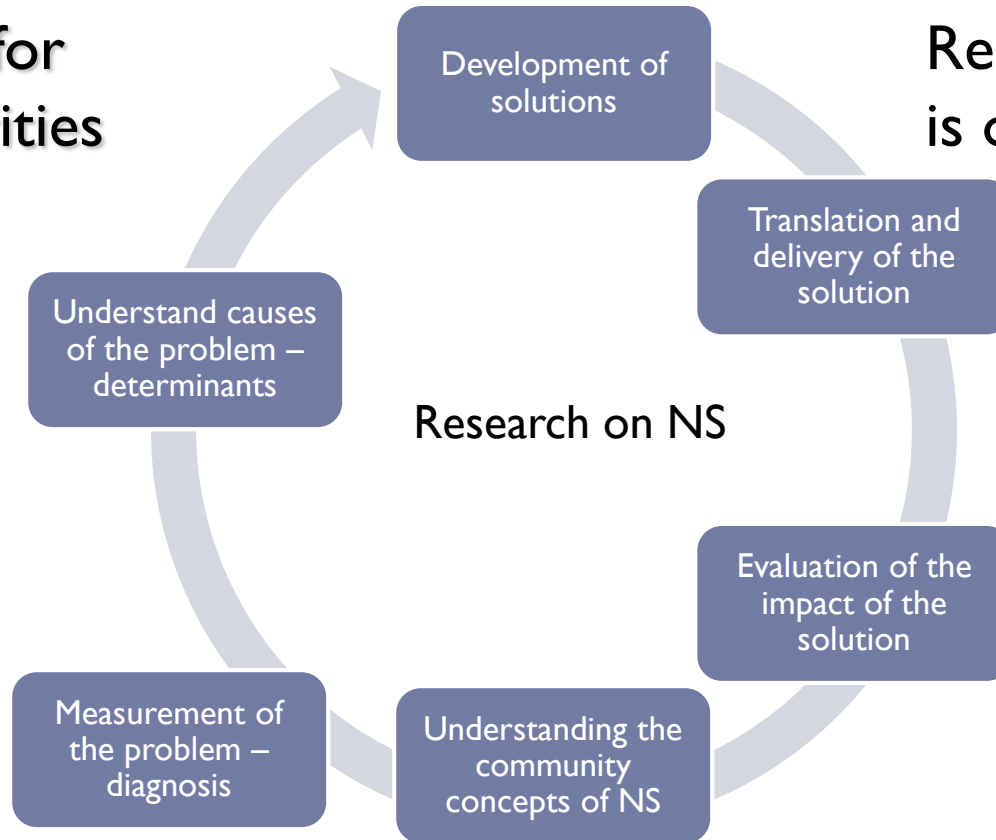
Activity-4:Annual support supervision visits....

- ▶ The findings at these visits and the concurrent clinical research on NS were used to advise on and develop interventions and conduct additional trainings for health workers.



Activity-5: Research

A Framework for Research Priorities on NS



Research Activity is ongoing

Research on NS

Publications from Research Activity

1. **Idro, R., Opar, B., Wamala, J., Abbo, C., Onzivua, S., Mwaka, D.A., Kakooza-Mwesige, A., Mbonye, A. and Aceng, J.R., (2016). Is nodding syndrome an Onchocerca volvulus-induced neuroinflammatory disorder? Uganda's story of research in understanding the disease. *International Journal of Infectious Diseases*, 45, pp.112-117.**
2. **Mwaka, A., Okello, E., Abbo, C., Odwong, F., Olango, W., Etolu, J., ... Neema, S. (2015). Is the glass half full or half empty? A qualitative exploration on treatment practices and perceived barriers to biomedical care for patients with nodding syndrome in post-conflict northern Uganda. *BMC Research Notes*, 8(1), 386.**
3. **Idro, R., Namusoke, H., Abbo, C., Mutamba, B. B., Kakooza-Mwesige, A., Opoka, R. O., Opar, B. T. (2014). Patients with nodding syndrome in Uganda improve with symptomatic treatment: a cross-sectional study. *BMJ open*, 4(1**
4. **Mutamba, B., Abbo, C., Muron, J., Idro, R., & Mwaka, A. (2014). Stereotypes on Nodding syndrome: responses of health workers in the affected region of northern Uganda. *African health sciences*, 13(4), 986-991.**
5. **Musisi S, Akena D, Nakimuli-Mpungu E, Abbo C, Okello J Neuropsychiatric perspectives on nodding syndrome in northern Uganda: a case series study and a review of the literature *African Health Sciences Vol 13 Issue 2 June 2013***
6. **Idro R, Musubire K A, Byamah Mutamba B, Namusoke H, Muron J, Abbo C, Oriyabuzu R, Ssekya J, Okot C, Mwaka D, Ssebadduka P, Makumbi I, Opar B, Aceng JR, Mbonye AK, Proposed guidelines for the management of nodding syndrome *African Health Sciences Vol 13 Issue 2 June 2013***

Lessons Learnt-What Went Well.

- ▶ The following activities went well:
 - ✓ Planning meetings chaired by DG herself
 - ✓ Developing the training manual-Led by Richard Idro
 - ✓ Initial setup of the treatment centers and
 - ✓ Training of health workers.
- ▶ Also researches have been going on well!

What went well..

- ▶ An audit about 12 months later reported great improvements in seizure control, nutritional status, independence, functioning and general well being.

