

**ACCESS BARRIERS TO FORMAL HEALTH SERVICES:
FOCUS ON SLEEPING SICKNESS IN TESO DISTRICT,
WESTERN KENYA //**

KENNEDY WANJALA BARASA

**A THESIS SUBMITTED TO THE INSTITUTE OF
ANTHROPOLOGY, GENDER AND AFRICAN STUDIES
IN FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF DOCTOR OF PHILOSOPHY IN
ANTHROPOLOGY OF THE UNIVERSITY OF
NAIROBI**

University of NAIROBI Library



0546035 7

2012

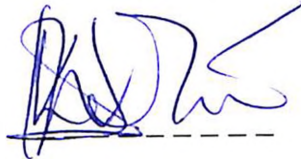
Ed 340305

las
~~APR~~
GN
296
B3

DECLARATION

This thesis is my original work and has not been presented anywhere else for a degree.

Kennedy Wanjala Barasa



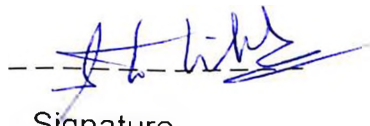
Signature

5/11/2012

Date

This thesis has been submitted with our approval as University Supervisors

Prof. Simiyu Wandibba



Signature

5/11/12

Date

Dr. Salome A. Bukachi



Signature

5/11/12

Date



DEDICATION

This thesis is dedicated to my late sister, Hellen Nangila, whose encouragement made me the person I am.

TABLE OF CONTENTS

| | |
|--|------|
| List of Tables | vi |
| List of Figures | vii |
| Acknowledgement | viii |
| Abstract | x |
| List of Acronyms and Abbreviations | xii |
| CHAPTER ONE..... | 1 |
| BACKGROUND TO THE STUDY | 1 |
| 1.1 Introduction..... | 1 |
| 1.2 Disease Morbidity in Kenya | 2 |
| 1.3 Indicators of Sleeping Sickness | 6 |
| 1.4 Statement of the Problem..... | 8 |
| 1.5 Study Objectives..... | 11 |
| 1.5.1 General Objective..... | 11 |
| 1.5.2 Specific Objectives | 11 |
| 1.6 Rationale of the Study..... | 12 |
| 1.7 Assumptions of the Study..... | 13 |
| 1.8 Scope and Limitations of the Study | 14 |
| 1.9 Definition of Terms..... | 16 |

| | |
|---|----|
| CHAPTER TWO..... | 18 |
| LITERATURE REVIEW..... | 18 |
| 2.1 Introduction..... | 18 |
| 2.2 Sleeping Sickness | 18 |
| 2.3 Disease Management and Control | 22 |
| 2.3.1 Disease Management | 22 |
| 2.3.2 Disease Control | 25 |
| 2.4 Impact of Trypanosomiasis | 29 |
| 2.5 History of Sleeping Sickness in Kenya..... | 32 |
| 2.6 Perceptions of Disease and Health-seeking Behaviour | 35 |
| 2.7.1 Factors Influencing Patients' Choice of Health Facilities..... | 38 |
| 2.8 Theoretical Perspectives on Disease and Health-seeking Behaviour..... | 40 |
| 2.8.1 The Health Care Utilisation Model | 41 |
| 2.8.2 The Pathway Model..... | 44 |
| 2.8.3 Social Learning Theory..... | 45 |
| 2.9 Theoretical Framework | 46 |
| 2.9.1 Health Belief Model (HBM) | 46 |
| 2.9.2 Disease Theory (DT)..... | 47 |
| 2.10 Relevance of the Theories to the Study | 49 |
| CHAPTER THREE..... | 51 |

| | |
|---|-----------|
| METHODOLOGY | 51 |
| 3.1 Introduction..... | 51 |
| 3.2 Study Site | 51 |
| 3.2.1 Location and Physical Features | 51 |
| 3.2.2 Administrative Divisions | 54 |
| 3.2.3 Religion..... | 55 |
| 3.2.4 Health, Belief Systems and Status..... | 56 |
| 3.2.5 Education | 57 |
| 3.3 Research Design..... | 60 |
| 3.4 Study Population and Unit of Analysis..... | 61 |
| 3.5 Sample Size and Sampling Strategy..... | 62 |
| 3.6 Methods of Data Collection..... | 66 |
| 3.6.1 Structured Interviews..... | 66 |
| 3.6.2 In-depth Interviews | 66 |
| 3.6.3 Key Informant Interviews | 67 |
| 3.6.4 Focus Group Discussions | 68 |
| 3.6.5 Secondary Sources | 69 |
| 3.7 Data Processing and Analysis | 69 |
| 3.8 Ethical Considerations..... | 70 |
| CHAPTER FOUR..... | 71 |

