

An ethnographic study of local community and peripheral health centre staff perceptions and practices regarding sleeping sickness (r-HAT) to improve treatment access and extend case detection in Uganda



FINAL REPORT

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ACRONYMS

CDD	Community Drug distributors
FGD	Focus Group discussions
HAT	Human African trypanosomiasis
LC	Local Council
MOH	Ministry of Health
NTDs	Neglected Tropical Diseases
r-HAT	<i>T. b. rhodesiense</i> Human African trypanosomiasis
UDHS	Uganda Demographic and Health Survey
VHT	Village Health Teams
WHO	World Health organization

EXECUTIVE SUMMARY

This report presents the findings of r-HAT ethnographic study conducted in Kaberamaido District which is part of Teso sub-region Eastern Uganda. The main objective of the research was to understand the perceptions and practices of the local community and peripheral health centre staff regarding r-HAT in order to improve case detection, referral and access to treatment. Specifically, the study sought to: assess the health seeking behaviour of the target populations and its links with delayed access to treatment; understand the experience of existing or cured patients as well as their families, including those of deceased patients; devise mechanisms for community and peripheral health workers engagement regarding r-HAT access to case diagnosis and treatment.

The research employed qualitative methods using in-depth interviews (n=20), focus group discussions (n=8), key informant interviews (n=12). Data was collected in November 2019. A follow-up study was conducted in February 2021 understand other care options rHAT patients seek. The main objective of the research was to understand the alternative care available for people with sleeping sickness-like symptoms. During the main study in 2019 findings pointed to the fact that many patients first utilize other care before they appear at the government health care facilities, and more so at the gazetted facilities that provide rHAT care. Such health care providers included those in private clinics, drug shops; traditional healers, hawkers, faith-based prayer/intercession providers. Key informant interviews from these providers were conducted and included private clinics and drug shops (n=10), traditional healers (n=10), hawkers; in-depth interviews with those who consulted the alternative care (n=20), and focus group discussions with community members (n=8). Thematic content analysis was used for analysis.

Key findings

- Most participants were aware that a type of tsetse fly was the “cause” of sleeping sickness and knew the high-risk places such as bushes around homes, forested areas, stagnant water, streams, wells and swamps as habitats. However, misconceptions related to the cause of the disease is still prevalent.
- People got infected as they went along with their daily chores such as digging, herding, fetching water making it difficult for them to avoid such infested areas. By age and gender, it was also mentioned that most of the those infected are older children (who go to fetch water, firewood and grazing), women (who go to fetch water and firewood, gardening) and men (who are grazing, gardening). There are few elderly people who got infected.
- Lack of knowledge about the disease affected their health seeking behaviour. The study noted the poor health seeking behavior led to delayed access to treatment especially at clinics. There were delays at home, clinics, health centres and hospitals not specialized in sleeping sickness diagnosis and treatment. The study found that that some community members who believed in witchcraft first went for that option. The lumbar puncture diagnosis procedure was seen as a deterrent for seeking sleeping sickness treatment.
- The pattern of resort for patients with rHAT was more hierarchical where by most of them sought care first from small private clinics, health centres, failure to recover they resorted to prayers and traditional healers, until they were referred to Lwala hospital designated for testing and treating rHAT. A lot of time was wasted as they wandered in these alternative care options.

- Traditional healers are an important community resource and interface with rHAT patients more especially when mental health problems surface. They are willing to work closely with the biomedical health workers in the prevention and referral of rHAT patients. Their involvement is crucial.
- Sleeping sickness was reported to affect the patients, their families and the community. The effect was physical, economical, and psychological at the individual level, family level and community level.
- Local councillors (LCs) at all levels, health service providers and VHTs were considered to be the best motivators when it came to health issues. Other motivators reported were: - parents, religious leaders and opinion leaders including the district officials (CAO, CDO, LCV etc) elders, Peers/friends, teachers, politicians and relatives. Community involvement plans can include VHTs and local leaders (LCs) to be part of the programme to provide leadership since they are messengers in the community. The community can help in reporting the disease outbreak and get involved actively in the programme through VHTs.
- The study showed that the most appropriate channels to reach communities affected by r-HAT are verbal announcements by VHTs, door to door, fliers and posters with viable information/message in local languages, as well as local FM radio messages. Forming groups and health clubs could simplify their access to information since such groups can be easily managed by informers and peer counsellors.
- In case a new drug is to be provided, they suggest the best way it could reach the patient is through government health facilities. This is where patients access treatment. The VHTs would inform the sick people about the availability of the new drug at the health facility. The new drug would be accepted if it is not as painful as the current one. The community members should be sensitized about the new drug including its side effects.
- Suggestions on some key messages to include in an awareness campaign for positive behavior change regarding early diagnosis and treatment related more to informing the people about the signs and symptoms of sleeping sickness, the dangers of the disease, dangers of delays in seeking treatment (stressing the need for early check-up and diagnosis), and the positive aspects of the disease being curable. The fact that treatment is free of charge and the need for family support should be emphasized. It was recommended that people should be informed about the health facilities that offer sleeping sickness treatment. This would encourage patients to access treatment promptly.

Recommendations

- Misconceptions and myths regarding r-HAT are still common and requires a communication strategy that is effective through different access channels that have been identified especially those targeting the community directly. In order to reach the target audience who, live in villages in the hinterland of Lwala hospital, there is need to select and optimize effective means for reaching these target audiences via appropriate channels. Champions and recognizable actors in the community have been identified to raise awareness of sleeping sickness These champions would work with the

DHT, more especially the health educators and other health workers. This also calls for an integrative sustainable community engagement strategy.

- Health workers at the peripheral health centers need to be trained in r-HAT diagnosis and treatment to improve treatment access and extend case detection; and on attitude change towards r-HAT patients.
- Training clinic staff, village health teams (VHTs) and traditional healers on the common symptoms of rHAT, diagnosis and referral mechanisms will help in early detection of the disease hence reducing death cases.
- Traditional healers are an important community resource and are willing to work closely with the biomedical health workers in the prevention and referral of rHAT patients. Their involvement is crucial.
- A multisectoral approach in social mobilization and health education communication campaign is called for at district, facility and community level.

CHAPTER ONE: INTRODUCTION AND BACKGROUND

1.1 Background

Neglected Tropical Diseases (NTDs) are common chronic infectious diseases that are poorly researched. The 17 core diseases are macro (helminthic) and micro (bacterial and protista) infections that affect the poorest populations, largely in sub-Saharan Africa, and include schistosomiasis, soil-transmitted helminth infections (ascariasis, hookworm infection and trichuriasis), lymphatic filariasis, onchocerciasis, dracunculiasis, Chagas' disease, human African trypanosomiasis, leishmaniasis, Buruli ulcer, leprosy and trachoma [1,2]. These diseases affect the world's poorest people and are especially common in tropical areas, where people have little access to clean water, proper ways to dispose of human waste, or good housing. NTDs affect over a billion individuals worldwide; where applicable mass preventive chemotherapy and transmission control (PCT) campaigns have been put in place to curb the situation. In remote and rural areas of low-income countries the NTDs are responsible for life-long disability, disfigurement, reduced economic productivity and social stigma [3].

Human African trypanosomiasis (HAT), also known as sleeping sickness, is a vector-borne parasitic disease. There are two forms of HAT caused by related parasite subspecies; the more prevalent *Trypanosoma brucei gambiense* (g-HAT) in West and Central Africa, and the less frequent *T. b. rhodesiense* (r-HAT) in East and Southern Africa, which accounts for 2% of annual reported cases [4]. Many wilderness areas of East and Southern Africa are foci for Rhodesian sleeping sickness, a fatal zoonotic disease caused by trypanosomes transmitted by tsetse flies. Although transmission in these foci is traditionally driven by wildlife reservoirs, rising human and livestock populations may increase the role of livestock in transmission cycles [5].

The two forms of HAT are separated by the Rift Valley and the Great Lakes Region, and both are present in Uganda. The parasites concerned are protozoa belonging to the genus *Trypanosoma*. They are transmitted to humans by tsetse flies (genus *Glossina*) that have acquired the infection after biting humans or animals harbouring the human pathogenic parasites. Tsetse flies are present in at least 36 sub-Saharan African countries. For g-HAT the reservoir is almost exclusively the human being while r-HAT is considered a zoonotic disease, with the main reservoirs being cattle and wildlife, thereby ensuring the maintenance of a population of infected tsetse flies that occasionally transmit the disease to humans. Although there has been a steady reduction of r-HAT in Uganda (where cattle are the main reservoir) since 2005, the country reported 88% of all cases of r-HAT between 2010 and 2016. Its zoonotic nature and the existence of a wildlife reservoir make disease control objectives more challenging for r-HAT compared to g-HAT [6].

Over the past 15 years, efforts by the national HAT control programmes of endemic countries, including Uganda, have brought down annual patient numbers of r-HAT to 53 in 2016 [3]. However, under-detection in this acute form of HAT is suspected. Studies show that internal displacement, collapse of control programs, environmental modification and livestock migration are the principle factors contributing to the re-emergence of HAT [4, 5].

For both g-HAT and r-HAT, clinical diagnosis is difficult because the signs and symptoms are relatively nonspecific. Diagnosis requires a complex series of specialized and invasive tests to detect the parasite in body fluids. Particularly, a lumbar puncture is mandatory to differentiate between the disease stages and decide on stage specific treatment. For this reason, and because HAT is highly focalized in rural areas, most endemic countries have organised vertical HAT control programs, which consist of a series of specifically equipped and trained diagnosis and treatment centres, as well as mobile teams in disease-endemic areas. Lack of awareness among clinicians and diagnosticians implies that r-HAT may be overlooked during differential diagnosis. Unlike for g-HAT, there is no option for serological screening for r-HAT. Diagnosis is mainly done at fixed health facilities. Since initial symptoms of HAT (e.g., fever, malaise, headache) overlap with what is observed in the more prevalent malaria, diagnosis is often accidental while examining malaria slides under the microscope, facilitated by the fact that parasitaemia is considerably higher for r-HAT than for g-HAT[7].

Adding to challenges of diagnosis is the ability of r-HAT to break out into epidemic form as was experienced in the last century, but also recently in Uganda (1998-2000) [7,8,6,9]. Therefore, effective and safe HAT diagnosis and treatment is an ethical request to avoid arsenic derivate drugs to treat humans in the endeavour to eliminate r-HAT. Making available an oral drug will facilitate the integration of r-HAT treatment in the rural health system and subsequently improve treatment access. But a better drug is also required to address outbreaks of r-HAT.

In 2012, WHO set the target to eliminate HAT as a public health problem by 2020 in its roadmap for elimination and control of NTDs. Recognizing the role r-HAT would play in an overall HAT elimination strategy, in 2014 WHO stakeholders urged for a safe, effective and preferably oral treatment for both stages of *T.b. rhodesiense* [10] This will require a safe, effective, easy-to-administer treatment for both disease stages in r-HAT, as well as g-HAT.

There are challenges of case detection and reaching patients. Studies in several endemic countries showed that r-HAT patients needed up to seven visits to various health care providers before their disease was properly diagnosed [11] Such delays increase the risk of patients needing treatment for stage-2 r-HAT, which is associated with a fatality rate 2.5 times higher than for stage-1, thus constituting a public health problem [12]. Further r-HAT patients and their households experienced increased financial expenses in seeking for treatment and utilized varied options in seeking treatment, sometimes making several visits to different health facilities before getting diagnosed for r-HAT and this results in delays in diagnosis [13,14,15]. HAT illness and deaths have been found to affect food security by reducing the household's ability to produce and buy food, depleting assets, and reducing the insurance value of social networks [16]. One specific challenge for treating r-HAT is the rapid disease progression, and the fact that few patients are diagnosed before reaching stage-2 that is more difficult to treat given high toxicity of the only drug available for that stage (melarosprol). Making progress towards disease elimination requires effectively targeting populations at risk to create awareness towards seeking diagnosis and treatment; strengthening surveillance activities, especially in areas where the risk of infection remains high and where resurgence could occur; and promoting the existence of a safe and simple treatment.

NTD actors are more than ever appreciating the importance of culturally sensitive community engagement strategies to make universal technologies work but this requires capacity-building efforts to help health workers interpret patient accounts of disease symptoms and provide messages about available services in intelligible, relatable ways [17; 18]. Therefore, programs require a much more detailed understanding of local NTD symptom knowledge than is currently available. Communicating with targeted communities and engaging them as active participants in r-HAT case detection and management efforts will be critical to ensure progress during the clinical trial, and for treatment uptake post-trial, should results be positive. Community engagement will also be necessary to strengthen the network of health services at the village level, in coordination with district and local health authorities for case detection, programme monitoring and disease surveillance. Having an oral treatment would potentially facilitate community participation and overcome barriers related to the current treatment, which includes the dreaded lumbar puncture and toxic drugs.

Indeed social scientists have contributed to the understanding of NTDs from the emic view of patients by giving voice to social suffering [19; 20], causes and perceptions of illness [21; 22; 23]. However, there are few anthropological studies on NTDs especially in informing programming and clinical trials [24; 25; 17].

One of the major hindrances to early diagnosis and timely treatment of sleeping sickness is the presence of few centres with diagnostic and treatment competencies, even within endemic districts. Personnel in many peripheral health units have never diagnosed sleeping sickness; stage-1 of the disease usually goes undetected as it shares symptoms with other febrile illnesses. Overall, there is a low degree of disease awareness at the health facility level, exacerbated by the low prevalence of r-HAT. Thus most patients with r-HAT are treated for other conditions before HAT diagnosis [18].

Using anthropological lenses, this study investigated the bottlenecks, limiting factors leading to fear and failure of uptake of r-HAT drugs; and informed further community engagement and sensitization for better treatment outcome.

1.1 Objective of the anthropological study

The anthropological study was nested in a larger clinical study. The overall objective of the main study was to assess efficacy as well as safety and facilitate access to an effective oral treatment for r-HAT patients in both stages of the disease.

The anthropological study objectives were the following:

Main objective: To understand the perceptions and practices of the local community and peripheral health centre staff regarding r-HAT in order to improve case detection/referral and access to treatment in Kaberamaido and Dokolo districts

Specific Objectives

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

1.2 Research issues, activities and process

Understanding and experiencing illness: We wanted to understand how patients or caretakers and community made sense of illness and in particular r-HAT-like symptoms. We shall particularly seek to understand the following:

- a) To what degree and in what combinations is r-HAT seen in spiritual, moral and/or medical terms?
- b) How do these understandings affect the help and health seeking behavior? What is the pathway of a person suffering from sleeping sickness to arrive to a health Centre providing adequate treatment, including experiences outside the formal health system?
- c) How are the symptoms of sleeping sickness experienced in everyday life - especially when they are chronic and persistent?
- d) What do those symptoms make people think and do?
- e) What are their attitude towards existing treatments?
- f) How best can they assist in the new drug interventions by actively demanding for health care services?

Understanding bottlenecks to healthcare access: We explored the bottlenecks to healthcare access and addressing these to improve the delivery of sleeping sickness information to the communities.

- a) What are the barriers to accessing r-HAT treatment (demand-users and supply –provider side).
- b) What are the best ways suggested by the community to improve uptake of the drugs to treat sleeping sickness?

Community sensitization

Awareness creation: The results of the study are to inform activities at community level to increase awareness on sleeping sickness and assess acceptability and monitor challenges in uptake of the available treatment. Engaging community leaders and individual households will provide communities with correct health information regarding sleeping sickness and the proposed clinical trial with an oral treatment. This knowledge will hopefully improve case detection and reduce the

barriers and reluctance to seek treatment associated with the disease. The findings will support the clinical trial, as well as post-trial access through community engagement [19; 20].

CHAPTER TWO: METHODOLOGICAL APPROACH

2.1 Introduction

This chapter presents the methodology that was used in the study. It provides information on the study area, study population and sample, sampling techniques, data collection instruments, data quality control, ethical considerations, data analysis, and limitations of the study.

2.2 Data collection

Fieldwork commenced in November 2019 in Kaberamaido district in three subcounties: Otuboi, Alwa and Kaberamaido. The district is part of Teso sub-region in Eastern Uganda. The three subcounties were purposively selected. According to the Lwala hospital records they had the highest number of sleeping sickness patients. Data collection methods included key informant interviews, in-depth interviews, and focus group discussions.

Key informant Interviews

Key informant interviews were conducted at the district, subcounty, and village levels. These included local governments and community leaders (civil, social, political, religious), In total 12 Key informants were interviewed.

In-depth Interviews

In-depth interviews were conducted with community members purposively sampled i.e. the patients, and those who have ever had sleeping sickness to understand their perceptions and lived experiences (phenomenology) and coping strategies. Others were caretakers especially if the patient was a child or was too ill to respond. We explored their health seeking behaviours and drugs uptake. A total of 20 interviews were conducted. These were recruited from Lwala hospital register and followed in their villages. With the help local village council authorities, we sampled others within the villages.

Focus group discussions

Focus group discussions were conducted with community members comprising of 6-9 participants. Group categories included gender and age organized separately. A total of 8 FGDs were conducted. For the follow-up study that took place in February 2021, we conducted key informant interviews with health care providers in the private clinics and drug shops who reported to provide treatment to sleeping sickness patients (n=10), traditional healers (n=10), hawkers; in-depth interviews with those who consulted the alternative care (n=20), and focus group discussions with community members (n=8).

Picture 1: Focus group Discussions with community members following SOPs for Covid-19 in Kaberamaido – February 2021



2.3 Data Management

All interviews were recorded digitally, transcribed and typed ready for analysis. Notes collected during the interviews (formal and informal,) including participant observation data were expanded every evening by the data collectors. A transcription and analysis workshop was conducted in Kampala. Audio recordings from the focus group discussions, in-depth interviews and key informant interviews 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. We read through the transcripts to get intimate with the data and understand the meaning and overall feeling of the data. The code structure evolved inductively reflecting participants' experiences and voices. After coding, the 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. The results were categorized and interpreted in relation to the objectives of the study. Quotes have been used extensively in the report to further explain and provide evidence for the emergent themes (Creswell, 2013).

