



## **An anthropological study on local community and peripheral health centre staff perceptions and practices regarding sleeping sickness in Vwaza Marsh Wildlife Reserve in Malawi**

by

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## TABLE OF CONTENTS

Acronyms .....	vi
<b>1. Introduction</b> .....	<b>1</b>
<b>2. Statement of the Problem</b> .....	<b>2</b>
<b>3. Objective</b> .....	<b>3</b>
3.1 Overall objective .....	3
3.2 Specific Objectives .....	3
<b>4. Methodological approach</b> .....	<b>4</b>
4.1 Study Design .....	4
4.2 Study site .....	4
4.3 Data collection methods .....	4
4.3.1 Non-participant observations .....	4
4.3.2 Review of literature/documents .....	5
4.3.3 Key informant Interviews .....	5
4.3.4 In-depth Interviews .....	5
4.3.5 Focus group discussions .....	5
4.4 Recruitment and training of research assistants .....	5
4.5 Data management .....	6
4.6 Data analysis .....	6
4.7 Ethical considerations .....	6
<b>5. Results</b> .....	<b>7</b>
5.1 Local terminologies for sleeping sickness .....	7
5.2 Signs and symptoms of sleeping sickness .....	7
5.3 Causes of sleeping sickness .....	8
5.3.1 Biomedical explanation of causes of sleeping sickness .....	9
5.3.2 Witchcraft as a cause of sleeping sickness .....	9
5.3.3 Other causes of <i>kaskembe</i> .....	10
5.4 Sources of information on sleeping sickness .....	11
5.5 Stigma and sleeping sickness .....	13
5.6 Treatment of sleeping sickness .....	14
5.6.1 Self-medication with medicines .....	14
5.6.2 Traditional healers .....	15
5.6.3 Seeking treatment from health facilities .....	16
5.6.3.1 Diagnosis of sleeping sickness .....	16
5.6.3.2. Treatment from health facilities .....	17
5.7 Motivators to finish treatment .....	18
5.7.1 The desire to get cured .....	18
5.7.2 Seeing people with sleeping sickness recovering .....	18
5.7.3 Treatment for sleeping sickness being administered at the health centres around Vwaza .....	19
5.7.4 The drug should have minimal side effects .....	19
5.7.5 Sensitization of communities about sleeping sickness treatment .....	19
5.7.6 Other factors .....	20
5.8 Challenges in seeking treatment for seeking sickness .....	20
5.8.1 Demand for diagnostic and treatment services among men is low .....	21
5.8.2 Late diagnosis of sleeping sickness .....	21
5.8.3 Stockouts of medicines and other medical supplies .....	21
5.8.4 Transportation .....	22

5.8.5 Lack of involvement of private clinics in the fight against sleeping sickness .....	23
5.8.6 The process of diagnosing sleeping sickness is painful .....	23
5.8.7 Lack of food items .....	24
5.8.8 Belief in traditional leaders .....	25
5.8.9 Misperceptions about testing for sleeping sickness .....	26
5.8.10 Poor attitude of health workers .....	26
5.8.11 Lack of testing equipment.....	27
5.8.12 Late communication of results from Rumphu .....	27
5.8.13 Shortage of staff.....	28
5.8.14 Abandonment of hospitalization .....	28
5.9 Effects of sleeping sickness .....	28
5.9.1 Effects of sleeping sickness on the individual and his family.....	29
5.9.1.1. Impoverishment of families .....	29
5.9.1.2 Development of physical impairments.....	29
5.9.1.3 A person is at risk of suffering from mental illness .....	31
5.9.1.4 Death of people with sleeping sickness .....	31
5.9.1.5 School performance .....	32
5.9.2 Effects on the community .....	32
5.10 Coping with sleeping sickness .....	32
5.10.1 Communities sometimes contribute money for transport for patients with sleeping sickness	32
5.10.2 Sale of property to raise money required for hospitalization .....	33
5.10.3 Cultivating a farm belonging to a person with sleeping sickness .....	34
5.11 How new drugs for the treatment of sleeping sickness can best reach patients.....	34
5.11.1 Create awareness about the new drug among community members .....	34
5.11.2 Health workers should avoid selling the new drugs.....	35
5.11.3 Make drugs for sleeping sickness available at the health centre.....	35
5.11.4 Oral administration of drugs for sleeping sickness .....	35
5.11.5 Use HSAs to distribute the drug .....	35
5.12 Involvement of the community in the fight against sleeping sickness.....	36
5.12.1 Encouraging people with sleeping sickness to seeking care.....	36
5.12.2 Cheering up the sick at the hospital .....	36
5.12.3 Some communities cultivate field belonging to hospitalized patients .....	37
5.12.4 Creation of awareness about sleeping sickness.....	37
5.13 Prevention of sleeping sickness .....	37
5.13.1 The installation of tsetse fly traps .....	38
5.13.2 Relocation to areas where there are no tsetse flies.....	40
5.13.3 Introduce a vaccine against sleeping sickness .....	41
5.13.4 Put a wire fence around the game reserve.....	41
5.13.5 Empower communities around the game reserve economically .....	42
5.13.6 Distribute repellants for people in areas surrounding the reserve .....	42
5.13.7 Wear special protective clothing.....	43
5.13.8 Introduction of the <i>chitetezo mbaula</i> .....	43
5.13.9 Drilling of boreholes .....	43
5.13.10 Introduce bylaws .....	43
5.14 Factors contributing to failure to adopt preventive measures for tsetse flies.....	43
5.14.1 Poverty .....	44
5.14.2 Difficulties controlling mosquitoes.....	44
5.14.3 Ignorance.....	44

5:15 Motivators for health around Vwaza Marsh Wildlife Reserve .....	44
5.16 Messages would motivate people to change .....	47
6. Discussions, Conclusions and recommendations.....	48
References.....	52

## List of Figures

- Figure 1: Photo of a lollipop: the size of the lollipop stick is equated to the syringe used to draw specimen from spine 30
- Figure 2: Tsetse Fly Trap put up by the Department of National Parks and Wildlife, Vwaza Marsh Wildlife Reserve 38
- Figure 3: Tsetse fly trap installed by the College of Medicine 38

## Acronyms

ADC	Area development committee
AFIDEP	African Institute of Development Policy
AIDS	Acquired immunodeficiency syndrome
COVID-19	Corona Virus Disease 2019
DHO	District Health Officer
DNDi	Drugs for Neglected Diseases <i>initiative</i>
DRC	Democratic Republic of Congo
ESCOM	Electricity Supply Commission of Malawi
FGD	Focus group discussions
FIND	Foundation for Innovative New Diagnostics
g-HAT	<i>T.b. gambiense</i> human African trypanosomiasis
HAC	Health Advisory Committee
HAT	Human African trypanosomiasis
HIV	Human immunodeficiency virus
HSA	Health surveillance assistants
IDI	In-depth interview
KII	Key informant interview
MoH	Ministry of Health
mRDT	Malaria rapid diagnostic test
NGO	Non-governmental organisation
NTDs	Neglected Tropical Diseases
RA	Research assistants
SHSA	Senior Health Surveillance Assistant
r-HAT	<i>T. b. rhodesiense</i> human African trypanosomiasis
UNIMAREC	University of Malawi Research Ethics Committee
VDC	Village development committee
WHO	World Health Organization

## 1. Introduction

Neglected tropical diseases (NTDs) constitute a group of diseases that affect 1.5 billion people in the world. Forty percent of the people who have NTDs live in Africa (United to Combat Neglected Tropical Diseases, 2018). There are 17 core NTDs or conditions which are caused by either microparasitic or macroparasitic pathogens. Macroparasitic pathogens involve vectors. NTDs caused by microparasitic pathogens include schistosomiasis, soil-transmitted helminthiasis, lymphatic filariasis, onchocerciasis, dracunculiasis, taeniasis/cysticercosis and echinococcosis while those caused by macroparasitic pathogens include Buruli ulcer, Chagas' disease, dengue fever, human African trypanosomiasis (HAT), leishmaniasis, leprosy, trachoma and rabies (WHO, 2013). In general, all NTDs share several characteristics: they cause disfigurement and disability resulting into loss of productivity and they also worsen poverty as patients and their guardians incur high cost of long-term care (Neglected Tropical Diseases Programme, 2015; Bukachi et al., 2017; Hasker, et al., 2011; Lutumba et al., 2007 & Bukachi, Wandibba and Nyamongo, (2017)). The morbidity and mortality due to HAT reduces household capacity to produce and buy food; hence, resulting into food insecurity (Uba, et al., 2012). These diseases affect very poor people especially in sub-Saharan Africa where access to clean water or adequate sewage system is inadequate (Mweninguwe, 2019). Poor hygiene is a risk factor for NTDs (WHO, 2013). It has been argued that the control of NTDs is a means of tackling poverty (All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases, 2009). NTDs are classified as neglected diseases because, unlike other diseases such as tuberculosis, HIV and AIDS and malaria, they lack funding and that there is generally inadequate research on these diseases and conditions (All-Party Parliamentary Group on Malaria and Neglected Tropical Diseases, 2009). R-HAT is also classified as a neglected disease because they are restricted to rural and remote areas surrounding game parks and reserves (Chisi et al., 2011).

In Malawi, there are 8 NTDs that are known to be endemic, and these are schistosomiasis, soil transmitted helminthiasis, lymphatic filariasis, trachoma, HAT, leprosy, onchocerciasis and Buruli ulcer (Neglected Tropical Diseases Programme, 2015). HAT, also commonly known as sleeping sickness, is a vector-borne parasitic disease. The disease is caused by a protozoan parasite of the genus *Trypanosoma brucei* which has two species causing two disease patterns in human beings and these are *Trypanosoma brucei gambiense* (g-HAT) and *Trypanosoma brucei rhodesiense* (r-HAT) (WHO, 2013). g-HAT is found in the central, west and some parts of Eastern Africa whereas r-HAT sickness is found in Southern and Eastern Africa (WHO, 1998). The g-HAT is chronic in nature and it progresses more slowly and causes less severe symptoms while r-HAT sickness is usually acute, causing severe symptoms and can lead to death within a few weeks. There has been a significant decrease in the number of cases of both types of sleeping sickness, globally, than used to be the case previously due to national and global commitments to eliminate the disease: there have been less than 1,000 cases of g-HAT since 2018 and more than 100 cases of r-HAT in 2019<sup>1</sup> mainly due to the outbreak in Malawi. Both r-HAT and g-HAT can be fatal if patients do not timely access effective treatment.

Malawi experiences only r-HAT and not g-HAT. R-HAT sickness occurs in areas around three conservation areas namely Nkhota Kota Game Reserve, Kasungu National Park in central Malawi and Vwaza Marsh Wildlife Reserve in Rumphi and Mzimba Districts in northern Malawi. About 1 million people are at risk of infection with r-HAT in Malawi (Franco, et al., 2020). While r-HAT sleeping sickness is generally acute in nature, studies conducted in Malawi have demonstrated that the disease also has a chronic profile (Maclean, et al., 2004). Wild animals are the main reservoirs of this acute form of HAT and the parasites are transmitted to human beings by tsetse flies that have been infected after biting infected human beings or animals. On average Malawi has been reporting about 35 cases per annum between 2008 and 2018 (Global Health Observatory data Repository, 2018). However, in 2019 and 2020 Malawi reported 92 and

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<sup>1</sup> [GHO | By category | Number of new reported cases \(T.b. rhodesiense\) - Data by country \(who.int\)](#)

90 cases, respectively, of r-HAT sleeping sickness due to an outbreak and this was the highest number of r-HAT cases per country in Eastern and Southern Africa (see also AFIDEP, 2020).

Case detection for sleeping sickness in Malawi is mainly passive in nature and happens when patients visit health facilities, but active screening on a limited scale is also performed. Most people are diagnosed at an advanced stage experiencing severe symptoms. Rumphi District Hospital was the only health facility able to diagnose sleeping sickness for areas around Vwaza Marsh Game Reserve before 2013: at that time cases were diagnosed late and about a fifth of such cases died. This high fatality rate was due to poor access to diagnosis resulting into late identification of cases and initiation of treatment (Lemerani, et. al., 2020). For both g-HAT and r-HAT sleeping sickness, clinical diagnosis is difficult because the signs and symptoms are relatively non-specific. R-HAT patients present with similar symptoms as those found in patients with malaria or other diseases. Since symptoms are not specific it is generally difficult to make a diagnosis in resource poor countries with limited diagnostic facilities such as Malawi (Chisi et. al., 2011). Such delays in case detection increase the risk of patients needing treatment for stage-2 HAT, which is associated with a fatality rate 2.5 times higher than for stage-1 (Odiit, Kansime, & Enyaru, 1997).

All identified cases of r-HAT are supposed to be treated with recommended drugs namely suramin injections for the first stage and this is associated with occasional but mild reactions. On the other hand, patients who are in the second stage are treated with intravenous injections of melarsoprol which causes frequent and severe adverse reactions (Lemerani et. al., 2020). It is important that HAT should be diagnosed and treated rapidly as the disease evolves to invade the central nervous system, eventually leading to coma and death (WHO, 2013). Some cases of self-cure have, however, been reported for chronic forms of this disease (Lemerani et. al., 2020). Drugs for the treatment of sleeping sickness in Malawi are donated by the WHO through an agreement they maintain with the producers, Sanofi and Bayer. MoH organizes the storage and distribution to the health structures. The Foundation for innovative New Diagnosis (FIND) helped MoH in the endemic areas to set up mini laboratory facilities in four facilities around Vwaza Marsh. Over the years, the Pan African Tsetse and Trypanosomiasis Campaign Initiative has played a role of advocacy and social mobilization (Neglected Tropical Diseases Programme, 2015). The NTD Programme has functional diagnosis and treatment centres in all endemic districts and central hospitals.

In 2012, the WHO set the target to eliminate HAT as a public health problem by 2020. Recognizing the role rhodesiense sleeping sickness 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* (World Health Organisation, 2014). This will require a safe, effective, easy-to-administer treatment for both disease stages in r-HAT as well as g-HAT. While the target of eliminating HAT was set, the challenge is that total elimination will be difficult for r-HAT because of its zoonotic nature i.e. the parasite circulates among wild animals such as buffaloes and warthogs and domestic animals such as cattle (AFIDEP, 2020 & Fevre, et al., 2001). However, globally there is significant progress in eliminating HAT as a public health problem (World Health Organisation, 2014).

## **2. Statement of the Problem**

HAT remains a public health problem in many sub-Saharan African countries Malawi inclusive. As mentioned earlier, the rhodesiense form of the sleeping sickness is a zoonotic disease: its main reservoirs are cattle and wildlife. This ensures that a population of infected tsetse flies is maintained which occasionally transmit the disease to human beings. Since 2015 Malawi has been reporting largest numbers of r-HAT cases globally. While the numbers of cases of sleeping sickness have been relatively stable at around 35 cases per annum between 2008 and 2018 (Global Health Observatory data Repository, 2018), in 2019 Malawi reported 92 cases of r-HAT, the second highest number of cases per country in the Africa after the DRC (g-HAT) (see also AFIDEP, 2020). Most of the cases of sleeping sickness occur around

Vwaza Marsh Wildlife Reserve in northern Malawi. Between 2011 and 2014 the cases around Vwaza Marsh represented 90% of all the cases reported in the country (Lemerani et al., 2020).

As is the case elsewhere in Africa it will be difficult to eliminate sleeping sickness in Malawi because of the zoonotic nature of its causal parasites but elimination as a public health problem is possible. There are challenges of case detection and reaching patients with sleeping sickness in Malawi. Most sleeping sickness cases are detected passively among people visiting health facilities. Most people with sleeping sickness are diagnosed when the disease is at advanced stage and they experience severe symptoms such as convulsions (AFIDEP, 2020). The delays in detection of sleeping sickness and subsequent initiation of treatment impacts negatively on patient outcomes: the disease progresses rapidly and in most cases it is diagnosed in Stage 2 for which case fatality rate is 2.5 times higher than stage 1 (Odiit, Kansime, & Enyaru, 1997). Other studies have found that patients with sleeping sickness are usually stigmatized and often considered "desiring of infection" for entering game parts without official government permission which may act a barrier to report to health facilities to seek care (Chisi et. al., 2011).

In order for Malawi to achieve WHO's sleeping sickness elimination targets, there is urgent need to effectively reach populations at risk living around the three game reserves namely Vwaza Marsh Wildlife Reserve, Kasungu National Park and Nkhota Kota Game Reserve and create awareness about this disease: its etiology, methods of prevention and the need to timely seek treatment when diagnosed with the disease. Understanding people's perceptions, beliefs and practices with regard to sleeping sickness will help to inform policy and programming regarding this disease. This anthropological study investigated the bottlenecks to accessing health care among patients with sleeping sickness and determined what needs to be done to improve uptake of treatment and other services with regard to this disease including the strategies that can be used to ensure adequate information reaches target communities. The results of this study will inform further community engagement and sensitization for better treatment outcome.

### 3. Objective

#### 3.1 Overall objective

The overall objective of this study was to explore the perceptions and practices of the local community and peripheral health centre staff regarding sleeping sickness in order to improve case detection/referral and access to treatment in communities around Vwaza Marsh Wildlife Reserve in Rumphu and Mzimba Districts in northern Malawi.

#### 3.2 Specific Objectives

The specific objectives of this study were as follows:

1. To determine people's perceptions about the etiology of sleeping sickness and how it can be prevented.
2. To explore the health seeking behavior for sleeping sickness and its links with delayed access to treatment in communities around Vwaza Marsh Wildlife Reserve.
3. To understand the experiences of sleeping sickness among existing or cured patients as well as their families, including those of deceased patients.
4. To devise mechanisms for community and peripheral health workers engagement regarding sleeping sickness treatment access and case detection.

## 4. Methodological approach

This section describes the study design, study area, population of study, sampling process, data collection, ethical issues, data quality assurance, data management and analysis including community engagement.

