Economic and Social Consequences of Human African Trypanosomiasis in Muchinga, Lusaka and Eastern Provinces of Zambia

By

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A dissertation submitted in partial fulfilment of the requirements for the award of a degree in Master of Science in One Health Analytical Epidemiology

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DECLARATION

I Allan Mayaba Mwiinde do hereby declare that the contents of the dissertation being submitted herein are my original work and have not been previously submitted to any University for the award of a degree or any other qualification.

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CERTIFICATE OF APPROVAL

This dissertation submitted by Allan Mayaba Mwiinde is approved as fulfilling the requirements for the award of the degree in Master of Science in One Health Analytical Epidemiology.

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ABSTRACT

Human African trypanosomiasis (HAT) causes severe economic production losses in humans due to loss of man power and death. In Zambia most of the studies that have been done have focused on analysing the parasite while none have been conducted to establish the economic consequences of the burden of the disease on the affected populations. This study therefore aimed at determining the economic and social consequences of HAT in Lusaka, Muchinga and Eastern provinces of Zambia. This was achieved by a cross sectional survey, using a mixture of qualitative and quantitative research methods. Specifically, the economic and social consequences were measured at the household level using structured interviews and focus group discussions. In addition, mapping was done to determine the spatial distribution of HAT in the study areas. In order to assess the adequacy of the health delivery system in the management of HAT at the district level in the affected areas, structured questionnaires were administered to the medical officers and government officials (District Health Management Officers). All qualitative data were analysed using inductive approaches with two independent researchers working together to review the transcripts, develop the coding structure and extract the overarching themes and sub-themes emerging from the focus group discussions.

From the quantitative data collected, descriptive statistics were generated for the variables under study. Analysis of variance (ANOVA) was used to determine associations between continuous variables. The burden of HAT on the study population was estimated using the Disability Adjusted Life Years (DALYs). This was calculated as Years of Life Lost (YLL) +Years of Life Lived with Disability (I×DW×L)].

Results from the study indicated that once a patient contracts HAT, an average of 4.9 months' worth of productive time would be lost due to the illness. In economic terms, this loss in productivity translated to a total of K1, 914.68 incomes lost for one individual due to the illness. Further, it was found that on average, a family would end up spending five times more than their monthly income on the cost of health care for a HAT patient. For the whole sample, (n = 64) the income lost due HAT (estimated as DALYs) was about K3.7 million. According to results, there were a lot of misconceptions about HAT that could be attributed to ignorance. The social consequences of the disease included stigma, dropping out of school, loss of friends due to amnesia and deformity. It was found that the current health care system was not able to adequately handle HAT cases because of inadequate qualified man-power and diagnostic equipment.

From this study, it is evident that HAT has high economic and social consequences at both household and community levels. There is therefore need for the country to put up concerted efforts to reduce the burden of this disease and also to educate the communities so as to reduce stigmatisation that is associated with the disease.

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DEDICATION

I dedicate this research to my late mother Linda Mukale, my uncle Allan Mukale and his family for their love and great contribution rendered to me during my academic lifetime.

I further dedicate this to all people who were diagnosed with HAT and ended up with either disabilities or died.

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LIST OF ABBREVIATIONS

ANOVA …….. Analysis of Variance

BCA ……. Benefit Cost Analysis

CDC ……. Centre for Disease Control and Prevention

CI ……. Confidence Interval

CSO …….. Central Statistics Office

DALYs …….. Disability Adjusted Life Years

DNA …… Deoxyribonucleic acid

DW ……..... Disability Weighting

EU …….. European Union

FAO …… Food and Agriculture Organisation of the United Nations

FIND …….. Foundation for Innovative New Diagnostics

FRA ……..... Food Reserve Agency

HAT …… Human African Trypanosomiasis

IAEA ……International Atomic Energy Agency

LAMP …… Loop-mediated Isothermal Amplification

LE . ……...Life Expectancy

MoH …….. .. .Ministry of Health

NGO ……. Non-Governmental Organization

NTDs ……. Neglected Tropical Diseases

OIE ……..The World Organisation for Animal Health (OIE)

PATTEC…… Pan African Tsetse and Trypanosomiasis Eradication Campaign

PCR ……. Polymerise Chain Reaction

QALYs……..... Quality Adjusted Life Years

UNZA ……..University of Zambia

UTH ……..University Teaching Hospital

WHO ……World Health Organisation

YLL ……..…..Years of Life Lost

YLD …….....Years of Life Lost with Disabilities

ZMW ……..Zambian Kwacha

CHAPTER ONE

1.0 Introduction

Human African trypanosomiasis (HAT), also known as sleeping sickness, is caused by infection with one of two parasites, *Trypanosoma brucei rhodesiense* and *Trypanosoma brucei gambiense*. These organisms are extra-cellular protozoan parasites that are transmitted by insect vectors of the genus *Glossina* (tsetse flies). The parasites can be distinguished through molecular methods, but not parasitological (Fe`vre *et al.*, 2008).The geographic range of the parasites has been a key component in differential diagnosis of HAT, as *T.b. gambiense* which causes a chronic form of the disease, occurs in West, Central and part of East Africa and *T.b. rhodesiense* which causes an acute form of HAT occurs in Southern and part of East Africa, although there are concerns that an overlap may now have occurred in their ranges. If HAT is not treated it can be fatal (Fe`vre *et al.*, 2008).

Historically, HAT has been a major impediment to the social and economic development in most of the African rural communities, affecting the poorest people. With the use of modern drugs, insecticides, and other control methods, this disease was effectively controlled in most countries by the mid-1960s. In the past 20 years, however, major epidemics have occurred in East and Central Africa, mainly because control programs were disrupted by war (Gubler, 1998).

Although the number of cases of HAT in Zambia is reported to have declined (Mwanakasale *et al.*, 2014), sporadic cases of the disease continue to be diagnosed in some areas from time to time (Namangala *et al.*, 2012). HAT causes severe economic production losses in humans due to loss of manpower and death, as well as in domestic livestock. Thus, the impacts of both the human and animal forms of the disease can be devastating for affected households (Machila *et al.*, 2013). The social and economic impact of HAT is often underestimated in most of the countries in Africa. Some affected countries have agriculture based economies, and workers on maize and coffee plantations are at risk of contracting the disease, consequently the labour force is reduced (Kibbona, 2001). At community and family levels, stigmatisation, mental confusion, personality and behaviour changes, which often characterize central nervous system involvement in late-stage disease, may lead to school drop outs, mortalities, divorce and break up in homes and present unfavourable climate for bringing up children (Kibbona *et al.*, 2002). In some cases, such people become mentally disturbed, suicidal and violent constitute a danger to themselves and to

the community (PATTEC, 2011).These economic and social issues are neglected by the scientific parts of the studies (WHO, 2001).

To assess the global burden of disease (GDB), the World Bank commissioned a comprehensive disease assessment of over 100 diseases and injuries (Lopez, 2005). This 1996 GBD report was the first one to attempt to quantify the burden of HAT (Reid, 2012). This lead to the use of Disability Adjusted Life Years (DALYs), which are now being applied in several economic analyses for HAT control as proposed by Murray and Lopez (1996). According to the Centres for Disease Control (CDC, 2012), only a few studies concerning the economic effects of HAT have been undertaken at the house hold level in most of the African rural communities. Therefore, when outbreaks of HAT occur (PATTEC, 2011), most governments are unable to respond quickly, either because there is no specific financial allocation for HAT control in the ministries of health (MoHs), or those who are responsible for allocating resources for management of the disease often do not understand the extent or implications of the problem at household and probably at the national levels. According to Hackett (2014), studies that are done at the community level in the countries where the disease is endemic or sporadic, provide valuable estimates of local burden in affected areas.

Therefore the work presented in this document aimed at assessing the economic and social consequences of HAT at household level in areas where there have been sporadic cases in Zambia. Estimating the economic and social consequences of the disease at household level, is the best way to accurately ascertain the impact of the disease (CDC, 20012). The research also tried to assess the adequacy of the healthcare delivery system in the management of HAT in the affected districts. This information would assist in the broader policy-making and prioritization of interventions necessary to ease the burden HAT in affected areas.

1.1 Statement of the problem

The impact of HAT at community and family level has received little attention by most of the governments in Africa. The disease is also associated with social consequences such as mental confusion, personality and behaviour changes and others symptoms, which may lead to divorce and break up in homes and present an unfavourable condition for bringing up children (PATTEC, 2011). In some cases, HAT patients become mentally disturbed, suicidal violent and constitute a danger to themselves and to the community. These economic and social issues are

neglected by the scientific parts of the studies (WHO, 2001). Thus, the impacts of HAT result in affected households having to pay for the cost of treatment which increases the economic burden of the already impoverished families (Machila *et al.,* 2013).

Available literature on trypanosomiasis reveals that studies on the disease have largely been conducted from scientific and ecological points of view focussing on the parasitic host relationships. No studies have examined the economic and social impact of HAT in Zambia. Such studies are important to assist in developing the much needed evidence based policies in order to curb the pandemic in Zambian communities, especially Eastern, Muchinga and Lusaka provinces where sporadic cases of HAT are being reported.

1.2 Justification and Significance of the study

There has been a sporadic case of *rhodesiense* HAT in humans in parts of Lusaka, Muchinga and the Eastern Provinces of Zambia (Mwanakasale & Songolo, 2014). There have been no estimates of the economic impacts of the disease in these affected households and communities. Furthermore, no information on the social consequences of the disease in the affected communities is available. Therefore there was a need to carry out research on the economic impacts and the social consequences of the disease so as to guide policy on the management of the problem in the affected communities.

1.3 General Objective

To assess the economic and social burden of HAT in Eastern, Muchinga and Lusaka Provinces of Zambia.

1.3.1 Specific Objectives

- To determine the economic consequences of HAT at household level
- To assess the social consequences of HAT at household level
- To assess the adequacy of the health delivery system in management of HAT in health institutions in the study area

CHAPTER TWO

2.0 Literature Review

2.1 Aetiology of HAT

Human African Trypanosomiasis (HAT), also known as sleeping sickness, is caused by infection with either *T. b. rhodesiense* or *T. b. gambiense*. These are extra-cellular protozoan parasites that are transmitted by insect vectors belonging to the genus *Glossina* (tsetse flies) (Fe'vre *et al.*, 2008). Both male and female flies feed on blood and thus serve as vectors of trypanosomes (PATTEC, 2011). HAT is endemic in sub-Saharan Africa, stretching from latitude 14 degrees north to latitude 29 degrees south of the equator. In Eastern and Southern Africa (including Zambia), HAT is caused by *T. b. rhodesiense*. This parasite causes an acute form of the disease with death occurring in a few weeks or months after onset, if no treatment is available (Namangala *et al.*, 2012). On the other hand, *T. b. gambiense* is found in 24 countries in west and central Africa (WHO, 2015). This form of the disease currently accounts for over 98 percent of reported cases of HAT and causes a chronic infection which lasts for months or years after onset of symptoms. When more evident symptoms emerge, the patient is often already in an advanced disease stage where the central nervous system is affected similar to the acute *T. b. rhodosiense* signs and symptoms (WHO, 2005). Uganda is the only country which presents both forms of the disease but in different locations (WHO, 2005).

Other species of the parasites that are responsible for animal African trypanosomosis (AAT) include *Trypanosoma congolense*, *Trypanosoma vivax*, *Trypanosoma evansi*, *T. b. brucei* and *Trypanosoma evansi.* (Truc *at el.*, 2013).

2.2 Transmission

HAT is transmitted primarily by bites from infected tsetse flies (Yun *et al.*, 2010). Transmission is also possible through contamination with infected blood or through the placenta (congenital) as well as through sexual contact has been documented (WHO, 2016). Both male and female flies are vectors of trypanosomes and it is assumed that all tsetse species can act as trypanosome vectors (Aksoy, 2003). Within the tsetse fly, trypanosomes undergo cycles of development and multiplication, involving different parts of the alimentary tract and salivary glands, depending on the trypanosome species (Aksoy, 2003). During a blood meal on the mammalian host, an infected tsetse fly (genus *Glossina*) injects metacyclic trypomastigotes into skin tissue (CDC,

2015). At this stage the parasites enters the lymphatic system and passes into the bloodstream were they transform into bloodstream trypomastigotes and are carried to other sites throughout the body were they reach other body fluids such as lymph, spinal fluid. They continue the replication by binary fission (CDC, 2012). Parasites become patent in the blood within 1–2 weeks of infection, heralding the haemolymphatic stage (stage 1), which is characterised by non-specific signs and symptoms. Eventually, parasites penetrate the blood–brain barrier, leading to the meningoencephalitic stage (stage 2), which features more specific signs and neurological symptoms, and leads to coma and death (Checchi et al., 2008).

2.3 Clinical Signs and Symptoms of HAT

The clinical disease of HAT is divided into two stages, i.e. the early or hemolymphatic stage (stage I) and the late or neurologic stage (stage II).

2.3.1 Symptoms of stage I HAT

In the first stage of HAT, the trypanosomes multiply in subcutaneous tissues, blood and lymph after two to 15 days of tsetse fly bite. This is also called haemo-lymphatic stage, which is characterised by intermittent fever, headaches, joint pains and itching (WHO, 2005). Intermittent fever (refractory to antimalarial drugs), general malaise, myalgia, arthralgias, and headache, generalized or regional lymphadenopathy, facial oedema usually occurs to the minority of patients (Odero, 2013). Transient urticarial, erythematous, or macular rashes occur six to eight weeks after onset of signs. Trypanids (ill-defined, centrally pale, evanescent, annular, or blotchy oedematous erythematous macules on the trunk) are the other signs (Gorby *et al.*, 2013).

2.3.2 Symptoms of stage II HAT

During late stage (neurological) of HAT, the patient may experience a range of mental and psychiatric symptoms including characteristic sleep disturbances which gave the disease its name of “sleeping sickness” (Peter, 2013). Persistent headaches (refractory to analgesics), day time somnolence followed by night-time insomnia, behavioural changes, mood swings, and, in some patients, depression, loss of appetite, wasting syndrome, weight loss and seizures are seen (Gorby *et al.*, 2013).

2.4 Diagnosis

Several methods such as microscopy, serology and those that are molecular based, can be used for the diagnosis of HAT.

2.4.1 Microscopy

The simplest techniques are microscopic examination of wet, thick or thin films of fresh blood, usually obtained from the ear or jugular vein. Amongst the direct examination techniques, stained thin blood films are generally regarded as more specific but less sensitive (OIE, 2013). The actual specificity and sensitivity of these techniques is directly dependent on the volume of blood which is actually examined and the skill and experience of the microscopist (OIE, 2013). According to Mwanakasale & Songolo (2011), the methods are used to diagnose HAT in endemic areas (Kasempa and Kabompo (North Western Province), Isoka (Northern Province), Serenje (Central Province), Chongwe and Luangwa (Lusaka Province) and Kaoma (Western Province). used Giemsa stain thick smear microscopy which was the routine diagnostic method used to detect HAT and the Micro haematocrit centrifugation method (Woo's method) was routinely used to detect HAT. Woo's method is more sensitive than Giemsa stain thick smear microscopy in the diagnosis of HAT (Mwanakasale & Songolo, 2011).

Light-emitting diode (LED) fluorescence microscopy was introduced for screening mycobacteria tuberculosis (Albert *et al*., 2010). It has been estimated that fluorescence microscopy is approximately 10 percent more sensitive than Ziehl Neelsen (ZN) in detecting acid fast bacilli (AFB) in clinical specimens (Albert *et al.*, 2010). The microscopy is being developed for cross disease examination for diseases such as HAT (FIND, 2015). The accuracy of LED microscopy was more sensitive than conventional Ziehl-Neelsen microscopy and it had qualitative, operational and cost advantages over both conventional fluorescence and Ziehl-Neelsen microscopy (WHO, 2011). An evaluation of LED fluorescence microscope has been completed and demonstration studies are on-going in the DRC (FIND, 2013).

On the basis of these findings, WHO recommends that conventional fluorescence microscopy be replaced by LED microscopy, and that LED microscopy be included in as an alternative for conventional Ziehl-Neelsen light microscopy (WHO, 2011).

2.4.2 Serological tests

The indirect fluorescent antibody test (IFAT) and the antibody-detection enzyme-linked immunosorbent assay (ELISA) are routinely used for the detection of antibodies in cattle and human (World Assembly of Delegates of the OIE, 2013). In humans mass screening of the Gambian form can be done using the field-adapted Card Agglutination Test for Trypanosomiasis

(CATT). However, the specificity of this test is low because false positive results can be caused by other infections such as malaria (Truc, 2002). The test is performed on whole blood sampled in capillary tubes from fingertip puncture, and it may be followed by plasma dilutions to improve specificity (Bouteille & Buguet, 2012). ELISA has high sensitivity and is genus-specific but can only be used for the presumptive diagnosis of trypanosomiasis (OIE, 2013). According to FIND (2015), the antibody-detection ELISA, in particular, lends itself to automation and will allow a high degree of standardisation when recombinant antigens have been developed and validated (OIE, 2013). Immunofluorescence or ELISA tests are efficient for *T. b. gambiense* and *T. b. rhodesiense* antibody detection, but they are not currently used in endemic countries (OIE, 2013)

The serologically positive are considered 'suspect' and are subjected to parasitological confirmation tests (Mitashi *et al.,* 2012). As a rule patients are treated for HAT only if trypanosomes have been detected in their body fluids, although in areas of high endemicity high titters in serology are also used by some as a criterion for initiating treatment (Mitashi *et al.,* 2012).

2.4.3 Molecular detection

Detection of trypanosome DNA from body fluids of a HAT patient could be a significant improvement on parasitological examination. However, DNA amplification techniques that include Polymerase Chain Reaction (PCR), PCR- enzyme-linked immunosorbent assay ELISA and Loop-mediated Isothermal Amplification (LAMP) as a diagnostic tool, are n not easily applicable for routine field diagnosis (Bernard & Alain, 2012).

2.4.3.1 The polymerase chain reaction

The polymerase chain reaction offers a solution to the problems of failure to detect trypanosomes in blood, since it is, theoretically extremely sensitive, where minute amounts of nucleic acid can be amplified, as well as being highly specific due to use of specific primer sets (IAEA, 2007). Polymerase chain reaction is advantageous in terms of specificity and sensitivity, however, the requirements for continuous electricity, trained staff, sophisticated equipment, and the cold chain makes its use in endemic areas not easy (Magasa *et al.,* 2012).

2.4.3.2 PCR-ELISA

Polymerase chain reaction-ELISA) is an immunodetection method that can quantify PCR product directly after immobilization of biotinylated DNA on a micro plate (Sue *et al.,* 2014).

This method, detects nucleic acid instead of protein. It is a much more sensitive method compared to conventional PCR, with shorter analytical time and lower detection limit (Sue *et al*., 2014).