2.4 Ethical considerations

The study protocol was approved by Makerere University School of Social Sciences Research Ethics committee (MAKSSREC) and ethical clearance granted by the Uganda National Council for Science and Technology (UNCST) – No, SS 5086. All data collection was conducted respecting confidentiality. A number of procedures were used to protect the confidentiality of the respondents and the information collected: a) Interviews were conducted only in a private setting e.g. under a shade in the compound or in a hut; b) interviewers were trained in research ethics and

received strict instructions about the importance of maintaining confidentiality, c) the information collected has been kept strictly confidential and names do not appear on any of the data transcripts. When the recorder was used during interviews permission of the participants was sought before digital recording. Participants were informed of confidentiality procedures as part of the consent process. Consent forms for each type of instrument, translated in the local kumam language, were administered before the commencement of the interviews.

For the follow-up study, an amendment was requested from Makerere University School of Social Sciences Research Ethics Committee and granted in February 2021.

CHAPTER THREE: FINDINGS: EXPERIENCES OF r-HAT

3.1 Introduction

This chapter presents the findings of the study based on the objectives of the study and the research questions.

3.2 Socio-demographic characteristics

Overall, participants from the in-depth interviews had low education status, with 3 out of 20 having attained some secondary level of education. The age range of FGD participants were between 13-50 years. Nearly all the participants were subsistence farmers as their main source of livelihood, with a few engaging in other income generation activities like petty business, apprenticeship, doing odd jobs, and a few professionals like teachers and mechanics. The specific characteristics of the study population are illustrated in table 1. For the followup phase the Socio-demographic characteristics for the FGDs and IDIs did not differ much the above. However, for the key informants, most of the traditional healers had some primary education (6/10) and 2/10 had never been to school while only 2 had secondary education; 4 were female and 6 were male; most were in the age range 41-56 years of age with the oldest having 67 years of age. Other key informants were mostly religious leaders (5/10) comprising of pastors and reverends of Anglican faith and a priest from Catholic faith. The rest were private health care providers from clinics and drugs shops within the communities.

Table1: Socio-demographic characteristics of study population**In-depth interviews**

No	Category	Sex	Age	Education	Marital Status	Occupation
01	Patient	M	41	Primary 7 (P7)	Married	Subsistence Farmer
02	Patient	M	46	P1	Married	Subsistence Farmer
03	Patient	M	44	P4	Married	Subsistence Farmer
04	Patient	M	54	P6	Single	Subsistence Farmer
05	Patient	F	45	P1	Married	Subsistence Farmer
06	Patient	F	21	P6	Married	Subsistence Farmer
07	Patient	M	24	Not indicated	Married	Subsistence Farmer
08	Patient	M	42	P5	Married	Subsistence farmer
09	Patient	F	40	P2	Married	Subsistence Farmer
10	Patient	F	42	P3	Married	Subsistence farmer
11	Patient	M	58	Not indicated	Married	Black Smith
12	Patient	M	24	Not indicated	Married	Subsistence farmer
13	Patient	M	Not indicated	P3	Married	Subsistence farmer
14	Caretaker	F	37	Senior 1 (S1)	Married	Subsistence Farmer
15	Caretaker	M	35	P7	Married	Subsistence Farmer
16	Caretaker	F	32	P5	Married	Subsistence Farmer
17	Caretaker	M	42	Diploma	Married	Teacher
18	Caretaker	M	45	P7	Married	Subsistence Farmer
19	Caretaker	F	38	S2	Married	Subsistence Farmer
20	Caretaker	F	34	P7	Separated	Petty Business (sale of Pancakes)

Focus Group Discussions

No.	Category and Gender		Number of participants		Age range (years)	Village/centre
1	Community members – Male		8		18-57	Kaberaimaido Sub county
2	Community members- Female Youth		6		19-30	Oculoi Village
3	Community members- Female		6		18-36	Angoram Town council?
4	Community members – Male		8		19-59	Angoram Village
5	Community members/ Female		6		32-57	Oculoi Town Council
6	Community members- female		7		19-40	Kaberaimaido Sub county
7	Community members. Male Youth		8		17-32	Asal Village
8	Community members – Male		9			Oyam Village
Total			58			

Key Informant interviews per level

	Number interviewed
District (local government officials)	2
Sub-county (local council officials, health centres/hospital)	4
Village/community (local council leaders, opinion leaders)	6
Total	12

Picture 2 below showing the nature of livelihood which is mainly subsistence agriculture



3.3 Experience of sleeping sickness diseases

Questions were targeted to existing or cured patients as well as their families, including those of deceased patients to understand the experiences they pass through. We also wanted to understand their views on the sleeping sickness diseases, causes, common signs and symptoms.

3.3.1 Cause of sleeping sickness in the community

Regarding the perceived aetiology, most participants in focus group discussions and in-depth interviews reported the tsetse fly was the cause. If a person was bitten by that fly which they knew distinctly it would cause sleeping sickness.

The big brown fly with long wings - "Laugher". I even remember that year in 2013, but I think it is called "Omelu" (tsetse fly) which if it bites you, it can give you the disease (IDI, patient, Asal Village)

Yes it is specific in that it is hairy and has laying wings when resting, it is also common in grazing areas "not necessarily that all tsetse flies cause sleeping sickness."one gets sleeping sickness after being bitten by tsetse fly which is infected and in the process of biting, it transmits the disease to human beings (KII, Local Leader, Kalaki district follow-up)

However, some respondents reported they did not know what the fly looks like - *I have not yet seen it but they say it is dark and big, is it the tsetse fly?* Participants reported the high risk places where to get bitten by these flies were the bushes around homes and swamps as habitats for the flies. The fly was also believed to breed from stagnant water and streams.

"In fact now what I have identified: most of the people are people who go fishing in this swamp of Abalangmost of these patients go to the swamp and I understand they used to get bitten by these tsetse flies along the swamps" (KI, farmer, Ocucoi, Village)

There was a mention that some plants such as Lantana attract the tsetse flies that if it is near homes, the lives of the people are at risk of being bitten by tsetse fly since it is their hiding places.

“There is a plant called “Lantana” which attracts this insect and if it smells it, it feels like there is a female one and it rushes there (Engureboladare- smells like female one)”
(Youthful male FGD, Asal village)

However, a few mentioned that drinking unboiled milk and eating beef from infected animals with Nagana or animal trypanosomiasis also cause sleeping sickness. Such kind of beliefs may be imbedded indirectly given that the animals already have a similar disease or are bitten by a similar fly. Quite unexpected was a few who mentioned that mosquitoes also “cause” sleeping sickness. *For me I think it is tsetse flies and sometimes mosquitoes that cause sleeping sickness.* Eating cold food in the morning, drinking unboiled water from the wells were also some of the causes. Obviously there is quite some misinformation; however the fact that the respondents recognize animals as a potential source of a disease that affects them will facilitate their acceptance of messages towards control of the animal reservoir. Witchcraft was also mentioned as a cause and that this used to be the first thing people would think about given the chronic nature of the disease and so traditional healers were sought.

“It makes them weak, if it jumps in their heads it makes them to be like they are mentally ill and that makes them to suspect that they have been bewitched” (KI, Local Leader)

Predisposing activities for r-HAT

Most respondents recognized that the “cause” of sleeping sickness was the fly and they knew its main habitat which was a swamp or forested/bushy area; That people got sleeping sickness as they went grazing and that the flies like being near animals especially cows and that is how they get access to bite people. Others were infected while they were in their gardens digging or going to fetch water from the wells or swamps, they could easily be bitten by tsetse flies in the bushes. This affected their livelihood. *“Me I think when you go where the fly is and it bites you, you can get the disease, you know we cannot just stay at home. Then how shall we survive? We have to go to the swamp to look for fish”.* The flies could also be found in places with stagnant water and dark places around homes. There were some individuals who could not tell how they got infected.

I: How did he get sleeping sickness?

P: “I cannot tell where and how my son got the disease but what I remember is that we used to send him to graze cattle and I hear that tsetse fly loves being around cattle, so maybe he got while grazing” (IDI, Care taker of former patient)

“I suspect he got it from grazing (in the swamp) where he used to go for grazing every day. That is all I know, he liked grazing so much.” He got infected by the disease in 2010 and that was after moving to clinics and finally Health center IV (IDI- Teacher, Ojong village)

“Ummh, my home being near the swamp and near the forest, I think I got bitten by the tsetse fly because of the nature of environment surrounding my home.”

There seemed to be some seasonality on when the flies are many that *“For the fly it times some seasons then it attacks. If you have cases starting to show up you just have to be alert that it is there in that community”*. The community are aware of the seasonality- *During seasons of the disease business is low because people from other villages fear to come to us*. Whereas majority of the patients reported having known about the disease before they got infected many still had not known about it. This calls for more sensitization on the disease including the high risk places and the symptoms for early.

By age and gender, it was also mentioned that most of the those infected are older children (who go to fetch water, firewood and grazing), women (who go to fetch water and firewood, gardening) and men (who are grazing, gardening). There are very few old people who got infected.

3.3.2 Local terms for the disease

Sleeping sickness in local terms is commonly known as ‘*tuo me omelu*’ meaning disease caused/brought by a tsetse fly. At times it is called “*Tuo me nino*” meaning disease of sleeping or “*tuo me*”, It is also called “*man be aganotuo me ajominy*” referring to the infected person that “you have been infected”. The fly that transmits the disease is called *omelu*.

3.4 Common signs and symptoms of sleeping sickness.

The study revealed that the common signs and symptoms presented by all categories of respondents were primarily “feeling sleepy and sleeping all the time which seemed to be abnormal, fever, headache, general body weakness; joint and muscle pain. These were followed by loss of appetite and loss of weight. This initial phase of the symptoms were mostly mistaken to be malaria and many reported to first treat these symptoms with malaria and antibiotics from drug shops, private clinics and health centres.

“You see my home is near the swamp where there are many flies, so the first sign I got was severe headache which took some time, I tried to treat it, but there was no change. I could also over vomit which was unusual and this made me to think that maybe it is malaria which I even tested but it was negative. Haa! I had serious loss of weight within a short period of time. In fact “Anoko wudo atoo” (I almost died by the way because it was serious)” [IDI patient, Asal Village]

Other symptoms presented in the long- run (at a later stage) included change in hair colour and texture that is light and slippery (though this is not a known R-HAT symptom)), swollen limbs, back and general body aches; difficulty in walking and talking. Mental instability and memory loss was mentioned by most participants as the main symptom at the late stages of the disease. The patients also showed features on their body parts such as yellow or red eyes, pale body.

“First, after seeing the black spot on my leg where the tsetse fly had bitten, I started experiencing daily fever, which was on and off even after treating malaria. I also started losing appetite, I could not eat much for some good time and as a result, it made me lose weight of which I failed to explain what was happening in my life.” (IDI- Patient, Asal village)

Citing out a few, some key informants explained that patients suffer from joint pain and other major complications at later stages.

“They always experience joint pain, sometimes they go into mental confusion at a later stage. Then there is also wasting advanced age. It has complications like organic dysfunction like liver enlargement, it affect the nervous system and the later stage and you may think someone is mad among others” (KII Clinical officer, Kaberamaido Health Center IV)

“I always hear that people with sleeping sickness over sleep all the time due to the disease. I understand they get severe headache when they get this disease to the extent that others even lose their memories if they delay to go to the hospital. People with it also lose a lot of weight, they also have general body weakness and I understand even back pain” (KII-Parish Chief, Kaberamaido Sub county)

3.5 Stigma and sleeping sickness

Most participants in the in-depth interview and focus group discussions mentioned that the disease is stigmatizing. That the patients were singled out from the other members of the family as infected persons, different from the rest of members of the family and the community. Various types of stigma were identified among the sleeping sickness patients as indicated below. They equated it to AIDS stigma as the two diseases can share symptoms such as loss of weight. Loss of weight has been associated with AIDS. Immediately the person is emaciated, they think the person has gotten AIDS and hence stigma coming in.

Yes. It does since we were even given names like the HIV affected people, this really makes you too small in the community.

The former and current patients mentioned that they felt lonely with limited or no association at all, they were mentally unstable; they experienced unexplained loss of weight, they were neglected due to the condition they were in both by family and community members, they were given nicknames; they don't understand the disease, they were scared of the signs and symptoms of the disease; they feared to test and get treatment, they completely refused to go to health facilities for help, they feared to associate with others as they felt different and abnormal and considered themselves persons with disabilities hence self-enacted stigma.

“We the affected ones could call ourselves “omeluomelu” meaning we the affected ones. But community people could call us” HIV affected people” which seriously stigmatize us the affected”. (patient, male 44 years, married)

Such types of stigma affected the patients differently as reported by the different categories of respondents.

“Haa we the affected ones could call ourselves ‘omeluomelu’, meaning we are the infected ones. But the community people could call us ‘HIV affected people”, which seriously stigmatizes us the affected” (IDI-H/H Head, Oculoi village)

More views on stigmatization were presented in the Focus Group Discussions and by the key informants.

“Yes, it stigmatizes once you are diagnosed with the disease, you as a woman, you have to tie (cover) your head with a scarf all the time and for men, he has to put on a cap/hat due to the severe headache it brings”. (female in FGD-Kaberamaido Sub county)

Young patients, it was reported could get stigmatized to the extent that one could not play with friends just because he had fear they would make fun of him. So it could not make them happy as some could not stay with or among other people because they feared to associate with them.

“Yes. It is stigmatizing, my son was really stigmatized that he could only stay indoors all the time. He could also no longer play with friends because of being weak and even for that they would laugh at him” (caretaker of former patient, Otuboi trading centre)

More observation about stigma was that the patients felt lonely, felt cold always wanting to put on heavy jackets even in sunshine, which was abnormal to a healthy person. Such patients who delayed to get treatment were reported to be mentally disturbed and became rude to their caretakers. In other words they were always moody, a condition that could not allow them to associate with other people.

“Even the clothes they are putting on since they lost weight become buggy and even the patient is not taken to hospital immediately and they convulse. For that, most of our people in the community become negligent to take care of such patients because they affiliate them to being infected with HIV/AIDS, when it is actually the sleeping sickness” (KII-Peasant farmer Oculoi village)

Further still, as reported by a female political leader that the disease is stigmatizing and discouraged others from getting treatment.

“For example, a family had two people with the disease and because they were stigmatized they refused to go to the hospital and preferred to go to witch doctors who did not even give them any help and ended up failing to make it to the hospital.” (KII - LCIII Woman councilor).

Creation of fear in a patient is one of the most experiences a patient goes through as it obstructs accessibility to services. This was commonly mentioned among participants in the study.

“Yes the disease is stigmatizing they fear to be in public places because any time they can fall asleep and like she said that they call you “amino”, you cannot want to be with them (Woman 50 yrs in FGD, Oculoi Trading centre).

“By the way even them, the people who have suffered from the disease normally want to associate among themselves” (Woman 32 yrs in FGD, Oculoi Trading centre).

The disease was reported to have changed or disrupted or altered the women’s menstrual cycles and relationship with spouses. They were stigmatized further as they mainly stayed at home in doors without interacting. They were mocked at by members of the community and this generally caused hatred. However, a few participants in the FGDs reported there was no stigma because the disease is curable and not deadly like the other known epidemics. More so now that there was treatment in Lwala hospital

“No, there is no stigma at all since it is a disease which is curable, unless if it was a deadly disease like Tuberculosis, HIV/AIDS, cancer, Hepatitis B, Asthma which do not delay to kill you (Young males – FGD, Asal village)

Also that because service providers shared with them through counseling, when they went to the health facilities, they got to understand the infection and were encouraged to adhere to treatment as the signs they saw were short lived and they were given hope.

“The only challenge is that it takes time for people to know that they have sleeping sickness because it is one of the neglected diseases. But once it is there and diagnosed, they take the medicines” (KII - Kaberamaido Health center IV).

“It does, only the stigma goes off once they have known it is sleeping sickness, because they know it is not infectious (contagious), and they know it is curable. So, the stigma is there before they get to know it is sleeping sickness. Once the family, the patient knows it is sleeping sickness the stigma goes off” (KII- Health worker, Lwala Health Centre)

One patient reported no stigmatization because her husband/spouse was not tired of meeting the costs of treatment. They also reported that some young patients never played with others genuinely because of the pain they went through, not necessarily stigma. Also that the community were aware of the effects of the injection and many believed they were not the only ones affected and remained normal and in peace with other community members.

“No it has not caused any stigma because majority were aware about it in the community since some have got cured and other died due to the disease” (IDI- Patient, Asal village).

3.6 Sources of information for Sleeping Sickness

The main source of information about the disease was reported by all categories of respondents to be service providers (doctors and nurses) in health facilities and others got it from community members who may have heard of the disease. Other sources were friends, clinics, other patients, the media (radio talk shows), VHTs, LCs at all levels and drug shops.

“Me it was a friend who had the disease and accepted to share with me without fear and that was how I got to know as we talked.” (Male farmer, male FGD, Oyamu village).

“Normally they get information from fellow community members who have ever heard about the disease. They are the ones who advise sick ones to go for checkup, suggesting it could be sleeping sickness” (KII-Parish chief Kaberamaido Sub County)

“Most people used to go to Serere but later on people started coming to Lwala having found out that Serere was too far. Aaah, I got information from people in the community and also in the hospital in Kaberamaido Health center IV” (IDI-Female Abed village)

However, according to the KIIs there were times when people did not get access to information because there was no reliable source of information on sleeping sickness, as many hospitals did not even talk about it. They also reported that some people even feared to get information for fear

to discover serious infections. Further still, others were said to be rigid, who thought and believed that all diseases were caused by witchcraft and resorted to traditional healers for answers.

3.7 Health and treatment seeking

One of the objectives of the study was to assess the health seeking behavior of the target populations and its links with delayed access to treatment. When asked about their help and health seeking experience with sleeping sickness, they each explained how they started until they got to the right place for proper diagnosis. Most patients mentioned that they initially did not actually know what they suffered from. Majority of the people mentioned that most people who get sleeping sickness do not come to the hospital immediately to get treatment. They try local treatment including self-medications, when the symptoms continue they resort to clinics, where they spend most of the time treating fever-like ailments. The treatment at the clinics and health centres did not work for them because it started like a simple ailment (they did not get any change) and were in the long run referred to Lwala referral health facility for proper diagnosis. By the time they go to hospital, it is almost too late for some of the patients. It was reported that some community members who believed in witchcraft first went for that option.