### 4.1 Study Design

The study employed an ethnographic design to be able to capture the lived experiences of community members with regard to sleeping sickness. Ethnography, defined as a process of recording and interpreting another people's way of life (Keesing, 1981), uses several data collection methods such as participant observation and face-to-face interviews including informal interviewing in a naturally occurring situation. Observing the behavior in the context in which it occurs is a characteristic of ethnographic approach. In this study the community members including persons with sleeping sickness and those who were cured and health care providers at health facilities as well as health surveillance assistants (HSAs) were targeted to participate in the study.

### 4.2 Study site

The study was conducted in communities around Vwaza Marsh Wildlife Reserve in Rumphi and Mzimba Districts in northern Malawi. In 2019 Malawi unexpectedly reported 92 cases of sleeping sickness and this was the second highest number of cases per country in Africa (see also AFIDEP, 2020). Most cases of sleeping sickness in Malawi occur around Vwaza Marsh Wildlife Reserve. Between 2011 and 2014 the cases around Vwaza Marsh represented 90% of all the cases reported in the country (Lemerani et. al, 2020). Before 2013, Rumphi District Hospital, located about 60 km from Vwaza Marsh Wildlife Reserve, was the only health facility equipped to perform diagnosis and treatment of sleeping sickness in the district. In 2013 the Ministry of Health (MoH) strengthened the capacity of four health facilities, namely Thunduwike, Malidade, Katowo, and Mwazisi, very close to Vwaza Marsh Wildlife Reserve to diagnose sleeping sickness with the support of FIND (Lemerani et. al., 2020).

In areas around Vwaza Marsh Wildlife Reserve, at community level, there are HSAs who are supervised by senior HSAs who constitute the lowest cadre in the MoH and based at community level. These HSAs are attached to health centres which are in turn staffed with nurses and midwives, medical assistants and clinical officers and microscopists. These health centres provide outpatient care including for sleeping sickness, maternity wards and basic laboratories. Rumphi District Hospital provides additional specialised services. Regarding sleeping sickness, health centres around Vwaza Marsh Wildlife Reserve can diagnose rHAT cases and then refer cases to the district hospital.

### 4.3 Data collection methods

In this study a number of data collection methods were used namely literature/documents review, key informant interviews (KIIs), in-depth interviews (IDIs) and focus group discussions (FGDs). Through this process, we built up a picture of people's perceptions about sleeping sickness and their reactions to the interventions on this disease, identified challenges being experienced in the management of sleeping sickness.

#### 4.3.1 Non-participant observations

Using this approach to data collection, any events related to the study interviews, or tsetse fly traps etc. were recorded on the spot by use of recorders, cameras or field notes. During fieldwork attention was paid to the everyday life, narratives of events, social interactions, and the cultural meanings and practices of the

community related to the sleeping sickness. Local terminologies were elicited to understand how the community members express themselves regarding illness and the medicines for sleeping sickness.

#### 4.3.2 Review of literature/documents

Malawi's NTD Programme provided some literature on the sleeping sickness situation in Rumphu and Mzimba districts around Vwaza Marsh Wildlife Reserve. These reports summarized the number of cases of sleeping sickness in Malawi since 2012. Additional literature was obtained using internet searches. DNDi provided some published articles on sleeping sickness. We also reviewed policy documents such as the National Health Policy, the Health Sector Strategic Plan 2017-2022 and the NTD strategy in order to have an idea of the plans that government has at national and district level in the fight against NTDs especially sleeping sickness.

#### 4.3.3 Key informant Interviews

Key stakeholders involved in the management of sleeping sickness at both district and community levels were identified with the help of the national sleeping sickness programme. These key informants included programme coordinator, senior health surveillance assistants (sHSAs), HSAs, medical assistants, community leaders including religious and traditional leaders. A total of 16 key informant interviews were undertaken in both Rumphu and Mzimba. These key informants were selected purposively. These interviews with key informants focused on the etiology and prevention of sleeping sickness, how the disease is experienced, inhibiting and facilitating factors for seeking healthcare services for patients with sleeping sickness; and ways of improving access to diagnosis and treatment of sleeping sickness. Annex 1 is a KII interview guide.

#### 4.3.4 In-depth Interviews

IDIs were conducted with purposively selected community members. These informants included persons who have ever had sleeping sickness mainly to understand their perceptions and lived experiences and coping strategies. Interviews were also done with caregivers and family members who through their experience we understood the challenges of seeking care within Malawi's health care system. In this study, through interviewing persons who had previously sleeping sickness and their family members we also understood people's health seeking behaviour and drugs uptake during episodes of sleeping sickness. A total of 18 IDIs were conducted around Vwaza Marsh Wildlife Reserve. These informants were recruited from communities around Vwaza Marsh Wildlife Reserve with the help of HSAs. An in-depth interview guide is in Annex 2.

#### 4.3.5 Focus group discussions

FGDs were conducted with community members. Between 8 and 10 participants attended each FGD. Six FGDs were conducted: one with men, two with women, one with caregivers/guardians, one with recovered sleeping sickness patients and one with active sleeping sickness patients. Focus group discussion guide is in annex 3. In these FGDs the focus was on their perceptions regarding sleeping sickness, how it is experienced, inhibiting and facilitating factors for seeking healthcare services for patients with sleeping sickness; and ways of improving access and treatment uptake of the sleeping sickness drugs.

### 4.4 Recruitment and training of research assistants

Five research assistants (RAs) were recruited. All of them were fluent in Tumbuka/Chichewa and had a minimum of a Bachelor's degree with at least not less than 2 years of collecting qualitative data. The RAs were responsible for conducting FGDs, IDIs and some KIIs. These RAs were also responsible for

transcribing the interviews. Informed consent was obtained from study participants prior to the start of the interviews. All participants in this study were aged 18 years and above.

RAs were trained over a period of 4 days. This training was aimed at building the capacity of the RAs to collect data using qualitative methods and understanding the ethical and confidentiality requirements of the study protocol. The training included the rationale of the study and its objectives, data collection methods, going through the data collection tools and research ethics including confidentiality and interviewing techniques. At the end of training, mock interviews were conducted in which RAs interviewed each other in order to determine whether the guides were easy to follow including whether informants would be able to understand the questions. Mock interviews helped the RAs to familiarise themselves with the data collection instruments. The data collection tools were pretested in one village around Vwaza Marsh Wild Reserve and, in the evening, discussions were held with RAs to get feedback on their experiences of pre-testing the data collection tools. At the end of the pre-test, the team revised the tools and various strategies as needed.

#### 4.5 Data management

All the interviews and FGDs were recorded and transcribed by RAs. Notes taken during the interviews including participant observation data were expanded and typed. Audio recordings during the FGDs, IDIs and KIIs were collected by the Principal Investigator and checked and then compared with the transcribed interviews for purposes of quality control. All the transcripts were read and re-read to determine emerging themes. The major themes identified were (i) causes of rHAT and how this disease is transmitted; (ii) local terminologies for rHAT including signs and symptoms of the disease; (iii) health seeking behavior including barriers to seeking treatment and community involvement in seeking therapy; (v) prevention of rHAT; (vi) effects of rHAT (on individuals, families and wider community), (vii) coping strategies for individuals, families and communities, and (viii) motivation for seeking treatment. A coding framework consisting of themes and sub-themes was developed in NVivo 12 software. All the transcripts were imported into NVivo 12. Relevant texts from the transcripts were coded under each sub-theme. When all the transcripts were coded, each sub-theme contained all the responses that were provided by informants. One RAs was engaged to code the transcripts. The Principal Investigator checked the coding of the transcripts.. The NVivo software was helpful in organizing the qualitative data.

#### 4.6 Data analysis

Transcripts from the field were read and re-read and each evening discussions were held with the RAs to determine emerging themes. As mentioned above, NVIVO software supported the qualitative data analysis in this study. After the final NVIVO Project File was produced, we made print outs of each theme. Each theme was read several times. This qualitative data was analyzed using thematic content analysis approach. Excerpts/quotes including cases have been used extensively in the report to further explain and provide evidence for the emergent themes.

#### 4.7 Ethical considerations

This protocol for this study was approved by the University of Malawi Research Ethics Committee (UNIMAREC) for ethical review and approval. All study participants were assured that the data collected will be solely for the purposes of this study and their identity will not be disclosed to anyone. To protect the identity of the informants including the data collected (i) all interviews were conducted in private settings; (ii) all research assistants in this study were trained in research ethics and they were advised to maintain confidentiality and c) all the data collected was anonymized and names of informants do not

appear anywhere. Recorders were used during the interviews and FGDs and permission was sought from informants before tape/digital recording. Verbal consent was obtained from all the study participants.

## 5. Results

### 5.1 Local terminologies for sleeping sickness

The local term used for sleeping sickness in both Rumpfi and Mzimba in areas around Vwaza Marsh Wildlife Reserve is *kaskembe* or *kamembe ka kaskembe* [a type of fly that causes sleeping sickness]. People around Vwaza Marsh use this term to refer to the tsetse fly itself as well as the disease.

“... I can say that, in this area when people say *kaskembe* they mean the tsetse fly and at the same time they also mean the disease [sleeping sickness]”, (Medical Assistant, Malidade, Mzimba).

A game ranger at Vwaza Marsh Wildlife Reserve said that he had worked in Nkhota Kota where they call this disease *matenda a kaodzera* [the disease that makes people doze/sleep] because people with this disease tend to sleep over extended periods. This was also mentioned during an FGD at Katowo in Rumpfi.

“Other people call it “*kaodzera*” because a person suffering from sleeping sickness sleeps too much. For example, he/she can even sleep when eating *nsima* or even when you are chatting with him/her”, (P4<sup>2</sup>, FGD with women, Katowo, Rumpfi)

Therefore, in both Mzimba and Rumpfi the local term for sleeping sickness is *kaskembe* while in other districts such as Nkhota Kota it is known as *kaodzera*.

### 5.2 Signs and symptoms of sleeping sickness

Most informants in this study including current and previous patients with sleeping sickness and their guardians, microscopists and clinicians reported that patients with sleeping sickness present with signs and symptoms similar to malaria namely fever, headache, anaemia, general body pains especially in the early stages of the disease.

“...They feel cold ... fever. The signs and symptoms for *kaskembe* are the same as malaria. Once a person notices these signs and symptoms, what comes first is ‘I am sick with malaria’ you go and ask a patient; ‘how are you this morning?’ ‘ah still cold, fever is there still’ it’s when we say; ‘you better go and get tested of *kaskembe*’. So, 3 days the fever still persists even if the patient takes panadol, we know for sure that this is *kaskembe*. If they go for treatment at health Centre and still the signs and symptoms persist, we know that ‘this is sleeping sickness’ so for testing people for *kaskembe* people go to Kabwafu, Malidade and Thunduwiki”, (Female leader, Manolo, Mzimba).

Many informants in this study mentioned that when a person is diagnosed with malaria some clinicians do not do any further investigations to determine if the patient has sleeping sickness. When the diagnosis for sleeping sickness is missed, the patient may be diagnosed later with an advanced stage of the disease. In addition, most study informants including current and previous patients added that people with *kaskembe* doze or sleep during the day while chatting.

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<sup>2</sup> In an FGD participants were numbered P1, P2, P3, P4, P5, P6,.....and they refer to the FGD participants.

“... According to my experience, she felt discomfort. She had fever. Then she easily went to sleep. You are speaking to her and then you realize that you are alone. She is asleep. I used to shake her to say; ‘are you with me?’ you see. ‘I am speaking to you’ then 2 minutes she is gone. She is asleep again’ yeah it was like that. Then fever came in. little by little. And then I noted that she started speaking alone .....”, (Caregiver of a patient with sleeping sickness, Thunduwike, Mzimba).

Some informants narrated that even when they are eating they would fall asleep and their wives or relatives would wake them up. Most people including a teacher at Thunduwike reported that malaria is differentiated from sleeping sickness in that a person who has sleeping sickness tends to sleep more often.

“Yes, they do sleep during the day because during the night they have severe pains. So, they fail to sleep during nighttime due to severe pains. So, during the day it is when they feel like relieved. So, they want to sleep during the day. But during the night, the pains become severe”, (Medical Assistant, Katowo, Rumphhi).

Another symptom that most informants mentioned in this study was that patients with this disease experienced malfunctioning of some body parts and consequently become disabled in the process. They feel a lot of pain especially in the joints and they fail to walk when the disease is in advanced stages.

“...I could not walk instead I was crawling like a baby because I could feel pain in all joints and there was no energy for me to walk to the extent that I could feel as if I have worked over my capacity, especially this was happening with knee joints....”, (recovered patient, Mwazisi, Rumphhi).

Other signs and symptoms which were mentioned included loss of appetite, oedema, dermatitis, fatigue and body weight loss.

“... but for me I feel the clinician that we have now at least he knows the signs and symptoms of *kaskembe* and sometimes its him who suggests they do the tests for *kaskembe* in some patients. Some patients of *kaskembe* their face swells or even their legs they swell (*kumaso or malundi ghakuzulanga*) and sometimes they lose appetite. So the first time to go to the health centre they might miss it but the second or third time they would suggest a *kaskembe* test”, (P4, FGD with guardians of sleeping sickness patients, Katowo, Rumphhi).

When a person has sleeping sickness, he and his guardians and clinicians as well might conclude that he has malaria as the signs and symptoms are largely the same. The patient might even be given malaria treatment and there is no change. When this happens that is when friends, community members and even clinicians and other health workers, might advise that the patient should be tested for sleeping sickness either in nearby facilities around Vwaza Wildlife Reserve or Rumphhi District Hospital. Many informants in this study reported that in some cases there are delays in diagnosing sleeping sickness and by the time it is diagnosed in some cases the disease is in advanced stages and many people around Vwaza Wildlife Reserve have lost their lives due to delayed in diagnosing the disease and initiating treatment.

### 5.3 Causes of sleeping sickness

Participants in this study mentioned two causes of sleeping sickness namely microorganisms and witchcraft. These causes are described below.

### 5.3.1 Biomedical explanation of causes of sleeping sickness

Medical personnel were able to describe the causes of sleeping sickness and how this disease is transmitted: one key informant said that sleeping sickness is caused by protozoa called trypanosome which is usually found in wild animals such as elephants and buffaloes. A tsetse fly can bite an infected animal, becomes infected in the process and when this infected tsetse fly bites a person, it transmits trypanosomes to his or her body. This key informant specified that in Malawi the trypanosoma which is most prevalent is trypanosome rhodesiense (r-HAT). In general, all informants in this study were aware that people get sleeping sickness after being bitten by infected mosquitoes.

“Sleeping sickness comes from animals. When Tsetse flies bite these animals and suck their blood they carry it. Whenever they bite human beings they transfer that parasite into human bodies and that is how sleeping sickness is caused. *Kaskembe* [the fly] is like a general player as it feeds on both human and animal blood”, (Traditional leader, Thunduwike, Mzimba).

Study participants were also knowledgeable that sleeping sickness is very common in their community because people live very close to the Vwaza Marsh Wildlife Reserve. Many people even go inside the wildlife reserve without permission to either kill animals or do something else and, whilst they are there, they are bitten by tsetse flies.

“In Malawi, most of the people use firewood for cooking, so they are forced to go into the reserve or around the reserve to fetch firewood. During the rainy season, people are allowed to go into the reserve [Vwaza Marsh Wildlife Reserve] to collect mushrooms and also firewood. So, in the course of collecting firewood and mushrooms, people are being bitten by infected tsetse flies ..... in the end people suffer from sleeping sickness”, (Microscopist, Katowo, Rumphi).

In addition to this, people around the reserve also go into the Vwaza Marsh Wildlife Reserve to wash their clothes, prepare their tobacco nurseries, bee keeping and charcoal production. People around Vwaza Marsh Wildlife Reserve prefer to get water from the game reserve because water from their boreholes is salty and not good for both drinking as well as washing their clothes. Some people from surrounding communities do look for jobs in the park such as clearing paths in the reserve, clearing the area around the fence wire for them to take care of their families. It is not only when people go inside that they are bitten by tsetse flies: informants reported that these days the tsetse flies are everywhere even outside the reserve area including in residential areas around the reserve.

“...the thing is that during the rainy season sometimes we go into the reserve to look for mushrooms and one can get bitten at that time, some people their fields (*minda*) are close to the game reserve and they get bit as they are working in their fields”, (Guardian of patient with sleeping sickness, Mwazisi, Rumphi).

### 5.3.2 Witchcraft as a cause of sleeping sickness

While all study participants reported that tsetse flies transmit sleeping sickness from animals to human beings, some participants for example a teacher at Thunduwike in Mzimba reported that there are some people around Vwaza Marsh Wildlife Reserve who believe that they have been bewitched. A key informant in the MoH at district level reported that he knew some patients who thought that they had been bewitched: one has signs and symptoms of malaria and when they go to health centre, they are told that after testing

for malaria using both microscopy and malaria (mRDT), they are found negative. They make several trips to the hospital and they do not get healed, then they conclude that have been bewitched.

“I have some cases which have spent quiet a long period of time going from one traditional healer to the other to seek medical attention. At the time they are coming to the hospital, the disease is far much advanced .... So, this thing also happens”, (Key informant, Rumphu)

A number of informants especially at community level reported that some people believe that sleeping sickness can be caused by witchcraft – they actually say that ‘*kuli nyanga za kaskembe*’ meaning that there is sleeping sickness witchcraft. Consequently, people with such beliefs do not access formal health services and eventually die. The belief is that diseases caused by witchcraft can only be dealt with by traditional healers. Some health workers also reported that most of the people around Vwaza Marsh wildlife Reserve visit the health facilities in the late or advanced stage of sleeping sickness because they believe that they have been bewitched. People believed or believe that they were being bewitched because it was mainly being mistaken for malaria and upon being given malaria treatment nothing could change so people believed that it was being caused by witchcraft and a lot of people lost their lives not knowing that this was transmitted by Tsetse fly bites.