When using PCR, DNA is extracted from a tissue or blood sample without microscopic determination of trypanosomes (Williams *et al.,* 2009). A PCR reaction is followed by capturing the PCR product to a microtiter plate coated with a probe against the PCR product (FAO and IAEA, 2007). A second probe associated with an enzyme is bound to the captured PCR product and the enzyme produces a reaction, e.g. changing the colour of a marker substrate or producing chemo luminescence to detect the PCR product. Alternatively, the PCR product could be labelled and the label detected by an antibody associated with an enzyme. The enzyme product is in principle quantitative to the PCR product captured by the microtiter plate. As such, if the PCR reaction was quantitative the number of the trypanosomes could be estimated (FAO and IAEA, 2007). The advantage of PCR-ELISA is that the assay allows large-scale screening to be done using only standard laboratory equipment, making it suitable to be used in clinical laboratories. This should serve as another incentive for laboratories with fewer resources (Sue *et al.,* 2014).

2.4.3.3 Loop-mediated isothermal amplification (LAMP)

Loop-mediated isothermal amplification (LAMP) is a DNA amplification technique whose advantages over traditional PCR have put it at the forefront of the search for innovative new diagnostics for various infectious diseases such as HAT (Wastling *et al.,* 2010). Loop-mediated isothermal amplification is a cost-effective tool for HAT diagnosis (Namangala, 2014). The test amplifies target DNA at a constant temperature, meaning that it can be carried out with minimal equipment in the field (FIND, 2010). Loop-mediated isothermal amplification is highly sensitive and specific, it is a potential diagnostic tool for parasite infections in remote rural areas where such diseases are endemic (Ndao, 2009).

2.5 Treatment of HAT

Treatment of HAT has received little attention in terms of funding compared to other diseases like Malaria by most of the African governments in the endemic countries and donor community (FIND, 2015). This has caused the current primary approach of control to resort to treatment with drugs that are expensive and not readily available, bringing out the economic issues that need to be addressed by African governments affected by HAT (Gubler, 1998). Furthermore,

Gubler (1998) stated that, to reverse this trend, an integrated sustainable control program must be implemented, including effective surveillance for case finding, a network of treatment centres with a supply of drugs, and vector control using trapping and spraying techniques which is a lesser cost than treatment. The case fatality rate of HAT is 100 percent if untreated (PATTEC, 2011).

Treatment of major insect-borne diseases, such as trypanosomiasis, malaria, dengue and leishmaniasis has re-emerged as an important priority for biomedical and public health agencies, agricultural sector and the scientific community. These diseases are complex and require the interactions of all stake holders (Askoy, 2003).

The choice of HAT therapy depends on the infecting subspecies of the parasite and the disease stage (Cherian *et al.,* 2010). The first line drugs for both first and second stage disease are highly effective in humans (CDC, 2012). Only four drugs are registered for the treatment of HAT. These are pentamidine, suramin, melarsoprol and eflornithine (Steverding, 2010). Pentamidine which was discovered in 1940 and suramin in 1920 are used in the first or early stage of *T. b. gambiense* and *T. b. rhodesiense* infections, respectively (WHO, 2015). Most of the treatment that focuses on *gambiense* HAT usually gives 99 percent cure, with few side effects as compared to *rhodesiense* HAT (Gwadz & Knirsch, 2012). Melarsoprol or eflornithine are used for first or second-stage of the *T. b. gambiense* disease, although it's high cost has dramatically limited its use and production has been sporadic (Marr *et al.,* 2003). Eflornithine is safer and often more effective than melarsoprol, which is associated with high toxicity and is even fatal at times (Yun *at el.,* 2010). After its inclusion in the WHO 'Essential Medicines List in April 2009, the combination of eflornithine and nifurtimox has been adopted as first line treatment for second stage *gambiense* HAT (WHO, 2014). The combination of both drugs (eflornithine and nifurtimox) reduces the duration of eflornithine monotherapy treatment and is easier to administer, while maintaining the same level of efficacy and safety (WHO, 2014). Melasoprol exhibits high rates of treatment failure in numerous HAT-endemic foci (Yun *at el.,* 2010). Suramin is used to treat first stage *rhodesiense* HAT. It is also effective against *gambiense* HAT, but it is not often used because severe reactions occur in persons who are co-infected with *Onchocerca volvulus* (CDC, 2013). Adverse reactions to suramin are frequent, but usually mild and reversible. These include drug rash, nephrotoxicity, and peripheral neuropathy. In rare

instances, suramin administration results in a hypersensitivity reaction and for this reason, a small test dose is usually given prior to the full first dose (CDC, 2013).

Melarsoprol is used in the second or advanced stage of both forms of the disease, being the only treatment available for late stage of *rhodesiense* HAT, it remains the only option despite its toxicity (WHO, 2014). Furthermore, melarsoprol is associated with a reactive encephalopathy in up to 10 perecent of treated patients that sometimes ends fatally (PATTEC, 2011).

The use of toxic melarsoprol has declined markedly in the treatment of *gambiense* HAT, with only 12 perecent of reported cases being treated by this drug by 2010 (Alsford *et al.,* 2013). This is because of this new treatment was based on limited experience; a reinforced pharmacovigilance system was introduced in 2010 (WHO a, 2013). According to WHO a (2013) a total of 22 sentinel sites were set up in the Central and Western African Republics, Chad, Congo, Côte d'Ivoire, Democratic Republic of Congo and, Equatorial Guinea which have helped to improve the routine use of the treatment for the sickness caused by *T. b. gambiense*. In 2010, the average cost to treat one patient with second-stage gambiense HAT was US$ 440 compared with US$ 30 in 2001. This burden might render treatment unsustainable in the future; thus it important that research continues to look for safe and effective medicines that are simpler to administer and cheaper than those currently available (WHO a, 2013).

However, there are signs of risks associated with the frequency and extent of use of the standard drugs for HAT, such as melarsoprol and pentamidine on one patient, which is likely to lead to development of resistance, of which there are already signs of resistance for melasoprol (PATTEC, 2011).

2.6 Prevention and Control of HAT

Preventive measures of HAT are aimed at minimizing contact with tsetse flies as much as possible. However, according to Gubler (1998), effective and sustainable control of HAT is unlikely to be achieved unless traditional uses of land change and socio-economic conditions improve in rural Africa communities, which are highly affected by the disease. The following are some of the available control measures against HAT:

2.6.1Traps

The first trapping devices for controlling tsetse were black overalls worn by workers, coated in glue and hung up in the plantations of Sao Tome and Principe in 1910 (Dramane *et al.*, 2014).

Later, in the 1930s, Harris developed a trap that was employed with great success in Zululand. A further series of trap types latter followed but not as effective as the use of chemicals (Dramane *et al.*, 2014). Odour baited traps and screens impregnated with insecticide and appropriate attractive colours were latter developed and have been used in many countries to effectively suppress tsetse population by 99 percent. These artificial bait methods are cheaper than ground and aerial spraying but communities and governments cannot deploy them on sustainable bases, as they are labour and management intensive (Jordan, 2014).

2.6.2 Ground Spraying

The use of persistent insecticide applied from the ground has a long history in most of the African countries in tsetse control operations. The technique is based on the knowledge that tsetse flies spend a greater part of their life resting in cool, shady places provided by trees, holes, and other places (Chadenga, 2012). Directing a persistent insecticide at these sites should achieve a good control measure which should not cause resistance (Chadenga, 2012). Ground Spraying became so popular after Second World War which led to the use of chemicals like dichloro-diphenyl-trichloroethane (DDT) which were very effective resulting in the abandonment of the use of traps (Dramane *et al.*, 2014).

2.6.3 Aerial Spraying

Basically, this is the sequential ultra-low volume (ULV) aerial application of an insecticide. Aerial spraying is a feasible and rapid technique for dealing with emergency situation, as well as treating large areas with less manpower than required in ground spraying operations over comparable areas (Chadenga, 2012). However, successful implementation of mass treatment and insecticide-spraying of animal reservoirs demands for inter-sectorial cooperation among veterinary, agriculture and health services at all levels to reach the required goals (Magona & Walubengo, 2011). Aerial application of insecticides to control tsetse is based on the sequential aerosol technique (SAT), whereby tsetse flies are sprayed with a non-residual insecticide at intervals designed to kill all adults initially, and then subsequently to kill young adults after they emerge from their pupae, but before they deposit larvae. Usually five cycles are required, at roughly 15-day intervals (Shawa *et al*., 2013).

While aerial spraying can achieve good control, the operation requires a high level of technical sophistication, strict timing of repeat sprays as areas sprayed are open to reinvasion and therefore require protection. In addition to this, there is the added public concern about blanket spraying of insecticides into the environment (Chadenga, 2012).

2.6.4 Deforestation

Vegetation serves as habitat for different species of tsetse flies. When the thick forest (habitat) is removed, tsetse flies also disappear. Clearance of vegetation was applied either by total eradication or by artificial removal of vegetation that was vital to the support of tsetse flies (Malele, 2011). However this method, coupled with clearance of large areas for farming left the areas which had widely practiced this methodology with permanent effects, including reduced rainfall (Malele, 2011).

The concern of conservation programs in relation to matters of sustainable land use in tsetse-freed areas is a great concern today. This concern is borne out of the realization that tsetse and trypanosomiasis control is inextricably linked with problems of land development usage, human health and wildlife conversation. In some areas the infection of trypanosomes is due to the encroachment of the game reserve areas (Chadenga, 2012).

2.6.5 Sterile male insect release and transgenic insects

The sterile insect technique (SIT) is only being applied if the above techniques cannot achieve elimination and have to be followed by a final SIT 'mop-up' phase (Askoy *et al.,* 2001). According to FAO (2015), the SIT is a form of pest control that uses radiation to sterilize male flies that are mass-produced in special rearing facilities. Sterile insect technique involves the mass production, reproductive sterilisation and regular release (usually weekly for up to 18 months or more) of sterile male flies of the target species (Askoy *et al.,* 2001).By continually releasing sterile males in sufficient quantities over the period of 18 months to cover several generations of the target species, its reproductive capacity, and hence the fertile population, is progressively reduced (IAEA, 2003). In order to archive eradication of the tsetse, sterile males need to be competitive and outnumber fertile females of the target tsetse population by at least 10:1 (Van der Vloedt & Klassen, 2014). According to Askoy *et al.* (2001), there should be sufficient sterile male to be released in order to achieve an over-flooding of the ratio to sufficiently cause a decline in population size. Wild females mated with sterile males and

inseminated by sterile sperm will produce no offspring (Peter, 2013). By continually releasing sterile males in these numbers over a period of three or four generations, the target population can be eradicated (Serap *et al.*, 2001).

2.7 Distribution of HAT in Zambia

According to a research conducted by Mwanakasale and Songolo (2011), the seven districts in Zambia that used to report HAT cases no longer had any cases after January, 2000 (Figure 2.1). These districts were Kasempa and Kabompo (North Western Province), Isoka (Northern Province), Serenje (Central Province), Chongwe and Luangwa (Lusaka Province) and Kaoma (Western Province). Laboratory records obtained from these districts showed that the last reported cases of HAT were detected as follows: Kasempa District was in 1996, Kabompo in early 1990s, Isoka in 1995, Serenje in 1991, Chongwe in 1994, Luangwa in 1988 and Kaoma in 1998 (Mwanakasale and Songolo, 2011).

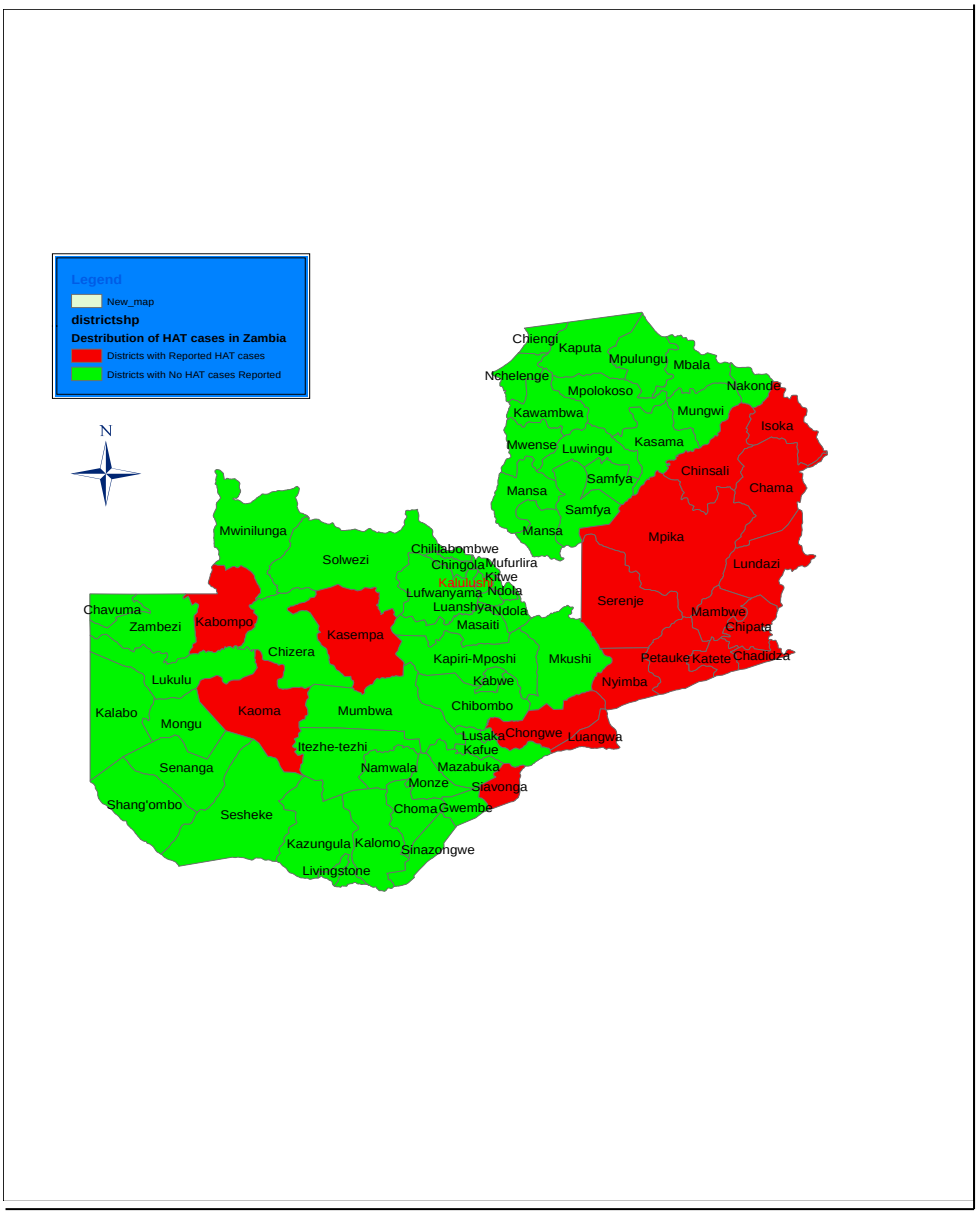


Figure 2.1: The distribution of reported HAT cases in Zambia since 1988-2015.

From the existing literature records, two epidemics of HAT have occurred in Zambia since the 1960s. The first outbreak occurred in Kasempa District in North-western Province from 1960 to 1968 in which 300 cases were reported (Mwanakasale *et al.*, 2014). The second outbreak occurred at the head of Luangwa valley in Eastern Province in 1971 when 16 deaths occurred out of the 36 reported cases (Anderson *et al.*, 2015). By 1974, about 410 cases were recorded in the

Luangwa Valley (Mwanakasale, 2014). The two outbreaks could not be compared to each other since the populations of the two areas at that time were not known (Mwanakasale *et al.,* 2014).

Of the 26 districts that were surveyed by Mwanakasale & Songolo (2014), only Chama, Mpika, and Chipata were still reporting HAT cases between 2005 and 2014. The survey by Mwanakasale and Songolo (2014) used the retrospective hospital records of cases which were being recorded. This meant that these districts still had active HAT transmission areas. Mpika had been reporting cases of HAT consistently from 2000 to 2004. Rufunsa, Chama and Chipata districts appeared to be either emerging or re-emerging HAT transmission districts (Mwanakasale & Songolo, 2014).

2.8 Economic Estimates of the Burden of HAT

Neglected Tropical Diseases (NTDs) such as HAT, have the ability to trap people in a perpetual cycle of poverty if intervention measures are not put in place. There is, therefore, a need to assess and fully understand their impact at household level, so that adequate resources can be allocated for their control (Hotez *et al.,* 2014).The economic estimates of HAT focuses on the use of the 1996 Global Burden of Disease (BoD) report, which was the first attempt to quantify the burden of the disease (Hotez *et al*., 2014). An important limitation of these estimates, however, was the failure to distinguish between *T. b. gambiense* and *T. b. rhodesiense*, due to differing disease progressions and sequel (Reid, 2012). This resulted into a commonly used index for expressing the burden of disease i.e. the disability adjusted life years (DALYs) which helps measure the burden of disease and the effectiveness of health interventions (WHO, 2015). The DALYs is a generic health measure incorporating both mortality and morbidity and used to gauge the relative public health importance of different diseases (Fèvre *et al.,* 2008).HAT afflicts an estimated 50,000–70,000 people each year, all in sub-Saharan Africa, with only a minority of cases (nearly 12,000 in 2008) being reported (Yun *et al.,* 2010). Human African Trypanosomiasis tends to affect the poorest and marginalized rural communities with least access to health care (Magona & Walubengo, 2011).

2.8.1 DALYS and QALYs

The DALYs is a summary measure of population health widely used in disease burden assessment studies and cost-utility analyses (Lopez *et al.,* 2006). According to Fox-Rushby & Hanson (2001), defined DALYs as the sum of the present value of future years of life time lost

through premature mortality and the present value of future year's life time adjusted for the average severity (frequency and intensity) of any mental or physical disability caused by disease or injury. DALYs represents the incident number of healthy life years lost due to disease or disability, and does so by incorporating non-fatal and fatal health outcomes, calculated as the years of life lived with disability (YLD) and the years of life lost due to premature death (YLL), respectively (Brecht, 2014). This implies that DALYs are the measure of something lost rather than gained (Fox-Rushby & Hanson, 2001)

DALYs, however are limited in the assessment of disease burden because they do not tell the complete story of the harmful effects from NTDs such as HAT. Furthermore, DALYs measure only direct health loss. For example, they do not consider the economic impact of the NTDs that results from detrimental effects on school attendance and child development, agriculture (especially from zoonotic NTDs), and overall economic productivity, direct costs of treatment, surveillance, and prevention measures (Hotez *et al*., 2014). Other aspects not considered by the DALY metrics are the important elements of social stigma for many of the NTDs and the spill over effects to family and community members, loss of tourism, and health system overload at national level (Hotez *et al.*, 2014).

The term 'quality-adjusted life year' (QALY), was first used in 1976 by Zeckhauser and Shepard to indicate a health outcome measurement unit that combines duration and quality of life (Sassi, 2006). A QALY embraces both of these components and is the arithmetic product of life expectancy and a measure of the quality of the remaining life-years. QALYs provide a common currency to assess the extent of the benefits gained from a variety of interventions in terms of health- related quality of life and survival for the patient. They are used to assess the effectiveness of interventions and are combined with the costs incurred in providing the interventions to generate cost–utility ratios (Phillips, 2009). When calculating the QALYs, premature death is combined with morbidity by attaching a weight to each health state such that value 0 represents death, while value 1 represents full health. The number of QALYs for a health profile is found by multiplying the health related quality of life weight (HRQoL) of the health state, with the duration of the health state (Robertstand, 2005).