“When I fell sick my husband was not around...so when he came back he took me to a health centre III for check up, but nothing was found. We were then sent to Gwetom Medical center for more tests, but still when we went there they would not find the problem. They tested for malaria but there was nothing detected. We went to Kaberamaido Hospital (HC IV) believing they would now know the real disease, they also failed until they advised us to go to Lwala referral hospital to test for sleeping sickness. I was tested for sleeping sickness and they indeed found the disease” (IDI – Patient, Apiri village).

Yes, the hair also turns brown and slippery like for a child, the hair looks like as if it was burnt by fire. In fact, he becomes too skinny and not meet in the body. One's joints become weak and even fails to walk, too much aching on the joints which makes one think that they have bewitched him/her. ...The last one I can tell you is that one becomes sleepy all the time. He told me that “they could feed him while sleeping just put for him food in the mouth by force. As a traditional healer, I received some cases. Yes, they come because they were tired of conditions they were going through and the situation was just worsening which made them to believe that they were bewitched and needed help from me. Yes, that is why they come to my shrine. Others believe that the joint pains and loss of weight could be caused by magic (witchcraft for them) so they come so that I can know what exactly is the problem (KII, Traditional Healer, Kaberamaido Town)

The delays with the infection, as patients went around for inappropriate treatment without proper diagnosis, caused a lot of issues and problems for them. They went to health center IIIs, clinics, traditional healers to consult for solutions and churches for prayers until referrals were made to

Lwala referral hospital, the only facility for sleeping sickness diagnosis and treatment. During their back and forth seeking for cure, the disease was becoming worse with consistent and serious headaches, loss of memory, serious body itches, general body weakness, loss and gaining of appetite, mental problems, impotence and failure to fulfill conjugal obligations, loss of weight, and psychological torture.

A participant mentioned that they lost a member in this community in 2005 who wasted a lot of time going to the witch doctors and by the time they took him to the hospital he was weak and died. The case below illustrates the patterns of resort that is usually followed during sleeping sickness illness

Case 1

When my uncle fell sick, the first thing they went for was treatment in the clinic - continuous treatment in these small clinics. Then secondly, after that one failed we would only hear that uncle is completely down that they have taken him elsewhere. Uncle has been taken for prayers, you know he was a catechist. So, he was taken for prayers, when prayers failed, I think the family even had to seek for the help of a traditional healer. Then finally when they saw that was not even moving them any further, he was taken to the hospital and the hospital they took him to was in Lwala and was diagnosed with sleeping sickness.. But to the wife, she did not really believe that her husband was suffering from sleeping sickness. She kept saying her husband was bewitched. Until even the day we buried him she still had that in mind. So they do not think of sleeping sickness immediately, even when they know it is there. But it is least thought of. And you know also they have poor health seeking behaviors that we don't really - the community no longer love the facilities - the recognized facilities. They think when you go there you are going to pay money or the drugs are not there, and if it is a private clinic they think you are going to pay money. If it is government, they know there are no drugs always. And yet even in the clinics where they go, they pay money. They ask them for money. But the only difference there is, they will ask you whatever you have whether you have 1000/= they will give you something, because they are treating what they do not know. (Key Informant)

But because the symptoms are severe some people opted for government health care services. However, even at the health facilities, they mentioned that they were first treated with malaria drugs and antibiotics delaying in accessing the actual treatment.

When I got the disease I first went to hospital and treated malaria for one week, I came back home but there was no change at all. So I went back to hospital for the second time and after several tests again, that is when I was now diagnosed with sleeping sickness.....Actually it took me like six months before I was correctly diagnosed with sleeping sickness and I was taking antibiotics and treating malaria (IDI, former patient, Ochula Village)

"I went to the clinic from the clinic I went to the referral hospital (HCIV, Soroti) and when I came back to Lwala referral hospital that is when they got I had the disease after diagnosis" (IDI, Patient, Asal village).

The study revealed that by virtue of the time taken by patients “roaming” in the various places to get treatment for sleeping sickness it took individual patients different periods to correctly get diagnosed with sleeping sickness. From the IDIs there were those who took less than 3 months some took 3-6 months, others took 4-9 months, 10-12 months while to others it took them more than one year to get proper diagnosis. Some of these estimations can however be erroneous as some patients might have had the typically non-specific symptoms from ailments other than rHAT before they got infected with trypanosomes.

Those who went straight to Lwala hospital were treated and got better faster as illustrated by the quote below:

“I got to know about the disease after the death of one of the member in the community here that now made people alert to go for check up in the hospital (Lwala,) that is what made me also to go to the hospital and indeed it turned positive. I was admitted and finally got cured. I became a reference to many people. They would say that person straight went to Lwala hospital and was cured. Let us take our patient there”. IDI, former patient, (IDI, former patient, Angorom Village)

“When one gets sleeping sickness, they go direct to the hospital and here it is Lwala referral hospital “ (farmer – Male FGD; Oyamu Village)

“Now you will appreciate the fact that when someone gets sleeping sickness, they go for diagnosis, we refer them after the doctor in question who has examined and has had a high index of suspicion we refer them to the HAT treatment center and that is Lwala hospital “(clinic officer –Kaberamaido H/C IV)

All the IDIs reported that the treatment given after proper diagnosis was successful because the results on review were negative meaning they were okay and got healed, except for the painful spot in the back and the side effects. This was because as they reported, the patients were not discharged until one was completely cured. The findings above regarding the health seeking behavior of people in Kaberamaido show delayed access to treatment. There were delays at home, clinics, health centres and hospitals not specialized in sleeping sickness diagnosis and treatment. Those who went directly to Lwala referral hospital received timely treatment. A typical case is indicated below:

Case 2

I: When you got sleeping sickness what happens? What did you do? Where did you seek treatment?

R: When I got the disease I first went to a health centre and treated malaria for one week, I came back home but there was no change at all. So I went to hospital for the second time and after several tests again, that is when I was now diagnosed with sleeping sickness.

I: How long did it take before you were correctly diagnosed with r-HAT?

R: Actually it took me like six months before I was correctly diagnosed with sleeping sickness and I was taking antibiotics and treating malaria.

I: Was treatment successful?

R:	Yes. It was successful because I even went back for review three times and the doctor told me the results are negative. (I am now cured and safe - laughs.)
I:	What problems did you encounter when seeking treatment?
R:	Haa!! The treatment itself was painful, more so if they are removing the fluid from the spinal cord, the needle used was too long that if you did not have a strong heart, you could give up. My dear, the worst experience was when a nurse who was giving me last treatment, accidentally inserted the medicine in a different vein and it became swollen “I got scared than before.” We also lost a lot of things as a family due to the disease, remember it first started with my wife.
I:	What problems did you face after treatment?
R:	After treatment I realized that I had lost four goats which I did not even replace up to now in search for money for treatment. I remember selling simsim like one bag and maize two bags in order to raise some money. “I even sold them cheaply since it was urgent”
IDI, Former Patient, Otuboi	

The follow-up study with alternative practitioners revealed that they provided array of services though patients did not get any better.

Service provided and referrals by providers from private clinics

It was revealed from the IDIs that all health care providers in the private clinics provided treatment for symptoms patients came with. They were referred to Lwala and Serere hospitals. These are gazetted sleeping sickness hospitals and were reported to have had the equipment and laboratory services for sleeping sickness, with trained personnel in sleeping sickness management; hence proper diagnosis done with appropriate treatment given. Patients were reported to have recovered from sleeping sickness and discharged. The clinics were reported to have made prescriptions for their patients to manage the simple ailments like malaria for complete recovery, presented sleeping sickness symptoms like fevers, vomiting, headache and the like; and those for first aid, but not for sleeping sickness management. For the minor ailments patients reported to have recovered. Clinic health care providers also reported that some patients would be referred to other health facilities (IIIs and IVs), though these had technical professional medical staff in place, they made prescriptions for other ailments but not for sleeping sickness because they did not have equipment in their laboratories to detect and manage sleeping sickness. Patients were reported to have recovered fully from the usual ailment like malaria and temporarily from the presented sleeping sickness symptoms which were recurrent. Hence never got any better in case of a sleeping sickness patient. These health facilities after failing would refer such patients to Soroti and Lwala Hospital.

Churches and mosques

One other category of respondents from KIIs revealed that because patients and their families did not know much about sleeping sickness symptoms, some of them would suspect that they had been “bewitched”. They did not have an idea of it and thought that there were spirits following them and went to church for spiritual intervention and warfare. They were reported to have gone for deliverance and healing as the disease was also seen as a family curse (Chinere). On experiencing

the various signs, some patients were advised to go to religious leaders (Reverends, pastors) for prayers because they were told that God heals when one believes. That some of such prayer warriors were usually charismatics, a branch of the Catholic church, who offered prayers for the sick both at home and in churches. There were also reported to be born again churches like Mary Ministries, Open Bible and many others where patients went for prayers because the disease could not be easily detected by the clinics and some health facilities where they had gone first for care.

Services from churches and mosques

At church, it was reported patients were prayed for to get healed by God through the priests, pastors and imams. Home visits as one of the fundamentals in the church, they visited the patients and also offered counselling services giving them hope. They also referred them to HC IV for further investigation. To supplement on the KIIs responses the FGDs and IDIs gave more to the services offered at the churches and mosques and these included: giving prophecies about the disease, praying and fasting for healing and driving out demons that cause sleeping sickness, they gave financial assistance to the patients to go for further investigation and management, and helped patients to confess of their sin to speed up the healing process. Some patients it was reported in KIIs went to church, but they would be advised by the church leaders to go to hospital for proper diagnosis where a number of cases were confirmed to have had sleeping sickness when they went to hospital. They were managed and got well.

Traditional healing

Traditional healers reported they have interfaced with rHAT patients several times and that traditional medicine was easily available and accessible to people compared to medical services. Similarly the patients reported to have gone to the traditional healers and this

depended mostly on their belief, looking for help. Responses were obtained from the FGDs where there was majority of participants reported going people went to traditional healers

The traditional healers also gave reasons why patients and their relatives went to them in particular for alternative health care because they believed they had been bewitched.. One of them gave one reason below:

That though some patients went to health facilities, they did not go to such facilities that could manage sleeping sickness. It was such patients who got frustrated because they could not get appropriate services for any change after treatment and went to traditional healers.

Picture 3: An Ethnographer conducting an interviews with a traditional healer



Treatment at the traditional healer shrines/homes

Because patients took long wondering in other health care places like clinics and health facilities that did not manage sleeping sickness, the moment one went for tests in such facilities and did not get the proper diagnosis they believed it could be something else outside medical care and resorted to traditional healers. Traditional healers themselves reported that like it was done in health centres, before giving any treatment, traditional healers also consulted their spirits to diagnose the problem, got the source or cause of the problem, gave treatment and cleansed the patient by removing the charms. One of them had this to say: At consultation and diagnosis in the shrine, they reported other causes of the ailment which may arise, and may bring confusion causing delays in proper diagnosis of the disease and proper management as revealed in one FGD.

After diagnosis at the traditional healer's shrine, it was reported that patients were given treatment in form of mixed herbs to drink, had their skins cut open (incisions) and smeared mixtures of 2-3 herbs in the open cuts (Teo Dano) and massaging was done in case a patients came complaining of pains in the joints or any other part of the body (be Rwagodano). The period every type of treatment took to administer on the patient depended on how long the patient had been with the problem.

However, it was reported by some patients that the healers went to extremes to perform ritual sacrifices as treatment claiming it is the spirits of the dead disturbing the patient and in order to appease the spirits they took one to a swamp in a dark forest with the body smeared with medicines; but still the patient does not get any better. Instead the condition will be deteriorating yet the healer is going ahead asking for goats and chicken plus money for treatment.

Referrals by the traditional healers

Traditional healers reported they referred patients to the health centre IV nearby since they did not have referral forms (books) given by government; then it was from there that they were sent to

Lwala to test for sleeping sickness. Most of those brought to the traditional healers had mental health conditions.

“It has really been long I hope I can remember. They used to be brought to me when they were mentally ill. Most of them used to be brought with this condition. There was a man that was well known called Tom and he used to take and test their blood. He used to be in hospital. When they would test and find they had sleeping sickness, they would be taken to hospital”. (KII - Male traditional healer, 56 years old)

They also reported to have referred patients to Lwala hospital and when tested they were found with sleeping sickness and started on treatment. Sometimes patients did not even have any means of going to Lwala when referred. One traditional healer mentioned that he helped some of them with money for transport because he did not want the patient to die in his home and be blamed for the delays.

“I normally refer them when they come to go and test and prove that the disease is not for “Kizungu” (Literally meaning it cannot be treated in health care facilities). That it needs black magic. They come saying that “Otunokaramorodedede” (We have reached all places and we have not seen any change) Then they thought that they needed a traditional healer. ike you go to the hospital and you are referred to another place.” (KII – Male traditional healer, 42 years).

“I have my medicine (herbs) that I would give them when I see they were mentally ill and it would calm them down. But if it didn’t work, then I would refer them to hospital for further treatment.” (KII - Male traditional healer, 56 years old)

Unfortunately, there were instances where traditional healers saw things were beyond their abilities, though the symptoms were for sleeping sickness but could not establish because they had no testing kits to ascertain. That there could be a patient showing signs of sleeping sickness such as pain in all the joints, headache and body weakness but since traditional healers didn’t have a machine to check, they couldn’t prove it that it was sleeping sickness.

Other traditional healers were reported to have insisted on staying with the patients, trying out each and every possible mixture in vain until they gave up with the patient, not even referring them.

3.8 Problems encountered when seeking treatment

Financial problems were reported to have been the most pressing when seeking treatment by all categories of respondents because money was a determinant of transport to health facilities where they had to walk long distances and buying expensive drugs. Patients thus reported spending money on treatment, food, and transport, which prompted individuals to sell or dispose of their property and agricultural produce to meet such expenses, Therefore lack of money to carry out all transactions during treatment was the most reported problem in seeking treatment.

First and foremost they encounter financial problems. *“It is not a one day’s treatment. There are those who can even spend three months in the hospital”*; this is obviously inaccurate but stresses long hospitalization as a problem. It was thus expensive and they resorted to taking loans to pay hospitals bills.

“He had to struggled to look for even what to eat. Food was a serious challenge. Even transport costs were all on my husband. All expenses incurred from hospital were on him” (KII-Farmer, Abedi Village)

“They are advised to take different kinds of food, but financially they cannot manage. So it takes a long time for such patients to recover” (KII-Peasant farmer, Ocucoi Village)

Another issue mentioned by all former and current patients was the problem of the painful diagnosis procedure and treatment (bending the back and piercing with a big sharp needle).

“.....The injection is painful (the needle).That one can even feel like running away from the hospital if you were not strong hearted. The needle is for animals” (FGD-youthful male 32years, Asal Village parish)

There were other non-financial related problems reported like the problem of failure to continue with treatment (adherence) and going back for checkup; there was a problem of back pain, feeling weak and unproductive, hence could not do any heavy work especially in the garden. There was even lack of food (food insecurity). Other problems included mental instability/retardation and dropping out of school or halting school for some time due to strong drugs and their side effects for those in school; loss of appetite causing body weakness and loss of weight. A few reported the wrong administration in treatment by service providers causing accidents through mismanagement of patients. Noteworthy is that some of these allegations could not be verified in the present study.

There was a problem of stigmatization (as indicated earlier in the experiences), and serious and persistent symptoms such as headache throughout treatment.

“Community members could laugh at me saying I am HIV positive which could make me feel bad in the community”. (IDI-Patient ,Oculoi Village)

Long hospital stay (for a month, perhaps referring to Suramin treatment as current melarospol regimen is 10 days) was another problem as some patients reported having had no attendants to take care of them. They also reported getting poor or misleading advice from other people.

More to the problems was ignorance or lack of knowledge about the disease, as this could have been one reason for failure of patients to go to hospital in time to seek medical attention.

“One of the problems they encounter is ignorance about the disease and as a result they may not think of testing in case they fall sick” (KII-Local leader, Kalaki district)

There was another problem reported of patients not following instructions while on treatment as this made them compromise the treatment. Inadequate supplies at the health facilities especially to the poor who could not buy drugs from pharmacies brought about inconveniences in their adherence.

“Some instructions and restrictions are given to the affected women for example not having sex of which women are forced by their husbands and this affects their healing process I even saw a woman who became blind and was chased by the husband because he could no longer see any value in her” (KII-Local leader Achan Parish)

3.9 Problems encountered after treatment.

More problems were reported to have been encountered by patients after treatment the most outstanding being life becoming hard due to lack of food (food insecurity) and inability to do any work due to general body weakness and serious back pain, hence unproductive. They also struggled to look for money to help them survive and to continue with treatment and going back to the health facility for checkup. Those who had taken loans or debts during treatment were now struggling to pay them back. There was also reported continuous mental instability and bad mood. For the men who were already in a relationship, there was reported sexual impotence (erectile dysfunction) that eventually affected their conjugal relationships.

“I got a problem with my male organ that I even failed to have sex with my wife for even three months (I have no feelings, my manhood is on and off) which is worrying” (IDI, Patient, Asal Village).

The young, school going patients ended up dropping out of school due to lack money to pay their fees and the weakened bodies.

“There was no food at home and even what to give the boy. This is because we went up and down with the boy at the hospital.

“I used all the capital for my small business of bicycle and shoe repairing and I had to close the business for some time” (IDI-Household Head and farmer, Otuboi TC)

They reported that a lot of money was spent on treatment, selling off property to meet expenses and this let to household poverty have been avoided if patients had gone direct to Lwala and in time.

“The most experience and most challenging one was lack of money to buy food and transport to the hospital. “Remember we first spent a lot in clinic without knowing”. So it is at that time that we had to sell the cow and the goats since we had no option at all, but to sell them. Appetite became big problem/challenge for me. It took me three months without proper food. Just urged just imagine, yet I was on treatment which was very strong and needed food in order to recover.” (IDI - Patient, Asal village).

It was reported by most participants that even after treatment they took a while to get energy to do the usual chores. They would take long to go back to their subsistence farming.

3.10 Barriers associated with seeking treatment

Although patients delayed to seek health care at designated health facilities, they mentioned several barriers that included fear of the painful treatment, poverty. All reported the painful process in diagnosis and treatment of sleeping sickness

Haa!! The treatment itself was painful, more so if they are removing the fluid from the spinal cord, the needle used was too long that if you did not have a strong heart, you could give up. My dear, the worst experience was when a nurse who was giving me last treatment, accidentally inserted the medicine in a different vein and it became swollen "I got scared than before."