Some people around Vwaza Marsh Wildlife Reserve associate sleeping sickness with witchcraft because persons with this disease sleep during the day and people wonder why they should be sleeping during the day: they think that they sleep in day light because at night they were elsewhere bewitching others or ‘just flying up there’. Others will say they have been bewitched that's why they sleep during the day. This explains why the health workers have sensitized community members including traditional healers about the disease.

“Yeah, it took our efforts for sensitization. I remember one day I called all the traditional healers to inform them about this sleeping to say; ‘if any patient comes to you showing these signs and symptoms, please refer them to us at the health centre because if you delay with the patient, it will lead to permanent complications’. So, they do agree, sometimes they do refer the patients to us. They call to say; ‘I am sending you a patient who came for treatment. So, with these signs and symptoms, I am sending the patient to you to see whether it maybe trypanosomiasis’ so with the good relationship we have between us and the traditional healers. This is why it is easy to identify more trypanosomiasis’s patients. Yeah, but they do believe also in traditional practices”, (Medical Assistant, Katowo, Rumphu).

While witchcraft beliefs still exist in areas around Vwaza Marsh Wildlife Reserve, some informants such as an HSA at Manolo in Mzimba reported that these days people know that sleeping sickness is caused by tsetse flies unlike in the past when people did not know what was causing this disease. Beliefs about the causes of sleeping sickness at community level in Rumphu and Mzimba are changing, and more people seem to understand that this disease is transmitted by tsetse flies.

### 5.3.3 Other causes of *kaskembe*

While many informants reported that sleeping sickness is caused by *kaskembe* and then witchcraft, there were some study participants who reported that one can also get this disease after consuming contaminated bush meat.

“Sometimes you may develop sleeping sickness if you eat contaminated bush meat. *Usange warya nyama yakuthondo iyo yili ka kachibungu ka kaskembe unगतola matenda nangauli undalumikepo* (you can be infected with sleeping sickness after eating contaminated bush meat even if Tsetse flies don’t bite you). This is why some people who have never stepped their feet

in the game reserve still get infected. Some people don't cook meat thoroughly so the parasites that cause sleeping sickness may still be active and infect the consumers", (P2, FGD with men, Manolo, Mzimba).

This is why a community leader reported that he discourages community members from purchasing meat from game reserve/poachers because it may be infected with microorganisms that cause sleeping sickness. In addition to this, a key informant added that in some cases they have observed there is some kind of mother to child transmission of sleeping sickness.

"For instance; we had a patient (an expectant woman) at maternity, and she delivered right in the ward where there were no tsetse flies ... but she was diagnosed positive for sleeping sickness. Two weeks later, the baby was also tested for sleeping sickness and the results also came out positive which was evidence that it was purely from mother to child (mother to child transmission)", (Key informant, Rumphu).

A health worker at Manolo in Mzimba further explained that if someone has trypanosomes (even though he does not show signs and symptoms of sleeping sickness) and he donates blood to someone who is healthy (not infected with the trypanosomes), that person could also become infected and end up having sleeping sickness.

#### 5.4 Sources of information on sleeping sickness

Most informants in this study reported that health workers including HSAs, are the major source of information on sleeping sickness. Health workers emphasize on the causes of the disease, how it is transmitted and how it can be prevented.

"The main source of information is the health facility and also from some people who were first diagnosed with the disease. There is no other source of information apart from these", (Recovered patient of sleeping sickness, Malidade, Mzimba).

"The community members get information about sleeping sickness from the health workers, more especially the health surveillance assistants (HSAs). The HSAs conduct community sensitization meetings where they sensitize people about the signs and symptoms of sleeping sickness; what they are supposed to do when they experience the signs and symptoms of sleeping sickness; they advise people that they should be wearing protective clothes so that they should protect or prevent themselves from tsetse fly bites", (Microscopist, Manolo, Mzimba).

An informant at Thunduwike in Mzimba reported that health workers conduct health talks at health facilities and during such talks they also discuss in some cases issues around sleeping sickness.

"As one of the community members, we get information about sleeping sickness from the HSAs and at the health facility (medical health workers). Usually when we go to the health facility, before getting any kind of treatment or help from the health workers, the health workers conduct health talks. During health talks, the health workers advise people that whenever they have signs and symptoms of malaria, and happen to be tested negative for malaria, they would need to ask or request the health workers to do sleeping sickness diagnosis", (Teacher, Thunduwike, Mzimba).

A medical assistant at Katowo in Rumphu also reported that at their health centre, they do health talks at the start of each day before they start seeing patients. We do health talk before we start our daily treatments.

Apart from this each health centre has HSAs who conduct sensitization activities on immunization in communities surrounding the game reserve. In 2020 a health worker at Katowo in Rumphi reported that the DHO conducted sensitization meetings on sleeping sickness where he invited a wide range of people including traditional leaders, traditional healers, religious leaders, health workers, people who had recovered from sleeping sickness and community members. At this meeting he requested people who had recovered from sleeping sickness to share their experiences regarding sleeping sickness as well as how they get treatment or got cured from the disease as one way of creating awareness among other community members. This was also done to encourage religious leaders to advice their church members to seek treatment at the health facilities whenever they feel like they have signs and symptoms of sleeping sickness instead of sending them to the traditional healers for treatment. These sensitization activities by health workers have helped people to go to health facilities for diagnosis, and treatment.

“We have also oriented some traditional healers so that they should be aware so that when they receive the patients with the signs and symptoms of rHAT, we told them they should be able to refer the patients to the facility. The majority of the people have the information on issues regarding trypanosomiasis”, (Programme coordinator, Rumphi).

In addition to traditional leaders and religious leaders some community members also heard about sleeping sickness from fellow community members who have undergone treatment for the disease.

Some informants reported that staff from the Vwaza Marsh Wildlife Reserve visit communities and put tsetse fly traps to attract tsetse flies. These rangers have been sensitizing communities why they have installed tsetse fly traps in communities around the game reserve. In some interviews and FGDs participants including patients with sleeping sickness reported that the staff members from the Vwaza Wildlife Reserve create awareness about sleeping sickness in communities surrounding the wildlife reserve.

“For us to know that there is sleeping sickness, it’s because of the game staff members. They came and put tsetse fly traps to attract tsetse flies. I do not know if these things help much. They said that not all tsetse flies give us the sleeping sickness. It’s a special tsetse fly that does this”, (P5, FGD with sleeping sickness patients, Malidade, Mzimba).

Staff from the game reserve, also inform community members that is not all the tsetse flies that infect them with the sleeping sickness but a special type of tsetse fly ‘*that has poison*’ as narrated during an FGD with r-HAT patients at Malidade in Mzimba.

There are some committees that have been established at community level that are helping in disseminating information on sleeping sickness for example natural resources committee.

“We have the Natural Resources Committee at community level which works hand in hand with the Department of National Parks and Wildlife. These are the structures that work with game reserve management. There is great collaboration”, (Traditional leader, Thunduwike, Mzimba).

Some health workers mentioned other community level structures that are being used to disseminate information on sleeping sickness and these include village clinics, church gatherings, funerals and Area and Village Development Committee meetings.

“The ADC and VDC members have to take a role of disseminating information to the people on how they can prevent or protect themselves from contracting sleeping sickness. This could also help to target some community members who do not usually go for community meetings”, (Nurse midwife technician, Katowo, Rumphi).

The information that is disseminated in such gathering include what sleeping sickness is; signs and symptoms of sleeping sickness; how the disease can easily be transmitted either from one person to the other or from a wildlife animal to a person and methods of preventing sleeping sickness. Due to the awareness that has been created, many people in the community know how sleeping sickness is transmitted and that when they are diagnosed with sleeping sickness at health centre level, they go on their own to Rumphu District Hospital to access sleeping sickness services. Currently, there are no NGOs disseminating information on rHAT.

### 5.5 Stigma and sleeping sickness

In most cases study participants were of the view that the sleeping sickness is not stigmatizing as they look at it just as the same as malaria.

“You know what, this disease has affected the community and families at large, and is very difficult to be stigmatized because everyone can get infected with sleeping sickness. I have never been stigmatized and have never heard someone suffering from the same disease being stigmatized. It is a serious disease, and it will be childish for someone to be stigmatized by community members” (Sleeping sickness patient, Thunduwike, Mzimba).

Many study participants who had ever suffered from sleeping sickness reported that they never experienced any stigma during their illness that they received a lot of support during the illness from their families and the wider community and during hospitalization many community members visit the patients with sleeping sickness. Some informants reported further that patients with sleeping sickness stay together with others who do not have the disease, they eat together with them, if the patients are failing to walk, they give them support and relatives act as guardians when the patients with this disease are hospitalized. One of the reasons why stigma is not there for this disease is that it is curable.

“We know that this disease is curable. It is not a contagious disease. This is the reason why we do not sideline our friends. It is not dangerous disease”, (P5, FGD with caregivers, Malidade, Mzimba).

However, there were some informants, for example a key informant working for the MoH, who reported that he had come across some patients who at the time of diagnosis had lost a lot of weight and the community members thought they were suffering from HIV/AIDS. The community thought that these people got HIV through immoral ways and they were being stigmatized. He explained however that later these patients were cured and discharged from the hospital, gained weight, and were looking healthy. People in the community then confessed that they never thought it was sleeping sickness since they had been talking a lot of things behind the patient’s back.

“Yes! In the past, people who were suffering from sleeping sickness were regarded or treated like people who were suffering from HIV/AIDS. They were all [HIV/AIDS and Sleeping Sickness patients] stigmatized by the community members. Most of the times the physical appearance of a person who is suffering from sleeping sickness resembles someone who is suffering from HIV/AIDS because they all look thin [body weight loss]....”, (Microscopist, Manolo, Mzimba).

Most informants in this study reported that one of the outcomes for people with sleeping sickness is that they develop some form of mental illness which is somehow stigmatizing as narrated below by a guardian of a person with sleeping sickness at Thunduwike in Mzimba.

“Ah no, no discrimination, of course, sometimes people used to say or they do say; ‘those who suffer from sleeping sickness are abnormal’. As a mother I am happy to see my daughter alive. I am the one who gave birth to her. Seeing her alive I tell you I am so happy. Even if people call her mentally disturbed, I still cherish her. She is my child. She is alive. Of course, there is a change and I do notice the change. She is sort of mentally disturbed”, (Caregiver, Thunduwike, Mzimba).

Many people including some health workers reported that when one is treated for sleeping sickness the brain is affected which somehow lowers mental capacity as such some community members call them names such as *Iwe wakaskembe ungayowoyachi? Uli kufuntha* (What can a sleeping sickness patient like you say? You are mad). People with sleeping sickness generally feel offended when they are addressed in such a manner. In addition to this, there are also some people who fear that they can get the disease, and this is because they do not know that the disease is transmitted by tsetse flies.

“At hospital ward, some people fear us upon hearing that we do have sleeping sickness. They tend to wonder because they do not know this kind of disease. ‘she is suffering from sleeping sickness’ what is it? It is a new disease. If you go to dressing room at the hospital, they run away saying; ‘eh, she is suffering from sleeping sickness’ - so they fear. They think that its contagious disease and yet it is not. It is only the one who has been bitten by this tsetse fly [who suffers from this disease]”, (P3, FGD with patients with sleeping sickness, Malidade, Mzimba).

Nowadays, however, community members are not stigmatizing people who are suffering from sleeping sickness because of the information they receive from the community sensitization meetings and that everyone is at risk of contracting this disease in this community. Many patients with this disease or those who recovered acknowledge that they have never been discriminated just because of this disease. Most informants reported that relatives of the persons that have been diagnosed with this disease and the wider community are always very supportive especially when they have information that there is treatment. A health worker at Katowo, Rumphu reported that in the past, people were not even touching the patient with sleeping sickness because they assumed that in so doing, they would contract the disease but nowadays when they see someone being diagnosed positive for sleeping sickness, they immediately refer or send him or her to the facility or hospital so that he or she could receive treatment.

## 5.6 Treatment of sleeping sickness

Persons suffering from sleeping sickness can either self-medicate, seek treatment from traditional healers, churches or go to the health facility for diagnosis and subsequent treatment if diagnosed with sleeping sickness.

### 5.6.1 Self-medication with medicines

It has been mentioned earlier that the signs of sleeping sickness are similar to those of malaria. People at community level are aware of treatment for malaria. When one has sleeping sickness and presents with signs and symptoms of malaria, in some cases they will purchase drugs from the shops and self-medicate.

“There are several signs and symptoms about this disease, and if one is not careful it can be fatal. It was on 30th March when I started noticing that I was not feeling well. I was feeling cold (fever) and I thought I had malaria at first, then on 31st I took some pain killers, panadol, but nothing changed. On 1st April, I took fansidar [treatment for malaria] but still nothing changed, by then I started vomiting and my knees were also weak ... I reported to my supervisor and he took me to a health facility [Katowo] on a motor bike and they tested me

for malaria but the results were negative for .... Then I also asked for trypanosomiasis test because I was thinking about my work since we are always close or inside the game reserve and the doctor did not hesitate to do the test and the results were positive for *kaskembe* and I was referred to Rumphu district hospital the same day....”, (Patient, Katowo, Rumphu).

“In 2015, I used to have a colleague (Late or Deceased M. who was also working at this school as a Head Teacher but he died because of sleeping sickness. Late M. could not believe that he was suffering from sleeping sickness. He thought he was suffering from malaria and he kept on buying antibiotics whenever he experienced the signs and symptoms of this deadly disease. He used to have fever and complained about backache, more especially between the backbone (spinal cord) and the neck. He spent almost a month showing the signs and symptoms of sleeping sickness but the signs and symptoms were just on and off and because of that he was still coming to school for lessons. One day I went to his house and I found him in a very critical condition. I took him to Thunduwike and he was admitted. Later he was referred to Rumphu District Hospital for further treatment and since the disease reached the advanced stage, he did not make it. He passed away”, (Teacher, Thunduwike, Mzimba).

These two quotes just demonstrate that in the early days of sleeping sickness patients may self-medicate and they may realize in time that they need to be tested and get the correct treatment or they may die because of seeking appropriate treatment very late as it was the case with Mr. M. above.

#### 5.6.2 Traditional healers

There are ways of looking for treatment when one suffers from sleeping sickness. Initially they may not even know what they are suffering from and either self-medicate or seek treatment from traditional healers as they may think they have been bewitched.

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

Many previous and current patients with sleeping sickness reported that together with their families they sought treatment from traditional healers because they thought that they had been bewitched. A former sleeping sickness patient at Katowo, Rumphu explained that with his family they thought that he had been bewitched because he had quarreled with someone over land. At such time, the traditional healers never said that the disease these people were suffering from was sleeping sickness. In all cases of sleeping sickness the traditional medicine they took did not improve the situation of the patients and in most cases the condition worsened than before. It is when they find that the traditional medicine is not working that they decide to go to the health centres for further diagnosis and treatment. In some cases, these patients even bypass the health centres and go to the district hospital. Most participants were of the view that seeking traditional medicines for the treatment of sleeping sickness is a waste of time and financial resources. There was only one patient who visited a private hospital at Rumphu who prescribed some drugs for him but when the drugs finished he still had the signs and symptoms he had before.

“I went back to a private hospital and explained what I was going through, he referred me to Rumphu District Hospital to have sleeping sickness test where I was found positive and doctors told me that I was to be admitted for whole month for me to receive treatment of which I did. After treatment, doctors tested me again and I was found negative that is when they discharged me from the hospital”, (Recovered patient, Thunduwike, Mzimba).

It is evident that both traditional healers and private practitioners do not effectively treat sleeping sickness as in all cases cited patients were never cured. At the end of the day, they were successfully treated at the district hospital. One traditional healer at Thunduwike in Mzimba acknowledged that he had ever received patients with sleeping sickness but after finding out that they were suffering from sleeping sickness he referred them to the health facility.

“At first I tried to give them some herbs because I thought it was mild malaria. Serious malaria is treated at the hospital. I noticed a pale face and the client explained that he felt sleepy and lost appetite. So, I knew that it was sleeping sickness and therefore beyond my domain hence the referral to the health facility at Thunduwike for proper diagnosis. I don’t have equipment to diagnose [this disease]. I just use my God given instincts. It is only at the hospital that one can be thoroughly diagnosed of sleeping sickness”, (Traditional healer, Thunduwike, Mzimba).

People with sleeping sickness in some cases spend a lot of time visiting different traditional healers and by the time they get back to the hospital the disease is very advanced and some informants with sleeping sickness reported that they spent 5 months for them to be diagnosed with sleeping sickness.

### 5.6.3 Seeking treatment from health facilities

Before administering treatment for sleeping sickness, health workers conduct tests to determine whether the patient has the disease or not. This section describes the process of the diagnosis of sleeping sickness and the subsequent treatment they receive.

#### 5.6.3.1 *Diagnosis of sleeping sickness*

Initially the diagnosis of sleeping sickness was only performed at the district hospital. However, a key informant at Rumph District Hospital reported that, apart from Rumph District Hospital, there are 5 other health centres namely Bolero, Mwazisi, Katowo, Malidade and Thunduwike that provide diagnostic services for sleeping sickness.

“Okay, one of the common challenges is that once they are diagnosed positive. Initially the main challenge was to get access to test but through some assistance and some funding, we managed to scale up the testing to peripheral areas to minimize the distance because some previously could travel as far as 70 kilometers to access the services but this time around, I think it’s within the range of 5 to 10 kilometers to access the medical care services”, (Key informant, Rumph).

Manolo Health Centre in Mzimba, however, does not have a microscope: specimen collected from this health centre is sent to Malidade Health Centre where the samples are tested for sleeping sickness. A microscopist at Manolo in Mzimba explained the way they test for sleeping sickness.