| | |
|---|------------|
| KNOWLEDGE AND PERCEPTIONS OF SLEEPING SICKNESS..... | 71 |
| 4.1 Introduction..... | 71 |
| 4.2 Socio-Demographic and Environmental Characteristics..... | 71 |
| 4.2.1 Age and Sex..... | 71 |
| 4.2.2 Educational status | 72 |
| 4.2.3 Economic Activities..... | 74 |
| 4.3 Knowledge of Sleeping Sickness..... | 74 |
| 4.3.1 Symptoms Associated with Sleeping Sickness | 76 |
| 4.3.2 Knowledge of Predisposing Behaviour to Sleeping Sickness | 78 |
| 4.3.3 Knowledge of Sleeping Sickness Treatment | 79 |
| 4.3.4 Awareness of the National Sleeping Sickness Referral Hospital | 80 |
| 4.4 Community Experiences with Sleeping Sickness..... | 84 |
| 4.4.1 Perception of the Treatment Process | 86 |
| 4.4.2 Community Attitude towards Sleeping Sickness Patients..... | 89 |
| CHAPTER FIVE | 93 |
| HEALTH-SEEKING BEHAVIOUR | 93 |
| 5.1 Introduction..... | 93 |
| 5.2 Sources of Healthcare..... | 93 |
| 5.3 Determinants of Health Seeking Behaviour..... | 96 |
| CHAPTER SIX..... | 109 |

| | |
|--|-----|
| REFERRAL SERVICES..... | 109 |
| 6.1 Introduction..... | 109 |
| 6.2 Interaction between Health Providers and Former Patients | 109 |
| 6.3 Provision of Referral Services by Health Providers | 111 |
| 6.4 Impediments to Intra-community Referrals to the NSSRH | 115 |
| CHAPTER SEVEN..... | 121 |
| DISCUSSION AND CONCLUSION | 121 |
| 7.1 Introduction..... | 121 |
| 7.2 Effects of Knowledge of HAT and the NSSRH on Access to HAT Services..... | 121 |
| 7.3 Health-seeking Behaviour and Access to HAT Formal Health Services..... | 131 |
| 7.4 Determinants of Health-seeking Behaviour and Access to Services at NSSRH..... | 135 |
| 7.5 Interactions between Patients and Formal Health Providers in the District | 143 |
| 7.6 Conclusion | 149 |
| 7.6.1 Recommendations | 156 |
| References | 158 |
| Appendix 1: Questionnaire | 184 |
| Appendix 2: In-depth Interview Guide | 193 |
| Appendix 3: Key Informant Interview Guide for Sleeping Sickness Hospital Staff | 194 |
| Appendix 4: Themes for Focus Group Discussions (FGDs)..... | 195 |
| Appendix 5: Ethical Clearance..... | 196 |