Lack of money and ignorance about the disease (sleeping sickness) were reported to be the most outstanding by all categories of respondents. Similarly it was reported that they feared to know that they have sleeping sickness. Belief in witchcraft and lack of adequate information (ignorance) about sleeping sickness follow as reported by the IDIs.

"Lack of money is the major barrier in this community. People do not have money even to transport themselves, more so during the planting and weeding seasons, some people do not have any knowledge regarding the disease. That is why they do not mind even when they turn positive for RDT. The only sickness they think of is malaria." (IDI-Household Head and Farmer Otuboi T/C)

"Me personally, I do not have a problem with going to the hospital, but may be others who believe in witchcraft and by the time they go to the hospital the disease will be at a stage and heading to death." (IDI-Household Head and Farmer Oculoi Village).

"Traditional believers in witchcraft is another barrier in that some people are too local that they relate any kind of disease to witchcraft which is really too bad because these have made many to die believing that they were bewitched" (KII – District councilor).

Other barriers to health seeking behavior were reported to be long distance from their (Patients') homes to the health facilities. Lack of testing kits at H/C IIIs was another barrier because if one doesn't test there will not be proper diagnosis done and treatment given; and someone will eventually die of the disease or have permanent damage from it. Others feared testing for fear of finding out their HIV sero status.

"People fear testing because they think if they go to the facility they will test and find HIV. That is why they go when they are seriously sick (ill). (IDI- Household Head, Olio, Kaberamaido).

There was also dependency on clinics as another barrier. Patients wasted a lot of time at the clinics. This is because without money you cannot access their services. At clinics there were no testing kits for sleeping sickness. Negligence, mismanagement or poor management of patients by service providers was one other barrier reported creating negative attitude of patients towards health facilities.

“Sometimes the way doctors and nurses handled patients from the hospitals. Some were too rude and unapproachable and this as a result discouraged people from going for further checkup.” (Female farmer, 40 years- female FGD, Kaberamaido S/C)

Another barrier as reported by one KII, was mistaking the sleeping sickness infection with malaria so they think the infection simple, yet RDT kits did not test for sleeping sickness though sleeping sickness exhibited the same signs and symptoms with malaria for which the RDT is available. Even some service providers were said to be ignorant about sleeping sickness and could not differentiate the two and advise appropriately. They also talked of poor mobilization for sleeping sickness compared to other epidemics like HIV/AIDS and patients had a tendency of testing only for malaria because hospitals tested only for malaria (do only RDT) as peripheral labs did not have sleeping sickness testing equipment.

Patients were reported to have had negative attitudes towards health facilities because the service providers did not talk about sleeping sickness as some of them were not knowledgeable about it. At the same time they were said to be negligent of the patients.

“Oh ignorance among community people is the biggest barrier in this community of ours. Others fear going to the hospital for check up and confirm other diseases they do not know. There is lack of knowledge about the disease makes people not to think of any other tests like sleeping sickness tests” (IDI, Patient, Asal Village)

3.11 Effects and challenges of sleeping sickness

Sleeping sickness was reported to have had effects on the patients, their families and the community at large, hence at three levels: individual level, family level and community level. To the individual (patient), sleeping sickness was reported to cause general body weakness due to the strong drugs side effects and poor feeding. Such people failed to perform their work thus affecting their livelihood, leading to poor agricultural production. It also caused disabilities and mental illness or psychological disorders.

“I became weak that I could not dig much like I used to when I had not got this disease. As a family we lost many things, that is; animals, assets and even we had to borrow some money from saving groups and we had to struggle to pay back.”

“For me it reduced on my energy because the work I used to do before I no longer do the same as in the past. Even poverty has come in because if you stay for six months without digging, when a season is only 3 months, what about six months? (IDI- Peasant farmer, Ohio Village)

To young patients of school going age, some halted going to school for some time and repeated classes while others dropped out of school for good.

“The disease really affected him in that he has to miss school for a full year, which was a big loss and he has to repeat that class. This disorganized him a lot. It was due to the much cough he had and doctor advised us not to allow him in a noisy place” (IDI- Teacher, Ojony village).

There was reported to be loss of hope in individual patients and uncertainty made them worried about the disease and eventually isolation and discrimination came in as people never associated with them and called them names. Patients lost hope and eventually some died especially the poor ones who could not afford transport, food and any other payments associated with the sickness.

Effects of sleeping sickness at family level included reduced productivity or reduced labour output as a result of reduced concentration of family members on agriculture production. The little in place was sold off among other family property and spent most or all of it on treatment and upkeep. The money at times was not enough and they resorted to getting loans or debts which they later struggled to pay back after they were discharged. *It brings poverty. When you do not work you cannot earn.* Some property was lost to thieves as at times there was nobody to oversee their homes.

“The disease made me lose my manhood as a man, which worries me with my wife though she is patient with me. The disease reduced on the level of my output in agriculture since I could no longer dig much as before. That is to say, I used to get something like five bags of maize which reduced to two”. (IDI - Farmer, Asal Village).

There was low attitude towards educating children due to resultant poverty; children would thus either stop school for some time or drop-out of school for good. Sleeping sickness at community level created tension from the endless quarrels and fights in families as a result of aggressiveness and mental problems in the patients' families. *It can make one rude and aggressive like Asa's son would beat children from school....They even chased him from school, he could no longer study.* If the patients died it was reported sometimes they would leave the burden of orphans and a dependency syndrome would ensue. It also resulted into food insecurity due to less or no productivity in the affected families,

“Of course when you are sick you lose hope and become unproductive in agriculture and other domestic work, if you're the bread winner it becomes worse for the family, for example if the head is the one sick (man or woman), it is the family to suffer in that they will not be able to get better medication as expected children of such a family are also most likely to drop out of school due to lack of school fees since the father or mother is down” (KII District councilor, Kaberamaido)

When asked how much they spent on treatment majority of the IDIs respondents said they could not recall the amount though much was spent, but of those who could recall paid between 100,000/= and slightly above 1,000,000/= (Uganda shillings) which is between US\$30-300. Noteworthy is that HAT diagnosis and treatment are free. Therefore the quoted figures might include expenses on transport, food, as well as those incurred when they visited the various centres before accessing treatment at Lwala hospital.

CHAPTER FOUR: FINDINGS: MOTIVATION AND BEHAVIOUR CHANGE

1.1 Motivation

Participants were asked what motivates people when it comes to their health in general. Most of the participants desire to be healthy just like other members of the community. When asked what might motivate people to take sleeping sickness drugs more safely most participants mentioned. However others indicated that the fear of an illness in this case sleeping sickness.

I think fear of death motivates people to take their sleeping sickness drugs safely, since no one wants to die.

While majority of respondents in IDIs and FGDs reported desire to be healthy or fear to be ill as most motivating for change of behavior, respondents in KIIs reported people were mostly motivated by the level of sensitization on media and local leaders at all levels (I-III).

"I think it is out of sensitization they receive from media and also health practitioners, parish chiefs as they organize community awareness programs. (KII- Parish chief Alwa Sub County)

IDIs also revealed the availability of money as another motivating factor.

"Yes money can motivate everything in this world needs money. It is either you have it or you do not. Those who have it can do whatever they want" (IDI- female, Abedi village).

"Yes it does motivate in a way that if you have money in your pocket, you can do anything you want on this earth including even going for body checkup, which will not be the case when you do not have at all" (KII-District councilor Kaberamaido)

More motivating factors included: community concern through sharing other people's conditions, the fear of death was another factor; religious beliefs also had a role to play.

"Majority are motivated by religious beliefs so that they remain healthy. God says your body is my temple, so help me take care of it". (IDI- farmer Ochila village)

Another motivating factor was word given by an expert (a parent, service provider, etc) in form of advice or counselling.

"Parents are motivators to their children at home on the other hand---- they are the ones who know them best; a husband can also be a motivator to his wife or vice versa since all wish to live longer with one another. Political leaders that is, LCI-LCV, religious leaders are also motivators when it comes to health...." (KII-Parish Chief, Kaberamaido)

One other factor was survival of one's family and that responsibility of wanting the best for one's children. The pain they went through with the infection also motivated them to seek treatment and get healed, the need to know the real problem affecting them, together with handouts given at the health facility because these helped them to take their treatment consistently.

“The family, and peer influence can help one desire to go for treatment. “Friends motivates in that if you have a good friend who cares so much about you he/she will always advise you even on issues concerning health in case you are sick. She can tell you to go for checkup” (FGD-Female student, Kaberamaido S/C).

The urge or desire to work was really motivating as reported in the FGDs because first of all, they stayed long in the hospital until they completed their treatment. Secondly, they sold off most, if not all their produce to get money for treatment and upkeep, while thirdly, some had their produce stolen either from home or their gardens because they did not have anyone to see to their security. This was reason for them to wish for quick recovery and go back home to resume their daily agricultural activities.

There was also knowing one’s rights and responsibilities as a motivating factor:

“Me personally, I go to hospital because it is my right and the disease is not something to laugh at and anyone can get it” (FGD-Youth males, Asal village)

By extending services to the communities people said could be motivated as there would be no transport costs incurred. The way of handling by service providers can also motivate or demotivate people to seek for services at the health facility because sometimes rude and harsh service providers discouraged patients from seeking services. Offering free services (testing and treatment) they reported could motivate them to go seek services from health facilities because majority of them confessed they did not have money to go to for treatment and it was always reason they did not go for confirmation tests. Advocacy messages should further stress that HAT diagnosis and treatment are free of charge.

1.1.1 Motivation to take sleeping sickness drugs

All categories of respondents reported availability of food as the most motivating factor to take drugs, whether provided at home or at the health facility. Then provision of handouts by the health facility like they do for HIV/AIDS patients they said could also motivate them to take drugs.

Realizing that sleeping sickness kills if not treated well, that drugs were available and that sleeping sickness is curable, as reported by one key informant motivated patients to take drugs.

“They knew the importance of adherence, “yes people here after realizing the effect of the disease, more so after delaying to go to the hospital, the pain it has is just enough to encourage them to take the drugs safely since they want to recover and be like others.” (KII-Vice Chairperson, Kalaki District)

“When the people on the other hand have realized that sleeping sickness cures and the drugs are available they will then take the drugs more safely.” (KII-Vice Chairperson, Kalaki District)

“Others after realizing that the disease kills if not treated well, they will definitely accept to take the drugs since they don’t want to die early”. (KII-Local leader, Kalaki District)

Both IDI and FGD participants presented change in mode of treatment from injections to tablets as a big motivator because the injections were painful.

“It is easy to swallow the drugs since you can even move with them and swallow them from the bar and wherever you are and besides that the injection is painful” (FGD-Male 32, Youthful Males Asal Village)

More to motivating factors to take drugs by IDIs included previous experience with sleeping sickness, having sleeping sickness services at all health facilities or extending services near (drugs and testing) to health centre IIIs; desire to be healthy or fear of death by getting proper diagnosis; the pain they (patients) went through; and the continuous counseling for adherence they went through, success stories from patients who recovered and having many people in the family who have had sleeping sickness was reported by the KIs as a good motivating factor for adherence. They also reported that sensitization by health service providers could also help in uptake together with change in attitude by service providers as a motivating factor.

1.1.2 How people might be convinced to change

Participants from the focus group discussions, in-depth interviews and key informants were asked what would be done to make people change and go for treatment early enough. Several access channels were mentioned through which people could be convinced to change. They mentioned avenues through health workers, faith based religious leaders, VHTs, and community leaders,

It is better to use religious leaders to preach to people about the disease in churches, crusades and even radios since they are respected as representatives of God (messengers.)

Using local Radio programs in Kumam, the local language spoken by people of Kameramaido, was seen as a good channel for sensitizing the community about sleeping sickness.

People who do not want to change should be followed in their homes to be counseled and convinced and if that fails enforcement by police should be sought. On the ways of improving access and treatment uptake of sleeping sickness drugs, participants mentioned that drugs should be brought to nearby health centers to ease access.

4.1.3 Best motivators when it comes to sleeping sickness

Majority of the respondents reported that local councilors (LCs) at all levels, health service provides and VHTs were considered to be the best motivators when it came to health issues.

“Health workers’ advises are important and people always pay attention to it and they should continue with their work through outreaches in the community have health talks at health facilities, have health programmes on radios so that people are aware” (IDI- Farmer, Ochula village).

“Anything to do with health it is the VHTs they always listen to very well since they are the people from the community and they know their people.” (KII - district councilor, Kaberamaido).

Other motivators reported were: - parents, religious leaders and opinion leaders the district officials (CAO, CDO, LCV etc) elders, Peers/friends, teachers, politicians and relatives (brothers of spouses).

“My husband and brothers are the ones whose advice I take, when I was sick they were the ones who were close to me whether my husband says I take as true because he stood with me” (KII-farmer, Abed Village).

“Religious leaders in churches can do it well through preaching in churches, during crusades in communities and many others. Elders in the community also help a bit and they can do it through clan meetings” (IDI-Teacher, Ojony Village).

It was also suggested that sleeping sickness should be included among the neglected disease in training institutions so students should be mentored about the disease when in their medical field in the health facilities.

There was a proposal for destruction of reservoir host, symptomatic animals identified by veterinary doctors, in that way the diseases would be managed hence important to preventive and curative measures. Also that government should invest more money to motivate people on the ground involved in prevention and control efforts.

4.2 Community involvement

When asked how the community was to be involved, the majority of participants in IDIs and FGDs suggested VHTs and local leaders (LCs) involvement in the programme. They are the ones who can be involved at community level and provide leadership since they are messengers in the community. The community can help in reporting the disease outbreak and get involved in this programme through VHTs who will be liason between the community and the hospital in case of any changes. That the community members should be conscious about their health for example if one falls sick they should immediately go to hospital for confirmation. Also mentioned were community church leaders and experienced patients would spearhead the involvement. The community was thus expected to give support as well as report about the disease outbreak by the enlisted people, mobilizing and sensitizing the people in the community.

At the higher level mobilization was said to be made through the Resident district commissioner(RDC) and Chief administrative officer (CAO) and the DHT and health workers themselves.

On preventive measures of the participants mentioned vector control measures as they knew that the tsetse fly was the main transmitter of the disease.

“There are certain tress that should not be bushy like lantana and also nets should be for trapping the flies so that they can die, looking for ways of making the disease to disappear” (KI Local leader)

4.3 What needs to be done to help people change

Majority in all categories of respondents said that to convince people to change and seek treatment, it required regular/continuous mobilization of people sensitization moreover, through different media.

“Through sensitization and this should be through radios, from hospitals, burial places, social gatherings so that they are convinced” (IDI-Patients, Otuboi S/C)

“People can only be changed through sensitization both in English and in the local languages (in hospitals and outside hospitals) (KII-District Councilor, Kaberamaido).

Other means of change included giving handouts if properly diagnosed so that patients can consistently take the drugs. Some reported that if service providers changed their attitudes from being harsh to friendly service provision, patients would be encouraged to change their attitude to seek services. Verbal announcements by VHTs were said to be effective because they did it in their local language as they are the people the community understands.

It was reported that by printing fliers and posters with viable information/messages, the literate could read and explain to other community members who could not read.

They said forming groups and health clubs could simplify their access to information since they can be easy to handle by the informers. They also suggested peer counseling as it was easy to listen to a friend’s word and take it seriously.

Sharing success stories despite the pain the patients endured could also help people change and start going for treatment.

“Advise them where to go and seek treatment like at the health centre, mostly we start with the government facilities, sensitization through media and TV like we have radio Kaberamaido” (KII-Chief, Alwa S/C)

“The good behavior of medical personnel in the hospitals can convince people to change because they talk to people nicely” (IDI-Household wife, AcanPii Parish)

Wanting to know what to change to help people change, all categories of respondents stressed having effective sensitization programmes by increasing frequency of messages, changing message or information packaging through different media by the general community and by health facilities would be most effective. That people should learn to share information including relevance of tsetse fly traps in the bushes. Services should thus be extended near to people.

They went ahead to say that if counselling and other services were extended to people there should be home visits to follow up the counseling process.

“The way counseling should also change, that it should not only be done at the hospitals but rather, these people should be counseled even from their homes (one-on-one interaction) so that they are free to ask questions they have” (KII-Parish Chief, Kaberamaido S/C).

The respondents demanded that sleeping sickness services should be available at all health centers, even the mode of treatment should be changed from injections to tablets as one can carry them and take them from wherever they go.

That as the service providers’ attitude towards patients changed even people’s attitudes should change towards the service providers’ advice, especially to go for testing and adhere to treatment.

People’s mindset should change to recognize that sleeping sickness is not witchcraft, but is curable and stop leaving in denial.

“.....People understand in different ways, others are slow learners some illiterate, they fear to come out and say they are suffering for instance from HIV” (KII-Parish Chief, Arua S/C)

They suggested they should change the approach and use mobile clinics at the grass roots while dealing with sleeping sickness.

It was suggested also that sick animals that harbor Nagana should be treated. They also suggested introduction of sleeping sickness vaccines, although none is available to-date.

Further still, it was proposed that government should train clinics staff, village health teams (VHTs) and traditional healers on the common symptoms of sleeping sickness and also how to use the drugs as this will help in early detection of the disease hence reducing death cases. This will help them to do their work of sensitizing the community about the disease and the fly which bring the disease and how to prevent themselves from getting it. Patients should also be sensitized and counselled on the benefits of adherence if they are to live longer on earth and get complete healing.

“If possible, the government should train even traditional healers on how to handle these drugs well as long as they are tablets. This is because we traditional healers we also handle many patients. If the government can give me also their assignment, I cannot refuse just like the way you are sent to look for people like us (laughs)–that is all. (KII – Female Traditional Healer, 67 years old)

“Okay, another solution that should be done is they should get us and train us on sleeping sickness and even other diseases so that we shall understand what we are doing. You know when we are trained together we shall come to understand each other.” (KII - Male Traditional Healer, 41 years)

The traditional healers should then be allocated treatment centers/health facilities so that when a patient comes with symptoms of sleeping sickness, they can be referred easily in time for treatment.