“We take blood specimen either from the finger or arm, mix with reagents and examine this under a microscope to check for the presence of the trypanosomes in the specimen. If the person tests positive (specimen contains trypanosomes) for sleeping sickness, he or she is then referred to the Medical Assistant who then gives a referral letter to the patient to go to Rumph District Hospital for further confirmatory test and to receive treatment. If the patient is diagnosed with sleeping sickness, then he or she is admitted and provided with treatment”, (Health worker, Manolo, Mzimba).

Many informants in this study reported that when a person is diagnosed with sleeping sickness, he is referred to Rumphi District Hospital for further confirmatory test and subsequent treatment. The facilities around Vwaza are unable to provide treatment for sleeping sickness because, according to some community-based informants, such treatment requires a lot of [pieces] of equipment. This is, however, not true as the present treatment is simple as it is given through IV injections, but it has important side effects.

#### 5.6.3.2. Treatment from health facilities

When a health facility around Vwaza has diagnosed that a person has sleeping sickness, the patient is then referred to Rumphi District Hospital where further confirmatory tests are conducted before initiating treatment. In addition to diagnosing sleeping sickness at the health centres around Vwaza Marsh Wildlife Reserve as well as at Rumphi District Hospital, these facilities together with the district also go to the communities to test for sleeping sickness.

“Here at Malidade, doctors conduct sleeping sickness test, however, they do not treat it. Doctors from this health center also go into the community around the game reserve to test people but mostly they do not find people with sleeping sickness because their machines are not effective. The results are being delayed or sometimes confused to tell whether the person has sleeping sickness or not because they use solar panels instead of electricity powered by Electricity Supply Commission of Malawi (ESCOM) and those people are referred to Rumphi district hospital for further testing”, (Community leader, Malidade, Mzimba).

Once it is confirmed that the patient has sleeping sickness, he or she is either given *suramin* if the trypanosomes are not found in the blood system and not in the central nervous system. However, if the trypanosomes have affected the central nervous system, the patient is then given *melarsoprol*. In addition to these two treatments, recently a new drug called *fexinidazole* (taken orally) is being piloted in a clinical trial.

“... They are doing trials or investigations of that drug at Rumphi District Hospital. Currently, there are some sleeping sickness patients who have taken this treatment and other have finished taken their dosage”, (Microscopist, Manolo, Mzimba).

A KI working for the game reserve reported that government through the Department of National Parks and Wildlife has put in place a programme such that doctors visit at the end of every year at the camp and do sleeping sickness test for both game reserve staffs and people from communities around that camp.

“Yes, for example, last year, many people were tested positive of sleeping sickness and department of national parks provided a car for all people to Rumphi district hospital. However, at the hospital there is another project which also deals with sleeping sickness, they provide transport (a car) for people who have been discharged and come again to them for checkup”, (Game reserve staff, Vwaza).

While health centres around Vwaza Marsh Wildlife Reserve can diagnose sleeping sickness, at Rumphi District Hospital confirmatory tests have to be done before starting the patients on treatment. This is done mainly because there have been cases which have been diagnosed positive at the health centres but when they went to Rumphi District Hospital, they find some discrepancies. The lumbar puncture is done on patients to determine whether the trypanosomes have gone into the central nervous system and this can only be done at Rumphi District Hospital.

There is a ward at the district hospital where persons with sleeping sickness are admitted as narrated by a guardian of a sleeping sickness patient at Malidade in Mzimba.

“We were in mixed ward. Of course, the ward was called *kaskembe* ward but we were mixed. The time I was there I witnessed 3 deaths related to sleeping sickness: 2 males and 1 female. At first people were not aware that there is medication for sleeping sickness. A lot of people died in the community because they did not know that there is a remedy for this. This is the reason why one of us said that a lot of people lose their loved ones without knowing that it was sleeping sickness. They preferred to go to traditional healers not knowing that they are killing their loved one. The time they were realizing that its sleeping sickness, it was late, and they died upon reaching hospital. It was at late stage. You see”, (Caregiver, Malidade, Mzimba).

Rumphu is situated a bit far from the catchment areas of Vwaza Wildlife Reserve and guardians of sleeping sickness patients and other informants in this study reported that when one is found with sleeping sickness he or she is advised to go to the district hospital and start treatment at the district hospital.

### 5.7 Motivators to finish treatment

This study has generally found there are challenges with diagnosis of sleeping sickness and once the diagnosis is done patients experience challenges in accessing treatment for various reasons. Participants mentioned a number of factors that motivate persons with sleeping sickness to finish treatment.

#### 5.7.1 The desire to get cured

Most people with sleeping sickness would be motivated to take the new drugs for sleeping sickness because of the desire to get cured.

“Because they want to recover and stay alive, because this disease *munthu akuwa makola cha* (the person is critically sick) and I don’t think they would be in any position to refuse treatment or decide to stop treatment midway....”, (Senior HSA Manolo, Mzimba).

For the current treatment, patients complained that the injections are painful and that the period of hospitalization is long. While this is the case, the desire to get cured from the disease is what makes them complete treatment.

#### 5.7.2 Seeing people with sleeping sickness recovering

An informant at Manolo, Mzimba was of the view that a lot of people would be motivated to take the new drugs after seeing some people recovering from sleeping sickness. People who have recovered from sleeping sickness after taking *suramin* or *melarsoprol* [previous treatment of using injection] and also patients who ever received *fexinidazole* [new treatment of using drugs or pills] can be allowed to explain to other community members more about their experiences of using the different types of treatment, respectively. Such an approach combined with seeing people with sleeping sickness recovering would motivate people to finish the treatment, both the old one or the new one.

“Sometimes people are motivated to take sleeping sickness drugs when they see some people recovering from the disease after taking or receiving treatment. Seeing people dying while receiving treatment tends to demotivate people from taking the old treatment but with the current research, a number of people have recovered from sleeping sickness without having

complications and this has motivated a lot of people to opt for the new treatment”, (Nurse midwife technician, Mwazisi, Rumphhi).

People would be motivated to take the drug so long as they know that that the drug is effective in the treatment of sleeping sickness and they see others getting cured using the same treatment. A key informant at Rumphhi reported that those who have been cured of the disease act as motivators to others that it is possible to get cured after receiving the medication.

#### 5.7.3 Treatment for sleeping sickness being administered at the health centres around Vwaza

Many informants in this study including people who have or have ever had sleeping sickness complained that Rumphhi District Hospital is situated very far. This in itself is a barrier to seeking or completing treatment. They preferred instead that health centres around Vwaza Marsh Wildlife Reserve should have the capacity to administer treatment for sleeping sickness.

“Most of the people would be willing to take the drugs as they would not be required to go to Rumphhi District Hospital for treatment. At the facility we could easily provide drug treatment to the patients since the provision of oral drugs (pills) does not require any special thing or what you have to do is to follow the prescriptions of that drug”, (Laboratory Assistant, Manolo, Mzimba).

Currently, people with sleeping sickness receive treatment at the district hospital which is situated very far. Most study participants therefore would be motivated to seek treatment for sleeping sickness if this was offered in nearby health centres around the Vwaza Marsh Wildlife Reserve.

#### 5.7.4 The drug should have minimal side effects

Many people complained about the side effects that the current treatment has. Some study participants including patients with sleeping sickness were of the view that new drugs for sleeping sickness should not have any serious side effects.

“Side effects are also a barrier to treatment access. People get put off by the negative news they hear about the impact of some drugs on patients. Let the new drug have minimum side effects and people will love and easily accept it”, (Sleeping sickness patient, Mwazisi, Rumphhi).

A traditional healer at Thunduwike reported that there are many people including people with sleeping sickness who seek care from them. He was of the view that traditional healers can motivate people to seek treatment at the health centres for sleeping sickness.

“When they come for my services I can take advantage of that and encourage people to seek healthcare fast. People must go for sleeping sickness treatment quickly. We should motivate the people that way. Let us take advantage of each gathering to talk about such issues. I also work hand in hand with Health Surveillance Assistants who come to this community for Under 5 clinics to share my observations with them if I see something suspicious with my clients which may require their attention”, (Traditional healer, Thunduwike, Mzimba).

#### 5.7.5 Sensitization of communities about sleeping sickness treatment

The Ministry of Health and the Vwaza Marsh Wildlife Reserve visits communities around Vwaza and sensitizes people about sleeping sickness including its causes, the way it is transmitted and how it can be

prevented and that they emphasize that treatment is available. The expectation is that communities will understand the need to go for testing and if found with sleeping sickness they should timely seek treatment. These sensitization activities, as most participants argued, should continue using different approaches including people with sleeping sickness.

“They can even use people like us who have ever suffered from this disease to sensitize others, they can use us as examples that people get healed or they can train us to spread the messages about this disease even those that have cared for people suffering from this disease can also be used to spread the messages”, (P2, FGD with patients with sleeping sickness, Thunduwike, Mzimba).

#### 5.7.6 Other factors

Informants in this study also mentioned other factors that can motivate people to finish treatment and these included ensuring the availability of transport from Vwaza to Rumphi District Hospital, respecting persons with sleeping sickness including not treating them harshly, and ensuring that health workers especially HSAs have been capacitated to track or follow up patients at community level and there is a need for friends and relatives to support the patient. The following quotes illustrate these issues.

“Actually people might be willing but most of the times the challenge is transport”, (Microscopist, Rumphi District Hospital).

“... Consider us on this r-HAT disease. We are still having these tsetse flies and we will one day get sick. If you can consider us transport. We need transport to take our patients to hospital. We do fail to do this hence we have deaths. We go to hospital after the disease has already killed the patient. We delay to source transport because we are poor. We are just villagers ...”, (P4, FGD with r-HAT patients caregivers, Malidade, Mzimba).

“There is need to respect the patients when they come to the facility or hospital for assistance because there are some health workers who tend to ill-treat the patients and this usually discourage the patients from coming to the facility or hospital. Giving patients fair treatment or respect would easily motivate them to come to the facility and hospital for diagnosis and or testing and also to receive treatment”, (Microscopist, Manolo, Mzimba).

“...It’s important that we train and keep on orienting and refreshing the HSAs and even the health center staffs. It’s very important to accurately capture data of the patients because that becomes very important when you want to track the patient maybe when some patients are missing or maybe they haven’t made it to the hospital as they were taught, so you can easily track them and pick them”, (KII, MoH, Rumphi).

“When one is taking sleeping sickness drugs, he/she needs to be encouraged by friends from the community because sometimes the patient refuses to take drugs ... , if the patient has been encouraged by guardian or people from the community, he/she will be able to take that drug safely without any problem ...”, (P3, FGD with rHAT patients, Malidade, Mzimba), .

#### 5.8 Challenges in seeking treatment for seeking sickness

There are a number of challenges being experienced by health facilities as well as community members in the delivery and uptake of sleeping sickness services, respectively, as described below.

### 5.8.1 Demand for diagnostic and treatment services among men is low

While most people around Vwaza Marsh Wildlife Reserve are willing to go for screening for sleeping sickness and subsequently initiate treatment when found with the disease, some informants including guardians of people with sleeping sickness reported that not everyone is all that willing as in most cases men are very difficult and during the screening exercises that take place at community level very few of them turn up. Men would only go to a health facility when the condition is serious.

“... Usually sleeping sickness affects men as compared to women. So, most men do not easily go to a health facility when they feel sick. They only go and seek for treatment when they are weakened by the disease [sleeping sickness] as most of them assume that they are suffering from malaria. .... Most men with sleeping sickness come to the health facility with their family members when they are in the advanced stage of the disease or they are so weakened with the disease and they sometimes fail to walk on their own”, (Health worker, Katowo, Rumphu).

This health worker reported that their database has more men than women suffering from sleeping sickness probably due to the fact that it is men who go to the game reserve for poaching and other activities where they are bitten by tsetse flies. During an FGD with guardians of patients with sleeping sickness at Malidade in Mzimba, participants said that men will seek health care even for sleeping sickness when the disease is in advanced stages, when they have no choice and are in some cases forced to seek health care at the health facilities.

### 5.8.2 Late diagnosis of sleeping sickness

Many participants in this study reported that a person with sleeping sickness has the same signs and symptoms just like malaria. When they go to the hospital, they are given malaria treatment and when the situation does not change some decide to go back to the same health centre or they proceed to Rumphu District Hospital where they are tested for sleeping sickness. The feeling was that while some clinicians recommend that patients, especially those coming from communities around Vwaza Marsh Wildlife Reserve, should be tested for sleeping sickness the first time they come into contact with health facilities, others do not. There are therefore delays in diagnosing sleeping sickness which subsequently delays initiating treatment for the disease. Most informants including community members and health workers mentioned that the process of testing for sleeping sickness takes a bit of time. Some patients are tested many times before making a diagnosis that they have sleeping sickness. Some key informants at community level such as traditional leaders expressed worry that many patients are being diagnosed with sleeping sickness when the disease is at an advanced stage.

### 5.8.3 Stockouts of medicines and other medical supplies

Drugs for the treatment of sleeping sickness are given to patients free of charge. However, some patients with sleeping sickness or those who have recovered reported that at some point some drugs used for the treatment of sleeping sickness run out and the patients and guardians are advised to purchase these from pharmacies or Banja La Mtsogolo [a Malawian NGO that specialises in the delivery of sexual and reproductive health services but also provides other services]. A recovered sleeping sickness patient reported having bought medicines worth K9000 upon advice from health workers.

“We spent a lot of money because we were buying medication and one tube was costing us MK4000 and even glucose drip I was buying and it was costing MK2000 each and at the same time I had to buy food for myself as a guardian. We spent a lot of money, I cannot come up

with the total just like that but we spent a lot of money during that time we were in hospital”, (FGD with guardians of patients suffering from sleeping sickness, Thunduwike, Mzimba).

Study participants especially the current and former patients and their guardians reported that although services were free of charge at Rumphu District Hospital, they were being asked, however, to purchase the extras but for the actual treatment for sleeping sickness the district hospital was able to provide. Because some patients were not able to eat on their own at some points, they were being asked to purchase glucose which was being administered through a drip. Lastly, one laboratory assistant reported that some reagents require distilled water and sometimes health facilities run out of distilled water and this affect their performance as Microscopists.

#### 5.8.4 Transportation

Rumphu District Hospital has been providing diagnostic and treatment of sleeping sickness services all along until recently when diagnostic services have been established in health centres around the Vwaza Marsh Wildlife Reserve. Rumphu District Hospital is situated some 60-75 kilometers away from communities around the game reserve. As mentioned earlier, once health centres have diagnosed sleeping sickness, all cases are referred to Rumphu District Hospital for confirmatory tests and subsequent initiation of treatment.

“... Due to problems of transport, some patients after being diagnosed with sleeping sickness, go back to their respective homes instead of going to Rumphu District Hospital for treatment because they are poor and cannot afford to pay for their transport to the district hospital for treatment. Although they have the referral letter, they still go back home and wait until they find transport to go to Rumphu District Hospital for treatment”, (Teacher, Thunduwike, Mzimba).

Even if a person has been diagnosed to have sleeping sickness, he or she in some cases does not go to Rumphu District Hospital due to transport challenges. Study participants reported that sleeping sickness affects poor communities living below the poverty line. Transportation for persons with sleeping sickness in the communities around the game reserve is a major challenge and this explains why most patients travel to Rumphu District Hospital when the disease is at a very advanced stage.

There were many study participants who reported that a patient diagnosed with sleeping sickness at health centres around the game reserve cannot travel alone to Rumphu District Hospital: he has to be accompanied by a guardian(s). When looking for transport, they have to consider transport for the guardian as well which makes it very expensive.

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

Informants in this study estimated that the cost of transport one way to Rumphu is around MK3,500 and in addition to the patient, there is also a need to look for transport for the guardian(s). The lack of transport to go to Rumphu District Hospital is therefore one of the major factors contributing to the delays in seeking care for sleeping sickness. In terms of transportation, it is not only patients that have challenges to find transport to go to the district hospital, but even HSAs have challenges in travelling within their catchment areas to do their work including sleeping sickness and related activities.

“The other challenge is mobility. It is not easy to visit the patients [with sleeping sickness]. The area, I mean the community, is too huge. It is too big for us. We keep on changing the days upwards. ‘I will go tomorrow’ then tomorrow comes; ‘I will go tomorrow’ you see. These are the challenges we face”, HAS, Mwazisi, Rumphi).

#### 5.8.5 Lack of involvement of private clinics in the fight against sleeping sickness

One health worker at Katowo, Rumphi reported that private clinics are more interested in business and are not involved even in meetings and trainings that the MoH conducts on sleeping sickness. Such meetings and trainings are attended by people working in public facilities. The signs and symptoms of sleeping sickness are similar to diseases such as malaria, tuberculosis and meningitis. This health worker reported that private clinics just focus on the other diseases and not sleeping sickness. It is usually too late when private clinics realize that the disease is sleeping sickness, and this happens when they have failed.

#### 5.8.6 The process of diagnosing sleeping sickness is painful

A medical assistant at Katowo in Rumphi reported that people are afraid of lumbar puncture when they are referred to Rumphi District Hospital: this involves the insertion of a needle into the spinal canal to collect cerebrospinal fluid for diagnostic testing for sleeping sickness. This is done for staging the sleeping sickness as also reported by many participants in this study.

“The process of confirming the diagnosis of sleeping sickness at district level is a painful process: specimen has to be taken from the spine and once one goes to Rumphi District Hospital he or she has to undergo this process. “The same thing. My patient said that it’s a painful process because they have to bend much for the doctors to get the specimen [from spine]. It takes time also for the doctors to collect the specimen. So, the patient bends for some time and when they are done collecting the specimen, it is not easy for the patient to come back to normal state ...”, (P4, FGD with guardians of patients with sleeping sickness, Malidade.

