# BARRIERS TO ACCESSING TREATMENT AMONG PATIENTS WITH R-HAT AROUND VWAZA MARSH WILDLIFE RESEARVE IN NORTHEN MALAWI

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### R-HAT in Malawi

- Occurs around conservation areas: in Nkhota Kota Game Reserve, Kasungu National Park, Vwaza Marsh Wildlife Reserve in Rumphi and Mzimba District.
- About 2.5 million people are at risk in Malawi
- Wild animals are the reservoirs of parasites that cause sleeping sickness and these parasites are transmitted by infected tsetse flies to human beings.
- Malawi has been reporting about 35 cases of r-HAT between 2008 and 2018 but in 2019 this went up to 92 cases.

# The study

- It is difficult to eliminate r-HAT in Malawi because of its zoonotic nature.
- We can however eliminate this disease as a public health problems.
- We have challenges of case detection and reaching out to r-HAT patients.
- This rate detection of r-HAT and onset of treatment impacts negatively on patient outcomes.
- We need to create awareness about the disease, its aetiology and prevention, need to timely seek treatment.
- This paper explores the challenges in seeking treatment for rHAT in Malawi.

# Methodology

- The study was conducted in Vwaza Marsh Wildlife Reserve in Rumphi and Mzimba Districts who are at risk of contracting r-HAT.
- We use an ethnographic approach: a process of recording and interpreting another peoples' way of life.
- We will use participant observation, face to face interviews, informal interviews and FGDs.

### Methodology

- Literature review, IDI, KIIs, FGDs
- IDIs+KIIs= 33, 5 FGDs with men, women, rHAT patients (x2), caregvers
- People we will talk to will include the following:
  - Community members.
  - Relatives of family members who died of r-HAT.
  - Persons who had r-HAT and were cured.
  - Health care providers
  - Traditional healers
  - Health surveillance assistants
- Use health workers including HSAs and community leaders to identify informants.
- Snowballing as approach to identification of informants.

### Results

- Where do people seek treatment for rHAT?
  - Self medication, traditional healers, health facilities [health centres or Rumphi District Hospital].

#### • Barriers:

- Delays in seeking care,
- long distances to health facilities,
- transportation costs to the District Hospital,
- lack of food items,

# Delays in seeking health care

#### Self medication:

- Signs of sleeping sickness similar to malaria, people are aware of treatment for malaria, hence they may just purchase the drugs from shops.
- In some cases health facilities miss diagnosiung rHAT and end up providing treatment for malaria.
- People have died because of delays in diagnosing the disease.

#### Traditional healers

- Beliefs in witchcraft still prevail in Malawi and around the Vwaza Marsh Game Reserve.
- They may seek treatment from health facilities of they may self medicate and not get better, hence they resort to traditional healers as they think they have been bewitched..

# Delays in seeking health care

#### Traditional healers continued

- Since the disease is refractory to treatment they end up saying that they have been bewitched and then they consult traditional healers.
- These traditional healers may provide treatment and then they do not get better and they go back to the health facility for further assistance. This further delays treatment.

"When I started showing the signs and symptoms, I could not figure out that it was sleeping sickness. As a result, I went to different traditional healers who also told me that I was bewitched and they gave me traditional medicine which I was taking but there was no change", (recovered patient, Thunduwike, Mzimba).

### Fear of lumbar puncture

- Lumbar puncture is performed in order to determine if trypanosomes have gone into the spinal cord.
- Many patients of lumbar puncture and their relatives shared the fact that this process is very painful and study participants sai dthat in some cases when patients hear that they will undergo lumbar puncture they fear seeking care from the district hospital.

"We are tied and squeezed with the back bent so that the head touches the knees. Other people help in pinning the patient so that there is no movement as the injection is inserted on the back. They act as if they are killing a cow", (P1, FGD with men, Manolo, Mzimba).

# Long distances to the district hospital

- Local health facilities around Vwaza Marsh have been strengthened and they are now able diagnose rHAT.
- All persons who are found with rHAT are supposed to travel to Rumphi District Hospital for treatment which is located some 65-70 km away.
- The cost of transport is around MK3,500 one way and in some cases these are accompanied and it is very difficult for people in this rural community to raise this money.
- Many time rHAT patients will delay in seeking treatment because of transport challenges.

"It was very difficult for me to know that I was suffering from sleeping sickness. In addition, it was difficult for me to travel to Rumphi hospital due to long distance, and I had no money to use for transportation with my guardian. Due to this, my situation worsened and the brain was mostly affected which may also lead to madness ....", (Recovered patient, Thunduwike, Mzimba).

### Lack of food and other items

- When patients are admitted at the district hospital, treatment is given free of charge. They are also given some food free of charge by the hospital.
- However, the guardian that accompanies them also requires food, hence they need money to enable them purchase food and other items items to support them during periods of hospitalization an dthis can be very expensive.
- Many study participants narrated that they sold their crops and other household items in order to support themselves during hospitalisation.

# Lack of participation of private facilities

- There are a few private facilities around Vwaza Marsh.
- These facilities do not participate in the control and treatment of rHAT.
- Private clinics just focus on other diseases and not sleeping sickness.
- There might e a need to involve them in the diagnosis and treatment o rHAT.

### Other factors

- Poor attitude of health workers
- Lack of testing equipment at some facilities
- Shortage of staff
- Abandonment of hospitalization due to challenges being experienced such as food and the pain they experience

### Conclusions

- Most cases of r-HAT are diagnosed when the disease is at advanced stage and they experience severe symptoms including convulsions.
- In this study participants identified the major challenges being experienced in seeking treatment for rHAT, th emajor ones being the long distances to the district hospital and delays in seeking care.
- It is important that people in the community should be aware that the disease should be diagnosed and treated early, and that seeking care from traditional healers is not as helpful.
- The MoH should ensure that treatment is given in the nearby health facilities instead of people going to the District Hospital.
- Such an interventions would improve adherence.