QALYs and DALYs are currently widely used in most of the countries for the economic evaluation of health because they help set priorities in resource allocation (Marthe *et al.*, 2002).

HAT is a low-priority rural disease (Gubler, 1998). Among vector-borne diseases in Africa, HAT ranks second for mortality and fourth in terms of disability adjusted life years (DALYs), but the fact that this is a severely under-reported disease has largely prevented accurate assessment of its true burden (Matemba *et al.*, 2010).

There have been few attempts to quantify the full costs borne by households with HAT cases, which include the costs of care at home and during hospital treatment, the costs of seeking a diagnosis, income lost by the HAT cases and their care givers, medical fees, and the costs of transport (Lutumba *et al.,* 2007). The use of DALYs framework based on local life expectancy tables at this level might be appropriate for estimating the total burden of disease (Mara, 2007). The costs of HAT treatment that are borne by households may be so high that they inhibit the timely uptake of treatment (Boelaert *et al.,* 2010). When a household discovers that they have a case of HAT, they often take their time to prepare themselves financially and mobilize the necessary resources (often relying on the solidarity of the extended family), before the case is presented for treatment. High household costs or, rather, the fear of being identified as an HAT case and then having to bear such expense may partly explain the low levels of participation often seen at active-screening sessions organized by mobile teams (Boelaert *et al.*, 2010). According to Lutumba *et al. (*2007), estimated the mean household costs in DRC for a diagnosed and treated case of HAT to be equal to five months of household income, with such costs rising to over 10 months of household income for a case with complications.

2.8.2 Unreported DALYs

The term 'under-reporting' is used to refer to the proportion of the estimated total number of cases which are not detected by active or passive screening (Hackett *et al*., 2014). This lack of detection of HAT cases is difficult because of inadequate diagnostic equipment (Kyambadde *et al*., 2000). The number of HAT cases is known to be significant, yet remains poorly estimated (Hackett *et al.,* 2014). According to Fe'vre *et al*. (2008), proper quantification of HAT is of great importance as neglected tropical disease, because a primary reason for their neglect is that their true impact on society is not known. For *rhodesiense* HAT in Uganda, a model of under-reporting based on the early to late stage ratio of presenting cases estimated that approximately 40 percent of cases went unreported. In the DRC and Zambia, the level of under-reporting has not been directly estimated. However, the effectiveness of active case-finding and treatment is less than 50 percent (Hacket *et al.,* 2014).

2.8.3 Assessment of HAT burden

Quantifying the impact of a disease burden is a necessity in providing an evidence base for effective decision making in relation to planning for vector control and other interventions (Fev're *et al.,* 2008). Disease burden can be measured in terms of prevalence or incidence from the individual, families or groups to society at large (WHO, 2002). According to Fe'vre *et al.* (2008) when decision-making at the societal level e.g., government policy, national or regional budgetary allocation, a societal, or population based approach, is most appropriate. For this, a range of tools developed from the BoD are available including the DALY that is a useful estimates for informing policy decision and the assessment of risk factors that are most directly relevant to policy (WHO, 2003).

Economic assessment of the burden of disease arguments will continue to be important in guiding decision-making. Much information has been gathered over the past five decades, but today's decisions still rely on up-to-date field information appropriate to each country, socio-economic environment and tsetse trypanosomiasis interface (Shaw, 2009). It is important to determine disease burden at a range of temporal and spatial scales. However, in doing so there are some handles and challenges (Fe'vre *et al.*, 2008). Annual stochastic variations in the burden of HAT may result from annual variations in incidence rate of the disease which may be large and care should be taken not to over interpret the variations in order to have the actual information which will guide decision makers (Fe'vre *et al.*, 2008).

Life Years gained is a modified mortality measure where remaining life expectancy is taken into account. This method accrues more weight to young target populations, because saving the life of an infant yields more life years than saving the life of an old person (Robberstad, 2005). This is criticised by many economic scholars as discriminatory (Robberstad, 2005). Life years are calculated as the remaining life expectancy at the point of each averted death (Robberstad, 2005).

2.8.4 Years of Life Lived with Disability (YLDs)

The calculation of years of life lived with disabilities (YLDs) requires estimates of disease and injury incidence, average duration of associated disability, and disability weight which is the mortality component of the DALYs (Brecht, 2014). A disability weight indicates the average severity of any mental or physical disability associated with each disease or injury (Yongwen & Hesser, 2012. YLDs are computed for a given health outcome by multiplying the prevalence of

that outcome by a disability weight that has a value between 0 (equivalent to full health) and 1 equivalent to death, (Haagsma, et al., 2015). Disability quantification is thus stage specific, with late-stage illness implying substantively higher disability than early stage illness (Yongwen & Hesser, 2012). YLDs can be calculated if cases are confirmed, assuming that all fatal cases pass through a period of early- and late-stage disability before death. Disability weightings of 0.21 for early-stage illness and 0.81 for late-stage illness are used for rhodesiense HAT (Hacket *et al*., 2014).

2.8.5 Years of Life Lost (YLLs)

Years of Life Lost (YLLs) capture the loss of life associated with premature death due to a specific cause occurring due to an injury or disease at a particular age that affects an individual's way of living (Yongwen & Hesser, 2012). Age-specific mortality can be modelled using a quadratic function, with average mortality adjusted based on parasite type and disease stage (Hacket *et al.*, 2014). In a research in Tanzania (Hacket, *et al*, 2014), average mortality was estimated at 2.4 perecent for early stage and 8.1% for the late stage for rhodesiense HAT. This was consistent with estimated case fatality rates of 8.4 to 9.3 perecent for melarsoprol-treated late-stage rhodesiense HAT in Tanzania and Uganda. These estimates had an average mortality of 3percent, which was used to determine the YLL for late stage gambiense HAT (Hacket *et al.*, 2014). In 2002, Uganda changed its first-line treatment from melarsoprol to eflornithine which has about 1.2 perecent mortality if treatment is administered; this also changes the mortality (Hacket *et al.*, 2014). Furthermore, the newer nifurtimox-eflornithine combination therapy was tested in various sites in Uganda during the study period, and showed signs of improvement of lower-mortality treatment regimen for late stage *gambiense* HAT (Hacket *et al.*, 2014). The stage and parasite adjusted mortality distributions can be used to assign the age-specific probability of death in iteration of the DALY model. YLLs were calculated only for those cases that were randomly assigned as deaths, based on the age-specific mortality probability (Hacket *et al.*, 2014).

2.9 Economic and Social Impact of HAT

Information on age at death indicates that HAT mainly affects economically active adults (Cattand *et al.*, 2012). This is reinforced by the fact that the disease mainly afflicts agricultural-based economies. Workers on cocoa and coffee plantations are at risk of contracting the disease, consequently reducing the labour force, since patients who must stay in bed/in hospital for a long

time are unable to work (PATTEC, 2011). Data from a research in Uganda showed that nearly 25 percent of cases occurred in those aged between 20 and 29 years and more than 60 perecent in those aged between 10 to 39 years (Catt and *et al.,* 2012). Thus, when people become ill, their families, do not only become burdened with the care of seriously ill individuals, but also often lose their breadwinners (PATTEC, 2011). Poor diagnostic support in many areas means that families often invest in a number of treatments that have no effect on the disease since diagnosis of HAT requires confirming the presence of the parasites in the blood, lymph node fluid or cerebrospinal fluid (PATTEC, 2011). In a *T.b. rhodesiense* area of Uganda, it was found that some patients made up to seven visits to health facilities before being correctly diagnosed with the disease, with just less than three quarters initially being diagnosed with malaria, for the 11 of 12 who were never diagnosed or were told that they had a different fatal disease, the costs to and burdens on their families could only be imagined (Cattand *et al.,* 2012).

Because of the severity of the disease, treated patients often remain incapacitated, perpetuating the cycle of poverty, malnutrition, and disease (Cattand *et al.,* 2012).One case can affect all family members, placing a burden on the whole community, reducing the labour force, interrupting agricultural activities, and jeopardizing food security (PATTEC, 2011).

The social and economic impact of HAT is often underestimated (PATTEC, 2011). During epidemics, large proportions of communities are affected, with loss of life and untold suffering. These have serious social and economic consequences, which far outweigh the cost of maintaining surveillance (PATTEC, 2011). The report by FAO, (1998), showed new light on the impacts of HAT on human migration and settlement, as well as farming systems in Africa. It explains and emphasizes that expansion of animal trypanosomiasis into a new area can lead to massive out-migration and abandonment of settlements. In a survey in the Zambezi Valley of Zimbabwe, a third of households reported that tsetse infestation had an important influence on where they decided to settle (FAO, 1998). The disease has been a major cause of depopulation of large tracts of Africa (Grischow, 2004). The fear it causes has led to abandonment of fertile lands, and is an impediment to development. The importance of HAT lies not only in the number of new cases reported, but also in its potential for epidemic outbreaks causing thousands of deaths (Catt and *et al.,* 2001). In some villages in the DRC, up to 70 percent of the population became infected (Cattand *et al.,* 2001). HAT causes biological damage and leads inexorably to death and even if treated with merasoprol, it can still leave major irreversible damage (Cattand *et*

al., 2001). The toxicity is due to arsenical derivative which is associated with severe toxic effects in particular, reactive encephalopathy, which is fatal in 10 -70 percent of cases and affects 5 -10 percent of treated patients (Priotto *et al.,* 2007). Patients develop functional incapacities that increase their dependence on outside help. Time and money spent in search of a cure may be a serious drain on a family's resources (Cattand *et al.,* 2001). At community and family levels, mental confusion, personality and behaviour changes, which often characterize central nervous system involvement in late-stage HAT, are observed and sometimes lead to divorce and break-up in homes (PATTEC, 2011). In adults, loss of memory and ability to concentrate is common. Such disabilities are often accompanied by reading and writing difficulties and occasionally by extreme incoherence. These disabilities greatly affect everyday life, particularly for those school-aged children, who, even after successful treatment, do not recover fully and cannot pursue their studies (Cattand *et al.,* 2001). This may also present an unfavourable climate for bringing up children, not to mention the associated stigmatization of HAT patients (PATTEC, 2011).

2.9.1 Estimating the direct costs of hospitalisation at the health facility

According to Matemba *et al*., (2010) the costs of treatment per HAT patient can be estimated using four important components: (i) the product of the total number of days spent at the hospital stay due to HAT multiplied by an estimated daily cost for hospital services, (ii) the estimated cost of diagnosing HAT patients, (iii) the value for the drugs used to treat HAT and (iv) the amount of money that patients paid towards these costs.

Transportation of the patient to the hospital is one key component that should be taken into consideration during economic impact assessment of a particular disease(Matemba, *et al.,* 2010). This should include time taken for review and living costs during hospital stay. Costs to cover living expenses for one accompanying the patient or care giver can be regarded as an expense which is non-medical or indirect costs and should also be estimated (Matemba *et al.,* 2010).

2.9.2 Control Programs at Regional and International Level

The fact that HAT has such low profiles at national and international level, has prevented health systems in affected countries from allocating the appropriate resources for the control of the disease. The Millennium Development Goals, with their emphasis on poverty reduction, provide a unique 'window of opportunity' to raise awareness about HAT and other NTD, at international level (Boelaert *et al.,* 2010).

In January 2012, a number of partners from the public and private spheres came together in London, United Kingdom, to launch the largest coordinated effort against NTDs (WHO, 2012). The ensuing London Declaration on NTDs represented a new, coordinated approach for accelerating progress towards eradication, elimination or control of some NTDs by 2020 due to the impact they have at household, community, and national level (WHO b, 2013). According to Report of a WHO meeting on elimination of African trypanosomiasis (WHO, 2012), organised in Geneva, partners at the meeting pledged to work together to improve the lives of the 1.4 billion people worldwide affected by NTDs. Most of these people are among the world's poorest affected by HAT and to enhance the supply of existing medicines, stimulate collaborative research for new treatments and increase the funding needed for control or elimination activities. During the meeting, HAT was targeted for elimination alongside five other diseases, and the WHO Roadmap was endorsed by the participants, officially launching the elimination and control processes (WHO b, 2013).

A renewed interest in the tsetse and trypanosomiasis problem is reflected in several programs at national, regional and international level. Novel initiatives comprise the Program against African Trypanosomiasis (PAAT) and the Pan African Tsetse and Trypanosomiasis Eradication Campaign (PATTEC, 2011). The PAAT provides a forum that aims to facilitate the harmonizing and coordination of the activities of its four mandated international organizations the Food and Agriculture Organization of the United Nations (FAO), the World Health Organization (WHO), the International Atomic Energy Agency (IAEA) and the Inter-African Bureau for Animal Resources of the African Union (AU-IBAR), in relation to tsetse, human and animal trypanosomiasis and associated sustainable agriculture and rural development (Cecchi *et al.*, 2008). PATTEC is action focused and AU-led, and stems from the decision by the African Heads of State and Government to collectively embark on a campaign to render Africa tsetse-free through the creation and subsequent expansion of tsetse-free zones (Cecchi *et al.*, 2008).

According to WHO (2013), the Roadmap on NTDs targets the elimination of HAT as a public-health problem by 2020. The meeting was convinced and agreed to observe this goal. To define a threshold for elimination of HAT as a public-health problem the goal aimed at the detection of less than one new case per 10 000 inhabitants in at least 90 perecent of endemic foci (WHO c, 2013). The goal also was to be reporting less than 2000 new cases annually at continental level by 2020 (WHO c, 2013). Achieving elimination as a public-health problem by 2020 represents

an intermediate objective and a slow return of the disease over time (resurgence) in most endemic foci must be avoided through the development of new control and surveillance strategies (Simo *et al.,* 2014). Sustainable efforts should be maintained to achieve the interruption of transmission to avoid past experiences where the disease re-emerged after intense reduction of transmission without ensuring permanent surveillance to detect recrudescence (Simo *et al.,* 2014).

CHAPTER THREE

3.0 Materials and Methods

3.1 Study Site

The study was conducted in areas of Zambia where sporadic cases of HAT were still being reported (Mwanakasale *et al.,* 2014). These were Rufunsa district in Lusaka province, Mpika and Chama districts in Muchinga Province and Mambwe District in Eastern Province of Zambia (Figure 3.1).

The Eastern Province of Zambia has a tropical climate with three distinct seasons in a year, known as hot-dry season, rain season and cold-dry season (Imprint, 2015). The province has the altitude of 1,045 Metres with annual rainfall averaging 1000 mm. The average temperatures ranges from 12.3^{o} C to 32.6 ^{o} C (Aregheore, 2008).The main source of livelidhood is agriculture with Maize as the common cash crop grown (Living Conditions Monitoring Brach, 2011)

Muchinga province has a climate similar to that of Eastern Province (Imprint, 2015).The province has an altitude of 1,393 with average annual rainfall of 1110mmwith average temperature ranging from 10.1^{o}C to 30^{o}C (Aregheore, 2008). The main source of livelihood for people in this province is agriculture with maize and cassava as the most common crop grown (Living Conditions Monitoring Brach, 2011). The research was also carried out in Mpika district with a population of 203,379 and newly created political district of Chama with the population of 103, 89 (CSO, 2012).

Cases of HAT in Lusaka Province are mainly reported from Rufunsa District (Mwanakasale and Songolo, 2014). Lusaka province has eight districts (Chilanga, Chilundu Chongwe, Kafue, Luangwa, Lusaka Rufunsa and Shibuyuji). Lusaka's provinces climate has three seasons in a year, these being hot-dry season, rainy season and cold-dry season (Imprint, 2015). The province has an altitude of 1,272 metres with annual rainfall of 800 - 1000 mm. Average temperature range from 10.1^{o} C in the cold season to 31.6^{o}C in the hot-dry season (Aregheore, 2008). The main source of livelihood is agriculture with maize as the common cash crop grown in the study districts (Living Conditions Monitoring Brach, 2011). The research was carried out in Rufunsa. The population statistical data for this district is still merged with Chongwe. It is a newly created political district, (Central Statistical Office, 2010).

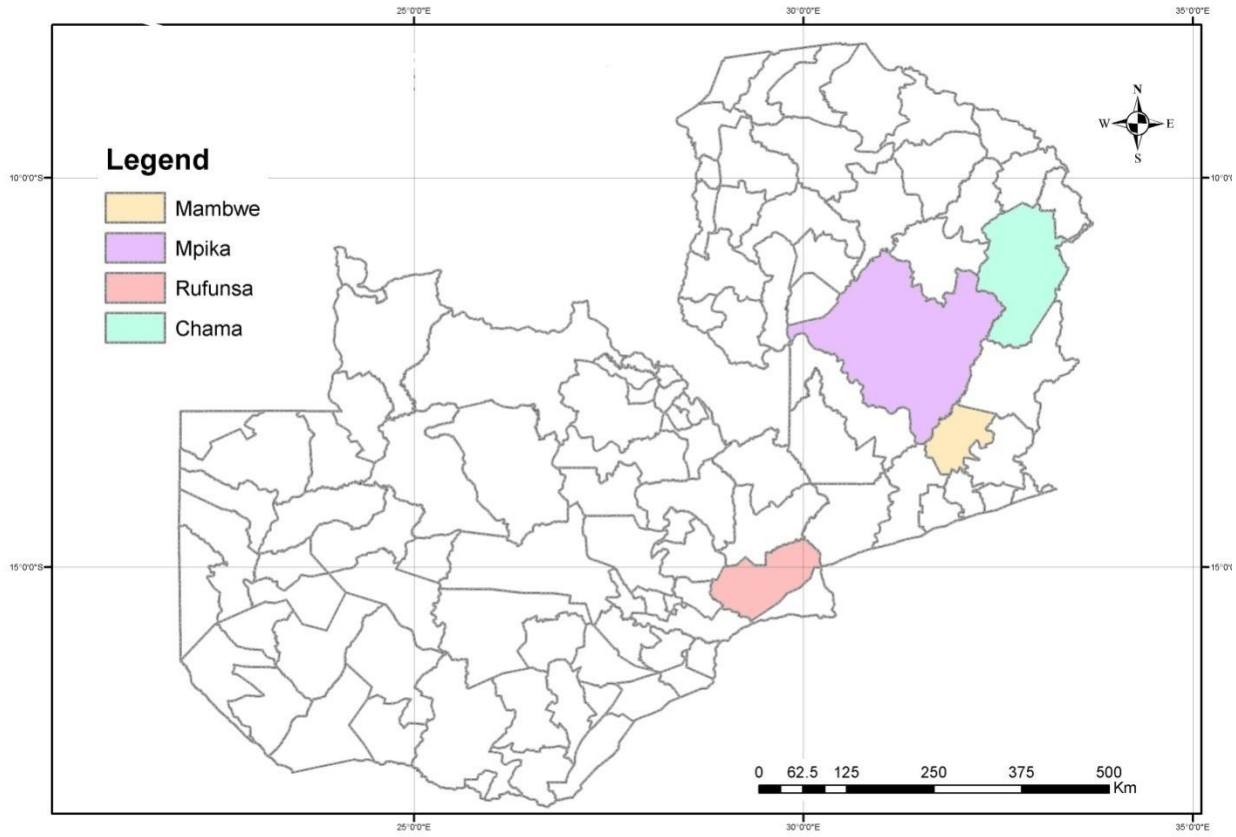


Figure 3.1: Map of Zambia showing the study area

3.2 Study Design

A cross sectional survey was conducted in the study areas to determine the economic and social consequences of HAT. The study involved recruiting previous and current cases of HAT. Active cases of HAT were confirmed using PCR and or LAMP. Old cases of the disease were determined from hospital registers and/ or the community those who had confirmed hospital records. In total 64 cases were included in the study. All cases (n=64) were traced, no refusals all were interviewed with at most two visits without a loss of any case. Of all the cases 26 were from active surveillance while the other 38 were from passive

The currency used is the Zambian Kwacha with an exchange rate of 6.3 of the United States Dollar (US $). The mode afflation rate for the period 2014 was k6.3 against the United States Dollars.