Also us traditional healers government should include us in programmers that deal with treatment of this disease. These herbs we use, it's just that the western world is better at science, but they can use them to create good medicine. (KII - Male Traditional Healer, 48 years old)

4.4 Ways of improving access of treatment uptake

When it comes to ways of improving access and treatment uptake of sleeping sickness drugs, most respondents suggested extending services, especially availability of drugs all the nearby health facilities (HCIIIs and IVs) and also train the HCIIIs staff to manage sleeping sickness cases as they access treatment.

“Oh I wish these drugs would be made available in other health centers like HCIVs even HCIIIs, it would become easy for people to get them and take safety rather than making it available only at Lwala referral hospital” (IDI - Patient Asal Village).

They also suggested that medicines should be given to VHTs as they are always with the patients and can work hand in hand with the LCs.

“Through the use of VHTs access and treatment uptake can be easy because they have information. The good thing is that these VHTs are in all villages but the only bad thing is that sometimes you go to the sub-county and find that there are no drugs” (IDI-Blacksmith, Odidip Village)

They also suggested that patients should stay at the health facilities until treatment is completed under doctor's supervision. Also that counseling be given both at health facilities and home. That even handouts in form of food stuffs be given to patients to support in adherence. That also health facilities be stocked fully to avoid stock outs for consistent adherence.

4.5 Suggestions on the new drug

Respondents were asked if a new drug was to be provided, how best it can reach the patients including issues of acceptability and use. They were of the view that the new drugs could only be kept at the hospital and the VHTs would inform sick people about new drugs which have been introduced. By that the new drug would be accessed and used well, as long as it is not like current one which is too painful to bear. *“No one will refuse if they change it.”* Further in case a new drug to be provided they suggest the best way it could reach the patients was to be put or distributed to all government facilities as it is where the patients went for treatment.

“The new drug should be kept at the hospitals, I believe people will accept them and use them, more so if they are tablets”.

They also suggested the drug should be kept at referral hospitals in tablet form and only doctors to be in charge. Another suggestion was that the drugs be extended to the communities and use the VHTs to inform the people that the drug is in place.

“The drugs can only be kept at the hospital and it is the role of the VHTs to inform sick people about the new drugs which have been introduced” (IDI- HH Head, farmer Oculoi village)

They also suggested the drugs be accessed at the clinics but dispensed by trained health care provider.

4.6 Messages

Respondents were also asked for messages that would best motivate those who did not want to change. Most reported that the messages should depict the signs and symptoms of sleeping sickness, its severity, how it is dangerous and painful when patients delay to seek health care services. Suggestions on some key messages to include in an awareness campaign for positive behavior change regarding early diagnosis and treatment related more to informing the people about the dangers of the disease, dangers of delays in seeking treatment (to emphasize early checkup and diagnosis), and the positive aspects of the disease being curable. Emphasis should also be on the fact that treatment is free of charge and that the family should be supportive.

The messages like sleeping sickness is curable, sleeping sickness is not witchcraft, sleeping sickness is with us, sleeping sickness is in the community. Sleeping sickness can lead to death if not treated” (KII – Clinical Officer, Kaberamaido HCIV).

There was justification of the need for information dissemination to the community members regarding suitable messages to send to community members to enable them access services. It was mentioned that the community people should be informed about sleeping sickness and that drugs are available. That people should also know where to get these treatment/drugs, which hospital treats sleeping sickness so that they should not delay to get it. The verbatim statements from KII, IDI and FGD participants indicated below would help in development of a communication strategy/messages towards elimination of sleeping sickness.

Table 2. Suggested Messages

Issues to consider	Actual reference from participants
Actual description of what sleeping sickness is	<i>Sleeping sickness is caused by a tsetse fly bite”</i> <i>“There are tsetse flies and sleeping sickness exist”</i> <i>Sleeping sickness is different from other infections”</i>

	<p><i>Sleeping sickness affects everyone children, men and women</i></p> <p><i>"Don't drink alcohol when sick with sleeping sickness"</i></p>
The signs and symptoms of sleeping sickness	<p><i>Always clear bushes around your homes especially Lantana, please be familiar with the signs of sleeping sickness for instance if you feel weak all the time seek medical advice.</i></p> <p><i>"Sleeping sickness has almost all signs and symptoms of malaria. So if anyone happens to have them they should immediately go for diagnosis"</i></p> <p><i>"Please be familiar with signs and symptoms of sleeping sickness"</i></p>
Go for checkup/testing	<p><i>One message that I would pass across is to ensure- when you are sick to go and check for sleeping sickness, and then sleeping sickness is thoroughly checked and it is simple to treat. And it is treated free of charge".</i></p> <p><i>"Always go for check-ups and test for sleeping sickness"</i></p> <p><i>"If you have sleeping sickness get treatment"</i></p>
Severity of sleeping sickness	<p><i>"Sleeping sickness kills if not treated"</i></p> <p><i>"sleeping sickness if not treated early can kill so be aware"</i></p>
Sleeping sickness is curable	<p><i>"Sleeping sickness is treatable and curable"</i></p> <p><i>. "Let us test and get treatment for sleeping sickness, if not it kills."</i></p> <p><i>"I would tell the people in the community that the disease is curable and treatment is free, so let us visit health facility more often for checkups.</i></p> <p><i>"I would say sleeping sickness is a treatable disease which cures. so people should take their drugs well so as to cure, rather than telling others scary words like, ' sleeping sickness kills, which will bring stress to people" (IDI –caretaker, Teacher, Ojary Village – Kaberamaido.</i></p> <p><i>Messages like sleeping sickness is curable, sleeping sickness is not witchcraft, sleeping sickness is with us, sleeping sickness is in the community, sleeping sickness can lead to death if not treated</i></p>
The health care services for sleeping sickness are free and available	<p><i>"There is free treatment at the health facilities and "Let us go for free sleeping sickness testing before treatment</i></p> <p><i>Sleeping sickness treatment is free"</i></p> <p><i>"I suggest a message of sleeping sickness is for free. So do not fear testing for the disease. Medicine is now available in the hospital and it is our responsibility to go to hospital. If I had stayed at home I would have died. (IDI – House hold head, Olio – Kaberamaido)</i></p> <p><i>"Sleeping sickness is in this community. There will be free testing. Let us test for sleeping sickness, if not it kills." (FGD - Female respondents, Angorom village - Kaberamaido)</i></p> <p><i>Don't fear to go to health facilities for sleeping sickness treatment"</i></p>

There was also a suggestion to use success stories for survivors of rHAT to convince the community members with their experience and one IDI had one respondent tell his story below:

“I would tell them treatment for this disease is free of charge; I would encourage them that the disease of sleeping sickness is curable just like the way I was cured, yet some thought I would die – so they should not fear. I would tell them to always go to hospital for check up whenever they are not well. This would help them to know whether they are sick of sleeping sickness or another disease, which is good.” (IDI – Patient, Apiri Village – Kaberamaido).

CHAPTER FIVE: CONCLUSION AND RECOMMENDATION

5.1 Introduction

In this chapter the conclusions and recommendation are provided based on the objectives of the study and key issues that were investigated based on the findings of the study.

5.2 Conclusion

- Most participants were aware that tsetse fly was the “cause” of sleeping sickness (not necessarily distinguishing between a vector and actual cause, the trypanosome) and knew the high risk places such as bushes around homes, forested areas, stagnant water, and swamps as habitats. However, misconceptions related to the cause of the disease is still prevalent such as taking unboiled milk and eating beef from animals infected with Nagana; mosquito bites, measles, eating cold food in the morning, drinking unboiled water, and witchcrafts. Most important here is that the respondents recognize animals, particularly cattle, as a potential source of rHAT. Thus it will be easy to pass on messages that address the animal reservoir. People got infected as they went along with their daily chores such as digging, herding, fetching water making it difficult for them to avoid such infested areas. By age and gender, it was also mentioned that most of the those infected are older children (who go to fetch water, firewood and grazing), women (who go to fetch water and firewood, gardening) and men (who are grazing, gardening). There are very few elderly people who got infected.
- Lack of knowledge about the disease affected their health seeking behaviour. The study noted the poor health seeking behavior led to delayed access to treatment. The findings regarding the health seeking behavior of people in Kaberamaido show delayed access to treatment. There were delays at home, clinics, health centres and hospitals not specialized in sleeping sickness diagnosis and treatment. The study found that some community members who believed in witchcraft first went for that option. The lumbar puncture diagnosis procedure was seen as a deterrent for seeking sleeping sickness treatment.
- The painful process in diagnosis and treatment, lack of money and ignorance about sleeping sickness were reported to be the most outstanding barriers to seeking the health facility by all categories of respondents. Belief in witchcraft and lack of inadequate information about sleeping sickness, long distances from homes to the health facilities, lack of testing kits at H/C IIIs for proper diagnosis and treatment; and fears of finding out their HIV sero status and long patient wait times at the facility were among the barriers.
- Patients had negative attitudes towards health facilities because the service providers did not talk about sleeping sickness as some of them were not knowledgeable about it. At the same time, the service providers were said to be negligent of the patients.
- Sleeping sickness was reported to affect the patients, their families and the community. The effect was at three levels: individual level, family level and community level. To the individual (patient), sleeping sickness was reported to cause general body weakness due to the strong drugs and poor feeding. It also reportedly caused disabilities as many had developed permanent mental illness or psychological disorders. School dropout was quite common. Effects of sleeping sickness at family level included reduced productivity as a result of diminished concentration of family members on

agriculture production. Sleeping sickness at community level created tension from the endless quarrels and fights in families due to aggressiveness and mental problems in the patients' families.

- Local councillors (LCs) at all levels, health service providers and VHTs were considered to be the best motivators when it came to health issues. Other motivators reported were: - parents, religious leaders and opinion leaders the district officials (CAO, CDO, LCV etc) elders, Peers/friends, teachers, politicians and relatives. Community involvement plans can include VHTs and local leaders (LCs) to be part of the programme to provide leadership since they are messengers in the community. The community can help in reporting the disease outbreak and get involved actively in the programme through VHTs.
- The study showed that the most appropriate channels to reach communities affected by r-HAT are verbal announcements by VHTs, door to door, fliers and posters with viable information/message. The literate could read and explain the content to other community members that are unable to read or write. Forming groups and health clubs could simplify their access to information since such groups can be easily managed by informers and peer counsellors.
- Use of success stories and the pain the patients undergo could also help people change and start going for treatment. Having effective sensitization programmes by increasing frequency of messages, changing message or information packaging through different media by the general community and by health facilities would be most effective. It was suggested that sleeping sickness services should be available at all health centers including changing the mode of treatment from injections to tablets.
- In case a new drug is to be provided, they suggest the best way it could reach the patient is through government health facilities. This is where patients would easily access treatment. The VHTs would inform the sick people about the availability of the new drug at the health facility. The new drug would be accepted if it is not as painful as the current one. The community members should be sensitized about the new drug including its side effects.
- Suggestions on some key messages to include in an awareness campaign for positive behavior change regarding early diagnosis and treatment related more to informing the people about the signs and symptoms of sleeping sickness, the dangers of the disease, dangers of delays in seeking treatment, and the positive aspects of the disease being curable, early check-up and diagnosis. The fact that treatment is free of charge and the need for family support should be emphasized. People should be informed about the health facilities that offer the sleeping sickness treatment. This would encourage patients to access treatment promptly.

5.3 Recommendations

- Misconceptions and myths regarding r-HAT are still common and requires a communication strategy that is effective through different access channels that have been identified especially those targeting the community directly. In order to reach the target audience who, live in villages in the hinterland of Lwala hospital, there is need to select and optimize effective means for reaching these target audiences via appropriate channels. For instance Radio, VHTs and local council leaders were reported to be key and preferred sources of reaching and mobilizing the community. These should be enhanced.

- Champions and recognizable actors in the community have been identified to raise awareness of sleeping sickness. These champions would work with the DHT particularly more especially the health educators and other health workers. This also calls for a community engagement strategy or plan. A multisectoral approach in social mobilization and public health campaign is called for at district and community level.
- Training clinic staff, village health teams (VHTs) and traditional healers on the common symptoms of rHAT and referral mechanisms will help in early detection of the disease hence reducing death cases.
- Health workers at the peripheral health centres need to be trained on r-HAT diagnosis and treatment to improve treatment access and extend case detection. The diagnosis of r-HAT should change from lumbar puncture procedure to something simple and not very painful. Health workers need also to be trained on attitudinal change towards r-HAT patients.

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ADDENDUM

Follow-up study to understand other/alternative providers that offer health care to rHAT patients

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August 2021

1.0 Introduction:

This report provides additional data collected for alternative care providers for sleeping sickness (r-HAT). During the main study in 2019 on *An ethnographic study of local community and peripheral health centre staff perceptions and practices regarding sleeping sickness (r-HAT) to improve treatment access and extend case detection in Uganda* the findings pointed to the fact that many patients first utilize other care before they appear at the government health care facilities, and more so at the gazetted facilities that provide rHAT care. The main objective of the research was to understand the alternative care available for people with sleeping sickness like symptoms. An alternative care provider in this study was any person that provided any form of treatment to patients with sleeping sickness other than the public government health care providers. Such care providers included those in private clinics, drug shops; traditional healers, hawkers, faith-based prayer/intercession providers (priests, pastors) among others.

1.1 Methods: The research employed qualitative methods using key informant interviews with health care providers in the private clinics and drug shops who reported to provide treatment to sleeping sickness patients (n=10), traditional healers (n=10), hawkers; in-depth interviews with those who consulted the alternative care (n=20), and focus group discussions with community members (n=8).

Picture A1: An Ethnographer conducting an interviews with a traditional healer



Fieldwork commenced in February, 2021 in Kaberamaido district in the same three subcounties: Otuboi, Alwa and Kaberamaido. The district is part of Teso sub-region in Eastern Uganda. The three subcounties were purposively selected. According to the Lwala hospital records they had the highest number of sleeping sickness patients. COVID-19 risk management plans were executed whereby the SOPs were instituted to include use of sanitizers, face masks, and social distance.

Picture A2: Focus group Discussions with community members following SOP for Covid-19 in Kaberamaido



1.2 Data Management

All interviews were recorded digitally, transcribed and typed ready for analysis. Notes collected during the interviews (formal and informal,) including participant observation data were expanded every evening by the data collectors. A transcription and analysis workshop was conducted in Kampala. Audio recordings from the focus group discussions, in-depth interviews and key informant interviews 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. We read through the transcripts to get intimate with the data and understand the meaning and overall feeling of the data. The code structure evolved inductively reflecting participants' experiences and voices. After coding, the 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. The results were categorized and interpreted in relation to the objectives of the study. Quotes have been used extensively in the report.

1.3 Ethical considerations

An amendment was applied from the Makerere University School of Social Sciences Research Ethics committee (MAKSSREC) to have additional questions and key informant interviews related to treatment of rHAT from non government/public care facilities. This was approved and all data collection was conducted respecting confidentiality and informed consent.

2.0 Results

2.1 Introduction

The results in this addendum are from the interviews with the traditional healers, private clinic providers, drug shops owners, and priests/pastors. We provide findings on why people go to consult these alternative providers, what services they provide and the referral mechanisms. We also provide some normative views from the community through focus group discussions. Results of patients who visited these health care options are also provided.

2.1: Symptoms patients went complaining about / presented

Patients reported and presented various symptoms of Sleeping sickness as mentioned by the alternative healers and private clinic providers. The physical symptoms reported included vomiting blood, blood stained stool, painful joints, severe headache, fever, dehydration, swelling of the stomach, itching and peeling off of the skin, loss of appetite and general body weakness, constipation, backache, chest pain, developing brown slippery hair with funny texture, loss of weight (looking like one with AIDS), high temperature any time of day or night and feeling cold all the time; and feeling sleepy all the time. Psychological symptoms reported were: loss of memory, mental instability.

2.2 Health care seeking for sleeping sickness-like symptoms

And also this disease when it gets into your brains it does not show up easily that is why people have to struggle to do anything; they go to churches, witch doctors, clinics because it cannot be easily detected.”
FGD05 – Married male from Acilo B, Kaberamaido

Study participants were asked where patients with sleeping sickness like symptoms went for treatment apart from the government health care facilities. Most participants in the KIIs, IDIs and FGDs reported patients go to various places for their health care, which included private clinics, drug shops, faith based, traditional healers and a few from hawkers.

Private clinics

Majority of those who had ever got sleeping sickness revealed they first went to the private clinics first for various reasons: one, because they did not know the problem; secondly, the clinics were the nearest places to go to and were later referred to health facilities/hospitals; to others, it was someone they knew at the clinic who would help even if they didn't have cash who could offer them services and they paid later. Other reported they went to nearby clinics for either first aid or real treatment because they did not know what they were suffering from.

“We first went to the clinic; we had not yet understood what our sister was suffering from. We even went up to Soroti. We tested several diseases but there was no disease being named. It was not until they told us to first check for sleeping sickness.” (FGD4 – Married male, 32 years old from Pakema centre, Angorom village).

“The first time my daughter started experiencing those symptoms, I went to the Nearby clinic for quick treatment.” (KII - Female parent, 45 years, Acilo village)

I was first rushed to the clinic by my parents simply because they knew that it was usual malaria which could be treated from the nearby clinics without any delay.(KII – Female patient 22 years old from Angorom villlage).

“The baby was only two months. So after taking the syrup and there was no change we took the baby to the clinic, they tried to test for malaria but there was nothing. They tried putting the baby on drip but still there was no change. It was from there that we now went to Lwala where they also tested for malaria and still could not find then they tested for sleeping sickness and it was found out that the baby had it. By the way she was even published on Daily Monitor newspaper”. (FGD 4 – Married male, 54 years old in Pakema Centre. Angorom Village).

Some patients went to clinics with such symptoms as severe headache and fever, loss of appetite and loss of weight, vomiting blood and blood stained stool.

“Because of diarrhea they even gave me medicine of diarrhea then I came back home when my people came and talked to me, they decided to take me to Lwala where they gave me some medicine and tested and found out that I had sleeping sickness in Lwala.” (IDI – Female patient, 45 years old in Olio village)

More to the reasons for going to the clinic as reported in FGDs and IDIs, was because they thought it was malaria, which they could easily report to clinics and got help because in most cases when they went to health facilities, they found drugs/medicines out of stock, but available in clinics and were served faster, yet they reported no change after treatment.

“ I knew I had the usual malaria so I had to go and get medication from the clinic. I went to the clinic but there was no change, the headache would only reduce but after a short time I start feeling so bad and a lot of body pain like my joints would pain me seriously”.(IDI – Female patient 34 years old Omuwa – Lwala, Otuboi).

