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# The gendered burden of epilepsy/nodding syndrome in Cameroon, Tanzania and Uganda

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# Introduction

- A high prevalence of Epilepsy/Nodding Syndrome(Ep/NS) has been reported in Southern Tanzania since the 1960s, Northern Uganda and Central Cameroon roughly since the late 1990s
- The social burden of Ep/NS in these countries has been described as
  - Stigma, lack of mobility & cognitive decline
  - Financial hardships
  - Burden of caretaking

## Larger study scope

To improve the understanding of the socio-behavioral-environmental factors linked to Ep/NS in Cameroon, Tanzania and Uganda



# Research questions

- Who bears the brunt of caretaking of Ep/NS patients in Cameroon, Tanzania and Uganda?
- What are the hardships faced by the person affected?
- Is there a disproportionate social burden of disease?



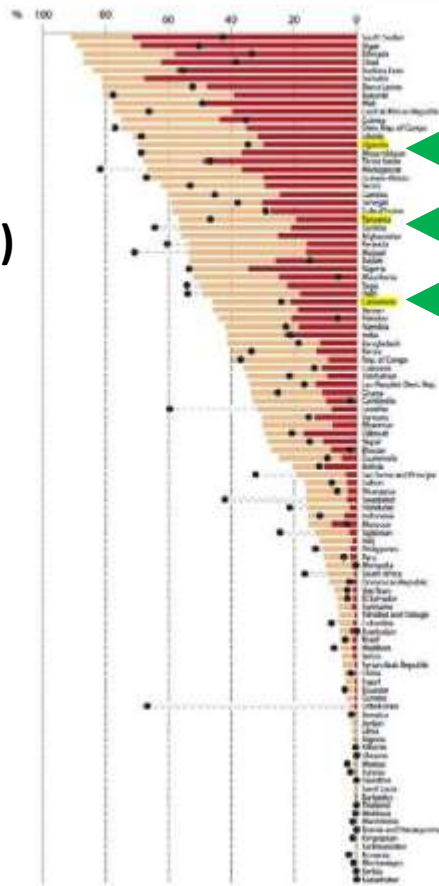
# Study setting

- The villages selected in all 3 countries are
  - rural / semi-urban
  - livelihood predominantly subsistence farming
  - onchocerciasis is endemic there
  - High prevalence of Ep/NS



Fig. 7. Comparing the headcount ratios of MPI poor, destitute, and \$1.90/day poor

**MPI**  
(multidimensional poverty index 2017)



Uganda - Northern Region 0.431

Tanzania - Southern Region 0.296

Cameroon - Central Region 0.179

## Data collection

	Tanzania	Uganda	Cameroon	TOTAL
N° villages	11	13	11	35
In-depth interviews	52	84	94	230
(Focus) Group Discussions	15	8	45	68
Informal Conversations	49	30	92	171

Participant observation was concurrent throughout data collection



# Social Burden of Epilepsy/Nodding Syndrome

Caretaker

Patient



## Expected Role



- household chores and cultivation
- For Ep/NS patients in HH: daily hygiene, nutrition, adherence to drugs, **keep them safe**



- Seasonal hard physical labour
- Financial support of household, however, in practice it is limited
- For Ep/NS, occasional assistance during seizures, washing of adult males...

## Consequence

- Spiral of poverty
  - ↑ work      ↓ productivity on farm
  - ↓ food/money
  - If affected female gets pregnant, added burden of caretaking
- Limited access to healthcare
  - With more work and responsibilities, it becomes more difficult to leave the home and access healthcare

# Burden of caretaking

## Uganda

- Mothers of Ep/NS frequently abandoned by father and burdened with caretaking
- Orphaned Ep/NS children or those cared for by female relative (step-mother, grandmother, aunt) reported more likely to be neglected/mistreated
- Men are less aware of treatment provided to their children

## Cameroon & Tanzania

- Comparatively, fathers more supportive
  - aware of medications/visit HC
  - help with some household chores
- In Tanzania, dominant belief is that it's hereditary, so the family is generally supportive

## Expected Role



- household chores, cultivation



- seasonal hard physical labour  
e.g. preparing land for  
cultivation.

## Consequence

- Reported fatigue leading to more seizures
- More exposure to fire (possibly water) hence burns (or drowning)
- Many had several burns before they were prohibited from cooking or got supervision
- Fatigue (sooner)

## Expected Role



- household chores, cultivation

## Consequence

- Reported fatigue leading to more seizures
- More exposure to fire (possibly or drowning)

Influenced by severity of condition  
 Many had several burns before they were prohibited from cooking or got supervision



- seasonal hard physical labour e.g. preparing land for cultivation.

- Fatigue (sooner)

## Expected Role



- household chores, cultivation

## Consequence

- Reported fatigue leading to more seizures
- More exposure to fire (possibly or drowning)

If stop being productive, e.g. treated as "useless" influenced by "severity of condition" M. had severe burns before they were prohibited from cooking



- seasonal hard physical labour e.g. preparing land for cultivation.

- Fatigue (sooner)

## Social challenges



- Stigma
- Marriage difficult
- If cognitive decline,
  - Social interactions difficult
  - Psychotic behaviour in some
- Excluded from schooling



## Consequence

- sexual violence, other diseases, single motherhood, added burden on caretaker, fall deeper into poverty
- Is sexual violence towards males hidden?
- (One report in UG of boy subjected to sexual abuse, where perpetrator was sent to highest offence jail (death penalty) )

# Social challenges for patient

## Uganda

- Sexual violence common (different sources)
- Victims often not believed without witness
  - Cognitive impairment
  - Hiding by caretaker due to fear of being accused of neglect
- Perpetrators often not convicted

## Cameroon & Tanzania

- Comparatively, less reports of sexual violence and single motherhood/pregnancies
- *“If they are lucky they can have a baby, but no one will marry them.” (female, community member, TZ)*



## Findings - Uganda

- *“there is too much abuse of human rights especially for the girl child... most of these girls get sexually abused and get pregnant at their tender age; a child gives birth to a child whose paternal father is not even known. This nodding diseased girl has to raise the child adding on the burden for their caretaker and when these culprits are taken to the court, the court is also very funny. It has become like some thing very usual in the community and the culprits are not punished...So in my own view since these children are sexually abused is it proper to offer them family planning?” – Female, Clinical officer, Uganda*

## Conclusion

- Women bear a disproportionate burden both as caretakers and patients
- The extent varies from country to country
- This is common knowledge for most clinicians and practitioners in the area, but very little is reported on it



# How can we incorporate this knowledge in further research and policy plans for Ep/NS?



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