A game ranger further reported that community members claim that when the health workers are taking specimen from the spinal cord they instruct the patients to bend their back until the head should reach the legs in order to take specimen from the spinal cord and that some community members actually added saying they tie the patient with rubber so that they should not have problems taking specimen.

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

“Yeah and another barrier is what I have said already that; when they realize that they have signs and symptoms of trypanosomiasis they are afraid of lumbar puncture so this is another barrier. ‘if you go there, they will do you lumbar puncture and the end result is awful’ so this is barrier...”, (Medical assistant, Katowo, Rumphi).

When community members hear such claims, they get so scared to access treatment for sleeping sickness at the health facility thereby contributing to delays in seeking treatment for this disease. Some community level participants also said that some health workers are not well experienced in taking specimen from the spinal cord: they attempt several times thus making the patient feel more pain.

“Yes, after I started receiving treatment at the hospital, I could see the change in my body. However, the process of getting some fluids from the spine is very painful. But all in all, I was feeling better when I started treatment at Rumphu district hospital”, (Patient with sleeping sickness, Thunduwike, Mzimba).

Some informants also mentioned that the process of taking specimen from the spinal cord is very painful because, among other factors, the doctors use big needles to take the specimen. The challenge with this is that it discourages some people from going for tests for sleeping sickness as they are informed that the process is very painful as such it can delay the initiation of treatment.

#### 5.8.7 Lack of food items

When a person with sleeping sickness is hospitalized at Rumphu District Hospital, he requires food and other necessities for himself as well as the guardians. Many informants in this study reported that patients and guardians lack food and money to sustain themselves at the hospital during periods of hospitalization.

“The other thing is to do with our upkeep. There is a need to have a guardian. They have to eat .... The main challenge from my experience is to do with transport. It happens that as the patient is taking the drug dizziness sets in. You know drugs. There is a reaction to any drug that you take. It happens that the family has not enough food and the patient is taking the sleeping sickness drugs. They think that dizziness comes in because the food is not enough. It happens that the dizziness comes in due to the drugs. The main challenge is transport to say. Their upkeep too since they are admitted. They have to stay there for several days”, (HSA, Mwazisi, Rumphu).

Guardians of patients with sleeping sickness admitted at Rumphu District Hospital sometimes have to work in order to find money and take care of the patient as well as themselves.

“While being a guardian, I had to leave her alone and go outside and source some piece works. The kind of piece work was to do with farming. You know it was farming season. So that’s the only piece work I would have done. I leave her and do the piece work and the money I use to buy what she needs or she wants. I managed this life until she was discharged. I came back home without even a debt”, (Guardian of patient with sleeping sickness, Thunduwike, Mzimba).

The challenge of lack of food and other items for the patient and the guardian(s) is exacerbated by the long periods of hospitalization characteristic of patients with sleeping sickness. Both current and previous patients with sleeping sickness as well as guardians of such patients reported that that people with this disease stay for a long period in the hospital for periods of up to 4 weeks or longer. One of the factors contributing to long period of hospitalization is that in some cases even after receiving the recommended dosage, a patient may not be cured.

“... After some time it is when you start receiving 10 injections for sleeping sickness. A sleeping sickness injection is given on a daily basis: 1 injection per day. Once you are done with 10 injections, you are tested again. If they see that no more sleeping sickness, they discharge you”, (P3, FGD with patients with sleeping sickness, Malidade, Mzimba).

People generally complained that the sleeping sickness injection is very painful. While people receive injections as treatment for sleeping sickness, others, however, reported that they received tablets because they hated injections.

“I was admitted on 21 November 2019. I came back 23 December same year of 2019. I can say I stayed for a month. I was not given the injection. I was given a privilege to choose between injections or pills. Then I opted for pills together with my friend who stays somewhere there. We hate injections hence we preferred pills. So, we were given pills for 4 days. After 4 days, we were given other pills up to the time I was discharged. Yes”, (P5, FGD with patients with sleeping sickness, Malidade, Mzimba).

Traditionally the treatment of sleeping sickness among other things, involved administering injections to patients with this disease. During an FGD with guardians of patients with sleeping sickness at Rumphi, participants were of the feeling that the current medication for sleeping sickness is very strong especially the injectable and if it happens that it spills on the skin it reacts as if you are burning. In my case it was spilled on the piece of cloth it faded where this medication was spilled. Some informants reported that the MoH is doing a clinical trial on the use of tablets in the treatment of sleeping sickness.

#### 5.8.8 Belief in traditional leaders

There are still some people living in communities around Vwaza Marsh Wildlife Reserve who still believe in witchcraft and that traditional healers can cure sleeping sickness.

“... They would first go to a traditional healer before considering going to the hospital. For example, there was another case which was found after a screening exercise just recently and we had to plea with him to go to the hospital for treatment instead of wasting time at the traditional healer. I don't know if it really works or not, but I believe that first we need to go to the hospital for treatment”, (Microscopist, Katowo, Rumphi).

“When I started suffering from this disease my wife and I visited the traditional healers to seek help because I was thinking that I have been bewitched due to what was happening. I told you that I was unable to walk, this on its own made me think it wasn't normal at all, hence, the visit to traditional healer. And the traditional healer told me that I was really bewitched and gave me some traditional medicine”, (Patient with sleeping sickness, Thunduwike, Mzimba).

This informant said that he visited more than two traditional healers and after receiving all traditional medicine, the situation never changed which made him to think of going to the hospital. In some cases when a person has signs and symptoms of sleeping sickness, he or she and his/her relatives may think that he/she has *vimbuza* (This is a healing dance popular among the Tumbuka people living in northern Malawi) which can only be treated by traditional healers.

“... I can be sick and showing many signs but some people can say its *vimbuza* and the person has to go to the traditional healer and dance for the evil spirits to come out of the patient. We lose a lot of lives seeking traditional medicine while that person is suffering from sleeping sickness”, (P3, FGD with women, Katowo, Rumphi).

The existence of such beliefs constitutes a major barrier in seeking treatment for sleeping sickness. Some people who had sleeping sickness and were cured acknowledged that if they still sought treatment from traditional healers, they would not have survived. Participants in this study cited many cases of people who sought treatment from traditional healers and went to health facilities very late when the disease was well advanced and died. The belief in witchcraft as a cause of sleeping sickness is changing as experience is increasingly demonstrating the failure of traditional medicine and the effectiveness of hospital treatment. Previously, traditional healers used to admit patients suffering from sleeping sickness but this is changing.

“... As of now the traditional healers no longer admit people with sleeping sickness. They just sensitize people about the disease. They refer the person to go to the hospital for treatment and testing”, (HSA, Mwazisi, Rumphu).

“You cannot go to the traditional healers to seek remedy. A lot of people they have lost their loved ones due to this philosophy. A lot of people I tell you have lost their loved ones. The time they said; ‘let’s go to hospital’ upon arrival, the patient also dies. You see”, (P3, FGD with caregivers, Malidade, Mzimba).

In addition to traditional healers, there was only one patient with sleeping sickness at Mwazisi, Rumphu who said that in some cases people also resort to Pentecostal churches.

“With the coming in of Pentecostal churches and prophets, they also tell people to go to their church to be prayed for and not going to hospital without knowing that we are giving sleeping sickness chance to damage some parts of our body. All these makes people delay in seeking treatment at the hospital”, (Recovered sleeping sickness patient, Mwazisi, Rumphu).

#### 5.8.9 Misperceptions about testing for sleeping sickness

People suspected of having sleeping sickness are tested for this disease either at the health facilities around Vwaza Marsh Wildlife Reserve or in some cases health workers from Rumphu District Hospital visit the Vwaza Marsh Wildlife Reserve to test game staffs and people around the reserve. Many informants reported that during such times many people get tested for this disease. However, there are some misperceptions about testing for sleeping sickness: in some FGDs for example during an FGD with women at Katowo in Rumphu, participants reported that some community members do not want to go to the hospital for the sleeping sickness test because they relate the test for sleeping sickness to that of HIV thinking that doctors use the same test to diagnose HIV. Some people therefore are afraid to know their status.

“Such people are afraid of going to the hospital to get tested even when the doctors come to our camp here, such people cannot come for the test because of the perceptions they have towards testing tools. Due to this negligence, patients may seek help or start treatment when the situation has worsened which has led to loss of many lives. However, when the doctors from Rumphu District Hospital come here they explain everything that they come to test sleeping sickness only and no other diseases and that there is no connection between sleeping sickness and HIV/AIDS”, (P4, FGD with women, Katowo, Rumphu).

Some people therefore can have the signs of sleeping sickness but very difficult for them to go to hospital for the test even though they may be living close to the game. This makes them start seeking care for sleeping sickness very late when the situation has worsened which has led to loss of many lives around the Vwaza Marsh Wildlife Reserve.

#### 5.8.10 Poor attitude of health workers

There were some informants in this study who reported that while they appreciate the assistance they get from their health workers in the nearby health facilities, some of them have poor attitudes.

“The health workers also need to change their attitudes towards the people because some of the health workers tend to ill-treat the patients. They have to learn to respect the patients and give them appropriate treatment. Some of the people or patients are discouraged to go to the

health facility because of the health workers attitudes”, (Nurse midwife technician, Mwazisi, Rumphhi).

Some informants were of the view that health workers from Rumphhi District Hospital welcome and treat them when they visit. For example, at one of the health facilities around Vwaza Marsh Wildlife Reserve, during an FGD with women, participants reported that when they request for a sleeping sickness because they live very close to the game reserve in some cases they are told that it is not sleeping sickness and that they should just go back to their homes and take Panadol or Flagyl if they found someone malaria negative or that some health workers tell the community members that “the process takes much of our time and makes us busy, just go back to your homes”.

#### 5.8.11 Lack of testing equipment

While health facilities around Vwaza Marsh Wildlife Reserve have been capacitated to conduct tests for sleeping sickness, these facilities however experience challenges in doing these tests due to inadequate testing equipment including reagents.

“It took a long time for the health workers to take your specimen or sample once you go to the health facility for diagnosis of sleeping sickness. Sometimes the health facility runs out of the reagents or chemicals that are used for diagnosis of sleeping sickness”, (Teacher, Thunduwike, Mzimba).

“The health workers usually complain that they have inadequate supplies or equipment for conducting diagnosis of sleeping sickness. For example; the bottles that are used for taking or keeping the specimen”, (Teacher, Thunduwike, Mzimba).

Hence, in some cases people from the communities around Vwaza Marsh Wildlife Reserve have travelled to Rumphhi for the sleeping sickness test incurring huge costs in the process or delaying going there due to lack of transport. In some health facilities such as Malidade Health Centre there is no electricity and instead they use solar energy to run the equipment used for diagnosing sleeping sickness. Sometimes, especially during the rainy season or when it is cloudy, the diagnosis procedures tend to be affected because of insufficient power supply from the inverters or solar batteries and affects and may delay the communication of results to people who submitted specimen.

#### 5.8.12 Late communication of results from Rumphhi

While there are health centres around Vwaza Marsh Wildlife Reserve that have been capacitated to conduct tests for sleeping sickness, there are challenges that in some cases health workers collect specimen from suspected cases of sleeping sickness and send these to Rumphhi District Hospital for testing and a long time passes without getting the results and communicating to people who submitted the specimen.

“The challenge is that sometimes the results don’t come out immediately. The Malidade Health Centre personnel has to send the samples to Rumphhi District Hospital for confirmatory tests. This takes long while the patient is kept waiting without proper treatment back home. It may take more than 2 weeks of waiting for the confirmatory results to come out. Apart from that, the laboratory equipment at Malidade seems to be of low quality and unreliable. Sometimes it fails to detect the disease hence the need to send samples to Rumphhi for confirmation. This process delays the treatment to the affected person and may complicate the health condition”, (P2, FGD with men, Manolo, Mzimba).

Delays in communicating results of the tests for sleeping sickness, according to some informants, put off community members and this further delay the initiation of treatment for people who are found with sleeping sickness. It is not only health workers from health centres around the Vwaza Marsh Wildlife Reserve who collect specimen: in some cases people from Rumphi DHO visit the community for sleeping sickness screening and they also collect blood samples for testing in Rumphi. In some cases people who have submitted specimen wait for a long time to get the results.

#### 5.8.13 Shortage of staff

While health centres have been capacitated to conduct tests for sleeping sickness, both health workers and community members reported that there are shortages of staff especially who conduct tests for sleeping sickness.

“There is one specialist who conducts the laboratory tests at Malidade and [they have] designated one day per week for testing for sleeping sickness. If you go there on a day which is not designated you are turned back unattended to. This affects timely health care access”, (P1, FGD with men, Manolo, Mzimba).

Apart from having designated days for testing for sleeping sickness, in some cases health workers who have trained to conduct testing for sleeping sickness are not available when one visits the health facility, hence people return to their homes without being diagnosed. A teacher at Thunduwike for example explained that this happens because they do not have adequate staff at the facility. There are 4 microscopists in total at both Manolo and Malidade Health Centres: 3 microscopists have just been trained and they are not well equipped with the procedures or they have less experience. This also discourages people to come to the facility for diagnosis and or testing of sleeping sickness because they have to wait for a long time before receiving their results [due to inadequate experience of the 3 Lab technicians who have just been trained]. Some informants in this study reported that there is a shortage of HSAs in the communities around Vwaza Marsh Wildlife Reserve and this is why some HSAs cover a large catchment area than is supposed to be the case. With regard to human resources for health, a key informant at Rumphi District Hospital reported that the programme has trained some health workers on how to manage sleeping sickness including diagnosis and treatment. In some cases there is high staff turnover and people who have not been oriented do the job.

“At times we trained people and they stay in the health centres, the clinicians, the nurses but we find that later they have chosen to move out or they are transferred to another place thereby bringing in some people who are not well trained or qualified, so that also bring in some kind of challenges whereby maybe you miss some key elements in as far as the identification of the suspects of trypanosomiasis is concerned”, (Programme coordinator, Rumphi).

#### 5.8.14 Abandonment of hospitalization

It has been mentioned earlier that when a person is diagnosed with sleeping sickness he or she has to be hospitalized for some time. While most patients adhere to this, there have been cases when patients have escaped from the hospital mainly because of the pain and other challenges they were experiencing during the hospitalization.

### 5.9 Effects of sleeping sickness

In this study participants were asked about the effects of sleeping sickness on individuals and the community as well as on the wider community and this are described below.

## 5.9.1 Effects of sleeping sickness on the individual and his family

### 5.9.1.1. *Impoverishment of families*

Many informants in this study reported that when one is found with sleeping sickness, he or she is hospitalized at Rumphu District Hospital where he or she receives treatment. Since the person is in hospital, his family members and relatives have to care for him by, among other things, providing food and other needs. The person with sleeping sickness and his family members would not be able to effectively do farming or engage in income generating activities as at the time the focus is on the patient. As a result of this, the patient and his relatives will not harvest enough food that season if the patient develops the disease during the rainy season.

“So many things were affected. I was admitted during the farming season for 3 weeks. During this time nobody took care of my gardens. I grow maize, tobacco and groundnuts. All these crops were not well taken care of when I was admitted and the harvest was poor. I failed to earn money from the cash crops. I failed to harvest enough food crops. My household became destitute. We became food beggars. We suffered”, (Sleeping sickness patient, Mwazisi, Rumphu).

“I want to agree with P3, there should be well-wishers to help us (patients). For example, when I was discharged from Rumphu hospital, I found all my crops had been damaged due to lack of care since my husband was again sick from sleeping sickness and my father in-law is aged and cannot manage farming activities. As a result, I experienced the problem of shortage of food and I was begging from my neighbor, this disease has left us in pain”, (P2, FGD with patients with sleeping sickness, Malidade, Mzimba).

Patients with sleeping sickness spend a lot of money in the process of seeking care including consultations with traditional healers and many informants reported that they have seen people in their communities who became poor due to sleeping sickness in their family.

“It is very difficult for a man or a man to give support to the family when they are sick, as a result, a family will lack food since when the husband is sick a wife is there to take care of him and vice versa and no one is looking for food or any income for the family and children are the ones suffering. As a result, sleeping sickness can bring poverty in family at large and in the community in general”, (Game reserve staff, Manolo, Mzimba).

An informant at Thunduwike in Mzimba reported that she failed to repay the loan she got from the village bank hence they came and took what they could manage to take while she was at hospital with her child. Since persons with sleeping sickness are not economically active or they have lost an income, they struggle economically and hence they fail to fulfil some of their responsibilities for example payment of school fees for their children. Many informants in this study reported that it is difficult for current patients of sleeping sickness for them to be economically productive and this is mainly because such persons spend a lot of time during the day sleeping such that they are not economically active.

“They spend most of their time sleeping which means they can’t be productive at all .....", (Traditional healer, Thunduwike, Mzimba).

### 5.9.1.2 *Development of physical impairments*

While effective treatment is available for the treatment of sleeping sickness, the major challenge as explained by many participants in this study including current and previous patients with sleeping sickness

is that it is difficult for them to be involved in doing hard work as men as their bodies become weak and some of them still feel pain in the back. This is exacerbated by the fact that the disease in some cases causes disability among patients and hence they cannot work or farm effectively compared to the period before they suffered from the disease.

“We failed to do many things at household level particularly farming. We failed to cultivate and feed our families the time we were sick. After we got discharged we could not bend our backs. Farming forces somebody to bend the back but for recovered Kaskembe patients like us that is very hard. “Any attempt to bend my back results into excruciating pain. That is the effect of that monster injection that pierced the backbone. Yogueta anakonza<sup>3</sup>!”, (FGD with men, Manolo, Mzimba).

Figure 1 shows a lollipop whose stick is equated to the needle used to draw specimen from the patient.

*Figure 1: Photo of a lollipop: the size of the lollipop stick is equated to the needle used to draw specimen from spine*



Some participants claimed that sleeping sickness does not only result into disability but also affects sexual performance of the men in particular.