Service provided and referrals by providers from clinics

It was revealed from the IDIs that all health care providers in the private clinics provided treatment for symptoms patients came with. They were referred to Lwala and Serere hospitals. These are gazetted sleeping sickness hospitals and were reported to have had the equipment and laboratory services for sleeping sickness, with trained personnel in sleeping sickness management; hence proper diagnosis done with appropriate treatment given. Patients were reported to have recovered from sleeping sickness and discharged.

“Yes, as I told you earlier, when I went to Lwala hospital the first day, doctors tested for malaria and indeed there was malaria and we were given treatment for three days - on the drip and coartem was also given for her to swallow. But after the treatment there was no change at all and doctor opted for sleeping sickness testing. Upon testing for sleeping sickness, the disease was then confirmed and they started her on drugs immediately.” (IDI – Female patient 40 years old, from Angorom village)

The clinics were reported to have made prescriptions for their patients to manage the simple ailments like malaria for complete recovery, presented sleeping sickness symptoms like fevers, vomiting, headache and the like; and those for first aid, but not for sleeping sickness management. For the minor ailments patients reported to have recovered. Clinic health care providers also reported that some patients would be referred to other health facilities (IIIs and IVs), though these had technical professional medical staff in place, they made prescriptions for other ailments but not for sleeping sickness because they did not have equipment in their laboratories to detect and manage sleeping sickness. Patients were reported to have recovered fully from the usual ailment like malaria and temporarily from the presented sleeping sickness symptoms which were recurrent.. Hence never got any better in case of a sleeping sickness patient. These health facilities after failing would refer such patients to Soroti and Lwala Hospital.

"When I went to Gwetom health centre after church, I was put on injections, drips five bottles and given drugs for one week. I did not get better as such, because the pain would go for short time and it comes back, to the level of me fainting and I could not know myself at all." (IDI – Female patient 63 years old).

One of the rHAT patient who first visited the private clinic and did not get any better and was referred to a government health centre had this to say:

"From the clinic they gave me coartem tablets and some pain killers which I took all and did not get change and when I was taken to Gwetan health centre, I was put on drip and injections for malaria till I was send to Lwala and confirmed that I had sleeping sickness and I was treated for one month and discharged." (IDI – Male patient 50 years old from Acilo B Village).

Churches and mosques

One other category of respondents from KIIs revealed that because patients and their families did not know much about sleeping sickness symptoms, some of them would suspect that they had been "bewitched". They did not have an idea of it and thought that there were spirits following them and went to church for spiritual intervention and warfare. They were reported to have gone for deliverance and healing as the disease was also seen as a family curse (Chinere). On experiencing the various signs, some patients were advised to go to religious leaders (Reverends, pastors) for prayers because they were told that God heals when one believes. That some of such prayer warriors were usually charismatics, a branch of the Catholic church, who offered prayers for the sick both at home and in churches. There were also reported to be born again churches like Mary Ministries, Open Bible and many others where patients went for prayers because the disease could not be easily detected by the clinics and some health facilities where they had gone first for care.

"We also have born-again churches, Mary's Ministries, open bible. There are generally many churches in this community that is, today you hear here, tomorrow there, and many others, they are however doing the same activities in the community. Patients go there for prayers since the clinics did not help them". (FGD 1 - Married woman, 48 years old from Alwa – Akwon Dongi village).

I thought there were some spirits following me so that is why I decided to seek God's presence in church. Some thought came on my mind that someone could have bewitched me, more so after the leg which was bitten by the tsetse fly had started peeling off. I said I should not first start with injection if it is witchcraft, but rather church, since I was in mothers' Union in church (I had wedded)." (IDI – Female married patient, 63 years old)

Services from churches and mosques

At church, it was reported patients were prayed for to get healed by God through the priests, pastors and imams. Home visits as one of the fundamentals in the church, they visited the patients and also offered counselling services giving them hope. They also referred them to HC IV for further investigation.

Prayers are for one's body and his/her soul". We do this anywhere that is, at home, in the hospital and many other places. We teach them to be strong amidst all the challenges they go through, believing that God is with them. (KII - Religious leader, 54 years old in Acolo B)

To supplement on the KIIs responses the FGDs and IDIs gave more to the services offered at the churches and mosques and these included: giving prophesies about the disease, praying and fasting for healing and driving out demons that cause sleeping sickness, they gave financial assistance to the patients to go for further investigation and management, and helped patients to confess of their sin to speed up the healing process

“There are those I hear who use white hankies. You hold a white hanky in your hand then they start telling you your problems. I think those ones are from Legu Maria. They are also able to send back someone’s charms and problems back to their homes (Gato).” (FGD08 – Females Youths 18&22 years old, in Olio, Alwa)

Some patients it was reported in KIs went to church, but they would be advised by the church leaders to go to hospital for proper diagnosis where a number of cases were confirmed to have had sleeping sickness when they went to hospital. They were managed and got well.

“Those ones normally happen, but when a person comes to us in church I help them with prayers then I advise them to go for testing and they find out what disease they are really suffering from. Mostly when this disease was there it was after testing that they would find out the disease that they were suffering from.” (KI - Religious leader, Asikimi B, Kalaki).

Traditional healing

Traditional healers reported they have interfaced with rHAT patients several times and that traditional medicine was easily available and accessible to people compared to medical services. Similarly the patients reported to have gone to the traditional healers and this depended mostly on their belief, looking for help. Responses were obtained from the FGDs where there was majority of participants reported going people went to traditional healers

But for me I know that majority go to traditional healers “shrines” (Abila) - to Real Witch doctors with moving spirits they consult who has bewitched them (laughter) “Kuomiowaolohe” and they don’t get any change at all. (FGD 1- Married woman, 48 years old from Alwa – Akwon Dongi village)

“They use traditional healers in most cases. Because they go to the health facilities and are treated like for six months without any change. They are given tablets. They go to the clinics but they fail to get better. The patients are referred to us- that go and look for the traditional healers. They come to us. (KI - Male traditional healer, 42 years old).

The traditional healers also gave reasons why patients and their relatives went to them in particular for alternative health care because they believed they had been bewitched.. One of them gave one reason below:

“Yes, they come because they were tired of conditions they were going through and the situation was just worsening which made them to believe that they were bewitched and needed help from me. Yes, that is why they come to my shrine. Others believe that the joint pains and loss of weight could be caused by magic (witchcraft set for them) so they come so that I can know what exactly is the problem.” (KI – Male traditional healer, 34 years).

That though some patients went to health facilities, they did not go to such facilities that could manage sleeping sickness. It was such patients who got frustrated because they could not get appropriate services for any change after treatment and went to traditional healers.

“Some go to hospital. You know in most cases they start from the health care Facilities so when they fail they then come to us and we also try our part. (KI – Male Traditional healer 41 years old).

Treatment at the traditional healer shrines/homes

Because patients took long wondering in other health care places like clinics and health facilities that did not manage sleeping sickness, the moment one went for tests in such facilities and did not get the proper diagnosis they believed it could be something else outside medical care and resorted to traditional healers.

"They go thinking that they have been bewitched and also because they go to hospital to test but nothing is detected. So it makes them to believe that it could be something else not related to health care." (FGD – Female, Oba trading centre)

Traditional healers themselves reported that like it was done in health centres, before giving any treatment, traditional healers also consulted their spirits to diagnose the problem, got the source or cause of the problem, gave treatment and cleansed the patient by removing the charms. One of them had this to say:

When they come, I first examine them to see what really the problem is. It is simple since I am gifted also, I just touch that area for example if it is the eye, I press it with my hand and if there is something I will definitely pull it out. (KII - Traditional healer, 34 years old)

At consultation and diagnosis in the shrine, they reported other causes of the ailment which may arise, and may bring confusion causing delays in proper diagnosis of the disease and proper management as revealed in one FGD.

"While at the traditional healers' shrine, the spirits are then consulted "Incarnations are done so that the spirits are called to name its problem of the patient. When the spirit comes "the voice (invisible) and tells you that your spirit has been taken, or your friend or relative has bewitched you maybe because of land or your wealth and other things such as having children who are more educated than others in the community, others even say that your spirit has been taken under the ground (in waters or on mountains)." (FGD7 – Female patients 66 & 48 years old from Alwa Akwon Dongi).

After diagnosis at the traditional healer's shrine, it was reported that patients were given treatment in form of mixed herbs to drink, had their skins cut open (incisions) and smeared mixtures of 2-3 herbs in the open cuts (Teo Dano) and massaging was done in case a patients came complaining of pains in the joints or any other part of the body (be Rwagodano). The period every type of treatment took to administer on the patient depended on how long the patient had been with the problem.

"Me as a traditional healer who is also gifted in my own ways, when they come, I give first local herbs to drink "Akunyo di akominogimato" meaning I dig them from the ground and I give them to drink". (KII – Female traditional healer, 67 years old)

"After removing the charm, I give the local herbs to drink in a bottle for two weeks and even the one you drop in your eye once in a day. I also carry out the activity of cut-cutting the skin "teo-dano" and I smear local herb in the areas I have cut. This smearing is also done for two weeks. There is also another type which is in powdered form. With this one, you just get half a spoon and pour in a broken pot (a piece) and then put some little fire and cover yourself with the blanket. That smoke will help you to remove the spirits that are in you and the serious sweating is also experienced here. It is also done for two weeks until change is seen". (KII - Traditional healer, 34 years old).

However, it was reported by some patients that the healers went to extremes to perform ritual sacrifices as treatment claiming it is the spirits of the dead disturbing the patient and in order to appease the spirits they took one to a swamp in a dark forest with the body smeared with medicines; but still the patient does not get any better. Instead the condition will be deteriorating yet the healer is going ahead asking for goats and chicken plus money for treatment.

Okay, they put water in a basin, then they look for leaves (olwedo, ekokai "Particular tree leaves") then they put the leaves in the water as they touch the pain part. But to tell the truth it has not helped. It has just made people more ignorant and some have lost their lives, because they think it is HIV and end up dying. (FGD6 – Male 29 years old, Atwigi village, Alwa S/C)

One patient narrated her ordeal at the traditional healer's place.

"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 got from certain plant and tied them together and she started beating them on my head so that the whatever witchcraft which is putting me down 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." (IDI – Female patient 35 years old, from Kaberamaido).

Serious Symptoms that patients came with to the traditional healer

The traditional healers reported the serious symptoms according to what patients present with as they came to them for help. The commonest serious symptom presented was severe headache, which eventually resulted into mental illness/madness and later loss of memory. Such headache it was reported does not cure even when treated with anti-malarial medicine both drugs and injection, compelling them to think of option B "Traditional Healer" and of which if they went, it could be treated and the patients got well as long as it was not sleeping sickness. Thus mental illnesses were mostly reported at the traditional health

"The most common and main symptom is mental illness. As soon as the patient would start saying uncoordinated things, people would think they have been bewitched and they would bring them to us. But I would know that this is sleeping sickness and I would refer them to a hospital that treats such." (KII – Male Traditional leader, 56 years old)

It's mostly the mental illness that leads people to us. You hear that the patient burnt down houses, is stabbing people and what not, they will remove all the things like clothes from the house and throw them outside. Many things they do. I even have scars from someone who almost stabbed me. In fact that one didn't get healed because they used to drinking alcohol and smoke marijuana. (KII – Male Traditional Healer 45 Years old)

The other compelling symptoms included feeling sleepy all the time, vomiting blood with blood in stool, nightmare loss of appetite and eventually loss of weight and general body weakness. The loss of weight, on and off fever were also equated to suspicion of having HIV or being bewitched.

The general body weakness as I discussed earlier on, on the other hand compels them to come to me to seek for help. This weakness makes them to have joint pains. In fact some even fail to walk or stand on their own without support from attendants. (KII - Female Traditional Healer, 55 years old)

First there are certain occurrences that disturb them in the night that makes them to start to fear. They wake up in form of bad dreams that make them scared. And when they are sited like this you find that they are always sleeping. And when they are sleeping they get shocks and that brings fear and that makes them come to consult from us. (KII - Male Traditional Healer 42 yrs old).

Referrals by the traditional healers

Traditional healers reported they referred patients to the health centre IV nearby since they did not have referral forms (books) given by government; then it was from there that they were sent to Lwala to test for sleeping sickness. Most of those brought to the traditional healers had mental health conditions.

"It has really been long I hope I can remember. They used to be brought to me when they were mentally ill. Most of them used to be brought with this condition. There was a man that was well known called Tom and he used to take and test their blood. He used to be in hospital. When they would test and find they had sleeping sickness, they would be taken to hospital". (KII - Male traditional healer, 56 years old)

They also reported to have referred patients to Lwala hospital and when tested they were found with sleeping sickness and started on treatment. Sometimes patients did not even have any means of going to Lwala when referred. One traditional healer mentioned that he helped some of them with money for transport because he did not want the patient to die in his home and be blamed for the delays.

"I normally refer them when they come to go and test and prove that the disease is not for "Kizungu" (Literally meaning it cannot be treated in health care facilities). That it needs black magic. They come saying that "Otunokaramorodedede" (We have reached all places and we have not seen any change). Then they thought that they needed a traditional healer. Like you go to the hospital and you are referred to another place." (KII – Male traditional healer, 42 years).

"I have my medicine (herbs) that I would give them when I see they were mentally ill and it would calm them down. But if it didn't work, then I would refer them to hospital for further treatment." (KII - Male traditional healer, 56 years old)

Unfortunately, there were instances where traditional healers saw things were beyond their abilities, though the symptoms were for sleeping sickness but could not establish because they had no testing kits to ascertain. That there could be a patient showing signs of sleeping sickness such as pain in all the joints, headache and body weakness but since traditional healers didn't have a machine to check, they couldn't prove it that it was sleeping sickness.

Other traditional healers were reported to have insisted on staying with the patients, trying out each and every possible mixture in vain until they gave up with the patient, not even referring them.

Hawkers

Itinerary hawkers randomly passed around the community with various drugs. They gave medicines basing on the problem a patient explained to them. These hawkers were said to have been cheaper, at the same time they moved with a variety of medicines. Very few, patients were said to have got help from hawkers. They used to be few, but of late the numbers have increased and the way they advocate for their medicines it is very easy to lure a desperate patient into buying them. These hawkers reach homes of the sick people.

"They say that their medicine heals every kind of disease that is why we chose them. We bought it to experiment. You also just try that maybe thy may have a cure. We found that it would not help." (IDI – Male patient 26 years old, from Ating village, Nwa S/C)

2.4 Problems/barriers encountered when seeking treatment in the "alternative" care

All categories of respondents (KIIs, FGDs and IDIs) presented almost similar problems except for a few. Money shortage was reported to have been the biggest problems because it was the determinant of all transactions (to buy essentials like food, drugs). This meant Lack of money to pay for the services at both the clinics (pay hospital bills) , traditional healers and hawkers because there were no free service as

traditional healers ask for a lot of things which included money and items required to perform their rituals, hence expensive because they ended up spending money in the shrines and failed to get results. Lack of money for transport meant patients with their attendants had to walk the long distances from home to the health care facility, which was impossible as the patients were already weak. This meant missing out on seeking medical help. So because it was required at every step, families spent cash to completion and ended up selling off the property at home to meet the expenses.

“Money on the other hand was another barrier which I encountered while seeking treatment. Money being the key everywhere made everything difficult. We had to spend money for going to Soroti hospital and coming back, buying drugs which are needed by doctors and even food itself. Money is a big problem “Senteenayaboniyo” (meaning that it’s money which opens for you the way—if you do not have anyone to stand for you, things do not move at all.)”. (KII – Female traditional healer, 67 years old).

“First those people need money. People lack money. The traditional healers may ask for chicken sometimes two or three they ask for different colours depending on what they are treating. Sometimes they can ask for black and then another time for white.” (FGD 04 – Male 43 years old from Pakema Centre, Angorom village).

“The problem of money was the main challenge. In fact, every place I was referred or sent to, it required money for transport and even buying drugs as required. Getting transport to go to the hospital was also a problem since cars are not here. Only motor bicycles which are even few and very expensive.” (IDI – Female patient 35 years old from Kaberamaido)

Lack of food to eat was another problem reported yet the disease made one hungry all the time. Being a big problem, patients and their families had to spend on food to the extent of borrowing from friends because many had sold most of the foodstuff they had at home and other property.

“There is also lack of money for the caretakers to buy good food which can boost immune system of these people hence being poorly fed”. (KII - Religious leader, Otuboi)

It was revealed in the KIIs that just getting the news / on learning that one was sick/infected with sleeping sickness was a heart breaking challenge because people believed one was going to die, more so admission to Lwala referral hospital meant isolation from one’s loved ones with other details attached especially to people with families.

‘There is always a challenge which people have to face. You know once you are picked from the village and isolated in may be a gazetted place like Lwala hospital, your stay there is a threat like people think that you are going to die. They think it will automatically kill you, but not knowing that when you reach there, they counsel you until your mind calms down but the concept of people thinking that the thing kills and even after treatment they think it will come back.’ (KII - Lab technician from a clinic)

It was thus a problem reported of leaving one’s home to go and stay in the hospital and getting treatment because one indeed had to leave home.

“You stay there for some good period of time without coming back home. So it is already beating the mind because staying out of home is another disease also. So automatically being a psychological torture staying out of home for that period of time.” (Lab Technician in a clinic)

It was also a problem as reported by one traditional healer, to ascertain where to go for help because people did not know where to go in case they had such a problem.

That they first wandered in many places and could not get help, even to hospitals and never recovered. They thus took long to detect and when they found out the problem, there was a lot of delay in hospital which made the disease to grow in the body.

“Since most of these people come from the villages, the health centers/ hospitals that treat sleeping sickness are not known and are far. They go around looking until they find someone who can help them. So they find difficulty in getting treatment. That’s why they end up starting with traditional healers until God has mercy on them and they get treatment”. (KII – Male traditional healer, 48 years old)

“One problem these patients have is that they first go to many places and don’t get help. They will even go to hospital and not recover. Before I treat them I usually all ask them where they have gone for help. I can’t work on them without first asking them that. They usually come to us when everything has failed. This job we do is very risky so we have to be careful to ask what kind of help they have got before.” (KII – Male traditional healer, 45 years old).