3.3 Target Population

Target Population consisted of all residents of Eastern, Lusaka and Muchinga Province as they are all at risk of contracting HAT with much focus in the rural areas.

3.4 Study Population

The study population included all patients who had been diagnosed with the disease from 2004 to 2014 (for the past 10 years) in Lusaka, Eastern and Muchinga Provinces of Zambia. According to Fe'vre *et al.*, (2008) Zambia is among the countries that have been reporting cases of infection with *Trypanosoma brucei rhodesiense* and the numbers of cases that are reported each year are below 100. The expected prevalence of the disease in the Eastern and Muchinga provinces of Zambia ranges from 1 to 6% annually (Namangala, 2014). The sample size was calculated using the following formula:

$$n = \frac{Z^2 p(1-p)}{d^2}$$

Where

$$\mathrm{d} = \text{absolute precision} = 0.05$$

$$\mathrm{p} = \text{average expected proportion of disease in the population} = 0.035$$

$$\mathrm{Z}(1-\alpha/2) = 1.96 = \text{value of the standard distribution corresponding to } \alpha$$

The probability of erroneously rejecting the null hypothesis when it was correct (α) was set at 5% (Z = 1.96).

$$n = \frac{(1.96)^2(0.03)(1-0.03)}{(0.05)^2}$$

$$n = \frac{3.8416 \times 0.03 \times .94}{0.0025} = 43.3$$

Therefore, the sample size of at list 43 people was determined, as respondents for all the study sites, the actual sampled was 64.

3.5 Inclusion criteria

3.5.1 Patients

All patients diagnosed with HAT between 2004 and 2014, and willing to participate in the study were included

3.6 Exclusion criteria

3.6.1 Patients

HAT Patients from outside the three provinces (Eastern and Muchinga and Lusaka Provinces) were excluded from the study.

3.7 Data collection methods

3.7.1 Questionnaires

Structured questionnaires, one for the former and current patients and another for health workers were administered. Furthermore, focus group discussions were conducted with the members from affected communities.

Structured questionnaires for patients were administered to patients themselves or their close relatives (care giver) to collect information on the economic and social impact of HAT in the communities or districts. Information on demographics, culture, and treatment seeking behaviour was also collected. In addition, hospital records of patients who were interviewed, where possible, were retrieved to confirm the time period the patient was undergoing treatment. This information was used in calculating the DALYs and the period of productivity lost.

A second questionnaire was administered to the medical officers (District Management Officers) for the purpose of assessing the adequacy of healthcare delivery system in the management of HAT at the district and provincial levels. Specific ally, the information collected included the number of health personnel available for the diagnosis of HAT, knowledge of the staff on HAT, the availability of drugs and equipment to manage and diagnose HAT.

3.8 Focus Group Discussions

The focus group discussion comprised of seven to ten people per discussion. The groups included people who have suffered from HAT and their relatives or friends to obtain in-depth information on concepts, perceptions and ideas of the group regarding social consequences of HAT. A total of eight focus group discussions were done during the study in all the districts, two in Chama, one in Mambwe, two in Mpika and three in Rufunsa.

3.9 Data Analysis

Focus group discussion data was analysed using inductive approaches with major themes being highlighted by two researchers. For quantitative data descriptive statistics were generated for all variables under study and, analysis of variance (ANOVA) was used to determine associations among the variables.

To determine the period a patient would lose his or her production time, it was estimated that a HAT patient starts being unproductive when the signs and symptoms of the disease occur until the patient is discharged from the hospital. The period of lost income from the time the patient developed the signs and symptoms to the time the patient was discharged from the hospital is shown in figure 3.3.

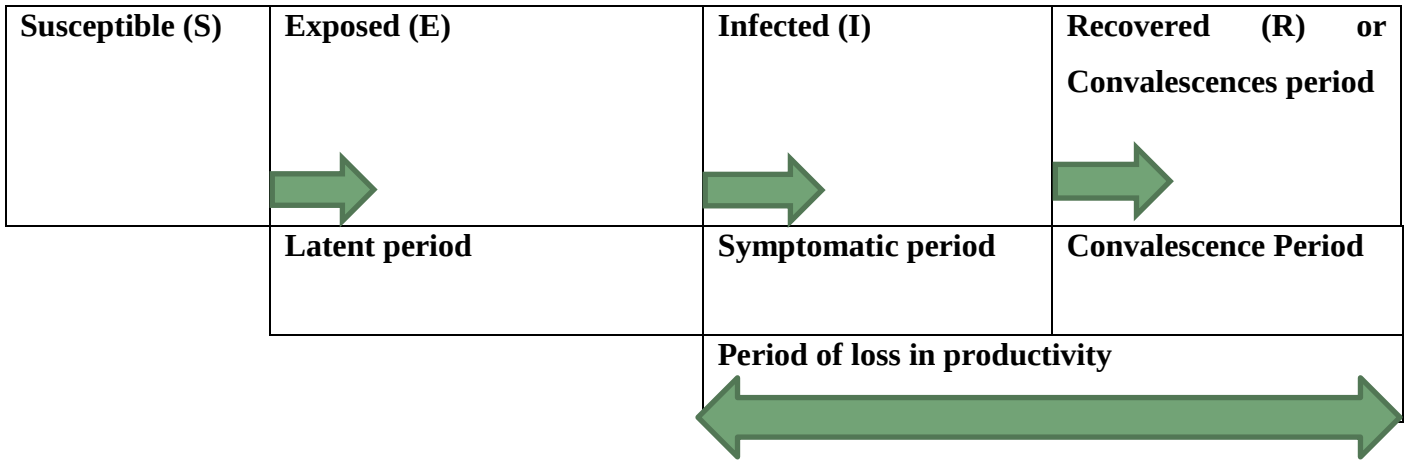


Figure 3.2: Period lost in Productivity due to HAT

The average individual's income lost for the whole period was estimated by the formula below.

$F = (Tt_1 + Tt_2)\, M.$

Where;

FWas an individual's forgone income in Zambian Kwacha (ZMW) due to the unhealthy days?

Tt_1Was the total number of productive time lost (in months) from the onset of the disease till a patient gets treated and discharged from the hospital.

Tt_2Was the period (in months) after a patient has been discharged and he or she is yet to return to full economic production. Therefore, Tt_1 and Tt_2 represent the time lost due to ill health.

M Is the average monthly income of an individual when they were most productive (Individual's active days) = the average stage of clinical disease + average Stage of recovery (Convalescence) × the average household income per month.

3.9.1 Calculation of the DALYs

To calculate the DALYs the methodology by Murray (1994) was used. The method identifies two key value choices, which are:

- How long "should" people in good health expect to live?
- How should we compare years of life lost through death, with years lived with poor health or disability of various levels of disease severity?

The first value of choice relates to the standard life expectancy which is used to calculate the YLL, and the second assist the development of disability weights (WHO, 2006).

The average degree of disability of persons in the first or second stages of HAT was calculated by using the weightings developed by Murray (1994).These are the only weights provided when calculating DALYs (Lutumba *et al.,* 2007). Mortality was evaluated based on the age-distribution of mortality attribute tables to each condition, using standard model life expectancies developed by CSO (2012), which also used the 2010 Census of Population and Housing for Zambia. Calculations of the burden of HAT were done with and without discounting. The rate for discounting was set at 3 percent, which is the standard measure of discounting however it was dropped by WHO team who considered it to be discriminatory against the old (WHO c, 2013). However, experts in Health Economics recommend the use of discounting because it provides the Benefit Cost Analysis (BCA) that aligns with empirical economic evidence (Debas *et al.,* 2015). Discounting means that future gains and losses are counted less than if they had

occurred today. The years lost in the future are discounted, so that years lost now are worth more than years lost in the future (Donev *et al.,* 2011). The non-discounted estimate was done for reasons that it is non-discriminatory on age and it was adopted as the more simplified calculation method for DALYs (WHO, 2014). The DALY scores for male and female were estimated and tabulated in the tables for each district then they were added to come up with the total DALYs for the districts and total sample population. DALYs were calculated as YLL (N+L) +YLD (I×DW×L)], Where:

YLL = years of life lost due to premature death = N × L

N = number of deaths

L = standard life expectancy at age of death in years

YLD = years lost due to disability

I = number of incident cases

DW= disability weight

L = average duration of the case until remission or death (years).

The onset of the disease was calculated for the 64 patients for each district age by age in months. To find the morbidity component of DALY, particularly the years of life lived with disability, weighting for *rhodesiense* HAT, was set at 0.35 for the first stage and second stage was at 0.8 (Fe'vre et al., 2008). This figure was based on the expert opinion or judgement of the severity of *rhodosiense* HAT and was independent from age both for admitted and non-admitted patients (Odiit *et al.,* 2000). The duration of the illness was the period from the onset of the disease or when the signs and symptoms were seen or felt by the patient before being admitted (combination of symptoms) up to the time the patient was discharged or returned to full production (Odiit *et al.,* 2000). Different average durations of hospitalisation (amount of time spent in hospital (Figure; 3) and sickness were determined for each age in a particular district. One DALY equates to one year of heath life lost.

3.10 Ethical Considerations

The research and ethical clearance was obtained and granted by the University of Zambia Research Ethics Committee reference number 011-09-13. Written consent, including willingness to participate in the study was obtained from each subject enrolled into the study. All participants were guaranteed with confidentiality.

CHAPTER FOUR

4.0 Results

4.1 Overview

A total of 64 patients and 11 health workers were enrolled in the study as respondents. Of these, 22 patients came from Chama, 11 from Rufunsa, 28 from Mpika and 3 from Mambwe district (Table 4.1).

Table 4.1: Health Centres Responsible for HAT Detection in Each District of Study

District	Number of cases	Health Facilities	Rural Health Facilities
Chama	22	Chama DHMH and Lumpi Hospital	Kanyerere
Rufunsa	11	St Luke Mission Hospital	Shikabeta, Lukwipa,
Mpika	28	Chilonga Mission Hospital	Nabwalya
Mambwe	3	Kamoto Mission Hospital	Masumba and Nsefu
Total Number	64	5	6

4.2 Socioeconomic characteristics of respondents

4.2.1Gender and Age of the Patients Interviewed

Of the 64 patients that were included in the study, there were significantly ($p<0.001$) more males (70%, 95% CI = 58.77 – 81.23) than females(30% 95% CI = 18.77 – 41.23). The age distribution of the patients ranged from 1 to 75, with a mean of 31 years (Fig.4.4).

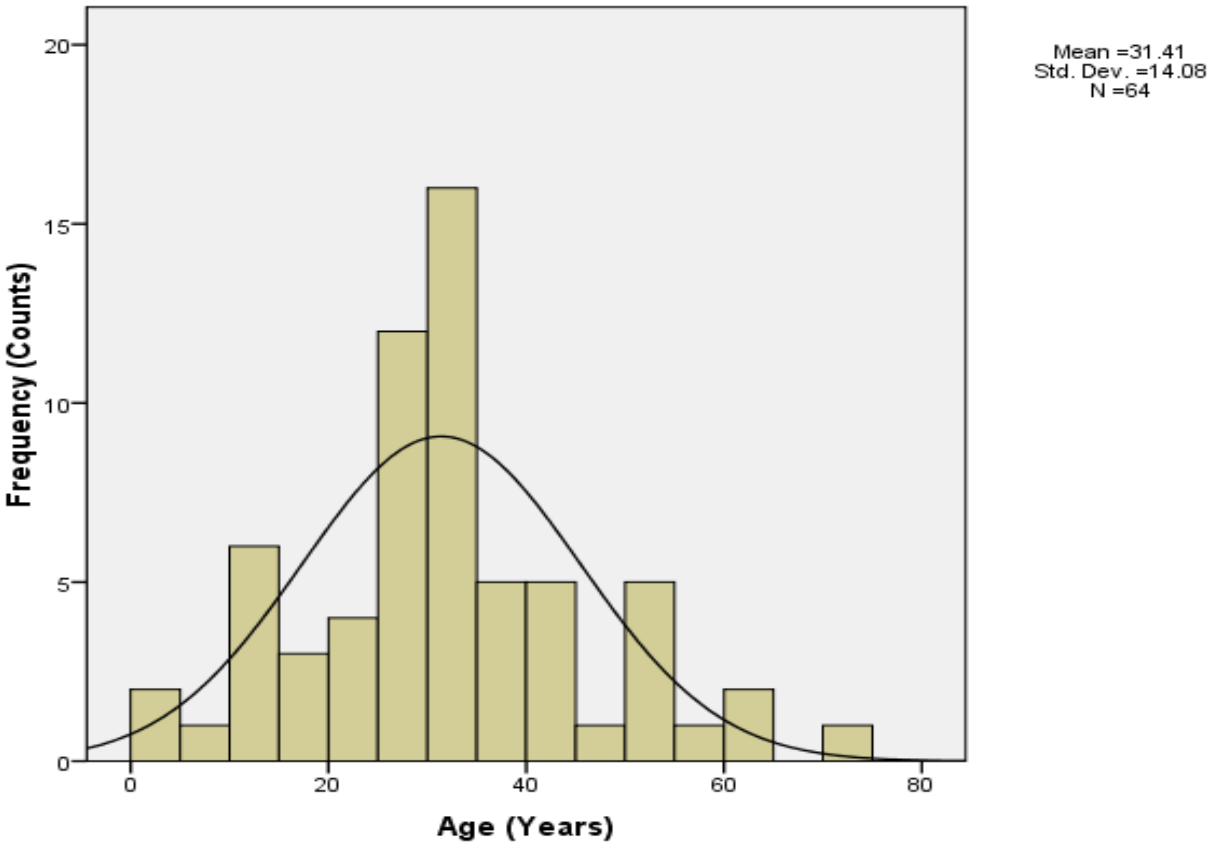


Figure 4.1: Age Distribution of HAT Patients

Most of the HAT patients were married (72%, 95% CI= 61 - 83), 23% (95% CI = 73.8 – 92.2) were single, only 3 percent (95% CI -1.18 – 7.18) were windowed and none were divorced (Table 4.2).

Table 4.2: Marital Status of Respondents

Marital Status	**Frequency**	**Percentage**	**95%, CI, For the proportions**	
Single	15	23	12.7	33.3
Married	46	72	61	83
Windowed	2	3	0	7.2
Divorced	0	0		

About 37% (95% CI = 25 – 48.9, n=64) of the HAT patients were from household sizes ranging from One - Five persons per household, while, 46% (95% CI 33.8 – 58.2, n=64)were from those with Six-ten persons per household, 10% (95% CI, 2.7 – 17.4, n=6) were from those with 11-15 persons, 2% (95% CI,0-5.4, n=64) from those with 16-20 persons per household and another 2% (95%, CI, 0-5.4) n=64) from those with 21-25 persons per household (Table 4.3).

Table 4.3:Family Size of Respondents

Household size	**Frequency**	**Percentage**	**95% CI for the Percentage**	
1-5	23	37	0	48.9
6-10	29	46	0	58.2
11-15	6	10	0	17.4
16-20	1	2	0	5.4
21-25	1	2	0	5.4

4.3 Occupation of the cases

Most of the HAT patients (55%, 95% CI 37.75 – 62.25) reported in this study were peasant farmers (Fig.4.5). The main crops the peasant farmers mostly grew in these areas were maize, groundnuts and tobacco. Famers in Chama District who were close to the Malawi border took advantage of the neighbouring country's market value of tobacco as their main market product. While those who grew cash crops like maize there market was the government through the Food Reserve Agency (FRA). Most households (99%, 95% CI 96.56 – 101.44) owned no cattle. Only one household from Chama District had cattle close to the border with Malawi. Figure 4.5 further reveals that 14% (95% CI 5.5 – 22.5) of the cases were teachers and game Rangers. These were in formal employment and 16% (95% 7.02 – 24.98) of the cases were not employed (dependents).

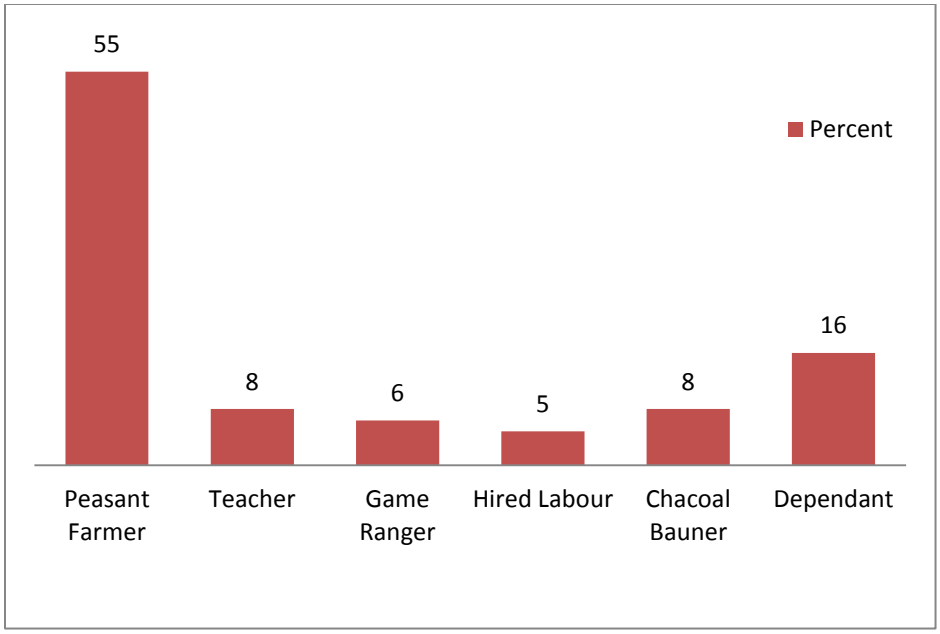


Figure 4.2: Distribution of Occupation among HAT victims

4.4 Spatial Distribution of the HAT cases in each District

The spatial distribution of all the HAT cases in the four districts of the study area is given below in Figures 4.11- 4.14. It was observed that all areas that had reported HAT cases were located near or in game reserve management places.

In Chama District, the distribution of the HAT cases was at two major points, one close to the Malawian border and the other cantered around the township (Fig.4.3). The cases of HAT patients centred on the township area were mostly business men and women including teachers had crossed the game park areas at some point during their duties.