“My life is not the same, I used to walk properly but now I cannot, I need someone to help me in doing everything, you can understand the feeling I have towards myself. The disease has really affected me psychologically, physically and economically. I am saying this because currently my brain is not functioning properly, I cannot perform any work including having sex with my wife because as you can see my body is still weak”, (Sleeping sickness patient, Thunduwike, Mzimba).

“I was failing to do sex with my wife because my penis was unable to erect and the whole of my body was weak. You can imagine that, I am a man and every time I could see my wife I wanted her to have sex with me but no erection, sometimes I could cry because I was thinking that I am failing to fulfill some tasks as a man. In addition, I was also afraid that my wife will

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<sup>3</sup> A lollipop is a type of sugar candy usually consisting of hard candy mounted on a stick and intended for sucking or licking. Yogueta is a brand of lollipop found in Malawi. In this FGD, participants were equating the size of the needle for drawing the fluid from the spine to the stick on lollipop saying that it is very big and that is why it is very painful.

leave me because of the disease and its effects”, (Recovered sleeping sickness patient, Mwazisi, Rumphu).

Even though patients can be cured from sleeping sickness, the challenge is that the disease may cause some disability, recovered patients continue feeling pain<sup>4</sup> and that others claimed that sleeping sickness affects sexual performance of the men with this disease.

#### *5.9.1.3 A person is at risk of suffering from mental illness*

Many study participants reported that after suffering from sleeping sickness some people, while they recovered from the disease, they however suffered from some form of mental illness. Both recovered and current patients of this disease acknowledged that they suffered from some form of mental illness.

“As I have said that we went to the hospital late. The patient was also mentally disturbed. We used to get hold of the patient to sleep properly at the bed in the ward. It was bad I tell you. It took weeks for the patient to come back to normal. It was pathetic condition. In terms of food, we had nice meals. The challenge that I had it was only to do with the condition of my patient”, (P4, FGD with caregivers of sleeping sickness patients, Malidade, Mzimba).

“Yes, we have such people. There is a person called Ch. who presented sleeping sickness signs but shunned health services because he and his family believed that it was witchcraft at work. Right now he has run mad because of negligence to be treated. He wasted time going to the traditional healers for help which hasn’t worked. As for me I went to the health facility and I am better now”, (Patient with sleeping sickness, Mwazisi, Rumphu).

Both health workers and community members reported that persons with sleeping illness experience some form of mental illness even after being successfully treated.

#### *5.9.1.4 Death of people with sleeping sickness*

Many informants in this study cited many cases of people they knew who died as a result of suffering from sleeping sickness. They cited for example the lack of transport for the patient to get to the hospital for early diagnosis and treatment of sleeping sickness as one of the factors contributing to the death of these patients.

“This disease has killed a lot of our relations only that at beginning we were not knowing what was killing them like this. We were not aware. Maybe the government was not aware about this sleeping sickness hence we died miserably. A lot of people have died. At Kabira, we also had a patient. She had a baby. The baby died also”, (P3, FGD with patients with sleeping sickness, Malidade, Mzimba).

A recovered sleeping sickness patient at Thunduwike in Mzimba acknowledged that sleeping sickness is a dangerous disease and that when he was admitted there were 10 other people suffering this disease: 7 of these died and he explained that chances of survival are very low if the patient sought treatment after the disease had advanced in its seriousness.

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<sup>4</sup> They did not specify for how long they still have weakness.

#### 5.9.1.5 School performance

Some informants in this study for example a teacher at Thunduwike, Mzimba reported that sleeping sickness affects performance of school pupils in class because he or she would not be able to concentrate much in class. Children with sleeping sickness who have been hospitalized for a long time miss classes hence their performance is affected.

“I will talk much on children affected with this disease, it takes long time for patients to be fully recovered almost one year plus. Sometime the patient is recovered with disabilities left on him/her and this hinders education in children in the sense that they may stay long time receiving treatment and to fully recover for them to go back to school. In addition, with the disabilities which develop makes it difficult for children to capture the lesson delivered to them by teachers”, (P2, FGD with women, Katowo, Rumphi).

#### 5.9.2 Effects on the community

Many informants in this study reported that a person with sleeping sickness does not participate actively in community development programmes as he is weak even after being healed. This disease hence negatively affects the implementation of development programmes in the community. During an FGD with men at Manolo, Mzimba participants reported that those who have recovered from sleeping sickness cannot fully participate in community development projects when not feeling well.

“In addition, as you can see me now I cannot contribute anything to the developmental activities. For example, if they say we should go and mould bricks for the school blocks, do you think I can manage? No! You can see the disability that is in me now because of this so-called sleeping sickness”, (recovered sleeping sickness patient, Rumphi).

“Some patients suffering sleeping sickness became mentally disturbed and are considered useless to the community when it comes to contribution of ideas during developmental meetings”, (P3, FGD with women, Katowo, Rumphi).

With regard to participation in community development, it is clear that those who with sleeping sickness and those who had suffered from this disease previously may not actively participate in development projects because they are weak.

### 5.10 Coping with sleeping sickness

People with sleeping sickness and their families experience a lot of challenges. Informants in this study were asked how people with sleeping sickness and their families cope with impacts of sleeping sickness.

#### 5.10.1 Communities sometimes contribute money for transport for patients with sleeping sickness

Patients diagnosed with sleeping sickness at health centre level are referred to Rumphi District Hospital for treatment. In most cases they are required to find their own means of transport to go to Rumphi District Hospital. Some people who are referred to the district hospital are very poor and cannot manage to find money for transport. A number of informants in this study including a Microscopist at Manolo, Mzimba reported that in some cases the community members contribute money in order to help that person or patient to access treatment at Rumphi District Hospital. In addition to this some informants such as a traditional

leader in Thunduwike in Mzimba reported that the Village Development Committee in some cases assists such people financially when they can't afford transport money. This, however, happens infrequently.

A health worker based at Katowo Health Centre reported that the facility used to save money with the aim of helping very poor people diagnosed with sleeping sickness to go to Rumphu District Hospital to seek treatment. He explained that at the time transport was relatively cheap unlike these days when transport fares have increased due to increased prices of fuel and also due to Covid-19 transport restrictions. Some health centres around Vwaza Marsh Wildlife Reserve such as Katowo and Manolo reported about the availability of transport for patients diagnosed with sleeping sickness to and from Rumphu. This service is free of charge. While the health worker mentioned the availability of the vehicle, none of the current and previous patients of sleeping sickness reported the availability of this vehicle. At Manolo Health Centre, a senior HSA also said that transport is not a problem when one is found with sleeping sickness as this is provided free of charge.

“There is nothing that would prevent people from seeking treatment for sleeping sickness. If anything, it would just be that someone is not interested in seeking treatment. I don't see any reason that would prevent someone from seeking treatment. Consultation is free, laboratory tests are also free and if one is diagnosed to be positive for sleeping sickness treatment is free and once you finish your treatment they take you home for free so I don't think anyone would have any reason to fail to seek treatment”, (Senior HSA, Manolo, Rumphu).

“If we have an emergency at the health facility, we use the ambulance to carry the patient to Rumphu District Hospital. The good thing is that when those patients have been discharged from Rumphu District Hospital, there is a special vehicle for sleeping sickness Project and most of the people who were suffering from sleeping sickness or sleeping sickness are sent back home using that vehicle free of charge. The clients are sent back to their respective villages like Mpherembe, Katowo and Mwazisi among others using sleeping sickness Project vehicle”, (Lab technician, Katowo, Rumphu).

In addition to transport being provided by the MoH/project, game rangers and other informants reported that the Vwaza Marsh Wildlife Reserve also provides transport to those having sleeping sickness or would like to access diagnostic services at the district hospital: the office of the Vwaza Marsh Game Reserve at Rumphu sends a car every month so that staff based at Vwaza Marsh can go and access their salaries at Rumphu. On these trips the Vwaza Marsh Wildlife Reserve offers lifts to all those who were supposed to go for sleeping sickness screening or treatment at Rumphu Hospital but are stranded because they can't afford transport costs. A member of staff of the game reserve reported that community members will wait for free transport provided by the Game Reserve each month. He added that even those discharged at the hospital wait for the car for them to return home. While there are interventions to address the problem of transport, it needs to be emphasized that many people diagnosed with sleeping sickness experience challenges in getting to Rumphu District Hospital to access diagnostic and treatment services for sleeping sickness.

#### 5.10.2 Sale of property to raise money required for hospitalization

There are many challenges that patients with sleeping sickness and their guardians experience when they are admitted at the district hospital. In some cases, informants with sleeping sickness, former patients of sleeping sickness and their related reported that they can be helped by their friends and relatives or borrow money to cope with the impact of sleeping sickness. There were others, however, who reported that patients and their families go to the extent of selling their property to raise money to enable them to travel to Rumphu to access services for sleeping sickness.

“I used my own money to say the truth. My relatives had to hire a car because I could not walk on my own. I could not sit on a motorcycle. I was too sick and helpless. I even went to the extent of selling my property to raise money to meet the transport cost”, (recovered sleeping sickness patient, Malidade, Mzimba).

“I am the head of the household. I was admitted. I failed to cultivate. We had no food at home. The time I was hospitalized I sold everything to sustain myself at the hospital”, (Sleeping sickness patient, Bolero, Rumphi).

“As I have already explained that I lost all what I had, for example selling goats and tobacco due to lack of money to be used at the hospital as well as at home. Even now I am not economically stable because I cannot do piece works that I used to do because of the problem of the arm”, (recovered patient, Thunduwike, Mzimba).

Some informants added that they sold all their maize to survive at the hospital. Some received fertilizer coupons but had to sell them. Some even borrowed money from village bank and failed to pay back in time thereby incurring increased interest rates. Various coping strategies are therefore used by patients with sleeping sickness and their families to cope with impacts of the disease.

### 5.10.3 Cultivating a farm belonging to a person with sleeping sickness

There were a number of informants who reported that the community members in some cases cultivate the farm and apply fertilizer for the patient with sleeping sickness who has been hospitalized. For example a laboratory assistant in Manolo, Mzimba cited a case in the catchment area of his facility where this happened and after being discharged the patient harvested his crops in 2019.

## 5.11 How new drugs for the treatment of sleeping sickness can best reach patients

A key informant at district level reported that the drug, melarsoprol, currently being used to treat sleeping sickness, has many side effects and cannot be administered at the health centre level. A new drug is currently being tested in a clinical trial which may have less side effects or complications and this informant said that it should be administered at health centre level so that persons with sleeping sickness can access the drug easily. There is research around this new drug being conducted in Rumphi with the aim of introducing a new drug that would be taken orally by patients with sleeping sickness. Some patients have already taken this drug and are reporting that it has less complications compared to the current treatment administered through injections. A number of strategies were suggested which can be used to ensure that any new drug introduced is accepted by the community and reaches the patients timely.

### 5.11.1 Create awareness about the new drug among community members

Most informants in this study reported that for the new drug to be accepted health workers should first of all call for a meeting to inform the community about the changes in the treatment of sleeping sickness. These health workers can call for a meeting assisted by chiefs at community level.

“There is need to sensitize the community members, including the traditional leaders and religious leaders among others so that they should also disseminate information to other community members. In so doing, patients or people would take the drugs without any fear since they have already been sensitized”, (Microscopist, Katowo, Rumphi).

These community leaders once sensitized should in turn sensitize other members of the community. The creation of awareness, as for example mentioned by a senior HSA at Mwazisi, Rumphu should not only target the communities but also the health workers such as HSAs. People need to know that the new drug for example is effective in the treatment of sleeping sickness and if it has side effects then these should also be communicated to them.

#### 5.11.2 Health workers should avoid selling the new drugs

There are claims that in some cases health workers tend to sell drugs to community members. These drugs are supposed to be provided to community members free of charge. A few informants at community level felt that health workers should not sell the drugs but give these to patients as intended.

#### 5.11.3 Make drugs for sleeping sickness available at the health centre

Currently, treatment for sleeping sickness is only being given at the district hospital which is located 60-75 km from communities around Vwaza Marsh Wildlife Reserve. Many participants including health workers suggested that the new drug should be made available at the health centres around Vwaza Marsh Wildlife Reserve. Some informants in this study were of the view that the new drug can be distributed in health centers because that's where a lot of people go when they are sick or be a guardian.

#### 5.11.4 Oral administration of drugs for sleeping sickness

Currently drugs for the treatment of sleeping sickness are administered through an injection. Some health workers suggested that it would be better if new drugs could be taken orally by the patients compared with the current injections which cause a lot of pain.

“Most of the people would prefer to take drug (oral pill) treatment because we would be able to give the patients treatment right at the facility and they would not be referred to Rumphu District Hospital. It is very far to travel from Malidade Health Facility (Mzimba) to Rumphu District Hospital (it is almost 75 kilometers). Most people would opt for oral drug treatment as this could also help to reduce the expenses of the patients or people”, (Medical Assistant, Malidade, Mzimba).

The new drug, *fexinidazole*, is being tried out and is being given orally. Most people prefer to take pills than the injectables treatment because, among other reasons, it only takes 10 days for a patient to finish his or her dosage.

“Yes! Most of the people would prefer to take drug (oral pill) treatment because we would be able to give the patients treatment right at the facility and they would not be referred to Rumphu District Hospital. It is very far to travel from Manolo Health Facility (Mzimba) to Rumphu District Hospital (it is almost 75 kilometers). Most of the people would opt for drug treatment as this could also help to reduce the expenses of the patients or people”, (Microscopist, Manolo, Mzimba).

#### 5.11.5 Use HSAs to distribute the drug

There were some informants at community level who suggested that HSAs should be involved in the distribution of the new drugs.

“The new drug should be with HSAs who live in our community so that when we tested positive, we should just carry our health passport to our HSA and get drugs. Sister, this is a very dangerous disease, and we cannot refuse the drug, we can receive it with our two hands so that this sleeping sickness should go for good”, (Recovered patient, Thunduwike, Mzimba).

A traditional healer at Thunduwike, Mzimba added that these HSAs should be trained on how they can administer the new drug. Since these HSAs are based at community level, they can easily be reached by community members who are diagnosed with sleeping sickness and such an approach would save money they would have used for transport to go to the district hospital. Some patients with sleeping sickness were of the view that if HSAs provided this new treatment, then they would also be able to follow up patients in their communities and check whether patients are taking the drug or not.

### 5.12 Involvement of the community in the fight against sleeping sickness

It has been mentioned that communities around Vwaza Marsh Wildlife Reserve in some cases come together and contribute money for the patient to use for transport when going to Rumphu to seek sleeping sickness services. This however is infrequently done as other members of the community are also poor. Informants in this study also mentioned other ways through which community members are involved in the fight against sleeping sickness in communities around Vwaza Marsh Wildlife Reserve.

#### 5.12.1 Encouraging people with sleeping sickness to seeking care

Many informants in this study reported that communities have an important role to play in the management of sleeping sickness by, for example, encouraging patients to follow the advice from medical doctors including going for testing for sleeping sickness and initiating treatment early.

“... when I was sick, everyone upon seeing the signs and symptoms they encouraged me to go to Rumphu District Hospital and have sleeping sickness test of which I did and was found positive. Even though they did not contribute financially, ideas from the community helped me a lot and I went to the hospital earlier. In so doing, the community is being involved because on my own, maybe I could have delayed going to the hospital and even dead”, (P3, FGD with sleeping sickness patients, Malidade, Mzimba).

Community members, therefore, encourage fellow members of the community to test for sleeping sickness and then initiate treatment if found with the disease.

#### 5.12.2 Cheering up the sick at the hospital

In addition to encouraging people with signs and symptoms of sleeping sickness to go for the test and then initiate treatment once found with the disease, many informants in this study said that community members also cheer the sick in the hospital.

“No, as I am speaking to you now, in my village close to my house there is a certain man, who nearly died of sleeping sickness, but when the car came to pick him up, I and people from the community managed to go and see him at the hospital, cheer him up and encourage him without showing any kind of stigmatization. Now he is fine and we do chat with him as always”, (Community leader, Malidade, Mzimba).

The community members provide social support to people suffering from sleeping sickness.

### 5.12.3 Some communities cultivate field belonging to hospitalized patients

There were several informants including health workers, as mentioned earlier, who reported that in some communities whenever a person is sick and has been hospitalized, the community members (either from the church or community) support the family of that person in such a way that they even cultivate on their farms if they happen to be at the hospital during the farming season. In addition to this, some study participants both at community and health facility level, reported that some community members provide financial support to people with sleeping sickness.

“My friends and relatives helped me with money while others were coming to Rumphu District Hospital to cheer me and brought food for us. This gave me courage and think that community really cares for me”, (Recovered sleeping sickness patient, Thunduwike, Mzimba).

“It is unfortunate that diseases attack the poor people, those without money. They lack transport money to travel o Rumphu. But as a chief, we have our Village Development Committee which assists such people financially when they can’t afford transport money for medical attention at the hospital”, (Traditional leader, Thunduwike, Mzimba).

Though infrequently, communities however also provide financial support as well as help with farming for persons with sleeping sickness who have been hospitalized.

### 5.12.4 Creation of awareness about sleeping sickness

There are many people around Vwaza Marsh Wildlife Reserve who are cured of sleeping sickness or have the disease. These people are playing an important role in creating awareness about the disease among people in their communities.

“Us, who were sick from sleeping sickness before, should be on the fore front to share experiences with the community and after that it will be the responsibility of the community to follow up with whoever is sick and making sure that people are going for sleeping sickness test regularly”, (Recovered sleeping sickness patient, Thunduwike, Mzimba).

In addition to patients with sleeping sickness or those who have ever had this disease, other community members including community leaders as described earlier on can also help to create awareness after being capacitated accordingly.

## 5.13 Prevention of sleeping sickness

People around Vwaza Marsh Wildlife Reserve are generally aware that sleeping sickness is transmitted by tsetse flies. There were however some people in both Mzimba and Rumphu who had the view that there is no way of avoiding sleeping sickness in their communities:

“There is nothing people can do as far as prevention of sleeping sickness is concerned in the community”, (P2, FGD with men, Manolo, Mzimba).