“Getting means of transport to come to my place for treatment is also another big problem. It is not however only mere means, but it all rotate around lack of money. Some patients can be too weak to move alone. But surprisingly some do not have even caretakers to escort them here. And they end up moving alone which is risky because they can even collapse on the road.” (KII – Female traditional healer, 67 years old).

One other reported challenge was the distance patients had to walk from their homes to the health facilities or alternative health care points. So, getting means of transport to the health care centre for treatment was also another big problem because everything rotated around lack of money.

“Sometimes they come from far villages so the problem here is long distance to the facility which at times makes them to delay with sickness and by the time they come, they be too weak.” (KII – Nursing assistant, Otuboi).

“Long distance from their villages of residence to church is the major problem they go through as they try to access here. From “Aburuhuru village” to here which is about 5-6kms”. (KII - Religious leader, Asikimi B, Kalaki)

“The problem they would find is that someone would be sick and weak and they don’t know what the problem was, and end up thinking they have been bewitched. They would go everywhere for help like going for prayers and then later come to me to help them. The problem was that the hospital was really far, there was no ambulance, no proper transportation as they would walk or ride bicycles. So you find if the patient was mentally ill, they would be tied up until help is found.” (KII – Male Traditional healer, 56 years old).

Some patients it was reported could be too weak to move alone. But surprisingly, some did not even have caretakers to escort them to the facilities and they ended up moving alone, which was risky because they could collapse on the way.

I stayed in the hospital and moved alone from hospital to hospital and there was no one to be there with me as a husband. Instead, he was at home taking care of my young ones which was not easy at all. At home even there was no food for children to eat or to be brought for us to the hospital. In fact, I could sometimes sleep hungry and only mind if my girl has eaten. (KII – Female patient, 28 years old from Angorom Village)

A similar response was got from IDIs where one talked of having no one to take care of the patient or home when on admission.

"Another problem was that the family had to remain alone with children since I was in the hospital with my wife (she was the one taking care of me) and no one was digging. This as a result, brought for us poverty in the family yet we used to harvest a lot of food in bags, this all declined." (IDI – Male patient 50 years old from Acilo B)

'By the time they go to test they would have become too weak. Those are the main challenges but also like I had told you they take long to recover leaving them when they are too weak some do not heal and even end up dying especially when they are delayed with. Another challenge they face is the place they test for the disease are few. (Religious leader 58 years from Akisim)

Worse still, because of the observable symptoms especially loss of weight, some people thought the patients were suffering from HIV and this stigmatised them. One religious leader made a general comment on the problems and barriers patients faced when they went to traditional healers:

"What I can only say is that it hurts a lot when you see the child of God in difficult situation. I feel pain in my heart. First they get the problem of money (lack of money) to pay to these traditional healers in order to get the services needed. This money however would help the patient to get what to eat so as to gain and be strong. Traditional healers after seeing that you are thin, the first practice they do is to cut-cut your skin with the razor blade and smear local medicine on the areas they have cut. This is not good practice since one already has little blood which can even lead to death. More to that, the razor blade is painful. So the patients just have to endure. Some ask for many things like goats, chicken, which as a result make the patient to give out all h/she has, hence remaining in poverty." (Religious leader 54 years old from Acilo B)

More to the barrier they faced was that patients were misled that the traditional healers believed they could treat all diseases and did not refer what they could not treat. So the patients were derailed from the right treatment and in the end became too weak. Another problem reported was domestic violence in families which have denied many people access to churches, because some men at times who were weak in faith and thought of other things denied their women from going to church. Yet, it was through prayers they believed they could move mountains.

"You see, people are really brain washed more so with alcohol, and they think that when women leave home, they go to look for men which is wrong. I wish people could change their lifestyles and come to Christ "shakes the head". (KII - Religious leader", Otuboi)

The other problems/barriers presented in IDIs and FGDs encountered when seeking treatment in such places included failure to do constructive work due to body weakness.

The painful diagnostic and treatment processes patients went through was a hindrance. For instance the injection in the back (lumber puncture) for obtaining the fluid for laboratory tests and the treatment administration process which involved cutting of the body to rub the medicines.

"I faced some problems like when I was moving up and down in the struggle of seeking treatment, I used not to walk, I would just be carried. Then when I went to hospital, I reached hospital I was thin and the nurse said she could not pull the water from my back so they just had to cut my spinal cord. And also when they cut my spinal cord, I have suffered till now I can no longer dig like I used to do. Even carrying heavy items. I just work because there is nothing that I can do." (IDI 101 – Married Female 51 years from Alindi, Acan Pii)

Other changes encountered by some patients were:

Female patients at times fell victims in the hands of the traditional healers and pastors as they conditionally became their wives. Church prayers took long, a condition that was not friendly to the already weak patients. The staffs in the clinics at times were not well trained to render medical services and they gave wrong medication for wrong diagnosis.

“Sometimes they are given overdose or under dosing due to lack of information. Sometimes they get nurses and doctors who are not well trained. Sometimes they are actually trained but not to the expected standards.” (FGD 07 – Male Youth from Otuboi Township PAG)

They also reported inadequate drugs, which inadequacy led to expensive drugs and eventually delay to get treatment at health facilities/Main hospital. Due to inadequacy, the patients they were at times given under/over doses due to lack of information. Another key issue was that some traditional healers worked in lies and deception to get money and patients ended up in worse prolonged conditions than they went. They at times brought enmity in families, neighbourhoods and communities as they put the blame on wrong people. In such lies, they tend to overstay with the patients and refer when the condition is irreversible or even not referring at all.

“They can make you believe what is not even there. For instance when they are performing their rituals they can get you charms to plant somewhere targeting your neighbour. So you start believing that it could be your neighbor responsible for your sickness.” (FGD 02 – Female 26 years old, from Oba T/C)

The nasty side effects like back pain were also some of the barriers because one could not even walk to the health facility as they were rendered disabled. Sexually some reported to be affected.

“I could not even sweep the compound as instructed by the doctor from the hospital. The fact that we were told not to do heavy work, some patients “my colleagues” came back and started digging seriously. Another one had two wives and he had to balance two houses - But remember they had told us to abstain from sex for six months and what happened was that they had to die - three of them the same month.” (IDI – (Married Female Patient 63 years old)

2.5 When referrals were made

Private clinic providers, faith and traditional healers were asked about when they consider referring certain patients with sleeping sickness to health centres when recognizes certain symptoms. Almost all the private providers mentioned referrals were made when conditions of patients became worse with no improvement. The private practitioners further indicated the referrals are normally done when you treat someone and finish the full dose but you do not see any change at all. The only option is to refer since it becomes out of hand.

A Nursing Assistant from one clinic said that when you treat someone and complete the full dose but you do not see any change at all, the only option is to refer since it has gone out of hand.

A similar response was generated from the traditional healers considering referral to hospital when they don't see any change in the patient's condition after administering the local medicine.

“When I have treated patient and I don't see any change after two weeks. Also when I see that a patient is too weak to walk or stand on his own and failure to eat, I refer them to hospital” (KII – Male Traditional Healer, 34 years old). “For us traditional healers, when you see someone and you give them your medicine but there's no improvement, you are left to send the patient to a better treatment center for checkup.” (KII - Male Traditional Healer, 48 years old)

“Here, as soon as I treat and I don't see any change in the patient, whether after a week or less than a week, so long as you are not improving I refer you the hospital. “I don't risk what if you die in my house - “shakes the head”. (KII - Female Traditional Healer, 55 years old).

It was also said that after praying for a patient in vain some priests delay in referring patients.

“Churches delay with people because for them they want to see someone change from their prayers. They can say let us continue praying, and you see from the person’s condition not changing and you decide to take a step as a person.” (FGD 04 – Male patient 22 years old from Pakema Centre, Angorom)

The traditional healers also said at times they referred when the patients were dehydrated because they were not eating, at the same time they did not have testing kits. The response is also supported by one from FGDs that when symptoms persist or condition has worsened and someone cannot walk or even see, but needs to carry out tests for diagnosis the clinics refer to the health centres and in case of an emergency, just call an ambulance on standby to take one to Lwala.

Another respondent said that automatically, immediately when someone came complaining of being bitten by an insect and the point swollen; may be after like a week and he or she was developing the usual signs that would be direct referral. However, though there were some other insect bites that could be treated, not all were treatable and one did not refer all, but it depended on each patient’s story.

“I was in a certain place around the lake, I was grazing...etc’, that one your mind will ring automatically because these tsetse flies always stay in areas and basing on the period, you will automatically ask how long the bite has taken. The person tells you that it has taken like one or two weeks, of course for one to start experiencing serious illness, it takes like one or two weeks. (KII - Lab Technician Clinic 15).

2.6 Challenges faced by providers in the treatment of sleeping sickness

Challenges faced by private clinics service providers

A number of challenges were presented by health care providers from the supply and demand sides in treating sleeping sickness patients as presented by the different respondents. One big challenge reported by a nurse was that of treating a patient and completing the dose, but when there is no change.

“The biggest challenge was treating someone/patient and you finish the entire dose and the Person does not improve. It hurts and worries service providers a lot because in Medical terms it is like one has not done anything, at least when someone improves it gives you hope of doing something”(KII – Nursing Assistant, Otuboi).

Another challenge reported was that sometimes clients failed to pay the bills which rendered losses to the service provider.

“You see sometimes we treat patients regardless of colour, tribe, financial status, trusting that they will pay, but I tell you, some disappoint by not paying completely. Others promise that they will pay but end up not paying. (KII - Nursing Assistant in a clinic)

One service provider working in a clinic confessed that there was no strong treatment they gave in clinics for tsetse fly or sleeping sickness disease, except for guidance and may be small treatment in form of first aid to keep a person or guide them where to go only. That it was only selected government facilities which brought drugs, they are no longer everywhere.

Challenges faced by traditional healers

The biggest challenge as confessed by most traditional healers was that they did not have medicines for sleeping sickness. Even collecting the different herbs from the different trees, shrubs and bushes was not an easy task because they got them from distant places

Getting these herbs from the bush is not easy since I have no one to help me (on one to delegate to). "I use my three legs including my stick which help me while walking". I have not yet trained my grandson whom I stay with, but I will train him (laughs). (KII – Female traditional healer, 67 yrs old)

The problem I particularly find, I as a traditional doctor, I don't have medicine to cure sleeping sickness. When they taught us about sleeping sickness, they said that for it to be detected and dealt with, you first give the patient pineapple to eat. So that's all I could do for the patient since It was said by the doctors. (KII – Male Traditional healer, 56 years old)

The next challenge reported was failure to pay for the services by the patients and their families after treatment even when they saw that their person had really been healed of the ailment they came with, et they also incurred costs of transporting these patients to the hospitals on referral. That they at times failed to ask for any pay from them since the condition of the patient could be so bad.

"I also have a challenge with my patients. In fact, you treat someone and after getting well, they fail to pay your money or what you asked them to do. Being old in the system I just volunteer to work for my community otherwise if you say that you want money, you will not manage. After all, you can plant a tree at times and when it bears siblings, I cannot know you who planted it. With neighbours, I don't know what they say about me after all, no one feeds me and I am at my home." (KII – Traditional healer 67 years old).

"Others come for treatment when they are too weak even to stand or walk. In fact, I even sometimes get scared that they will die in my home, but what I do is to make sure that I don't get any money from them until I have seen that there is some change and in most cases I end up sending them to main hospital for other investigations". (KII – Female traditional healer, 55 years old)

They also reported that sometimes they feared to treat/take care of patients who were in critical condition, more so, the mentally ill/mad patients because they were hard to manage /take care of.

"The other problem I would find with such patients was that they are hard to take care of especially when they are mentally ill. They would defecate on themselves, break things or even cause harm to me because they were very strong. This condition forces them to get medical help. (KII - Male Traditional healer, 56 years old).

Another challenge they presented was that traditional healers are not recognised by government as service providers for the good work they do especially as regards training or capacity building.

That if they happen to be involved very few are invited at times to attend some workshops and others are left out which is unfair since we deliver the same services. Even the people in the community have a bias towards them and their structures and find themselves disguising themselves as they seek services

"And there is one other serious challenge that I face is the people's negative perceptions about our work the patients fear to come to us openly they have to keep on hiding so that they are not seen accessing our premises". (KII - Male Traditional healer 41 Years old)

Related to the challenge above, traditional healers had issues with the born-again Christians who considered herbal medicine to be satanic, which affected the sleeping sickness patients' efficacy in seeking health care from them and using the herbal medicines.

"There's one problem we are facing of the born again Christians think that all our herbs are satanic. This medicine is not satanic. They have misled people. They take them for prayers and then you hear that the patient died. It's just chance for someone to get healed after being prayed

for, maybe only when God planned that the person gets healed. This has really killed many people. (KII – Male Traditional Healer, 45 years old)

Traditional healers presented more challenges faced when they took care of the sleeping sickness patients. There was a problem that though the patients presented with the sleeping sickness symptoms, there was no way they could establish the diagnosis signs to prove because they didn't have a machine to check/test. Some patients feared to take the local herbs, just like they did any other drugs they got from the clinics, which made it become difficult for them to improve or for easy monitoring.

Some patients it was reported, when it came to cut-cutting of the skin to administer the herbal medicines (Teodano), they got so scared and even cried that the razor blade was too painful and refused to be worked on and this affected the effectiveness of their medicines and level of adherence. Some patients were too poor to afford/raise money to buy the local herbs and were either given treatment on credit on seeing their presented serious symptoms /really sick or went away without treatment. It was said this may not only be with traditional healers, but also with other service providers like clinics because they asked for money even before starting on treatment. Hence one being ignored and the situation worsening.

"Me personally, I also get scared when I see someone in bad condition before and after treatment and that is why I refer them more so when someone does not eat, has sunken eyes which are just inside, one being skinny as if she/he is HIV positive, pale skin like someone who is lacking blood. All that combination scares "even if it were you." (KII – Male Traditional healer, 34 years old)

"Sometimes we ask for requirements which some patients cannot meet as individuals basing on their levels of earning. For example I sometimes ask for a white goat, black goat, chicken which is mixed white and black "Echerapus" and some actually fail to get hence being a barrier." (KII - Female traditional healer, 55 years old)

Another challenge they reported was church related where some church pastors could not tell whether the problem is of evil spirits or not and at the end of it all, they delayed these patients instead of referring them to the hospital.

"For example, in 2018 one patient died in church where he had gone for prayers since he was used to prayers and by the time the church realized, he was too weak and died before he was taken to the hospital which was not easy. It created a lot of tension in the community and enmity". (KII – Traditional healer, 34 years old)

They also reported that with the nature of work they did, they were not on good terms with their neighbours. That they are not happy about their progress and their work. Most people thought they just ate money for free, they said there was nothing that we do, but again when they got problems, they went to consult them and believed after they had been treated.

We are also segregated by people - they do not take us as important people. They take us as enemies because if someone wants to do a wrong thing, he says I will go to a traditional healer and yet we are people who do important things for the community. (KII – Male Traditional Healer, 42 yrs).

Challenges reported by patients

The next felt challenge by IDIs was stigmatization by the community after treatment/discharge. Patients were isolated as people in the community thought they had HIV. It was a bad experience for the recovering patients though in the end they coped and in the end, some overcame it.

"We also had a challenge in the community in a way that people started laughing at me that I have HIV/AIDS which brought for me a lot of stigma in the community. In fact, I used not even to go to the trading centre in fear of being laughed at by people." (IDI – Female patient 35 years from Kaberamaido).

The painful diagnostic process of getting fluids from the back with an injection and treatment was a big challenge as it worried patients and some could even evade testing.

There was also reported to have been another challenge of falsehood in service provision taking time treating symptoms before getting proper diagnosis.

That someone could confidently stage himself that he can treat the disease when actually they could not.

Another challenge cited was the strict meal time for patients during periods of food shortage as at times they had meals late or no meal at all.

Restriction from sex due to body weakness was another challenge which at times resulted into domestic violence because some patients were not fulfilling their conjugal obligations and denying their partners their conjugal rights. The weakness also rendered patients unproductive and regarded worthless, another basis for domestic violence.

“Yes, the fact that the drugs are too strong, it weakens you that you cannot do anything heavy.

In fact, you are not even allowed to have sex with your wife for six months. So, it was really a challenge even for me and my wife, but later on, we stabilized after her understanding my situation.

Lastly, this disease greatly reduced on our level of output. This is because it was now only my wife to actively participate in agriculture since I was not allowed to dig” (IDI – Male patient 50 years old from Acilo B).

The distance patients had to walk from home to the hospital was another challenge when the patients were very weak and the long hours they had to wait to be served at the health care facility. This could be a very big challenge as they could be waiting without meal, which could affect their adherence too.

2.7 Some of the ways of improving access and treatment uptake of sleeping sickness drugs

Several suggestions were given in the KIIs to improve access and treatment uptake of Sleeping sickness drugs. Most of the respondents suggested that government should bring those drugs to nearest health centre IIs, IIIs and IVs; including testing kits, because when that disease comes it kills people unknowingly because the signs are almost the same with those of other diseases.

“I suggest they distribute them even to HC II, HC III, HC IV for easy access by the patients since some come from far and at times, they do not have money and means of transport. (KII – Nursing Assistant, Otuboi)

The government should bring those drugs together with the fridges where they can be kept when at the level of HC III, HC II for easy access by the patients. (KII – Religious leader, 57 year, Otuboi Kalaki)

They went ahead to suggest that government should change the nature of the drug from injection to tablets or syrups to be taken orally to enable adherence and storage as the injectables require refrigeration. The government should scale up with more facilities with testing and treatment services in nearby areas to help mostly those points like lake shores not only depending on Lwala Referral Hospital, which is far from the lake shores to enable patients who have been bitten by tsetse flies to easily walk to the facility to get immediate attention.

As suggested by one traditional healer, patients should be sensitized and counselled on the benefits of using these drugs if they are to live on earth and cure well. Also that if possible, government should also train traditional healers on how to handle these drugs well as long as they are in tablet form because they also handle many patients.

If the government can give me also their assignment, I cannot refuse just like the way you are sent to look for people like us (laughs)–that is all. (KII - Traditional healer, 67 years old).

People must be taught that immediately when you have been bitten by an insect, you have to move where you can get help, not you again being reluctant. But at least you have to move where they can provide you some guidance or medication.