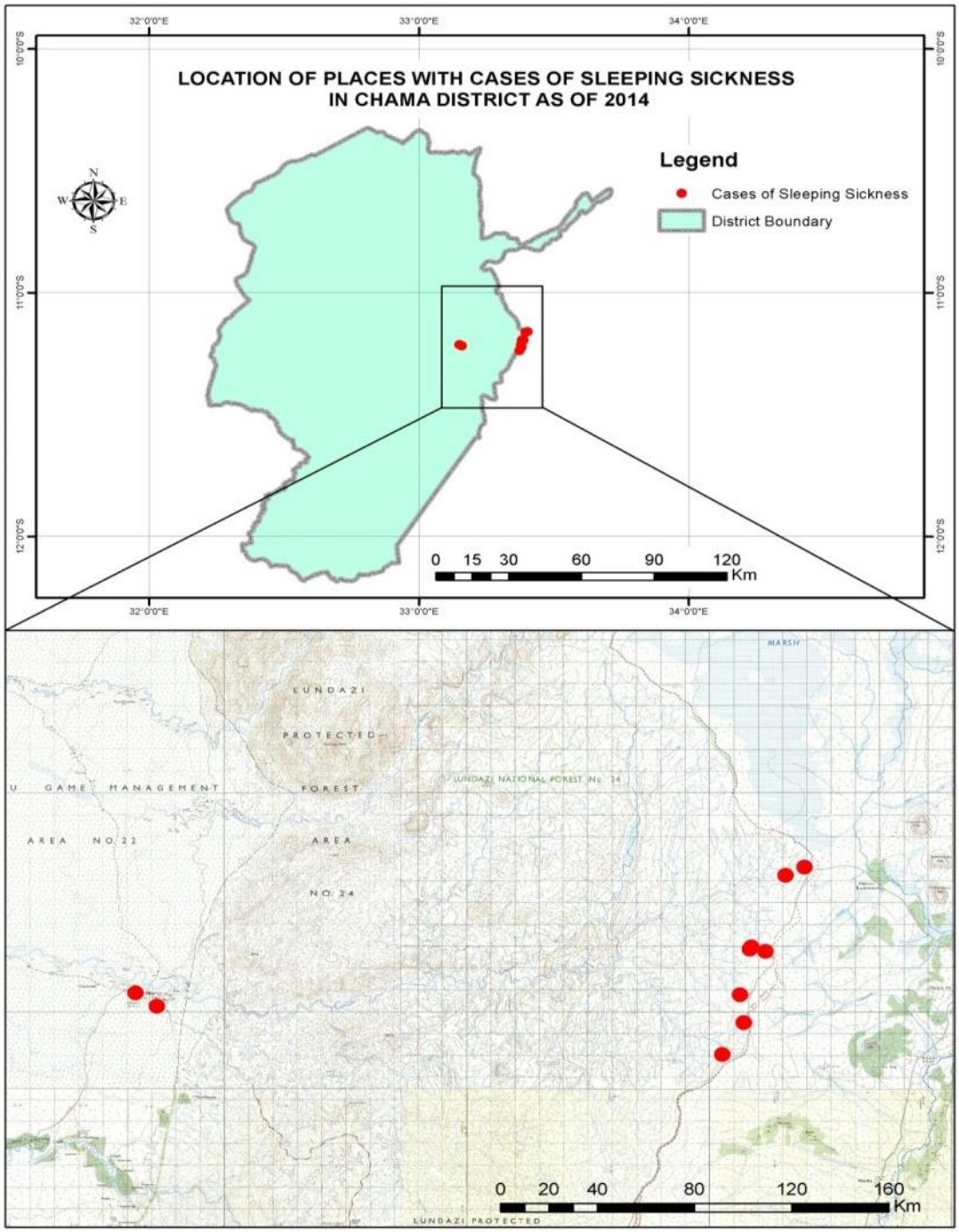


Figure 4.3: Spatial Distribution of HAT cases in Chama District, Muchinga Province of Zambia

In Mambwe district, three cases of HAT were recruited. The three cases came from one area and all patients were fishermen from the nearby river (Fig.4.4).

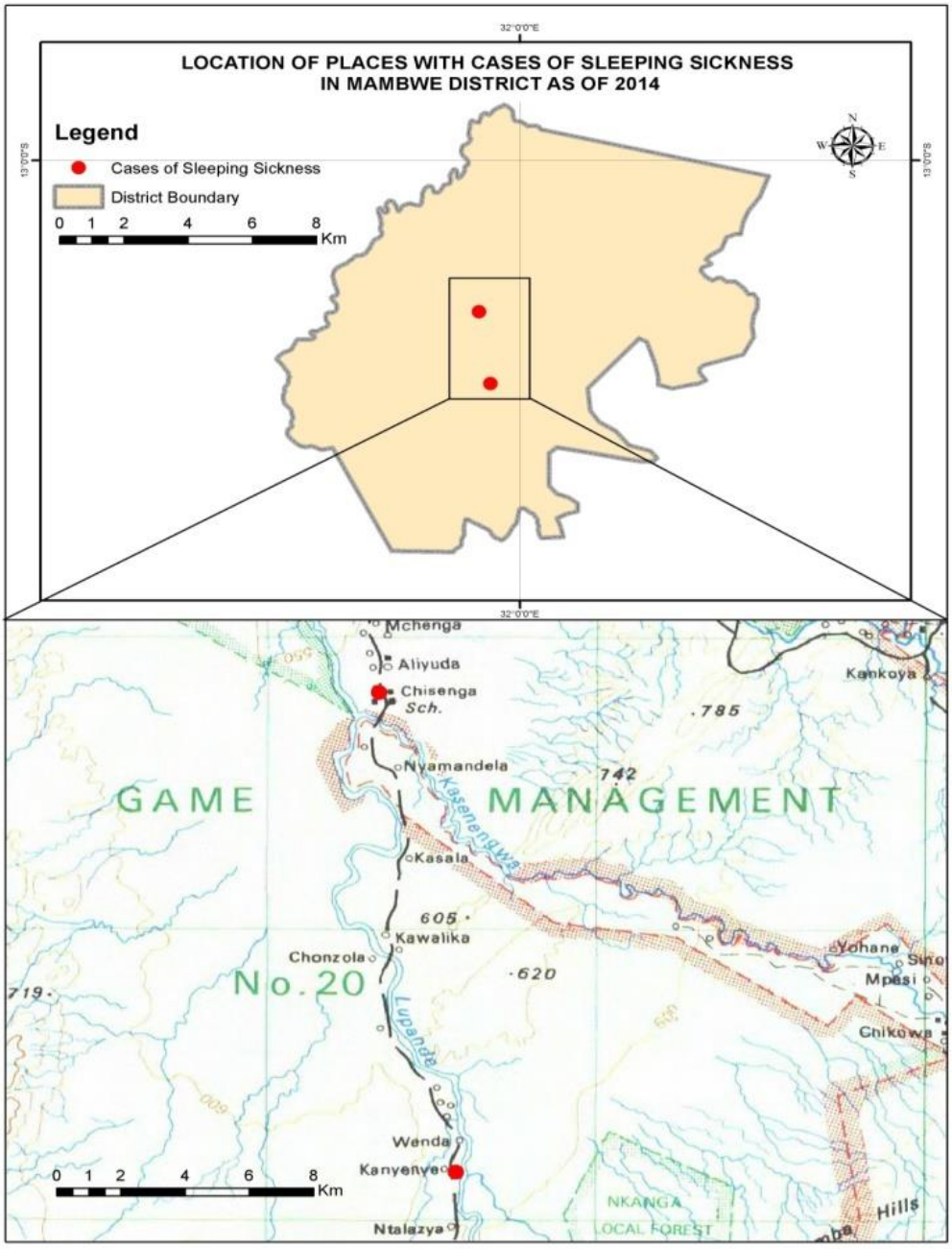


Figure 4.4: Spatial Distribution of HAT cases in Mambwe District Eastern Province of Zambia

Mpika District had two main areas within the Chiefdom of Nabwalya where HAT cases came from. These were (i) Kazembe and Uzimbwa villages and (ii) Dombo Zambia Wild Life Authority Camp (ZAWA), (Fig.4.5).

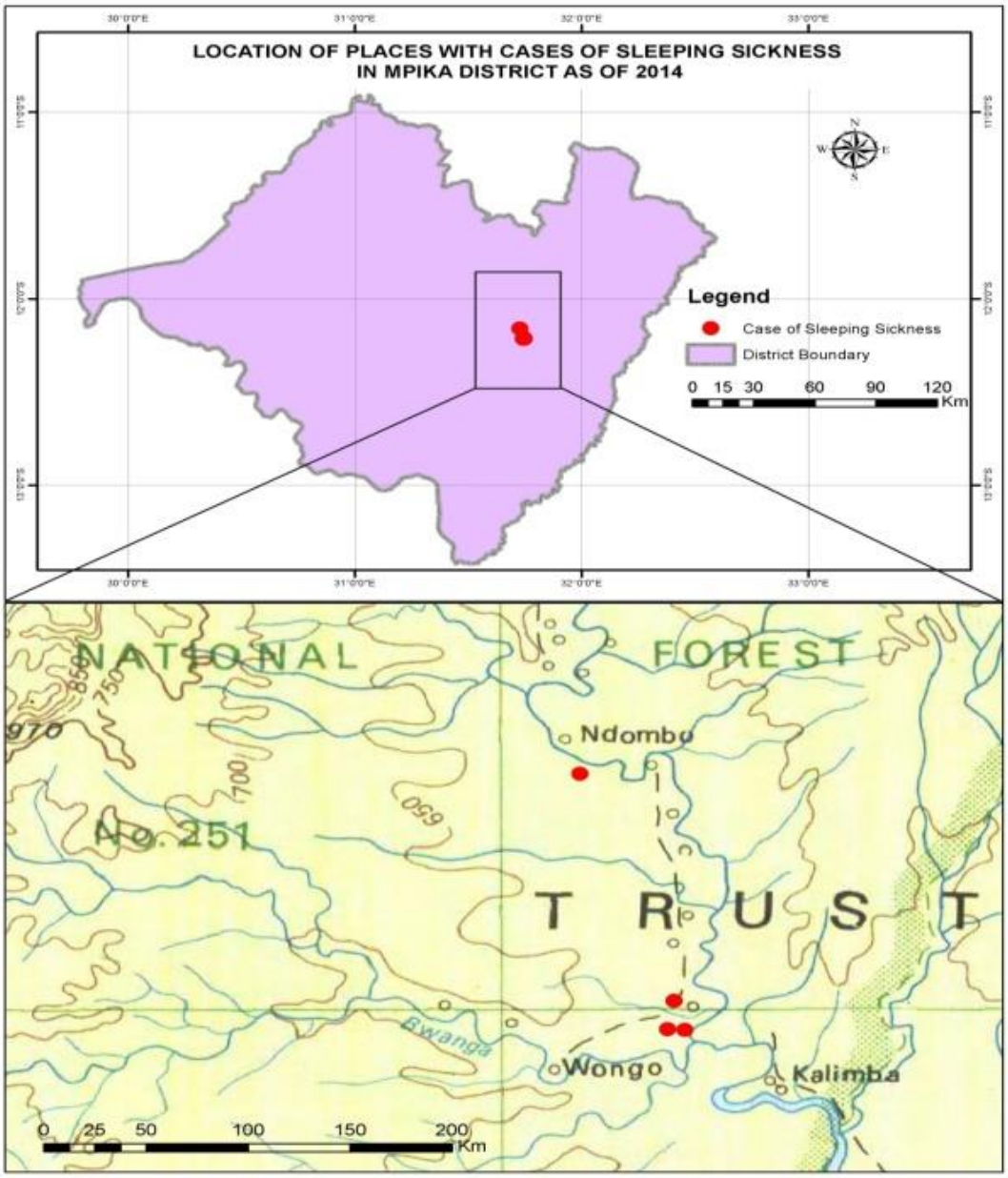


Figure 4.5: Spatial Distribution of HAT cases in Mpika District Muchinga Province of Zambia

In Rufunsa District, the distribution of HAT cases was mainly from three areas in (i) Shikabeta, (ii) Chomba and (iii) Lukwipa villages. All these villages were situated in the game reserve areas (Fig. 6).

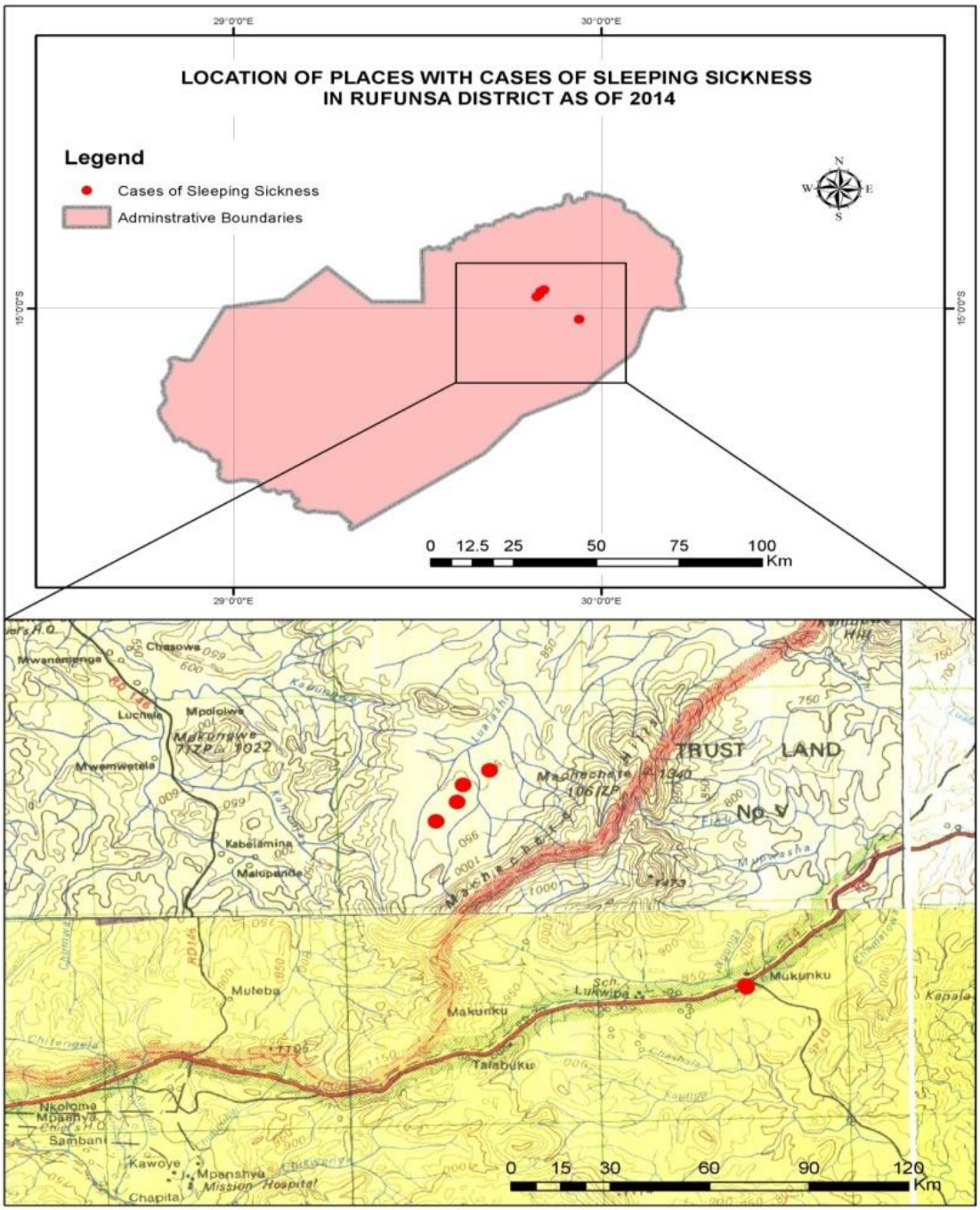


Figure 4.6: Spatial Distribution of HAT cases in Rufunsa District Lusaka Province of Zambia

4.5 Health Seeking Behaviour

The research revealed that health seeking behaviour was quite poor among HAT patients in the study areas (Table 4.4). Only 53% (95% CI, 2.65 -17.35,) of the patients went to the health facilities to seek medical care when they developed the disease signs and symptoms. Furthermore, about 28% (95% CI, 17% - 39%) did nothing when they felt that they had developed the signs and the symptoms of the disease. According to those patients, they did not consider the intermittent headache they initially experienced as a serious health problem.

Table 4.4: Health seeking behaviour of HAT patients

First action done by patient	**Percentage**	**95% CI for percentage**
Went to the Clinic	53	40.8 - 65.2
Self-Medication	9	2 - 16
Went to Traditional Healer	10	2.7 - 17.45
Did Nothing	28	17 - 39

In Mambwe District, one patient had sought health care for about two years from Kamoto Mission Hospital and was referred to Chipata General Hospital where the disease was also misdiagnosed until 2014. The disease was only detected in stage two of HAT, with signs of impaired judgement, sleeping disorders and intermittent headache. In a personal interview that patient said "*I think I have not gotten any help needed in all the hospitals I have attended. In my opinion they don't know what I am sick of. For this reason, I have decided not to continue seeking medication, but to stay with my disabilities of sleeping disorders, than going back to the hospital where they will just watch at me and tell me to go back home*."

There were cases that had not been diagnosed because patients felt that going to the health centre would be wasting time as they hoped to recover on self-medication and home-based care as observed during data collection.

Furthermore, about 10% (95%,CI, 2.65-17.35, n= 64) of the patients went to the traditional healers first (Table 4.4) before seeking modern medical attention. This was because in some

areas there were suspicions of witchcraft. In a focus group discussion, it was established that going to the traditional healers for medication was one of the most important aspect in one's life, which was difficult to neglect because of growing in the environment with cultural backgrounds which promoted traditional healers. There were suspicions of being be-witched by relatives, neighbours or friends. Seeking medication through the traditional healers had high indirect costs (Table 4.4), at the house hold level. Family members sacrificed animals or agricultural products to pay for the services of the. On average, an individual would spend ZMW 400 to pay the traditional healer. It was also mentioned in a focus group discussion that traditional healers exploited their clients economically. Consultations, diagnosing, prescribing and searching for traditional herb were the highest cost. In times when money was not available, livestock, including chickens, goats, pigs and cows were paid in kind to cater towards the cost of medication of the patients. None of the patients who sought intervention from the traditional healers, could recall the total costs of seeking traditional medicines.

The study also found that at least 9% (95%, CI, 1.99-16.01) of the patients were on self-medicating (Table 4.4) before seeking treatment at the health centres. The costs borne by self-medication amongst the patients were on average ZMW 618 per patient. The effect of self-medication caused delays in diagnosis and subsequent treatment. This also resulted in the disease being diagnosed in the late stage.

4.6 Income Earned by HAT patients at District Level

The income earned among HAT patient (households), when they were in normal health was determined (Table 4.5). The mean income earned was highest in Chama District (K 983.00, 95% CI, K307.38 - K1, 658.62). Patients from Rufunsa district were the second highest with a mean income of K456.00 (95% CI, K33.85 - K878.15). Those from Mambwe district earned a mean income of K490.75 (95% CI, K92.66 - K542.66). The patients from Mpika earned the lowest mean income, of K117.79 (95% CI, K80.83 - 154.7). There was significant difference in the mean of income of HAT patients between the districts ($p < 0.05$) Patients from Chama significantly earned more money than among those from Mpika ($P = 0.017$).