“You can avoid going to the game reserve and you can avoid eating bush meat as a way of preventing sleeping sickness. But during the hot weather, the tsetse flies move out of the Game Reserve because the trees under whose shade they hide have lost their leaves. These tsetse flies move in all directions including villages looking for shade where they can hide from the scorching heat. They come in large numbers to hide under the mango trees which rarely lose

leaves in summer. This makes prevention of the disease difficult”, (P4, FGD with men, Manolo, Mzimba).

Some members of the community have therefore given up and do not think that there are any methods of preventing sleeping sickness. Despite such perceptions among some community members, there are initiatives mentioned by informants being implemented around Vwaza marsh Wildlife Reserve to prevent sleeping sickness.

#### 5.13.1 The installation of tsetse fly traps

Study participants including key informants and community members reported that the Department of National Parks and Wildlife with support from KFW has installed tsetse fly traps in the communities around the game reserve.

“Yes. The government through Department of National Parks and Wildlife in the project known as KFW, it has a budget put aside, they buy piece of cloths blue and black in color and dip them in chemicals. These cloths are tied around game reserve and homes where we (game rangers) stay and even in the communities around game reserve to protect us from being bitten by tsetse flies. These cloths are called tsetse flies traps”, (Game ranger, Manolo, Mzimba).

Figure 1 below shows the tsetse traps that have been installed by the Department of National Parks and Wildlife while Figure 2 is a type of trap installed by the College of Medicine.

*Figure 2: Tsetse Fly Trap installed by the Department of National Parks and Wildlife, Vwaza Marsh Wildlife Reserve*



*Figure 3: Tsetse fly trap installed by the College of Medicine*



Tsetse flies are attracted by blue and black colors, and when it lands on these cloths, it has no chance of transmitting the disease to human beings even if the tsetse fly was a carrier of the disease due to the chemicals in which these cloths are dipped into. A game ranger at Manolo, Mzimba explained that when tsetse flies land on these cloths, they do not die but they are just weakened in the sense that they can bite a person but can never transmit the disease demonstrating that the chemicals that are used are very powerful. Some community members however said that the chemicals in which these are dipped actually kill the tsetse fly.

“As I have already said, the cloth has very bright colours which attract the tsetse flies. This cloth is treated with chemicals which kill the flies upon contact. Any Tsetse fly that lands on that cloth dies. The chemical smells like animals in the Game Reserve hence attracts the flies which think they have found food”, (Recovered patient, Zolokere, Rumphi).

Some participants added that the game reserve staff should consider putting more tsetse fly traps around the game reserve and even in people’s homes as this would help fighting against this disease.

“.... there is need to put more tsetse fly traps around the infested areas. Tsetse fly traps kill tsetse flies and this would help to minimize the presence of tsetse flies in the communities”, (Microscopist, Manolo, Mzimba).

These tsetse fly traps are coloured blue and black. A community leader in Malidade reported that as a community they also did their experiment during which they wore blue and white cloths: they then went close to the game reserve and found that these cloths were attracting a lot of tsetse flies. They concluded that if the cloths are dipped in chemicals they can indeed kill tsetse flies and minimizes their multiplication.

“During the dry session when trees are losing leaves in the forest and grass is drying, that is from August to December, the forest becomes clear and you can be seen from far. If you put on bright colours you will attract more tsetse flies thinking that you are an animal whose blood they can feed on. From January onwards they are not common because the bushes are thick and visibility for them is a problem. When you put on black clothes you are in danger. Tsetse

flies think you are a wild animal “*vikuganiza kuti ndiwe njati*” [they think you are a buffalo] (P2, FGD with men, Manolo, Mzimba).

There were some views from the community that these traps are not all that effective. During an FGD with men at Manolo, Mzimba participants cited a household which is very close to the game reserve about 50 metres away from the boundary: there is tsetse fly trap at his house and in the past 3 years everyone in this entire family has ever suffered from sleeping sickness. The chemicals expired a long time ago and are therefore not effective in dealing with tsetse flies. Community members reported that the staff from the game reserve do not even bother to go back to the communities to check on the traps with some of them even falling down. Hence, some community members were of the view that they did not see the reason of having these tsetse fly traps in the community.

“We do have these tsetse flies’ traps even in our compounds. The challenge is that they do not think of us that the drugs in the bottles have expired. They have not come to check since they put these traps. It is not working for its intended purpose. It is just like one of flowers”, (P2, FGD with sleeping sickness patients, Malidade, Mzimba).

While people appreciated the fact that tsetse fly traps were installed in their communities, they complained the chemicals in which these are dipped had expired hence ineffective in killing tsetse flies. This partly explains why study participants felt that the number of tsetse flies is on the increase.

#### 5.13.2 Relocation to areas where there are no tsetse flies

Sleeping sickness is transmitted by tsetse flies. Health workers reported that people around Vwaza Marsh Wildlife Reserve have been advised to relocate but they are refusing as it is their “father’s place” and therefore they do not want to leave their home area. In addition to this, many study participants suggested that people should stop going to the game reserve to avoid contracting the disease.

“We should stop going to the game reserve. Of course this cannot end the disease but can only minimize it. This means that is only the government that can help us in ending this disease”, (Community leader, Malidade, Mzimba).

“There is need to avoid going into the reserves or wildlife conservation areas because if they keep on going into the reserves, they might easily be infected with tsetse flies and end up having sleeping sickness”, (Microscopist, Manolo, Mzimba).

There were also some suggestions from the communities that the game reserve removed from Vwaza. One the game reserve is removed then all tsetse flies will no longer be there. Others suggested that the size of the game reserve should be reduced.

“Yes, as I told you that here we are affected much because of this Vwaza Game Reserve and that is where tsetse flies are multiplying a lot because of the wild animals. I urge the government to reduce the area of game reserve so that we can be far from it...”, (Community leader, Malidade, Mzimba).

While there were suggestions that the game reserve should move its boundaries further inside so that people can be as far away from wild animals as possible some participants argued that even if Government reduced the size of the reserve or communities relocate, some wild animals such as monkeys will follow them because they produce what they eat and hence they will still bring tsetse flies closer to their new settlements. While attempts have been there to stop people from going into the national park, it has been difficult.

”Frankly speaking the fish from Kazuni are very tasty ...; people have lost their lives, they have been killed by hippos but they don’t stop going there for fishing. People have lost their lives because usually they go there at night and sometimes they don’t see the hippos and end up being attacked but still more people are still fishing there”, (P3, FGD with guardians of patients with sleeping sickness, Thunduwike, Mzimba).

While people have been advised to stop going into the game reserve, it can be seen that they are still going there.

#### 5.13.3 Introduce a vaccine against sleeping sickness

There were a number of community members in both Mzimba and Rumphi who suggested the need for Government to introduce a vaccine against sleeping sickness.

“Even the use of vaccine could also be a very good development because people will be protected from contracting sleeping sickness. The vaccine could be given to people maybe once or twice a year. The use of the vaccine could be a very good and effective method of preventing people from contracting sleeping sickness”, (Teacher, Thunduwike, Mzimba)

A community leader at Malidade in Mzimba added that sleeping sickness is a very dangerous disease but as human being they have been protected against such diseases by the use of vaccines and further suggested that government should think about introducing vaccine against sleeping sickness. The suggestion to introduce vaccines was mentioned by 2-3 informants in this study.

#### 5.13.4 Put a wire fence around the game reserve

Many participants in this study said that Department of Wildlife and Natural Resources should construct a fence around the game reserve which will prevent wild animals from coming into where people live community and tsetse flies. This will reduce exposure of the community members to tsetse flies. As of now, each and every day wild animals go out of the reserve with tsetse flies which also put people at high risk of sleeping sickness. The construction of a wire fence around the game reserve would help to limit the transmission of sleeping sickness.

“... there is need to put strong protected wire fence around the reserve as soon as possible as this would also help to reduce or minimize the elephants from going into the communities. In so doing, we can prevent people from contracting sleeping sickness. People should also avoid going into the reserves because they might easily be bitten with tsetse flies which cause sleeping sickness”, (Medical assistant, Malidade, Mzimba).

“Government should also consider giving us a fence which will control the movement of the animals from the game to the community. Currently, we have a fence that allow wild animals to move freely and in some area there is no fence at all which also put the life of people at risk”, (Game ranger, Manolo, Mzimba).

There are certain areas of the game reserve which have a fence and others which do not. A senior HSA and others were able to identify places where there is no fence and said that a fence should be constructed.

### 5.13.5 Empower communities around the game reserve economically

People around the Vwaza Marsh Wildlife Reserve depend on the game reserve for their livelihood. They visit the reserve to collect water, mushrooms and firewood among other things. The game reserve allows them to visit the reserve and collect these items. There were suggestions by some study participants that people living on the borders of the game reserve should be economically empowered so that they stop visiting the game reserve.

“I think people living around the game reserve should be taught some livelihood skills that would ensure that they no longer depend on the game reserve resources for their survival. For example, they can be empowered with entrepreneurial skills for economic independence. In that way they would avoid poaching which exposes them to tsetse flies. They can be given livestock like goats, rabbits and guinea pigs for keeping. This can reduce the risk of invading the game reserve”, (P5, FGD with men, Manolo, Mzimba).

While some participants suggested economic empowerment there were other participants however who said there have been programmes around Vwaza Marsh Wildlife Reserve which economically empowered households around the reserve.

“It is hard to stop people from poaching. What P5 is suggesting here has ever been tried and failed. Total Land Care brought such initiatives for the same purpose. People were given goats and other animals for economic empowerment. It was the same people who were caught poaching in the Game Reserve. It solves nothing really. It is so hard to change the people’s behaviour and attitudes. My suggestion is that the government should recruit more Game Rangers to patrol the game reserve”, (P2, FGD with men, Manolo, Mzimba).

There have been attempts around Vwaza Marsh Wildlife Reserve to economically empower communities, but such attempts have never been successful. In addition to Total Land Care, government also distribute chickens and goats to communities around the reserve with the aim of stopping people from going into the reserve and when they want meat they can get from what government gave them but it did not help. During an FGD with men in Manolo, Mzimba participants reported that community members sometimes do not understand because well-known poachers never suffer from sleeping sickness but those who do not patronize the game reserve are the ones who are bitten by tsetse flies and suffer from the disease.

Lastly, one of the issues raised by some informants was that the government should provide safe water for them to drink in their communities and this will help to prevent people from going into the game reserve.

“If they can give us proper water for drinking then we will change. We need potable water. We can stop going to the Vwaza Marsh Wildlife Reserve seeking water. We will change if we have potable waters”, (P4., FGD with caregivers of patients suffering from sleeping sickness, Malidade, Mzimba).

### 5.13.6 Distribute repellants for people in areas surrounding the reserve

A game ranger reported that they use repellents which are bought by government. When they run out of repellents, they inform their bosses, and these are replenished immediately. Another game ranger proposed that the government should also help people around Vwaza Marsh Wildlife Reserve by providing them with repellents which can protect them from being bitten by tsetse flies. This was also mentioned by a teacher at Thunduwike, Mzimba who also proposed that the Government of Malawi through the MoH should make

available insect repellants that are being used by reserve staff in pharmacies and drug stores. This would encourage more people to go and buy the insect repellants with the aim of preventing themselves from contracting sleeping sickness.

#### 5.13.7 Wear special protective clothing

A game reserve staff suggested that there are some clothes which may protect people from being bitten by tsetse flies.

“... Therefore, if there are activities to be done in the game reserve for example fishing, people should try their best to put on working suit that will make the biting by tsetse flies difficult. This will minimize cases of sleeping sickness. You always see us as rangers, we are always in that attire, it prevents us from being bitten by tsetse flies”, (Game ranger Manolo, Mzimba).

“People wear thick and long-sleeved clothes when approaching the game reserve so that tsetse flies should not bite them. They dress like soldiers with gloves on their hands so that there should be no opening. Any small opening exposing the body would be utilized by the tsetse fly to bite you. Protective clothing is very important”, (FGD with men, Manolo, Mzimba)

In some FGDs participants acknowledged that health workers advise communities to put on thick and long clothes when they are going to their gardens. However, participants argued that it is difficult to do this all the time because sometimes it is very hot.

#### 5.13.8 Introduction of the *chitetezo mbaula*

One health worker reported that he had heard from a certain woman that there is a certain project that is being implemented to encourage community members to plant trees and use energy saver burners (*Chitetezo mbaula*) with the aim of conserving natural resources including trees. He emphasized that the use of such a mbaula would minimize going into the game reserve to look for firewood.

#### 5.13.9 Drilling of boreholes

It has been mentioned earlier that people visit the game reserve to draw water. One key informant suggested that Government of Malawi should drill more boreholes or taps in the communities because this would prevent community members from going into the reserve. In so doing it would help to prevent people from getting sleeping sickness because most of the community members get affected when they go into the reserve. While there are some boreholes, the problem is that the water is salty, hence there is preference to go to Lake Kazuni to fetch fresh water.

#### 5.13.10 Introduce bylaws

Only one key informant, a health worker at Katowo Health Centre, suggested that there should be bylaws on sleeping sickness in areas around the game reserve. These bylaws should be developed by both the game reserve, the community as well as health workers to among other things restrict the movement of people in the game reserve and other measure that can promote diagnosis of sleeping sickness, timely seeking of treatment and prevention of the disease among communities around Vwaza Marsh Wildlife Reserve.

#### 5.14 Factors contributing to failure to adopt preventive measures for tsetse flies

Participants in this study mentioned a number of factors that prevent people from adopting preventive

measures for tsetse flies.

#### 5.14.1 Poverty

During most FGDs and KIIs, study participants reported that while strategies exist for the prevention of sleeping sickness, poverty constitutes one of the barriers to the prevention of this disease.

“The majority of the community members fail to adopt the protective measures for sleeping sickness because of poverty. For instance, we advise the people to avoid going into the reserves or infested areas but they still go there to collect firewood, for bee keeping, for fishing and poaching among others”, (Medical assistant, Malidade, Mzimba).

As mentioned earlier, sleeping sickness mainly attacks people who are poor hence in this context they cannot do without going to the game reserve.

#### 5.14.2 Difficulties controlling mosquitoes

Tsetse flies transmit sleeping sickness from wild animals to human beings. In an area like Vwaza Marsh Wildlife Reserve participants reported that it is difficult to protect oneself against sleeping sickness because wild animals usually get out of the protected area and they bring with them the tsetse flies some of which are infectious. While they may avoid going inside the protected area, once these wild animals come out that means the people are still at risk.

#### 5.14.3 Ignorance

There were some participants in this study who said that neither health workers nor game reserve staff have ever told them about the preventive measures for sleeping sickness. They argued that ignorance for them is a major barrier to adoption of preventive measures for sleeping sickness. They, therefore, suggested that they need to be civic educated on sleeping sickness preventive measures and once they know then they can put them into use. A community leader in Malidade, Mzimba said that he got information from the game reserve staff on the use of tsetse fly traps in game reserve as well as communities around the reserve but that these tsetse fly traps were burnt up due to bush fire.

### 5:15 Motivators for health around Vwaza Marsh Wildlife Reserve

Most study informants were of the view that health workers are the best motivators for health issues mostly because they provide services including the diagnosis and treatment of sleeping sickness. They are able to cure patients.

“It is health workers because they treat people who are then cured. This is the reason why we listen to them. We trust them. Yeah, so if we hear that they are coming for sleeping sickness testing, .... we go and get tested. Yeah”, (FGD with caregivers of patients with sleeping sickness, Malidade, Mzimba).

Health workers are also the best motivators because they are listened to and are trusted and this is because, for example as narrated by a Microscopist at Manolo in Mzimba, they know more about human health than anyone else. Among health workers some informants singled out the HSAs as best motivators for health because they live within the community and also because they [HSAs] understand them [communities].

“... HSAs understand us very well because they also live with us in the communities and when giving us advice, we can also listen to them most because we know they cannot do something bad for us in the communities since they are also part of us”, (Community leader, Malidade, Mzimba).

A medical assistant at Manolo, Mzimba also emphasized that HSAs are the ones who motivate or influence people on health issues because they work in the communities hence communities have built trust upon them. He further explained that HSAs have better techniques which they use to attract people’s attention whenever they want to deliver health and related messages, and this tends to motivate most people to listen to their advice and take them into consideration.

In addition to providing treatment, health workers also conduct health education among community members to create awareness about sleeping sickness. At Thunduwike in Mzimba, a study participant gave an example of an HSA who conducts door to door sensitization meetings.

“Dr’ M. comes, and he provides the message door to door. I tell you and he is a hard worker. ... No one can say that ‘I know not about sleeping sickness’ in this community. Then the person is a liar. Our HSAs goes door to door sensitizing people about this disease. Talking about health in general. He does it. He goes door by door”, (sleeping sickness caregiver, Thunduwike, Mzimba).

In addition to this, in one FGD in Mzimba participants mentioned that the health centre has a committee, which among other things, also sensitizes community members including on issues such as sleeping sickness.

“The health centre has a committee. Each area has a committee under the health Centre. This committee we can listen to it and we do listen what they tell us. [HAC] once they are told out there. They come to us and tell us what they have been discussed up there. We do listen to them. The same with COVID-19. They came and sensitized us about this. We listen to them. We adhere because they are our eyes. ‘corona has come’ and we know because of them. ‘how can we prevent ourselves from corona?’ ‘wash your hands with soap. You put on masks’, (r-HAT caregiver, Thunduwike, Mzimba).

These sensitization activities conducted by health workers and members of the health centre committees motivate people for health. A few informants in this study mentioned that the chiefs are the best motivators for health.