It is like there are no special teams which move in villages to inform people about these cases. There are people who move telling people that we still have insects. Those who graze animals in swampy areas to take care. There is thus need to create such teams to mobilise and inform the communities. (KII – Lab technician at clinic C15).

It was also suggested that the drugs should be fully well monitored and approved by National Drug Authority (NDA) and with no serious side effects like the previous one which has made some people lame and others blind as well as paralyzed /caused disabilities.

Due to the long period the patients stayed at the hospital and the after effects of the disease with its treatment generally, the former victims felt body weakness and unproductive and asked government to give them a hand to render them productive in their community and in their homes.

As it was with the other service providers, traditional healers had their take on what should be done to improve access and treatment uptake of sleeping sickness drugs. Most of them suggested that Government should bring those drugs to nearest health centres, for example, HC IV, HV III close to the patients because the only sleeping sickness hospital in Lwala is very far to most of them that also the drug to be brought near to patients should be changed from injection to tablets, moreover smaller tablets that can be easily swallowed by the patients.

“My patient told me that with the current drugs if you are weak, it can kill you very fast. The drugs should be in tablet form which is not bitter and big, if it is injection, it should be done after one month since it is strong with side effects”. (KII - Male traditional healer, 34 years old)

That patients should be given support in form of food which they can at least eat before taking their drugs. This food should be the one which brings iron and proteins such that they are strong just like people with HIV who are supported.

Further still, government should train clinics staff, village health teams (VHTs) and traditional healers on the common symptoms of sleeping sickness and also how to use the drugs as this will help in early detection of the disease hence reducing death cases.

This will help them to do their work of sensitizing the community about the disease and the fly which brings the disease and how to prevent themselves from getting it. Patients should also be sensitized and counselled on the benefits of adherence if they are to live longer on earth and get complete healing.

“If possible, the government should train even traditional healers on how to handle these drugs well as long as they are tablets. This is because we traditional healers we also handle many patients (laughs).

If the government can give me also their assignment, I cannot refuse just like the way you are sent to look for people like us (laughs)–that is all. (KII – Female Traditional Healer, 67 years old)

“Okay, another solution that should be done is they should get us and train us on sleeping sickness and even other diseases so that we shall understand what we doing. You know when we are trained together we shall come to understand each other.” (KII - Male Traditional Healer, 41 years)

The traditional healers should then be allocated treatment centers/health facilities so that when a patient comes with symptoms of sleeping sickness, they can be referred easily in time for treatment.

Also us traditional healers government should include us in programmers that deal with treatment of this disease. These herbs we use, it's just that the western world is better at science, but they can use them to create good medicine. (KII - Male Traditional Healer, 48 years old)

In that regard, it was suggested that a herbal hospital be build just like government has a modern hospital. It should also provide space where herbs can be administered because they have them and can advise on how to prescribe them. So, as they help to treat the patients, the traditional healers will earn some money. That more tsetse fly traps should be provided as before to reduce chances of being bitten by the flies because the old ones were unfortunately reported to have disappeared and while others were consumed by wild fires. It was further suggested that that training of more service providers in sleeping sickness management at health centre IIs and IVs to increase on the number of health workers in those health facilities, increase on stocks/drugs at the health facilities (IIs and IIIs) and private clinics for easy access like it is for ARVs and to close supervision and monitoring of those stocks in the facilities.

Another appeal was that the Drug Authority should change the diagnostic method from the injection in the back to something better or less painful.

That there is need to carry out massive sensitisation about sleeping sickness in the community and that doctors/health workers, VHTs and Community Development Officers should work hand in hand to inform and guide patients and caretakers on treatment until they are discharged.

That as VHTs are trained in handling sleeping sickness patients, they should be entrusted with drugs to come and help people in the community with the disease like they have been working in the case of malaria.

Also that health facilities should provide rHAT patients with a balanced diet to enable them adhere to treatment.

There is need to carry out routine vaccination of animals since the disease is transmitted by animals and sleeping sickness testing should be at village level.

Ambulances should always be available on standby for referrals with service providers available at the health facilities to attend to emergencies.

That children in schools should be reached about sleeping sickness on radios, TVs and during assemblies and seminars.

2.8 How best the new sleeping sickness drug can reach the patients

One laboratory technician among the KIIs suggested that since it is new product on market, the government should first carryout research on it because with the given recommendations of how to execute it there will be no way it can be rejected by the users. So to reach people he went ahead to suggest new health facilities be set up to enable patients access it.

“As I had told you before that if the government can at least re-inject some new facilities around or nearby health centers, it can help so that when a person is bitten by an insect, he can attain the treatment there and then. So the drug will work without any hinderance”.

They also suggested sensitization should be done massively, both on radios, in hospitals, social gatherings like in burials, markets and it should be done by both doctors and Village Health Teams (VHTs) who know their people better informing them that drugs are available and machines for testing are also available.

“About acceptability yes, people will accept “If they can accept to take ARVs, why not”? People with HIV when they go for ARVs, they say that they are going to add more days. For me now if I had not added my days, would you find me, whom would you interview– They would only tell you that Okello died long time ago”. (KII – Traditional Healer, 64 years old).

Another suggestion was through bringing the drugs to nearby health centres, that is HCII, HC III, HC IV for easy access by the patients. In case they change these drugs from injections to tablets which can be swallowed, VHTs at this point can be the best to see that these drugs reach patients easily.

That by giving information so that people understand that there is a problem they are facing, it will become easy for them to go and look for the drug, but if they do not understand it will not be possible. There is thus need for sensitization so that people get informed because once informed one you can easily trace for the drugs.

“In case they are changed to tablets, then caretakers or parents should be the ones to pick for the patients in case they are too weak to move to the hospital. For the case of children, parents should be the ones to pick for them since they are young to understand the prescription by the doctor”. (KII - Religious leader (Rev), Otuboi).

The traditional healers also gave their suggestions on how best the drug could reach the the patients.

First, that due to lack of information among the patients and the community at large, sensitization should be done massively, both on radios, in hospitals, social gatherings like in burials, markets and it should be done by both doctors and Village Health Teams (VHTs) who know their people better; informing them that drugs and machines for testing are available.

Also that the medical doctors should know what to do because like what's happening with the corona virus, the traditional healers felt they had a limit on how they could advise on this. That there should be put a plan on how to provide drugs to the sick.

It was then suggested that the drug be given to the LC 1 and he/she becomes responsible for its distribution because he knows his people; he knows who is and who is not. That if taken to the health centers it will not reach all the people/some people will not have access to this drug. They should thus build a small structure at the chairman's place where people come first and he helps connect them to the medical workers to administer the medicine.

“The LC will work as the ‘askari’ (security guard) of the medicine. People will come through him and forwarded to the health workers. Maybe what I see is that government has many branches, they can decide that every parish have one doctor for sleeping sickness. Also how it dealt with Bilhazia tablets, it gave them at the LCs. And since LCs are close to the people, it would work well. (KII – Male Traditional healer, 48 Years Old)

They suggested that in this area, if they are given the drug, it would help people who cannot go to the hospital. The VHTs could also be trained and given the drugs

because they are the only ones who are near the people.

The VHTs can be of good help when it comes to this, since they have the list of these patients in each village. So they can move even to their homes informing them about new changes and what they should do as patients. (KII - Female Traditional healer, 55 years old) (KII – Female traditional healer 55 Years old)

Therefore, because the traditional healers very much wanted to be involved in information dissemination and drug distribution, one of them had this to say:

“Like us people who treat we can easily teach people because since we are able to heal it becomes very easy. And they can heal from the disease”. (KII – Male Traditional Healer, 42 Years old)

2.9 Acceptability of the new drug/Making sure people take the new drug

Majority of the respondents were positive about acceptability of the new drug by the patients in their communities giving reasons and conditions for acceptability. The drug was at one moment compared to the ARVs for HIV, which people accepted and have been taking them for a long time since ARVs came on market as long as people are sensitized on it.

“These patients should be sensitized and counselled well about these drugs, so that they Get to know how they are supposed to take them. When and for how long, then they will definitely take them very well. This work should be done by the VHTs since they are the ones who stay with these people.” (KII – Religious Leader (Rev), Otuboi).

“Yes, people will accept “If they can accept to take ARVs, why not”? People with HIV when they go for ARVs, they say that they are going to add more days. For me now if I had not added my days, would you find me, whom would you interview–“They would only tell you that Okello died long time ago”. (Laughs) (KII – Traditional healer, 67 years old).

They also reported it will be will definitely be accepted and used well since it's the VHTs who will be sensitizing people on the values of taking this treatment well. (KII – Religious leader 02, Acilo B).

It is also known on record that government programmes have been welcome and supported by people in the communities.

“By the way these days’ people like government programmes especially on health. When these things are brought closer to people, I know the challenge is to go and tell people that there is a new drug. People will embrace although they might think that the thing kills. So they need to be taught about the new drug. Lab technician (Lab Technician, clinic - C15)

All traditional leaders believed people will accept to use the newly introduced drug first, well by virtue of the desperate condition they will be in of wanting to get well. There is no one who doesn't want to be fine. That based on the situation people went through to get treatment, they would accept it especially if it's given to the LCs. More so, the drugs will be new and different from the first ones. They also believed in patients' acceptance because they know whatever comes from government does not harm people as it would have already been approved by the standards of the drugs (Uganda National Drug Authority).

On the other hand there was expected to be some fear from some people/patients; that's why there was need for the LCs to be involved to help people's trust because they are powerful persons in the community and people respect them. The traditional healers also committed to work together with the authorities to encourage people to take the medicines.

Involving stakeholders to make sure that people take up this new drug

While some promised to give health education to the masses on the drug like they would for any other medicines; others promised they would give / supply food stuffs for patients to help them in adherence. The faith based providers and the traditional healers suggested to offer counselling services to give patients hope that when they take the drugs they will not die but get better and live on.

I can educate them on how to take medicine that is to say: in the morning, afternoon or in evening just like anti malarial which we normally take and we recover. I can also give some foodstuff to these patients if I have. This work of ours does not need when you are selfish, doesn't allow because we receive many people and others even sleep at times if they are too weak. (KII - Traditional healer, 67 years old)

I will give them proper counselling - emphasizing that "if you take well your drugs, you will be healed, but if you do not follow what you are told to follow, you will not be well. I would on the other hand encourage them to always eat balanced diet so as to boost their immune system. This as a result, will lead to quick recovery. that is all I had (smiling). (KII - Religious leader 02, Acilo B)

The private clinics health practitioners emphasized the need to educate the patients and other community members on the advantages of taking the drug and disadvantages of not taking it.

I mean telling them the advantages and disadvantages of not taking drugs (good adherence and poor adherence). You see there are patients who do not want to sleep in the hospital. So it will be better and convenient for them to take their drugs from home (tablets) (KII - Nursing Assistant in a clinic).

Some talked of sharing ideas and success stories about the drug to build confidence in the People while others promised to remind the patients to take their medicines in the right prescription at the right time reminding them of the dos and don'ts during the therapy

Now that they are sensitized and accepted to take the drugs, my work is then to encourage them to take drugs well as prescribed and at the right time. "God heals you when you believe and take your drugs, he will do his part then well."

As a key stakeholder, I also encourage them to always have a meaningful life. "Live life of hope" and life is in your hands. Yes there are people in life who live life of whom it may concern (drunkards) who cannot even take time to go for any check-up if they are sick, rather, they want to be for God to go to the hospital. (Religious leader (Rev) Otuboi)

One service provider said that by government buying a new drug, they must have carried a lot of research on it; looking at its strength and viability. So his role will be to encourage people here to embrace and accept the new drug as it works like the first one which government used to provide earlier.

Of course that is it. They will come asking wanting to know the new drug the government is introducing to the community. As I have told you that the cases

for the tsetse fly are commonly treated in gazetted areas by the government.
(KII - Lab technician in a clinic, C15)

They also said they would encourage and educate patients on how to take medicine consistently for adherence and quick recovery. For instance, if it is in the morning, afternoon or evening, let it be, just like for other drugs like the antimalarial which people normally take and recover. As people who have participated in treating the disease, they could mobilise people in the community for sensitisation programmes on sleeping sickness because through their experience as traditional healers it was considered a bad disease. That they would also advise patients to take their drugs well since it has been improved as compared to the previous one which was seen as painful. That as health care providers they could participate/ take part in capacity building programmes (seminars and workshops), for new or more knowledge about the disease /sleeping sickness so as to deal with it from an informed point of view.

They promised that in case the new drug is brought and the disease is rampant again, they would use the same method they used in the past of referring patients to the government hospital for treatment because some of that medicine usually needs to be refrigerated, where if it's given to them they wouldn't have proper storage for it. So, the best they can do for patients in future will be to refer them to hospitals for proper management. That it would be nice if government gave out the medicines and traditional healers are allowed to participate in giving out /drug distribution after training them, because many people approached them for help.

"Two stakeholders are important in this process, LCs and traditional healers or modern medical workers". (KII - Male Traditional Healer, 48 Years Old)

Their responsibility they said was to treat people even sometimes when they did not have money, because it was their work as long as someone approached them.

The persons who come to us, come knowing what we are capable of doing.
(KII – Male Traditional Healer, 41 years old)

However, they expressed some disappointment because government through UCC blocked the channels through which they were passing information to the community as radios no longer advertised for them.

The FGDs also had their take on involving service providers/stakeholders in making sure patients access and take up the drug for sleeping sickness.

First, they suggested that the service providers should provide information on nutrition. Clinics should advise on nutrition as far as health issues are concerned and timely taking of the medicines. That is, right drug, right person and right time. They should also offer counselling services to the patients and then later refer those they cannot handle for proper management. Thus stop imposing themselves on patients they cannot handle/beyond their capacities; that is, learn to refer; they should also give guidance on .how to take the drugs on time and inform of the side effects of the drug. They should also have testing kits to be able to give treatment.

"Clinics also provide information concerning nutrition. That is, which kind of food to eat that is energy giving foods and proteins as well as minerals (balanced diet to boost immune system)". (FGD 7 – Female patient 76 yrs old, Alwa Akwon Dongi)

The church should provide counselling services and give patients hope; should also provide financial and material support. The church leaders should advise people to go to hospital for proper diagnosis and treatment as they pray for them; they should also visit the homes of the patients as they provide counselling

services to patients. More support should be given in form of information on availability of drugs in health facilities, financial and material support as they encourage patients to go to hospital.

“For churches should be taught to know the relevancy of hospital. There are some people who believe in their faith these do not take drugs. There are at times even when traditional healers are able to treat people but the churches do not allow.” (FGD 06 – Male patient 30 years old, Atwigi village, Alwa S/C)

They said traditional healers should be involved in meetings and advised not to only think about making money, but think about saving the lives of the patients in question; they should be sensitised on the symptoms of sleeping sickness to know what they are dealing with and be able to refer patients in time for proper diagnosis and treatment. They should rather be informed about the existence of such diseases and health levels they cannot handle and encourage patients to go to hospital.

Government should carry out compulsory education and training programmes to alternative health care providers, involve in drug distribution and set bylaws for care takers to be answerable for the patients' adherence; give authority and permission to traditional healers, religious leaders, local drug shops and Clinics to refer patients.

Involving the community to make sure people take up the drug

Participants mentioned that it was the duty of the community to respect the lives of the people/patients by making sure that they're safe by helping to take them to the hospital in case they are too weak or not able to be on their own. The relatives/caretakers in particular should monitor these people to make sure that they are taking drugs properly as prescribed, in the right quantities and time from the hospital. Caretakers should make sure that these patients go for refill/more drugs in case they are over, or even picks for them if they are unable, maybe due to transport or sickness. Further, the community should organize a team of representatives in charge of visiting and counselling patients and also give feed back to the VHTs for quick response.

The community generally should provide foodstuff both in kind and cash/money to such people just like government used to do with the HIV patients, who used to receive posho, cooking oil, as motivation to take the drug since they become too weak even to dig (for six months) without heavy work, to motivate them and know that they are not alone and feel loved in the community.

“Always when the government is introducing new programmes, the information is spread by the chairpersons in the community telling people to embrace it. Telling people that whoever has come across a bite in the swampy areas should get checked. People will be aware knowing that the government has brought a new drug for this disease so they will not reject it. They will embrace it automatically” (KII – Lab technician at clinic, C15)

The lab technician went ahead to explain that since there are very many strategies that the government uses they will come to radios spreading the information, teaching people that about another drug and encouraging them to accept and embrace it; that it's a new government programme for sleeping sickness, urging them not to resist, they will accept anything the health worker will be giving them.

Traditional healers went ahead to break down and specify the roles of stakeholders in the community. That the religious leaders, VHTs and LCs should carry on sensitization programmes in the community to help people understand the disease sleeping sickness, its causes, preventive measures and where to go in case one got bitten by a tsetse fly and even advocate for drugs to be extended to the community for easy access by the patients who were weak, disabled and even couldn't afford transport to the distant health facilities to get treatment. They were expected to make sure they report any problem faced by the patients to VHTs or at the district in case as members of the community convene meetings to discuss problems that may be affecting them through sharing that can help enhance patients' adherence.

To visit patients and give advice on importance of adherence and dangers in not taking drugs. They can then encourage patients by giving them hope that when they take them they will be fine and counselling them not to fear drugs as some have fear because they may not have food. Hence make sure that whenever one goes visiting, they carry something to help the patient.

They were also supposed to give material and financial support with a hand in domestic chores; to advocate for support from government; to help and buy drugs for patients and to offer counselling services.

Other concerns of the community include clearing all the lantana bushes which are habitats of tsetse flies; carrying out compulsory mass testing and quarantining patients; and to advocate for vaccination whether one is sick or not.

Conclusion

A number of rHAT patients visited other health care providers before they got the proper treatment. A lot of their time was wasted wandering in private clinics, churches and traditional healers shrines. The pattern of resort for patients with rHAT was more hierarchical where by most of them sought care first from small private clinics, government health centres, failure to recover they resorted to prayers and traditional healers, until they were referred to Lwala hospital designated for testing and treating rHAT. A lot of time was wasted as they wandered in these alternative care options without recovering. These providers after failing to treat rHAT like symptoms referred patients to Soroti and Lwala hospitals. They are willing to be trained in diagnosing rHAT and being part of the referral system.

Majority of the respondents were positive about acceptability of the new drug by the patients in their communities giving reasons and conditions for acceptability. Lessons learnt from the ARVs program in Uganda can help in the tolerability of the new drug.