Table 4.5: Mean Household Monthly Income in each District

Name of District	n	Mean Household Income (ZMW)	95% Confidence Interval for Mean		Minimum ZMW	Maximum (ZMW)
			Lower Bound	Upper Bound		
Chama	23	983.00	307.38	1,658.62	65	7,000
Rufunsa	10	456.00	33.85	878.15	60	2,000
Mpika	28	117.79	80.83	154.4	30	500
Mambwe	2	225.00	-92.66	542.66	200	250
Total	63	490.75	229.52	751.97	30	7,000

n = number of patients

4.7 Income Lost at District and individual levels

Table 4.6 shows the income lost due to loss in productivity at district level in Chama, Mpika, Rufunsa and Mambwe districts. The results reveal that households with HAT patients in Chama had the highest loss in income of K19, 880.00 as average. Households with HAT patients in Rufunsa lost about K 17, 338.00. Mpika, with 28 patients, recorded K18, 84.46 losses in income. Mambwe, earned little money and lost about K6, 525.00 from HAT patients.

Table 4.6: Total Average Income Lost

Name of the Districts	Total No of Patients per district	Average number of Months patients stayed with the disease	Mean monthly income (ZMW)	Total amount lost due to disease (ZMW)
Chama	22	20	983.00	19,660.00
Rufunsa	11	38	456.00	17,328.00
Mpika	28	16	117.79	1,884.64
Mambwe	3	29	225.00	6,525.00
Total	**64**	**24**	**490.75**	**11,778.00**

4.8 Indirect Cost Borne by Patients

The indirect costs are the costs which are not associated with treatment, however they were part of the costs which patients spend, when seeking medication such as transport, meals, washing paste, and other materials vital to the care giver and the patient. An observation was made that indirect cost varied from one district to another, due to different setups with different economic

hubs of the areas. In districts such as Mpika, patients did not spend much because they had to walk from their rural health centre to Chilonga Mission Hospital. The average cost of transport was calculated for all the four districts combined. The amount of money that was spent on transport to and from a health centre was on average (K618.18, 95% CI = 9.55 – 28.85) (Table 4.7).

Table; 4.7: Average Costs Incurred during hospitalisation

S/N	**Money Spent on**	**Average Amount (ZMW)**	**Percentage of Respondents**	**95% CI**	
1	Transport	618.80	19.2	9.55	28.85
2	Medication	453.57	6.4	0.4	12.4
3	Meals	419.04	16.64	7.52	25.76
4	Other Materials	138.42	**12.8**	4.61	20.99
5	**Total**	**1,629.83**			

4.8.1 Money spent on meals during hospitalisations

The amount varied according to the number of days the HAT patient would stay in the hospital. However, the amount of money that was spent on meals on average was about K419, per month (Table 4.7). According to this study, the money was spent on meals for the relatives or care givers looking after the patient as well as food supplements for the patients during medication. This was in addition to the food that was provided by the hospital which in most cases was not sufficient. On average, a total of K138.42 was spent for other expenditures such as sanitary materials (Washing paste, washing soap, toilet paper, bathing dishes, etc.) (Table 4.7).

4.8.2 Treatment Costs

In an interview it was observed that HAT patients, who went on self-medication, sought treatment from the traditional healers or were misdiagnosed by health centres or institutions incurred huge amounts on treatment cost. On average K453.00 was spent as treatment cost (Table 4.7) before being diagnosed correctly. Patients living in the rural areas used agriculture products such as livestock and cereals to sell and carter for medication.

4.9 Period Lost in Productivity (Period of lost income)

Average economic income per month was = ZMW 390.75 using the approach described in figure 3.3. This is the average amount an individual would lose in a month if not in full production or it's an average an individual would gain on a monthly basis if in full production.

The Lowest average economic income one would incur in a month was = ZMW 30

The Highest average economic income = ZMW 3500

Average months lost due to being diseased = 4.9 Months

The lowest number of months an individual would lose if diagnosed with HAT was one month and the highest was 36 months with average of 4.9 months for most cases of second stage of *T.b rhodosiense.*

Therefore, average Economic loss a person would incur from the time the symptoms and signs were observed up to the time of recovery and able to return to full production = 4.9 months ×ZMW 390.75 = ZMW 1,914.675.00.

4.10 Debt Incurred

This study revealed that 13 perecent of households (95% CI, 4.76 – 21.24, n=64) had gotten into debt in order to come up with financial resources the family needed for treatment of the patients (Fig.4.7). Only nine perecent of the HAT patients managed to pay back the credits while three perecent had not paid back the credits at the time of this study.

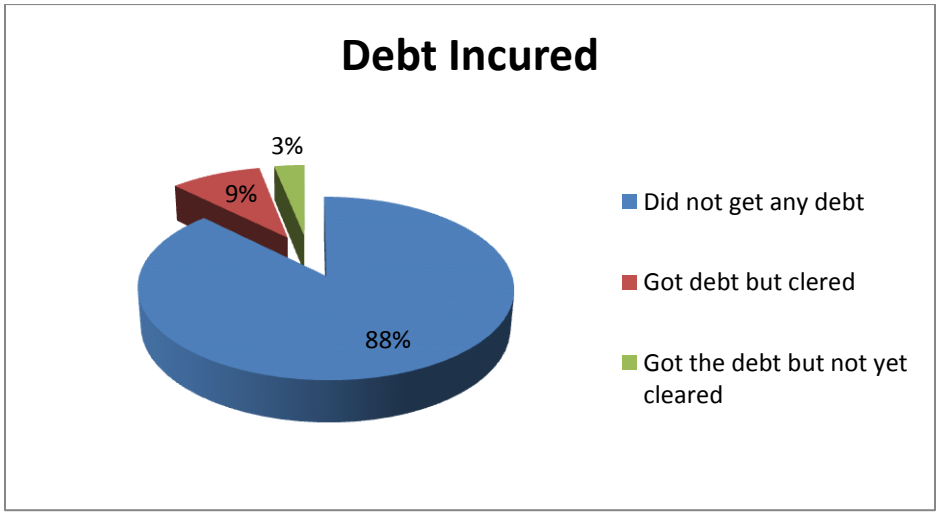


Figure 4.7: Percentage of debt incurred due to HAT

4.11 Disability adjusted Life Years

Disability Adjusted Life Years were calculated based on the reported cases from the health centres only. DALYs were calculated at individual and at population levels (discount 3%).

4.11.1Estimates of DALYs without discounting

According to the data obtained from this study, Mpika District had the highest DALYs of 469 lost (Table 4.8), followed by 204.9 DALYs lost for Chama District (Table4.9), while Rufunsa recorded 58.26 DALYs (Table 4.10) and Mambwe with the lowest of 51 DALYs (Table 4.11). Table 4.12 summarizes the Total DALYs for the whole sample size with age frequencies without discounting was calculated from all the four districts of study.

Table 4.8: Total DALYs for Mpika District

S/N	Gender	Age	Duration	Alive/Died	Life Expectancy	YLL	Years Lived with Disability	TOTAL DALYs
1	Female	3	0.6	0	60.4	57.4	0.48	57.88
2	Male	4	0.4	0	54.8	50.8	0.4	51.2
3	Female	5	0.4	0	60.4	55.4	0.32	55.72
4	Female	11	0.3	0	52.5	41.5	0.24	41.74
5	Male	12	0.3	0	46.9	34.9	0.24	35.14
6	Female	13	0.2	0	52.5	39.5	0.16	39.66
7	Female	17	0.2	0	48.5	31.5	0.16	31.66
8	Female	18	0.2	0	48.5	30.5	0.16	30.66
9	Male	20	0.2	1	42.5	22.5	0.16	22.66
10	Female	23	0.3	0	44.7	21.7	0.24	21.94
11	Female	26	0.2	0	41.2	15.2	0.16	15.36
1	Male	28	0.22	0	36	8	0.176	8.176
12	Female	28	0.2	0	41.2	13.2	0.16	13.36
13	Male	29	0.2	1	41.2	12.2	0.16	12.36
14	Male	30	0.8	0	36	6	0.64	6.64
15	Female	30	0.3	0	41.2	11.2	0.24	11.44
16	Male	31	0.2	0	33	2	0.16	2.16
17	Female	31	0.1	0	34.7	3.7	0.08	3.78

18	Female	32	0.3	0	34.7	2.7	0.24	2.94
19	Female	32	0.1	0	34.7	2.7	0.08	2.7
20	Male	32	0.3	0	33	1	0.24	1.24
21	Male	33	0.2	0	33	0	0.16	0.16
22	Male	36	0.2	0	29.9	0	0.16	0.16
23	Male	38	0.3	0	29.9	0	0.24	0.24
24	Male	38	0.2	0	29.9	0	0.16	0.16
25	Male	40	0.4	0	29.9	0	0.32	0.32
26	Male	42	0.3	0	27	0	0.24	0.24
27	Female	50	0.2	0	27.5	0	0.16	0.16
							Total DALYs	469.856

Table 4.9: DALYs for Chama District

S/N	**Sex**	**Age**	**Duration**	**Deaths**	**Life/Expectance**	**Years of Life Lost**	**Years Lived with Disability**	**DALYs**
1	M	12	2	0	46.9	34.9	1.6	36.5
2	M	14	1.9	0	46.9	32.9	1.52	34.42
3	M	14	0.4	0	46.9	60.9	0.32	61.22
4	M	16	1	0	42.8	26.8	0.8	27.6
5	M	25	0.3	0	39	14	0.24	14.24
6	F	28	2	0	36	8	1.6	9.6
7	M	30	0.3	0	36	6	0.24	6.24
8	F	31	0.4	0	33	2	0.32	2.32
9	M	31	0.3	0	33	2	0.24	2.24
10	M	32	3.2	0	33	1	2.56	3.56
11	M	33	0.5	0	33	0	0.4	0.4
1	M	33	0.3	0	33	0	0.24	0.24

12	M	36	1.2	1	33	0	0.96	0.96
13	M	42	0.4	0	29	0	0.32	0.32
14	M	50	3	1	24	0	2.4	2.4
15	M	50	1	0	24	0	0.8	0.8
16	M	51	0.5	1	24	0	0.4	0.4
17	M	56	0.4	1	21	0	0.32	0.32
18	F	62	1	0	17.9	0	0.8	0.8
19	F	62	0.3	0	17.9	0	0.24	0.24
20	M	72	0.1	1	11.4	0	0.08	0.08
							Total Daly's	204.9

Table 4.10: Disability Adjusted Life Years for Rufunsa District

S/N	**Gender**	**Age**	**No of Death**	**Duration**	**Life Expectance**	**Years of Life Lost**	**Years Lived with Disability**	**DALYs**
1	M	22	0	0.4	38	16	0.32	16.32
2	M	28	0	0.7	35.4	7.4	0.56	7.96
3	M	28	0	0.7	35.4	7.4	0.56	7.96
4	M	29	0	10	35.4	6.4	8	14.4
5	M	29	0	0.4	35.4	6.4	0.32	6.72
6	F	33	0	1	32.8	-0.2	0.8	0.8
7	F	31	0	0.6	32.8	1.8	0.48	2.28
8	M	39	0	0.7	30	0	0.56	0.56
9	M	41	1	0.3	27.4	0	0.24	0.24
10	M	43	1	1	27.4	0	0.8	0.8
11	M	50	0	0.3	24.5	0	0.24	0.24
							TOTAL	58.28

Table 4.11: Total DALYs for Mambwe District

Gender	Age	Duration	No/Death	Life Expectancy	Years of Life Lost	Years Lived with Disability	Total
Male	22	5	0	37.8	15.8	4	19.8
Male	26	2	0	34.4	8.4	1.6	10
Male	28	16	0	34.4	6.4	12.8	19.2
	49	3	0	22.8	0	2.4	2.4
					TOTAL	**DALYs**	**51.4**

The total DALYs recorded for all the four districts of the study area was 787.436.

Table 4.12: Total DALYs for the whole Sample Size with Age Frequencies without discounting

F/q	YLL/Males	YLL/Females	YLDs/Male	YLDs/Female	DALYs/Male	DALYs/Female	Total DALYs
≤ 10	0	0	23.44	47.361	23.44	47.361	70.801
11_20	0	28.31	89.266	135.887	89.266	164.197	253.463
21-30	78.026	0	228.876	127.635	306.902	306.902	613.804
31-40	46.969	0	263.026	116.651	309.995	116.651	426.646
41-50	20.178	0	161.421	16.142	181.599	16.142	197.741
51-60	0	0	38.416	0	38.416	0	38.416
61-70	0	0	17.838	0	17.838	0	17.838
80≥	11.154	0	5.341	0	16.495	0	16.495
Totals			**827.624**	**443.676**	**983.951**	**651.253**	**1635.204**

4.11.2Calculation of the DALYs with discounting

After discounting by 3 percent and uniform age weights considered for the entire sample taken, a total of 215.978 DALYs were found to have been lost among the HAT patients (n=64) (Table 4.13-4.14).

Table 4.12: DALYs with Discount of 3 perecent for Males

Freq	Males	No of Death	Average/ Duration	Life Expectancy	Years of Life Lost	Years Lived with Disability	Total DALYs
< 10	1	0	0.4	50.53	0	0.318	0.318
11_20	6	1	0.9	42	23.878	4.262	28.14
21-30	13	1	3.3	34.7	21.563	32.676	54.239
31-40	13	1	1.1	29.1	19.41	11.253	30.663
41-50	8	3	1.8	23.9	51.179	11.214	62.393
51-60	2	2	0.45	18.2	28.049	0.715	28.764
> 61	1	1	0.2	13.8	11.3	0.161	11.461
						Total DALYs	215.978

Table 4.13: DALYs with Discount of three percent for Females

Freq	Females	No of Death	Average/ Duration	Life Expectancy	Years of Life Lost	Years Lived with Disability	Total DALYs
< 10	2	0	0.5	54.4	0	1.43	1.43
11_20	4	1	0.45	45.6	27.1208	1.43	28.5508
21-30	5	0	0.6	38.4	0	2.379	2.379
31-40	6	0	1.3	38.3	0	6.121	6.121
41-50	1	0	0.2	26.6	0	0.16	0.16

51-60	0	0	0	0	0	0	0
> 61	2	0	0.6	18.1	0	0.67	0.67
						Total DALYs	**39.3108**

Table 4.14: The Disability Adjusted life years (DALYs) for the sampled population with 3 perecent Discount.

Age Frequency	**Total DALYs For Females**	**Total DALYs For Males**	**Total DALYs**
< 10	1.43	0.318	1.748
11_20	28.5508	28.14	56.6908
21-30	2.379	54.239	56.618
31-40	6.121	30.663	36.784
41-50	0.16	62.393	62.553
51-60	0	28.764	28.764
> 61	0.67	11.461	12.131
			255.2888

The DALYs which were lost with treatment for the whole sample size after 3% discount were 215.978 for males (Table 4.13) and 39.3108 (Table 4.14) for females.

To determine the amount of income lost due to DALYs for the sample using the discount rate of 0.03 and total DALYs lost were of 255.288 DALYs (Table 4.15) × average annual income of K 4,689 it was estimated that a total amount of K1, 197049 is lost (n = 64) in their life time in the four districts of Zambia which had sporadic outbreaks of HAT. The age between 20 and 50 had the highest DALYs (Figure 11) for males.

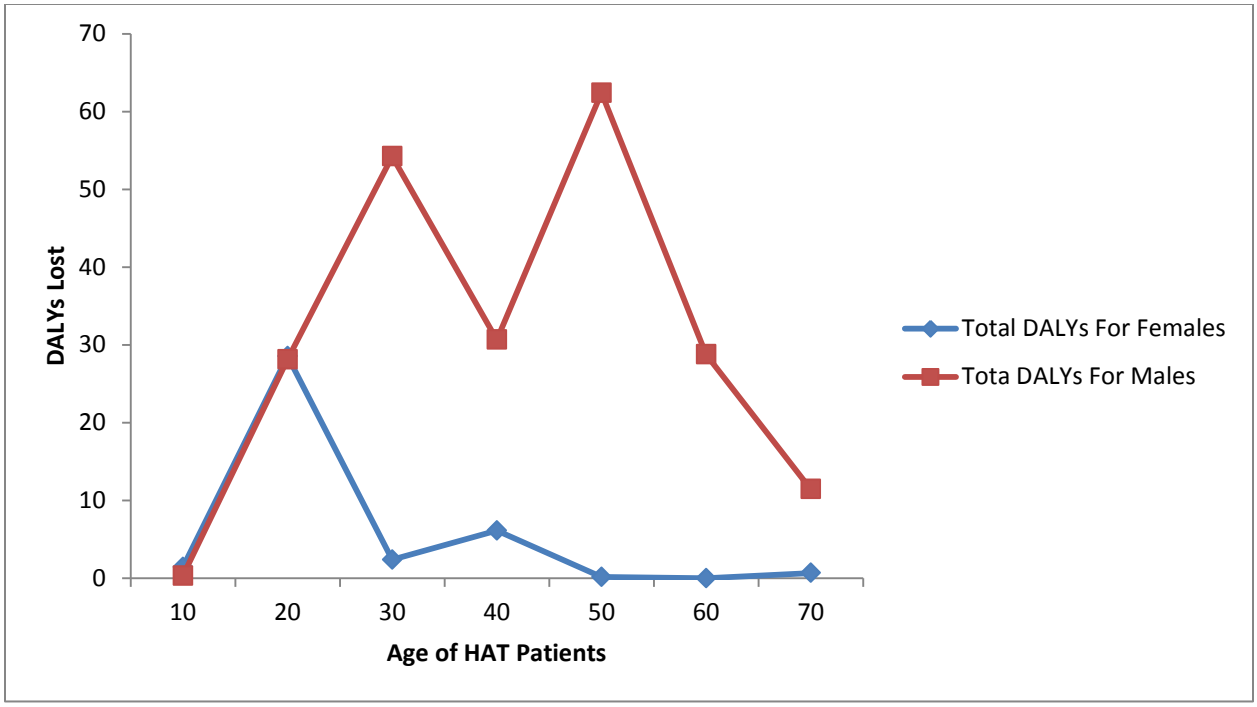


Figure 4.8: DALYs in males and females

4.12 Social Consequences of Human African Trypanosomiasis

Patients who had HAT were reported to experience high stigmatization in the areas of residence. The reported common stigmatization practices happened to patients who were initially wrongly diagnosed with other diseases or when the cause was not known. This resulted in them being suspected to have HIV/AIDs. In particular, the second stage symptoms of HAT presented suspicions that the patient was HIV positive, especially when the signs involved mental disorder and paralysis. The mental disorder was highly linked to meningitis, encephalitis and depression in these communities, which are common symptoms for HIV. In most cases people feared to be tested for HAT lest they are pronounced HIV/AIDs positive.