“The chiefs are obligated to call for community gatherings and say; ‘My people, this disease is real. You can see that figures are alarming. What should we do then before we die? Let us all follow all the precautions so that we should not die’. If chiefs can do this, people listen. The chiefs then can report back to the health centre that; ‘I have done my part. I have told them.’ Then the health center has also Health Advisory Committee (HAC). These people they also contribute much. They do sensitize people on the same together with chiefs. People listen to these people”, (Women’s leader, Manolo, Mzimba).

“... Religious leaders yes. Traditional leaders they can also be best motivators. If in their village a person suffered from this disease and get cured, they can use it as an example. ‘I once had a patient in my village who suffered from this disease. Now he or she is okay and participating in development activities[in the community]’ (HSA, Mwazisi, Rumphu).

Traditional leaders also acknowledged that they motivate people for health at community level and their views are respected by community members and suggested that any message targeting the people should come through them as they have a lot of influence. While chiefs are important, there were other informants however who said that the chiefs do not treat patients and a health worker at Mwazisi said that chiefs should not be trusted on health messages.

“We don’t trust the chiefs. They are not the right people to be entrusted with health-related messages. They are not experts in the field. They don’t know things better than other community members. It is better to listen to experts”, (HSA, Mwazisi, Rumphu).

Very few informants mentioned religious leaders as best motivators mainly because they have a large following. Many informants including health workers had the view that people who have ever had sleeping sickness should be the best motivators on health especially sleeping sickness.

“... We have a friend whom we play football together. He once suffered from sleeping sickness and he is cured. This person if he can sensitize his peers, it can help and they can listen more to him than us. He is a witness. We all know that he once suffered from sleeping sickness and he is cured. Unlike a person coming from far and tell us about sleeping sickness, it will be hard for us to understand. Since the person is amongst us, people will believe and trust him. It is true that this person once suffered from this disease..... (HSA, Mwazisi, Rumphu).

Informants with sleeping sickness or those who have ever had this disease agreed that they can play an important role in terms of motivating people for health issues especially sleeping sickness: they can encourage all patients who have tested positive to go and receive treatment timely, that they will not die of the disease and that it is better to go to health centres than traditional healers.

Many informants also reported that there are delays in diagnosing sleeping sickness or even delays in communicating results of the tests for sleeping sickness and this tends to demotivate community members who have provided specimen as well as those who desire to get tested. Most participants especially at community level were of the view that when samples are taken the results should be out within a reasonable time as delays put off healthcare seekers. The desire for everyone is that when they are ill they should seek treatment so that they can be cured. In this study many informants reported that the desire for good health and the fear of death are also motivators in some ways.

In addition to health workers, most informants then talked about the availability of finances that support seeking health care as a motivator as well. Without finances, it is difficult to seek health care considering that confirmatory tests and initiation of treatment for sleeping sickness is only available at Rumphu District Hospital.

“According to our situation here, if we can have money at hand, we can be able to go to the hospital which is far from here to receive treatment in time, but if we do not have money, we can die without receiving treatment .... money can really motivate behavior change”, (P2, FGD with caregivers of patients with sleeping sickness, Malidade, Mzimba).

Some participants in this study also reported that there are certain sleeping sickness drugs at hospital [containing 30 tablets] which patients are instructed to purchase on their own when they are hospitalized and these cost around MK1500. This means when a person has no money he cannot buy these drugs. The other motivating factor is that the period of hospitalization should be shortened.

“Yes. The period for treatment is too long: 3 weeks or one month at the hospital is too much. I wish the period for treatment was shorter. Two weeks or less than would be ideal to allow victims to be closer to their homes. When diagnosed with sleeping sickness, people know that they would spend a month at the hospital. This does not motivate some people to be willing to be tested for the disease hence risking death. Like malaria or other diseases, people should be able to access pills which they can take at home”, (Patient with sleeping sickness, Mwazisi, Rumphi).

A number of informants as well especially at community level reported that people can be motivated when they are receiving fair and good treatment from health workers and then they get cured without any side effects. This can contribute to people with sleeping illness easily going to the hospital without any fear as they are having now. A community leader reported that what has created fear among people in the community is that patients with sleeping sickness inform their colleagues that a big needle is used in the process of administering medicines to people with sleeping sickness.

“We are afraid of what people who ever suffered from sleeping sickness told us about the injections and even the disabilities that we are seeing in them now, which gives us stress especially with this situation that we are not protected at all”, (Community leader, Malidade, Mzimba).

This discourages or demotivates people from seeking treatment when they are suffering from sleeping sickness. As mentioned earlier, what can also motivate people for health especially when it comes to sleeping sickness is that diagnostic and treatment services should be offered in facilities around Vwaza Marsh Wildlife Reserve other than Rumphi District Hospital.

“As I already said, there is need to provide oral drug treatment to the patients instead of using injectables treatment because drug treatment could easily be administered or provided at the facility unlike injectables treatment which is currently being provided or administered at Rumphi District Hospital. This would motivate a lot of people to come to the facility for diagnosis and or testing of sleeping sickness because they would be aware that if they could be tested positive, they would be able to receive treatment right at the health facility”, (Medical Assistant, Malidade, Mzimba).

It can be observed that informants were of the view that health workers especially the HSAs are the best motivators. Other motivators were chiefs and patients who have recovered from sleeping sickness. In addition to this, availability of the money to enable people with sleeping sickness seek health care, timely communication of test results for sleeping sickness, provision of treatment at health centres around Vwaza and friendly health workers constitute some of the motivators for health in areas around Vwaza Marsh Wildlife Reserve.

#### 5.16 Messages would motivate people to change

Health workers are an important source of information about sleeping sickness. These health workers said that in sensitizing communities about sleeping sickness they tell them the cause of sleeping sickness, how it is transmitted, how it can be prevented and the effects sleeping sickness on individuals and communities.

“During sensitization meetings, we usually tell the community what sleeping sickness is, how is it caused, its signs and symptoms and how it is treated”, (Medical assistant, Malidade, Mzimba).

In addition to this they also tell communities that the disease is treatable and that if they do not get the

treatment, the patient can die. Such messages can motivate the patient and guardians to go to the hospital and get medication so that they can be cured. As mentioned earlier, such messages can motivate people to seek sleeping sickness services.

Some informants in this study including HSAs recommended that when communicating these messages on sleeping sickness there is a need for different stakeholders namely health workers, chiefs and staff from game reserve to work together including people who have ever suffered from sleeping sickness as well as using a multiplicity of communication channels namely the church, social media, TV and radio.

“There is need to coordinate with traditional leaders, religious leaders, other influential leaders and also the media like TV and radio stations”, (Medical assistant Malidade, Mzimba).

“The messages from health workers through radios, posters, health talks in churches, at the funeral or in any gathering done in the community or PA system on how sleeping sickness is caused, preventive measures and its effect when treatment is not received in time”, (Sleeping sickness patient, Thunduwike, Mzimba).

While a lot of information on sleeping sickness is being disseminated a health worker at Katowo, Rumphi was of the view that people in the communities surrounding Vwaza Marsh Wildlife Reserve in some cases do not take such messages seriously.

“We try our best to disseminate information to the people to avoid going into the reserves or parks, but the challenge is that most of the people do not listen to our advice or do not take the information seriously. Even National Parks have extension workers who stay in the communities so that they should be sensitizing the community members about dangers of poaching, but people still go into the parks and poach animals without getting any consent”, (Microscopist, Katowo, Rumphi).

## 6. Discussions, Conclusions and recommendations

This study was aimed at exploring the perceptions and practices of the local communities and peripheral health centre staff regarding sleeping sickness around Vwaza Marsh Wildlife Reserve in Malawi. In general community members know sleeping sickness which locally is referred to as *kaskembe* in Tumbuka. They are also aware of the signs and symptoms of sleeping sickness and that, in the early stages of this disease, the signs and symptoms are the same as that of malaria. Other studies have also found that the signs and symptoms of sleeping sickness are difficult to distinguish from malaria (Reid, et al., 2012). One of the signs and symptoms that was commonly mentioned in this study is that persons with sleeping sickness sleep quite a lot during the day. This just demonstrates that community members are aware of the signs and symptoms as the World Health Organization (WHO Expert Committee, 2013) also acknowledges that frequent sleeping is a major symptom of sleeping sickness<sup>5</sup> as the patient has uncontrollable desire to sleep anytime.

In terms of etiology, this study has found that health workers know that the disease is caused by microorganisms called trypanosomes and that these are transmitted by tsetse flies from infected animals to human beings. While community members were aware that human beings contract sleeping sickness after being bitten by tsetse flies, they did not talk about the fact that sleeping sickness is caused by microorganisms. In addition to internalizing that sleeping sickness is caused by tsetse flies, community members also reported that beliefs prevail in Vwaza about witchcraft causing this disease. However, over the years the number of people with such beliefs is declining as they have seen that the traditional healers are not healing people of this disease. All cases are cured by the health facilities. It is not only in Malawi

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<sup>5</sup> <https://www.dana.org/article/a-wake-up-call-about-sleeping-sickness/>.

where witchcraft is believed to cause sleeping sickness: a study conducted in South Sudan also found that people believed that they were bewitched especially in the early days of the disease (Bukachi, et al., 2018).

In the current study many informants who either were currently having sleeping sickness<sup>6</sup> or had ever had this disease spent long periods seeking traditional medicines as they thought that they had been bewitched. Diseases are perceived to be caused by witchcraft when they do not respond to treatment from health facilities: the initial stages of sleeping sickness especially where the disease is being treated with anti-malarials and does not respond to treatment is a determination that the disease has been caused by witchcraft and other supernatural powers. This study also found that some respondents had the view that r-HAT can be transmitted through mother to child or eating bush meat contaminated by microorganisms [transmitted by tsetse flies]. Although eating contaminated bush meat was mentioned in this study, however, WHO does not mention this as a route through which sleeping sickness is transmitted. WHO, however, mentions mother to child transmission and sexual contact as ways through which the disease is transmitted<sup>7</sup>.

This study found that in general there is no stigma and discrimination against persons suffering from sleeping sickness mainly because everyone can get the disease, the disease is curable and it is not a contagious disease. This result is similar to earlier findings from Tanzania which found that there was no stigma as the majority of the respondents reported that persons with sleeping sickness would get support and help from the wider community (Reid, et al., 2012 & Bukachi, et al., 2018). Around Vwaza patients with sleeping sickness were supported by their friends and relatives and even when they were hospitalized people from their communities would visit them to give them moral support which was a demonstration that there is no discrimination. It has to be mentioned that even in Reid et. al.'s study (2012) some few respondents reported that persons with sleeping sickness were discriminated. Around Vwaza initially people with sleeping sickness, since they lost a lot of weight, community members concluded that they had HIV which they contracted immorally hence there were being discriminated. In addition to this, it has been observed that people with sleeping sickness also develop some mental illness hence they can be discriminated due to this condition. However, not many people discriminate them on this basis.

The major challenge being experienced in the management of sleeping sickness is the diagnosis of the disease. This disease has similar signs and symptoms with malaria and this study found that community members will think that it is malaria and either self-medicate or take antimalarials. The elimination of sleeping sickness may not be achieved without improved case detection and management (Nolna, et al., 2020). This study at Vwaza Marsh Wildlife Reserve identified that community members can play and are playing an important part in the management of sleeping sickness and one of their key roles is the provision of advice to community members presenting with signs and symptoms of sleeping sickness to go to the health facilities and test for sleeping sickness. Nolna and others (2020) found that it is critical that community members should be involved in the identification of suspected cases of sleeping sickness as this would in turn enhance case finding strategies.

In terms of treatment of sleeping sickness, health workers, staff from the game reserve and community members reported that all cases are currently being treated at Rumphu District Hospital. While initially even the diagnosis was done at the district hospital, since 2013 health facilities around Vwaza Marsh Wildlife Reserve have been capacitated to provide diagnostic services for sleeping sickness. In South Sudan, the same scenario applies as the diagnosis and treatment of sleeping sickness is offered at designated places (Bukachi, et al., 2018). Since the signs and symptoms of sleeping sickness are similar to malaria especially in its first stages patients will resort to self-medication with pain killers, antimalarials or antibiotics.

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<sup>6</sup> While patients diagnosed with sleeping sickness are supposed to be treated immediately, there are some people who are still in the community due to lack of transport. Even those who have been treated, in some cases they still show signs and symptoms of r-HAT, they are not fully recovered, hence perceived as still having the disease.

<sup>7</sup> [https://www.who.int/news-room/fact-sheets/detail/trypanosomiasis-human-african-\(sleeping-sickness\)](https://www.who.int/news-room/fact-sheets/detail/trypanosomiasis-human-african-(sleeping-sickness))

Once diagnosed with sleeping sickness a patient is supposed to travel to Rumphi District Hospital to initiate treatment. Regarding treatment, informants mentioned experiencing a lot of challenges the major ones being transport, late diagnosis of sleeping sickness, lack of food and other items, poor attitude of health workers. Other studies have also found that patients with sleeping sickness experience challenges such as long distances to designated facilities that offer treatment for this disease and negative attitudes of health workers (Bukachi, et al., 2018). While in South Sudan the cost of health services was cited as a major barrier to accessing sleeping sickness services (Bukachi, et al., 2018), in Malawi these are offered free of charge, as determined as well in the current study. If a disease does not respond to treatment, then other causes will be suspected and, in this context, this is where persons with sleeping sickness will resort to consulting traditional healers as they think that the disease has been caused by witchcraft. All informants who reported that they consulted traditional healers reported that they were not cured. Some traditional healers acknowledged as having no treatment for sleeping sickness and that they had started referring patients with sleeping sickness to health facilities. All those who did self-medication were also not cured. Hence, they resorted to going to health facilities where they were tested and found with sleeping sickness.

Sleeping sickness impacted negatively on individual as well as the wider family. In this study patients with sleeping sickness and their families reported that once they are diagnosed, they are admitted. While the hospital provides free medicines for sleeping sickness the study found that patients and families incur other costs as well, such as food for themselves and their guardians and transport to the district hospital (see also Reid et al., 2012). While treatment for sleeping sickness is free, patients with this disease experience substantial economic burden as they need to purchase some medicines on their own, , travel and living costs away from home. As was the case in the current study, Reid et al (2012) also found that prior to diagnosis, patients with sleeping sickness had spent a lot of money and in the case of Malawi people talked about spending money on malaria and other treatments as well as on traditional medicine,

Many informants with sleeping sickness or those who had ever had this disease and recovered reported they did not resume their normal duties immediately after being discharged from the hospital because they were still weak or even feeling a lot of pain, especially in the back due to both lumbar puncture as well as long period of hospitalisation. Reid et al (2012) says that the recovery phase for this disease is long and patients could not resume their normal duties such as working in their agricultural field for a period of 6-12 months which resulted into loss of incomes as many informants stated as well in the current study. Impacts of the sleeping sickness. Some informants in this study reported that their penis would not erect and they had stopped having sex with their wives. These findings are similar to those of Reid et al. (2012) and Bukachi et al (2018) who found that their respondents complained that their male organs died (Bukachi, et al., 2018). None of the women with r-HAT reported any problems having sex.

This study shows that there are many problems that patients with sleeping sickness experience and there are various coping mechanisms that they use to cope with these problems, and these include communities and government helping with transport, sale of household property and communities working in the garden belonging to a person with sleeping sickness. These findings are similar to Bukachi et al. (2017) who found similar coping mechanism.

Based on these findings the following recommendations are therefore being made:

***Knowledge about sleeping sickness***

- Continue the creation of awareness about the signs and symptoms of sleeping sickness, how it can be prevented and treated.
- Encourage persons with sleeping sickness or former patients to actively create awareness about sleeping sickness within their communities.

- Build the capacity of community leaders including traditional healers so that they can play a role in creating awareness among community members and adequately refer the suspects for diagnosis and treatment to the health services.
- Organize football or netball bonanzas so that people can come and participate as football and netball activities tend to attract a lot of people.
- Introduce a programme on sleeping sickness on community radios in Mzimba and Rumphu Districts.
- Conduct sensitization meetings with private practitioners, traditional healers and their clients on sleeping sickness and the need for them to refer patients to the health centres.

#### ***Human resources for health***

- Make available more health workers including HSAs who can provide services to patients suffering from sleeping sickness.
- Train health workers in the prevention and treatment of sleeping sickness as part of their preservice as well as in-service training. Such in-service training shall be continuous especially because health workers in the public services can be transferred anytime.
- Recruit additional microscopists and train them to detect sleeping sickness. Such trainings can best be organized by Rumphu District Hospital as the facility has enough capacity to do this.

#### ***Laboratory services***

- Make available all equipment and reagents for diagnosing sleeping sickness at community level.

#### ***Treatment of sleeping sickness***

- Provide treatment for sleeping sickness at health facilities around Vwaza Marsh Wildlife Reserve to address the problem of transport to Rumphu District Hospital.
- Abandon the use of injections in the treatment of sleeping sickness by introducing alternative oral treatments.
- The period for the treatment of persons with sleeping sickness is 4 weeks of hospitalization with the old treatment. Currently, there are clinical trials for melarsoprol in Rumphu which is given over a period of 10 days. Once this new treatment is successful, it would be appropriate that the treatment is introduced as quickly as possible.
- Provide an ambulance to carry patients diagnosed with sleeping sickness from the communities to Rumphu District Hospital for treatment and even follow up visits.

#### ***Prevention of sleeping sickness***

- Install additional tsetse fly traps in and around Vwaza Marsh Wildlife Reserve.
- Construct a solid wire fence around Vwaza Marsh Wildlife Reserve.
- Minimize visiting the Vwaza Marsh Wildlife Reserve for poaching, cutting grass for thatching houses, cutting trees and fishing.
- The Ministry of Health and the Vwaza Marsh Wildlife Reserve should screen people around the game reserve periodically so that they should know their status. This would enable people to seek treatment timely.

#### ***The private sector***

- Promote the involvement of the private sector including private clinics in the management of sleeping sickness.

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