

# **Socio-cultural factors and experiences of r-HAT patients in Kaberamaido, Eastern Uganda: implications for treatment-seeking**

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# Introduction

- Human African trypanosomiasis or sleeping sickness is a fatal disease caused by *Trypanosoma brucei* protozoa and transmitted by tsetse fly
- Sociocultural factors play a critical role in individuals' treatment outcomes
- Early treatment is crucial for effective control of the disease.

# Objectives

- To assess the health seeking behavior of the target populations and its links with delayed access to treatment
- To understand the experience of existing or cured patients as well as their families, including those of deceased patients
- To devise mechanisms for community and peripheral health workers engagement regarding r-HAT treatment access and case detection

# Methods

- Part of a larger clinical trial which aimed at assessing efficacy and safety; facilitate access to and effective oral treatment for r-HAT
- Focus group Discussions, In depth interviews, key informant interviews, follow up study with other providers of care
- This paper is based on 20 in-depth interviews with community members who had ever had sleeping sickness or their caretakers were conducted
- Data was collected in November 2019 in Kaberamaido district, eastern Uganda
- Thematic content analysis was used.

# Training of Research Assistants

- Training was conducted to reinforce the data collectors' capacity to collect data using qualitative methods and understanding the ethical and confidentiality requirements of the study protocol
- Training included research ethics, confidentiality and best practices in interviewing techniques.
- The training content included:
  - Overview of anthropological study protocol
  - Research ethics/Consent forms
  - Review of Tools and role plays
  - Fieldwork schedule (day-by-day), team roles and responsibilities,
  - Field operations
- Practical exercises to familiarise with the particular instrument(s) to improve their competence
- A pretest was conducted that aided in the refining of the tools.

# Methods: Ethnographer at work: Indepth Interviews





# Data analysis

- Notes collected during the interviews (formal and informal) were expanded every evening by the data collectors
- Recordings from the IDIs were transcribed, verbatim by the research assistants and quality checked by the Principal investigator.
- Similar codes were grouped into themes and sub-themes and reviewed to identify meanings and relationships between themes
- Code structure evolved inductively reflecting participants' experiences and voices
- Transcripts were entered in Nvivo qualitative analysis package for coding and analysis
- Themes, concepts, dimensions and their interrelationships were extracted using iterative process
- Data was analyzed using a summative thematic content analysis approach conducted on a rolling basis as soon transcripts were typed
- Quotes have been used extensively in the report to further explain and provide evidence for the emergent themes

# Ethical Considerations

- The study protocol was submitted to and approved by Makerere University School of Social Sciences Research Ethics committee (MAKSSREC) and Uganda National Council for Science and Technology (UNCST) - SS5086
- All data collection was conducted respecting confidentiality
- Participants were informed of confidentiality procedures as part of the consent process
- The consent forms were translated in Kumam
- Consent forms for each type of instrument were administered before the commencement of the interviews



## Results: Socio-Demographic Characteristics of participants (IDI n-20)

Characteristics	
<b>Category</b>	
Patient	13 (65%)
Caretaker	7 (35%)
<b>Sex</b>	
Male	12 (60%)
Female	8 (40%)
<b>Age</b>	
20-30	3 (15%)
31-40	8 (40%)
41-50+	9 (45%)
<b>Education</b>	
Primary	<b>17 (85%)</b>
Secondary	2 (10%)
Tertiary	1 (5%)
<b>Occupation</b>	
Subsistence farming	<b>18 (90%)</b>
Teacher	1 (5%)
Petty business	1 (5%)

- Most 33 years plus
- **Low education**
- **Subsistence farming**

## Results: Perceived Causes of Sleeping Sickness

- Most participants were aware that a type of tsetse fly was the “cause” of sleeping sickness
- Knew the high risk places such as bushes around homes, forested areas, stagnant water, streams, wells and swamps as habitats
- Infected as they went along with their daily chores (digging, herding, fetching water etc.) making it difficult for them to avoid such infested areas
- Lack of comprehensive knowledge about the disease affected their health seeking behaviour

## Results: Who is affected and why: *socio-cultural factors*

- Most of those infected are older children, who go to fetch water, firewood and grazing
- By Gender, women, who go to fetch water and firewood, and gardening, most affected
- Men (who are grazing, gardening) are affected
- “This disease is for **poor people**”
- Few elderly people got infected as they don't roam about in thick bushes
- Misconceptions related to the cause of the disease is still prevalent (e.g. witchcraft)
- Cultural specific attitudes of the disease affecting getting treatment
- Poor health seeking behavior led to delayed access to treatment (home, clinics, H/Centres and hospitals not specialized treatment)

# Experiences of Patients with Sleeping sickness like symptoms

- Ok so tell me the symptoms of sleeping sickness.
- R: It makes one **cold all the time**, and **feel like being under the sun**. And instead of making one go to sleep in the house it makes a person to look for a hot place.
- Other than that one, it brings **severe headache**. The headache can leave you for only **10 minutes** but the rest of the two hours you have serious headache. The headache is as though it wants to **crack your head**. I was **getting mad**, I could **not see far** (**cultural experience of pain**)
- ***For me it even made me run mad that is why they even brought prayers. Mine I think was just going to kill me.***
- ***Because of that pain and the feeling I was taken to the traditional healer. When they saw like it was not possible they brought prayers. Then it was after prayers that people suggested that they test for sleeping sickness.***

# Witchcraft not ruled out

- ***I What are some of the symptoms you experienced?***
  - P: I could feel cold all the time (morning to evening) and during the day time, I was always ***under the sun like a lizard (Igulegule)*** which is ever under sunshine.
  - I could also experience ***severe headache more so from 7pm throughout the night***. This headache was too much that I could even sometimes feel like I am going to run mad. I ***knew it was related to witchcraft for real***.
- ***I: So now tell me where you went after experiencing all those symptoms and why?***
  - P: .., I got scare and thought that I was bewitched by someone since my ***husband also had the same symptoms*** when he got sleeping sickness and he went to some traditional healer around us here, but he did not get treatment as such.

# Witchcraft not ruled out (II)

- ***What was prescribed?***

- P: When I went to the traditional healer and explained all that I was going through she then started ***performing her activities on me*** that is: *She got some fresh leaves from certain plant and tied them together and she started beating them on my head so that whatever witchcraft which is in me comes out (Elwit) but she could not see anything. She did it the second time again she could not remove anything. Then later after her realizing that I was getting weak and weak, she then advised my husband to take me to the hospital and that is how we left her shrine*

# Conclusions

- Sociocultural factors need to be understood and factored in the control and elimination of sleeping sickness
- The experiences of the affected persons need to be incorporated in interventions.
- Selection and optimizing effective means for reaching the target audiences is suggested through **multisectoral approach** in social mobilization and health education communication campaign at all levels
- Community engagement plans need to be spelt out for any sleeping sickness interventions, including community dialogues
- More sensitization on the benefits of treatment vs fear of the drugs/side-effects
- Integrate sleeping sickness in primary health care activities and involve other sectors such as education, gender, water, agriculture and livestock etc