	Nodding syndrome, N=484			Other convulsive epilepsies, N=476		
	Before	After	P value	Before	After	P value
Seizure free > 30 days	8 (1.7%)	121 (25.0%)	<0.001	8 (1.7%)	243 (51.1%)	<0.001
Daily clusters of head nods, median (IQR)	4 (IQR 3,6)	1 (IQR 0,2)	<0.001			
Behaviour and emotional difficulties	327 (67.6%)	133 (27.5%)	<0.001	206 (43.3%)	105 (22.1%)	<0.001
Independence in basic self care	174 (36.0%)	402 (83.1%)	<0.001	206 (43.3%)	397 (83.4%)	<0.001
Attending school	107 (22.1%)	193 (39.9%)	<0.001	170 (35.7%)	250 (52.5%)	<0.001

Lessons Learnt-challenges/Solutions

- ▶ Poor seizure control in many children severe burns



Wandering away

Challenges-Possible reasons

- ▶ Some of the reasons reported for the worsening situation:
 - ✓ Antiepileptic drug stock-outs
 - ✓ Outreach: The clinicians mentioned that they had not been facilitated since Dec 2014 and last carried outreaches in July 2014



Challenges....

- ▶ **Trained health workers migrating away from their work stations..**
- ▶ **Recruitment of clinicians:**
- ▶ *‘There were five posts advertised for registered nurses, two applications were received and only 1 showed up for interviews. it is not clear why there were no applicants. Further, those trained in management of NS have not provided services ; others have left for further studies’.*

Revising and Retraining of health workers

- ▶ Revision to include management (diagnosis and treatment) of epilepsy other than NS
- ▶ Inclusion of management of teenage pregnancy and labour -input from Obstetricians
- ▶ Planning for refresher training- June, July 2017

POLITICIANS

GATE KEEPERS OF THE
DISTRICTS ARE INVOLVED



Richard emphasizing what a case of NS is



Cathy discussing Epilepsy



Feedback from GD

Group discussions





Practical sessions for Physiotherapy

Health breaks



Challenges-No multidisciplinary Team

Aim to restore function and prevent further disability through:

- ✓ Improve on ADL-**OT**
- ✓ Cognitive stimulation-**CP**
- ✓ Mx of speech and feeding difficulties-**SP**
- ✓ Physical therapy-**Physio**
- ✓ Control seizures-**clinicians**
- ✓ Treat malnutrition-**nutritionists**
- ✓ Special needs education-**Special needs teachers and rehabilitation centres**

very few multi-disciplinary team members in particular physiotherapists, occupational therapists and special needs teachers, to provide for the complex needs of the patients

- ▶ Clinicians most available, the rest, hardly available

Challenges- Poor feedback from researchers

- ▶ Concern from the community with regard to poor disseminations of findings to the affected community.
- ▶ Researchers never go back to the community to discuss with them their findings and way forward

Challenges-Early pregnancies

- Early Pregnancies
- Effects of AED to the developing baby
- Contraception



“Many patients with nodding syndrome are now adolescents and starting to engage in sexual activity. What is the role of providing contraception to the children?”

Some Policies already in place:

- ▶ Adolescent policy on supplying contraceptives to minors under 18 years
- ▶ Emancipated minors
- ▶ From UNICEF website:
https://www.unicef.org/esaro/5440_uga2015_end-child-marriage.html
- ▶ *Uganda, 16 June 2015: Government launches national strategy to end child marriage and teenage pregnancy*

Challenges-Sexual abuse

- ▶ **Beliefs: A father who believed that having sex with her daughter might cure her**
- ▶ **-Caregiver as the abuser and yet very non existent welfare services**
- ▶ **High sexual drive (? Sodium Valpoate), Normal adolescence but low understanding of social norms)**
- ▶ **On Sep, 21, 2017, 13,089 FDA reported people reported to have side effects when taking valproate sodium(between 1997 and 2017. Among them, 3people (20-29yrs; 30-39yrs) (0.02%) had Libido increased**

Challenges- Lack of special schools and rehabilitation centres

In Pader, there was a report of a Bishop from a Pentacostal church that had taken on some children with NS claiming to be praying for their healing while living in his church. There were concerns of possible child abuse as it was reported that he uses the children to cultivate his gardens.

There may be need for the MOH to follow up this matter in a non confrontational manner as the bishop may be providing the much needed psychosocial support to these children.



Discussions of physical therapy during training
But it stops at the training mostly



Challenges- Psychosocial issues

- ▶ Kitgum district overwhelmed with psychosocial issues
 - ▶ separations,
 - ▶ alcohol abuse,
 - ▶ child sexual abuse.
- ▶ **Suggestion:** Develop separate guidelines in management of psychosocial issues related to nodding syndrome followed by training of health workers, community development officers etc to curb the rising prevalence of psychosocial problems

Conclusion And Way Forward

- ▶ Ongoing research, regular quarterly, support supervision, refresher trainings and updates with new research findings are essential in improving outcomes and care of children with complex diseases.
- ▶ Support supervision reports challenges and suggests/implements solutions some are immediate e.g liaising with NGOs to raise the fire place, short term e.g resume outreaches and others long term e.g Policy issues
- ▶ Uganda already has very good policies that would include children with NS, the problem is implementation

Conclusion And Way Forward

- ▶ Better integrated care is needed across health, education and social sectors.
- ▶ Support in the following areas: Rehabilitation facilities for NS children, livelihood support for parents and caregivers
- ▶ Developing training guidelines for psychosocial interventions, training of implementers.

**THANK
YOU**

ASANTE SANA