Most of the areas where cases were found were located in the remote places and belief in witchcraft was common. During focus group discussion, it was reported that those who were hallucinating and were involved in charcoal burning, were suspected to have been bewitched because it was thought that they had stolen the wood used in making charcoal.

People who were on HAT treatment were stigmatised and perceived to have a short temper, especially when they got drunk with alcohol.

In most cases young children that had recovered from HAT dropped out of school because of challenges of concentration in class (Fig.4.12).They were considered as dull and failures by their parents and friends. Out of the total of nine pupils, six had completely dropped out of school due to failure to concentrate. Those who were being trained as Zambia Wildlife officers were considered as lazy when they failed to recover after being given medication for other ailments.

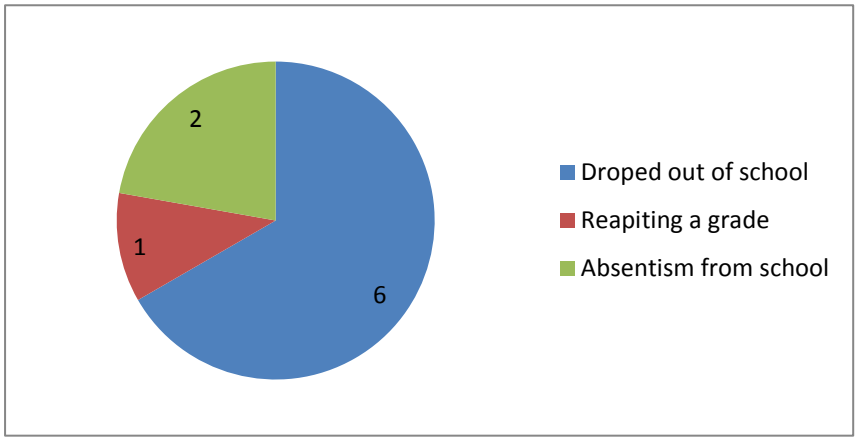


Figure 4.9:School drop outs, absenteeism and repeating a grade

4.12.1Physical Consequences of Human African Trypanosomiasis

About 40% (95% CI, 28 – 52, n= 64) of the patients complained of pain after treatment with melasoprol. The common side effects that were reported to be experienced following treatment with merasoprol were muscle pain, nerve pain similar to the feeling of heat, back pain and swelling of the body parts especially the hands and feet. These effects prevented the victims from having a full health outcome which could allow them to be with friends and family members at any time.

The majority of the patients who recovered from second stage HAT reported that they remained amnestic and were thus being stigmatized. The condition was reported to be worse among the school going children and one head teacher had this to say *"I don't know what makes some of the pupils not to be able to concentrate after being absent from school for so long, they end up being worse, than before., I am not aware that HAT can have such devastating consequences to the patient"*.

Physical deformities were found in some HAT patients (Fig.13). These disabilities tended to become permanent. The patients believed that the deformity was suspected to be associated with treatment of Merasoprol. Deformity effect had a strong social outcome on the ladies because they lost self-esteem.

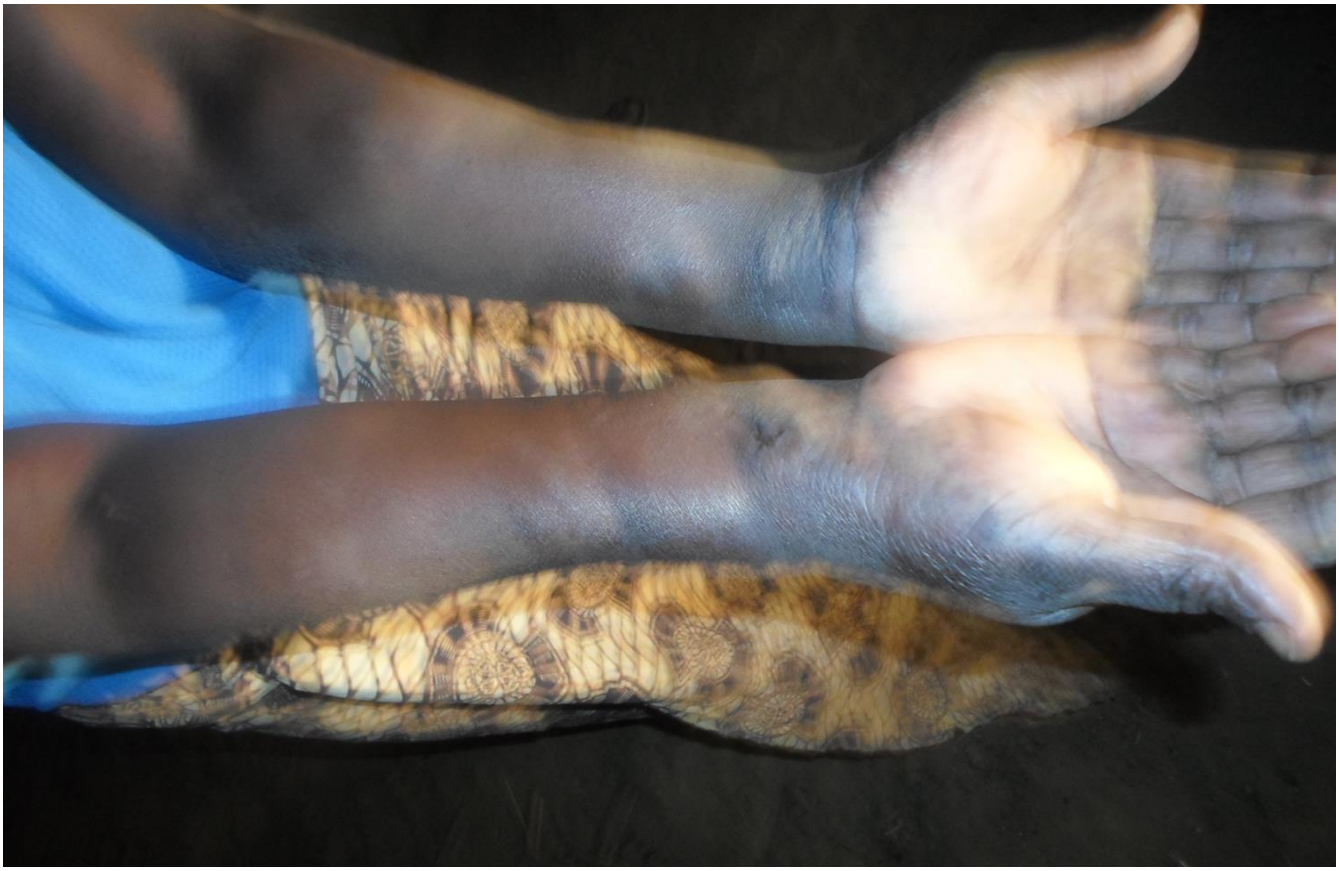


Figure 4.10: Deformed hands of a recovered HAT patient

4.13 Health Care Delivery Systems

The Health Care Delivery System was assessed in all the four districts of the area of study and was found to be inadequate to handle HAT cases. Record keeping was very poor in all the health facilities visited. It was also noted that poor documentation in the health institutions contributed to the poor estimation of the diagnosed HAT cases in the study area or the true prevalence.

All the five hospitals or district hospitals had a simple microscope (Table. 4.15- 4.18). Only one health centre (under the district, Mambwe) had a qualified laboratory technician. Compared with other districts, Rufunsa had the highest number of staff (7) who had previously diagnosed a HAT

case followed by Chama (4), Mpika (3) and Mambwe (2). Since 2012, there had been systematic documentations of the cases recorded in Rufunsa District. Before the district was created, it used to fall under the boundaries of Chongwe and at that time there were no records of any case or suspected cases of HAT.

Table 4.15: Adequacy of the Health Delivery System in management of HAT in Mambwe District

Health centre	Referral Centre	Equipment	Qualified staff	Staff Able to Diagnose HAT	Lab Staff in	Lab Staff Refresher Course	No of Hat Cases Encountered	Pharmacy	Drugs available
Kamoto M/H	UTH	Simple Microscope	5	4	2	Nil	1	1	No
Masumba	Kamoto M/H	0	3	0	0	Nil	Nil	0	0
Kakumbi HC	Kamoto M/H	1	4	3	2	Nil	1	1	0
Nsefu RHC	Kamoto M/H	0	2	0	0	Nil	Nil	0	0

M/H: Mission Hospital, HC: Health Centre: RHC: Rural Health Centre

Table 4.16: Adequacy of the Health Delivery System in management of HAT in Rufunsa District

Name of Health centre	**Referral Centre**	**Equipment**	**Stuffs Exam**	**Staff Able to Diagnose Hat**	**Staff in Lab**	**Lab Staff Refresher Course**	**No of HAT Cases Encountered**	**Pharmacy**	**Drugs available**
St Luke M/H	St Luke M/H	Simple Microscopy	9	7	3	Nil	10	1	No
Lukwipa RHC	St Luke M/H	0	1	1	0	Nil	1	0	0
Shikabeta Rural H/C	St Luke M/H	0	1	1	0	Nil	Nil	0	0

M/H: Mission Hospital, HC: Health Centre: RHC: Rural Health Centre

Chama staff was second to those from Rufunsa in their experience to diagnosed HAT cases. However, there is no information on whether they engage the staffs in active surveillance of HAT disease (Table 18).

Table 4.17: Adequacy of the Health Delivery System in management of HAT in Chama District

Name of Health centre	Referral Centre	Equipment	Staff Exam	Staff Able to Diagnose HAT	Staff in Lab	Lab Staff Refresher Course	No. of HAT Cases Encountered	Pharmacy	Drugs available
Chama DHMH	UTH	Simple Microscope	8	6	2	No	< 10	1	0
Kamfupu RHC	Chama DHMH	0	1	0	0	No	< 10	0	0

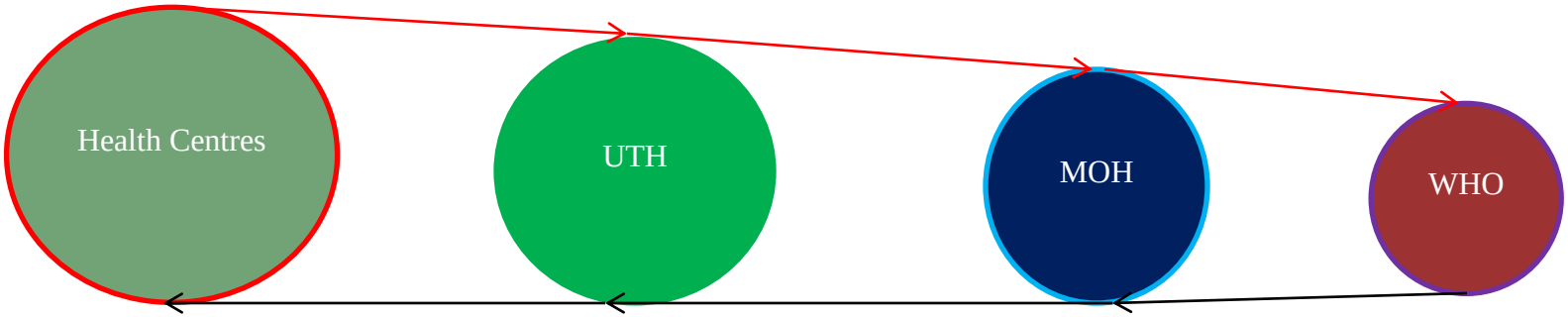
UTH: University Teaching Hospital: District Health Management Hospital: RHC: Rural Health Centre

In Mpika district, most of the HAT cases were diagnosed at Chilonga Mission hospital, with referrals mainly from Nabwalya Rural Health Centre which had no diagnostic equipment and qualified manpower (Table 18).

Table 4.18: Adequacy of the Health Delivery System in management of HAT in Mpika District

Name of Health centre	**Referral Centre**	**Equipment**	**Stuffs Exam**	**Staff Able to Diagnose Hat**	**Staff in Lab**	**Lab Staff Refresher Course**	**No of HAT Cases Encountered**	**Pharmacy**	**Drugs available**
Chilonga	Chilonga M/H	Simple Microscopy	9	4	2	Nil	< 10	1	0
Nabwalya RHC	Chilonga M/H	0	2	0	0	Nil	Nil	0	0
M/Mission	Hospital,	HC:	Health	Centre:	RHC:	Rural	Health	Centre	

All the health centres that were visited in all the districts or provinces had no drugs for HAT. The drugs are accessed through UTH, which got them from WHO (Figure; 4.14). It was also noted that the period from when rural health centre staff requested for drugs from UTH/WHO to the time they arrived at these centres took approximately 2-7 days depending on when transport was available.



Legend

Process of requesting the drug

Process of delivering the drug

Figure 4.11: Supply Chain of HAT Drugs in Zambia

CHAPTER FIVE

5.0 Discussion

To the best of my knowledge, this was the first study to be carried out in Zambia, to assess the economic and social consequences of HAT at household level. There have been sporadic cases of HAT being reported in the three provinces of Zambia (Namangala *et al*., 2012; Mwanakasale & Songolo, 2014). However the true burden of the disease has never been estimated in Zambia and the economic implication at household, community and national levels were not known (Machila, 2013).

Human African Trypanosomiasis has the economic burden at household level by reducing the labour force, thereby hampering production and reducing the income in susceptible populations (Georgina, 2003). The high economic burden HAT places at household level and communities cannot be easily seen by the district or national data because of its focal nature which has unpredicted prevalence (Georgina, 2003).

In this study it was found that the average loss at household level when a person (with an average monthly income of ZMW 390.75) is diagnosed with HAT was ZMW 1,914.68. This amount is five times more than a person would earn on a monthly basis. This cost is significant because of the amount a patient would spend seeking an intervention through self-medication, seeking treatment from traditional healers and seeking treatment in private health care institutions which do not have user fees but high health care cost. In other words the study found that costs were mostly centred on seeking treatment and hospitalization which is associated with huge indirect costs. In agreement with our findings, Lutumba *et al.* (2007), reported that the loss of income when a person is diagnosed with HAT was five times more than the average household monthly income. According to Franco *et al.* (2014), who also reported that the cost of patient care and the necessity of seeking medical services to look for a diagnosis and treatment removed that family from engaging in resource generation, thereby perpetuating the poverty cycle.

The average amount that was spent on transport for the patients to travel to and from the place where medical care was sought, was approximately ZMW 618.18. This amount is two times higher than the average amount a person would earn on a monthly basis (ZMW 390.75) in the areas of study. The reason for this two times increase in transport expenditure than the monthly

income is because a patient would spend money on transport frequenting the health care institutions on several occasions, seeking treatment in both private and government institutions before being correctly diagnosed with the disease. This is a negative drawback at household level because the financial constraints attributed to transport will result into the high financial constraint which paralyses household activities at a particular point in time. This amount varied from district to district because in some areas such as Nabwalya village of Mpika District, most of the patients travelled long distances on foot to the health facilities. This meant that well-wishers in the community carried the patient to Chilonga mission hospital on foot .This would take about three days.

Currently, the use of the DALYs is the only accepted measure for the burden of diseases that affect wide ranging communities or societies (Fèvre *et al*., 2008). It was important that the DALYs burden of *T.b. rhodesiense* which has been reported in various places of Zambia be made available in order to understand the burden it places at household level, community and the country at large.

The DALYs were high in the study areas because most of the HAT cases were in the second stage. This could be attributed to the delay in seeking treatment or cases being initially misdiagnosed preference for self-medication and seeking treatment from traditional healers. Low suspicion index among the health workers is also one of the causes of misdiagnosis resulting in the increase of the DALYs. These findings were similar to those reported by Odiit *et al.* (2000) from their first calculations of the DALYs for *T.b. rhodesiense* in Uganda in which they claimed that the delay in seeking treatment and correct diagnosis increases the burden of the disease. In order to reduce the severity of HAT, suspected patients need to present themselves to local health centres early during the course of the disease. However, that was generally not the case in the present study. Similarly, Lutumba *et al*. (2010) reported that nearly three out of four cases of HAT were presented to health facilities in the late stage of the disease, and almost all (98 percent) of these patients were presented passively. Late stage presentation has serious consequences: delays in seeking health care results in reduced chance of complete cure and increase the risk of drug-associated adverse effects or disabilities. In contrast, Lutemba *et al.* (2010) reported that the high DALYs found in Tanzania's Urambo district due to *T.b rhodesiense* was because of under-reporting of HAT cases in the health centres. The difference

in findings between this research and Lutemba *et al*. (2010) could be because this research did not include an estimation of underreported HAT cases.

The average duration that a patient would stay without visiting the health care centre was found to be two- three months. Patients would on average be on treatment for a month. This is in agreement with the report on Scientific Working Group (2001), who confirmed the data obtained by Odiit *et al* (2000) and concluded that such behaviour is the same throughout Africa for both forms of HAT. Accordingly, at the time of definitive HAT diagnosis, the patient will have been exhibiting symptoms of the disease for an average of 61 days and will then require hospitalization for an average of 34 days Odiit et al. (2000).

Furthermore, chances of treatment failure are higher at this stage which can result in death. Glubler (1998) reported that most of the index cases are given little attention, hence the majority of the cases become second stage of HAT. Early treatment is important in the context of good health and improved productivity, it reduces the disease burden. According to WHO (2015), diagnosis of HAT must be made as early as possible to avoid progressing to the neurological stage of the disease in order to elude complicated and risky treatment procedures. Furthermore, although patients' compliance with effective treatment is key to reducing the burden of the disease in the affected areas, compliance was poor among HAT patients in the present study.

This study suggests that the social consequences of HAT were misconception, stigma, school dropout, pain, amnesia and deformity. According to Kibbona *et al*. (2002) they also found that at community and family levels, stigmatisation, mental confusion, personality and behaviour changes, which often characterize central nervous system involvement in late-stage disease, may lead to school dropouts, mortalities, divorce and break up in homes and present unfavourable climate for bringing up children. Similarly, PATTEC (2011) reported that in some cases, people with such social problems become mentally disturbed, suicidal and violent, and constitute a danger to themselves and to the community. The documented stigma was as a result of low levels of awareness among community members, while mental confusion could be attributed to melarsoprol, which was associated with high toxicity and was even fatal at times (Yun *at el*., 2010). Suramin is used to treat first stage *T. b. rhodesiense*. Adverse reactions to suramin are frequent, but usually mild and reversible. In rare instances, suramin administration results in a hypersensitivity reaction (CDC, 2013). Mental confusion due to amnesia caused the victims not

to associate with friends, while pain made the victims to stay home in most cases with having time for social life. Deformity had much effect on women as they lost self-esteem.

More than 90 perecent of the cases recorded were from the areas that are close to the game management areas. These areas were both sources of tourism attraction and HAT infection at the same time. According to Simarro et al. (2012), 93 percent of the rhodesiense HAT cases diagnosed were foreigners traveling to endemic areas for a short period of time. Therefore, HAT has the potential to reduce attraction in the game areas if not controlled and indirectly affect the economy of the country at large. Epidemiological distribution of rhodesiense HAT is affected by the presence of wild animals which acts as reservoirs (Namangala et al., 2013; Lisulo et al., 2014; Haji et al., 2015). In agreement with Fe'vere et al. (2008), and Namangala et al. (2014) most of the HAT cases in this study were reported from remote rural areas, located in the game management areas or within their vicinity, where social amenities such as health care delivery systems are either non-existent or extremely poor.

This study further established that most of the affected people were those engaged in agriculture, particularly the peasant farmers. The other reasons could be because the households or fields were situated near or in game reserve areas, where these agriculture activities are done (Figure: 6,7,8 and 9). In a separate and independent study, PATTEC (2011) reported that HAT mainly afflicts agricultural-based economies and workers on cocoa, coffee or maize plantations were mostly affected. Workers involved in such activities are more likely to be bitten by tsetse flies and hence at risk of contracting HAT. These results in reduction of labour force, since the bed ridden patients who spend a lot of time in hospitals, are unable to till the land (PATTEC, 2011). Charcoal burners were also affected this could be attributed to the areas they go for the activities. Most of these areas are typical bush places where they look for thick trees which gave them quality charcoal for sell on the market. Further, there is a possibility that both the peasant farmers and the charcoal burners, some of them once in a while could engage themselves in the activities of poaching.

This study also found that HAT cases were more among males than in females. This could be linked to the kind of activities individuals are involved in. For instance, clearing of land for agriculture purposes (stumping/deforestation) and hunting (poaching), that predispose individuals to a risk of tsetse bite, are mainly restricted to men. This puts men to be more at risk

of contracting HAT than their female counterparts. Interestingly, the most affected age group with HAT was the productive age ranging from 20 to 50 years. In this age range, most adolescent men become heads of household and hence get actively involved in either agricultural activities and/or hunting in an attempt to provide food for the family. This is in concordance with Franco et al. (2014) who documented that HAT affects the adult productive age group of the households and communities, which is an economic hub. This finding is also in agreement with Odiit et al. (2000), who reported that HAT negatively affects the most economic productive individuals. (Figure 4.4) Indeed, the productive age function curve (Fig. 4.4) shows the direct impact HAT has to the labour force of the victims at household level. The Scientific Working Group (2001) further documented that the age distribution of HAT patients very closely follows that of the active adult population, so that the disease tends to hit the most economically productive group of society hardest, affecting family livelihoods and community prosperity.

Health seeking behaviour showed that people in affected districts do not access the health care services on time and that most of the cases are detected late. In the present study, this resulted in the majority (85 percent) of the HAT cases being second stage. For any country to eliminate HAT, there is need to have a strong health system which is easily accessible for early diagnosis of HAT to avoid severity of the disease (Mwanakasale et al., 2013). The behaviour and attitude reported in the present study, of ignoring the early symptoms of HAT, preferring self-medication or consulting a traditional healer, all result in delay in reporting HAT cases, hence increasing the chance of having second stage of HAT that may culminate in severe consequences of the disease. According to Odiit *et al*. (2004), the consequences of delayed diagnosis (poor health seeking behaviour) in HAT patients include poor prognosis at treatment and also raises the risk of tsetse flies picking up the infection when feeding on such an infected person, making disease control difficult.

In Mpika District, Chilonga Mission Hospital is the only hospital and referral centre that was admitting HAT patients for treatment (Mwanakasale *et al.,* 2013). The staff that administered the anti-trypanosomal drugs were medical doctors, medical licentiates, clinical officers and trained nurses.

In Chama District, patients, particularly from Munyakanyaka village, visited Lumpi Mission Hospital and a referral centre in Malawi. The crossing of the border by the Zambian patients was because Chama District Hospital (DHMT) did not stock the drugs. Human African Trypanosomiasis patients were referred to UTH at times (Mulenga *et al.*, 2015). However, the Malawian hospital is much closer and accessible to the local people. Information gathered in focus group discussion revealed that community members have more confidence in seeking treatment for HAT patients in Malawi (Lumpi Hospital) than Zambia.

Although Mambwe District has well equipped laboratory with one microscopist and four other laboratory specialists (Mulenga *et al.*, 2015), there was no deliberate active surveillance of HAT in the district. Consequently, the true prevalence of the disease in the area is not well known.

Rufunsa District has St. Luke Mission Hospital as their referral hospital. Although HAT cases are still being referred to UTH, St. Luke Hospital was able to handle HAT cases emerging from the district.

Antitrypanosomal drugs are only available at the district hospital on request from UTH who also have to make a request from the Ministry of Health. Disease endemic countries (DECs) such as Zambia are provided with drugs according to forecasts of usage. In non-DECs, pharmacy services in hospitals diagnosing and treating HAT have to address requests for drugs to WHO (Simarro *et al.*, 2012). The conditions of requesting for the drugs should also be accompanied by epidemiological and clinical data on the patient and contact details of the hospital and medical doctor in charge of the treatment. World Health Organisation ensures delivery of drugs between 24 and 48 hours (Simarro *et al.*, 2012). However, the challenge of transporting the drug to reach the remote rural areas on time, where HAT cases are usually reported from, may arise.

For all HAT cases diagnosed in Zambia, drugs for treatment are provided for free. However, the other costs associated with treatment create a substantial economic burden at household level. In accordance with the report of Kibbona *et al*. (2001) in Urambo District, northwest of Tanzania, these indirect expenses include transport, meals, soap, diagnostic tests, consultation and drugs from the available local pharmacies before being diagnosed with HAT. Hospitalisation is free of charge in all the hospitals in Zambia. In contrast, Matemba *et al.* (2010) reported that hospitalisation fee in Tanzania and Uganda ranged from $1 to $2, respectively. This difference

may occur due to different policies which are put in place regarding the health care system in each particular country.

In this study, it was established that the health care delivery system was ill equipped to handle HAT cases, a situation also highlighted by Mulenga *et al*. (2015). This problem has a much higher cost implication to the income lost when a person is seeking treatment and also increases the burden of the disease. According to Shaw *at el.* (2001), decision making and financial planning for HAT and tsetse control is complex in that it requires a particular range of choices to be made such as timing, methods, strategies and finances. Sutherland *et al.* (2015), noted that the year scheduled for HAT elimination was 2020, and as this deadline approaches there was need to improve the health care delivery system to have a holistic approach towards the elimination of HAT.

CHAPTER SIX

6.0 Conclusions and Recommendations

6.1 Conclusion

The study found that there was high economic loss of an individual at the house hold level in the four districts of study. Economic consequences showed that a person who earns on average ZMW 390.75 per month and would spend ZMW 1, 914.68 on average during hospitalisation up to the time of full recovery. This amount is five times more than they earn on the monthly basis, and would cause serious financial constraints at household level. The study also revealed that the disease comes with high economic loss in man power and DALYs because of the long duration of being hospitalised. The social consequences at household level revealed by the study also indicate that the effects at community level include: misconception, stigma, school dropout, pain, amnesia and deformity. The health care delivery system was found to be ill equipped to handle HAT cases in all the districts under study and currently there are no reformed policies in place to help cub the disease in Zambia. The long supply chain of the antitrypanosomal drugs could be one of the contributing factors in increasing severity of the disease to become second stage of HAT.

6.2 Recommendations

Based on the findings of the research the following are the recommendations:

1. Considering that people differed in the duration of being infected with HAT, there is need to carry out Research to determine if *Rhodosiense* HAT can be chronic. There is need to compare the burden of HAT to that of malaria in high risk areas to help in prioritising the disease and have informed policies in the management of HAT.

2. There is need to increase funding to the tsetse control and surveillance departments. Surveillance activities should involve communities to ensure success and sustainability.

3. Assistance should be rendered in terms of civic education and resource empowerment to people living with disabilities due to HAT in the endemic areas so as to lessen their suffering. Communities should sensitised about this disease and its effects so as to reduce incidences of stigmatisation and also to raise awareness about the disease.

4. Increase capacity for HAT case management in health centres in endemic areas in terms of both human resource and equipment. There is need for the trained laboratory personnel and physicians to be deployed to RHCs in these endemic areas. Awareness of the disease among the health personnel should be increased in order to raise their index of suspicion.

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8.0 Appendix One

8.0.1 Health Workers Questionnaire

This component of the questionnaire aims to gather additional information on all cases of *HAT* impact in human health and the available equipment for diagnosing HAT

Questionnaire: Economic Impact and Diagnosis of HAT

Ministry of Health/ Ministry of Community Development, Mother and Child Health

District……

Name of Institution……

Date of Interview……

Respondents names…….

Rank of Respondent……

Section One: HAT Detection Equipment

1. Do you have equipment for detection of HAT
   Yes ☐ No ☐
2. If yes in question 1 what kind of equipment please list
   ……
   …… ……
   ……
3. If no to question 1 do you refer patients with HAT symptoms to other health centres
   Yes ☐ No ☐
4. If yes to question 3 what is the name of the referral centre? Please specify
   ……..

Section Two: Staff

1. How many staff do you have for disease detecting……
2. Do you have staff trained in diagnosis of HAT through history and examination ?

Yes ☐ No ☐

3. If yes to question 2 how many?

4. Do you have staff trained in diagnosis of HAT through laboratory examination?

   Yes ☐ No ☐

5. If yes to question 4 how many?.....

   ❖ Please if no to question 2 or 4 end the questionnaire.

6. Have they gone under a refresher course?

   Yes ☐ No ☐

   If no to question 6 please go to question 10

7. If yes in question 4 how many times…….
8. If yes in question 4 where……
9. If yes in question 4 when……/……/…….
10. Have they diagnosed any HAT case

    Yes ☐ No ☐

11. If yes how many diagnosed reported cases……
12. How may unreported cases do you suspect in your catchment……
13. Have the staff ever misdiagnosed HAT cases/cases

    Yes ☐ No ☐

14. If yes how many cases…….

Section Three Treatment

15. Do you have a pharmacy

    Yes ☐ No ☐

16. If yes to question 13 do you have drugs for the treatment of HAT in your pharmacy

    Yes ☐ No ☐

17. If yes please specify the type of drugs……..
18. Approximate the cost of the drug administered to each patient until she or he recovers

    ……

Reported clinical outcome of patients

	Reported Clinical outcome	To be ticked or write	Total Number	Male	Female	Year
01	**Fully Recovered**					
02	**Minor Physical Disability**					
03	**Reported death case**					
04	**Unreported death case**					
05	**Major mental disability**					
06	**Major mental and physical disability**					
07	**Late stage abortion**					
08	**Suicide**					

Please provide any other information which may not be highlighted.

……
……
……
……
……
……
……
……

Completed By: …… Signature …… Date……/…../…….

Thank you for your participation. Please, return to the registry department

8.2 Appendix Two

8.2.1 House Hold Questionnaire

ENROLLMENT ID ….....

HOUSEHOLD NUMBER…….

DATE……/…../…

CLUSTER……..

Section One: Demographic Information

1. Name……..
2. What is your age in years? ……
3. Sex Male ☐ hale ☐
4. What is your marital status
   - Single ☐
   - Married ☐
   - Divorced ☐
   - Windowed ☐
5. What is your occupation?
   - I. Commercial Farmer ☐
   - II. Peasant Farmer ☐
   - III. Teacher ☐
   - IV. Game Ranger ☐
   - V. Cow herder ☐
   - VI. Hired Labor ☐
   - VII. Other specify

     ……
6. How many are you in your family……
7. How many of the family members are in:
   - I. Formal employment ☐
   - II. Informal employment ☐
   - III. Unemployed ☐

8. Kindly estimate the average household income per month…….....

Section Two: Knowledge about HAT/ HAT

1. Have you ever heard of the disease called Human African Trypanosomiasis (HAT)?

   Yes N☐ ☐

2. What transmits HAT?

   I. Tsetse flies ☐

   II. Housefly ☐

   III. Ticks ☐

3. Can HAT be transmitted through contact from one person to another?

   Yes No ☐ ☐

4. Have you ever had a HAT patient in your family?

   Yes ☐ No ☐

5. If yes to question 4 what were the signs and symptoms of HAT in the patient

   I. Abnormal sleep ☐

   II. Fever ☐

   III. Body pains ☐

   IV. Headache ☐

   V. Lymph node enlargement ☐

   VI. Weight Loss ☐

6. If yes in question 5 how many members exhibited such symptoms……

7. When did the symptoms observed……../……/……..

8. How did you handle the case or cases of HAT

   I. Told the patient to go to the clinic ☐

   II. Took the patient to the clinic ☐

   III. Did nothing ☐

   IV. To the patient to the traditional Healer ☐

   V. Treated the patient for yourself if so how……...

   VI. Others please specify……...

Section three; Economic and Social Impact

1. If you took the patient/ patients to the clinic/ traditional healer how much money did you spend on the following
    a. Transport……..
    b. Medication……
    c. Meals……
    d. Washing paste……
    e. Other Foods……
    f. Any other please specify……
2. How much time did you spend at the clinic/ traditional healers place……
3. Did you sell any item or valued commodity to help during medication?

    Yes ☐ No ☐
4. If yes to question 3 what item or commodity did you sell…….....
    ……..
5. At what value did you sell the item or commodity……...
6. If No to question 3 did you get any debt to help during the sickness

    Yes ☐ No ☐
7. If yes to question 6 how much did you get as a debt…….
8. Have you cleared or paid up the debt

    Yes ☐ No ☐

9. Were the sick individuals doing productive work at the period of infection,

    Yes ☐ No ☐
10. If yes to question 9how long were they absent from work.....?

11. Was the affected school going member/ members of the family?

    Yes ☐ No ☐

    If no to question 11 go to question 14
12. If yes in question 11 did the disease resulted in absenteeism from school?

    Yes ☐ No ☐

13. If yes in question 11 approximately how many days …….

14. Did the disease result into household children dropping out of school?

    Yes ☐ No ☐

15. Did the disease result the school going members repeating a grade?

    Yes ☐ No ☐

16. Was the patient discharged from the hospital

    Yes ☐ No ☐

17. If yes in question 16did you note any disabilities after the patient was discharged

    Yes ☐ No ☐

18. If yes to question 17 please specify the disabilities noted

    ……..

    ……..

19. Did the patient go for review?

    Yes ☐ No ☐

20. If yes when…../……/……

21. If no why……..

22. If no to question 19did any of the patients of HAT pass away?

    Yes ☐ No ☐

23. If yes when……../……/……..

24. If yes to question 25 whom did they outlive please specify……

    ……...

25. How are the family members who suffered from HAT perceived in the family and community……

Reported Clinical Outcome of the interviewed Patients in the community

	Reported Clinical outcome	To be ticked or write	Total Number	Year
01	**Fully Recovered**			
02	**Minor Physical Disability**			
03	**Reported death case**			
04	**Unreported death case**			
05	**Major mental disability**			
06	**Major mental and physical disability**			
07	**Late stage abortion**			
08	**Suicide**			

Please provide any other information which may not have been highlighted.

……..

……

……

……

……..

……..

Completed By:…….Signature ……Date……/…../……..

Thank you for completing this form.

8.3 Appendix Three

8.3.1 Focus group discussion questions for community members

GENERAL INFORMATION	
Province	
District	
Community name	
Total number of participants	
Gender composition	☐ Number of males ☐ Number of females

*[Directions to interviewer: In the focus group, start by asking the main questions in **bold**. The bulleted questions on the right are optional probes that you can use to encourage conversation or more sharing of detail.]*

Primary question	***Optional probing questions***
1. Would you please explain to me what you know about HAT?	• *How deadly is the disease?* • *How is the disease contracted?* • *Do you know of the remedies to this sickness>*
2. Could you describe to me any patient you know or seen with HAT in your community?	▪ How do the patients look like when they have this disease? ▪ How do patients with HAT behave before they go to the hospital ▪ What are the HAT patients reasoning abilities? Are they able to talk when they are admitted? ▪ What are the HAT patient's manual abilities? Are they able to work like they used to before they were discharged?

Now I am going to ask you about the Management of a patient with HAT disease	
3. Can you mention to me the best places to take a person suffering from HAT?	▪ What attributes of a place would you look for if you are to take a person sick with HAT to? ▪ Do you know of people that have been taken to this place? ▪ Who took the patient there? ▪ How was the reception you received at this place?
4. What do you think is the best way to handle a HAT patient?	▪ How would you take care of a patient? ▪ What foods would you give the patient? ▪ What precautions would you take to avoid contracting the disease?
5. Where would you obtain drugs for the HAT?	
Ok, now we're going to end the focus group shortly. But before we end I want to give everyone a chance to share any final thoughts.	
6. Do you have any final suggestions or comments concerning this HAT?	

8.4 Appendix Four

8.4.1 Concert Form

UNIVERSITY OF ZAMBIA
SCHOOL OF VETERINARY MEDICINE
DEPARTMENT OF DISEASE CONTROL
Informed Consent of Questionnaire on Human African Trypanosomiasis (HAT) Research

Project Title: Social and Economic Impacts on HAT in Eastern, Muchinga and Lusaka Provinces of Zambia.

Good morning/ afternoon.

My name is Mwiinde M. Allan and I am a student from the University of Zambia in Lusaka. This research we are conducting is part of the project titled: TrypanoGen: an integrated approach to the identification of genetic determinants of susceptibility to trypanosomiasis with main focus on the Economic and Social Impact of HAT Outbreak in Eastern, Muchinga and Lusaka Provinces of Zambia.

I would like to invite you to participate in a study whose aim is to assess the Economic and Social consequences of HAT. This will involve answering a number of questions on the management of HAT (HAT) disease in health in institutions in your area and will take less than 20 minutes to assess the adequacy of the health delivery system in management of HAT. The results from the test will assist the investigators know the challenges the health institutions face in the management of HAT. This will help the relevant stake holders like the Ministry of health to institute measures to ease the burden, if any, in your catchment.

The answers provided from all participants are strictly confidential and will not be disclosed to any one without your concern; you are also expected to answer truthfully. Please be informed that you are free to end this interview at any time and are free not to answer any question

because your participation is strictly voluntary. There are benefits, monetary or otherwise that you will be entitled to by your participation. However, your participation will be valuable to stake holders like the Ministry of Health concerning the HAT disease that occurs in your area.

If you have any question or query regarding this section of study contact Mr. Mwiinde M. Allan on 0979 84 17 05 or 0950201222

I……I have understood the objective of this questionnaire on the importance it has to me and my community , my participation is wilfully, therefore, do give consent to participate in it.

Signature of participant…….……. Date…did/.mm../my….

Signature of Investigator…….……Date…did/mm../my….

8.5Appendix Five

8.5.1 Ethical Clearance

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

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Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

10th December, 2013.

Your Ref: 011-09-13.

Dr. Martin Simuunza,
University of Zambia,
School of Veterinary Medicine,
Department of Disease Control,
P.O Box 32379,
Lusaka.

Dear Dr. Simuunza,

RE: **RE-SUBMITTED RESEARCH PROPOSAL: "TRYPANOGEN: AN INTERGRATED APPROACH TO THE IDENTIFICATION OF GENETIC DETERMINANTS OF SUSCEPTIBILITY TO TRYPANOSOMIASIS" (REF. No. 011-09-13)**

The above mentioned research proposal was re-submitted to the Biomedical Research Ethics Committee with recommended changes on 5th December, 2013. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- **Ensure that a final copy of the results is submitted to this Committee.**

Yours sincerely,

Dr. J.C Munthali
CHAIRPERSON

Date of approval: 10th December, 2013. **Date of expiry:** 9th December, 2014.