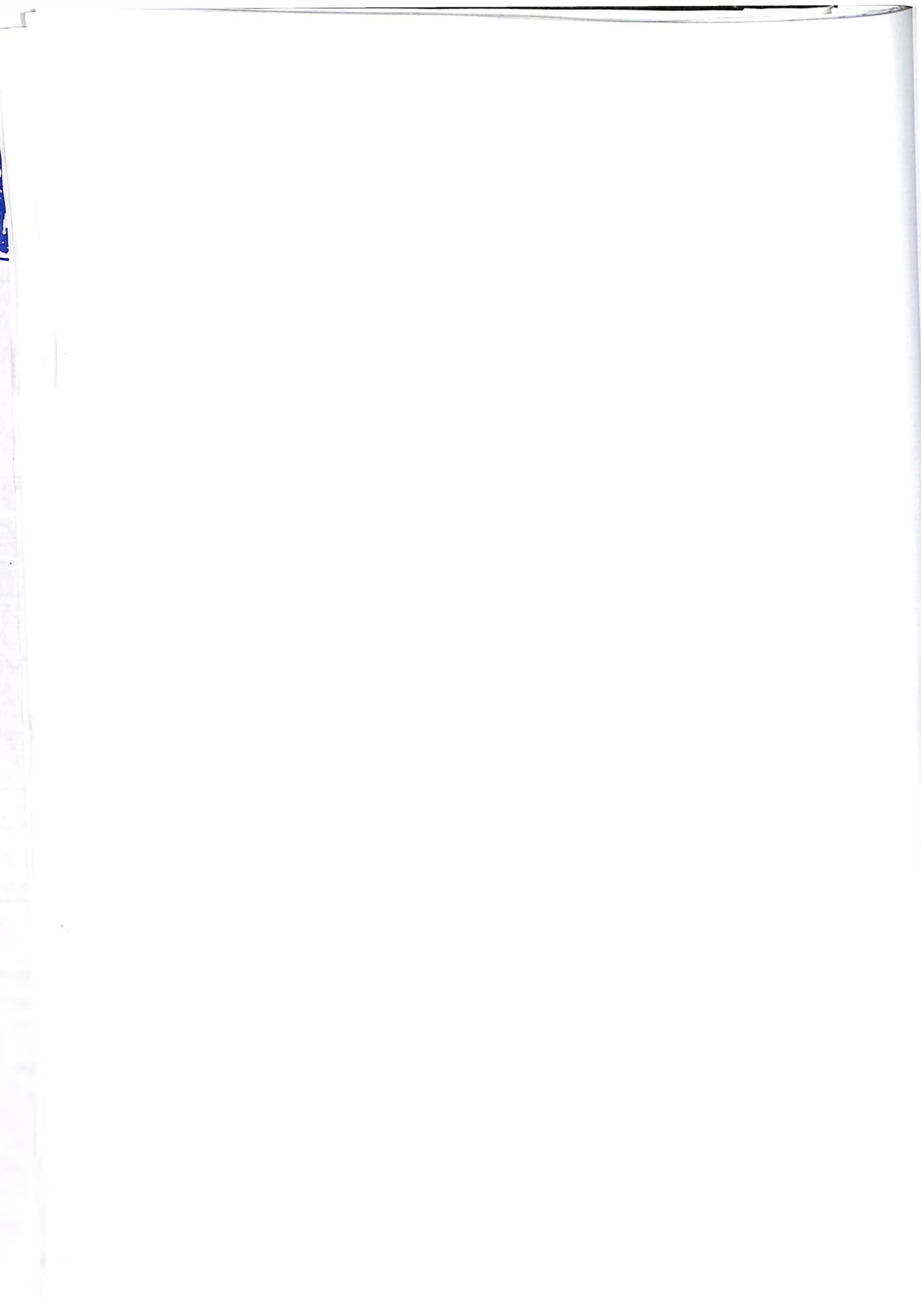
List of Tables

| | | |
|-----|---|-----|
| 3.1 | Administrative Units in Teso District..... | 55 |
| 3.2 | Population by Sex, Highest Level of Education Attained and Division..... | 59 |
| 3.3 | Raosoft® Sample Size Calculation | 63 |
| 4.1 | Knowledge of Sleeping Sickness Transmitting Agent..... | 75 |
| 4.2 | Knowledge of Sleeping Sickness Causes..... | 76 |
| 4.3 | Knowledge of Symptoms of HAT..... | 77 |
| 4.4 | Knowledge of Predisposing Behaviour for Sleeping Sickness..... | 79 |
| 4.5 | Knowledge of the HAT Hospital (NSSRH)..... | 83 |
| 4.6 | Initial Perceptions of Sleeping Sickness..... | 90 |
| 5.1 | Respondents' Utilization of the Various Healthcare Options/Sources..... | 95 |
| 5.2 | Reasons for Utilization of Traditional Medical Practitioners..... | 102 |
| 5.3 | Determinants of Healthcare Choices..... | 104 |



List of Figures

| | |
|---|-----|
| Figure 1.1: Sleeping Sickness Trends in Kenya (1950-2006)... | 4 |
| Figure 2.1: Reported Livestock Trypanosomiasis Cases in Teso District (April 2010)..... | 27 |
| Figure 2.2: Statistics of Sleeping Sickness Treated at SS Hospital..... | 35 |
| Figure 2.3: Healthcare Utilization Model..... | 43 |
| Figure 2.4: Janzen's Pathway Model..... | 45 |
| Figure 2.5: Diagrammatic Representation of the Conceptual Framework..... | 50 |
| Figure 3.1: Map of Teso District showing Administrative Divisions..... | 53 |
| Figure 3.1: Map of Teso District showing Villages in which Research Activities were undertaken..... | 65 |
| Figure 4.1: Duration taken by Respondents in Formal Education..... | 73 |
| Figure 4.2: Knowledge of the HAT Treatment Facility..... | 81 |
| Figure 5.1: Where People go when Illness Persists..... | 100 |
| Figure 5.2: Factors that May Prevent People from going to Hospital for Health Services..... | 105 |
| Figure 5.3: Principle Component Analysis (PCA) of Factors that may Prevent Hospital Attendance..... | 106 |
| Figure 6.1: Number of Visits made by Respondents Before Referral Services Were Given..... | 113 |
| Figure 7.1: Summary of Determinants for Health-seeking Behaviour and their Impact on Utilization of Health Services offered at the NSSRH..... | 148 |



Acknowledgement

The production of this thesis right from conceptualization to completion was made possible through the moral and financial support of various individuals and organizations. For practical purposes, I cannot mention each of them here. However, the following are just among the many who made contributions of various kinds towards the success of this work. I am grateful to Dr. Grace Murilla, Centre Director, Trypanosomiasis Research Centre (TRC), for her facilitation and encouragement that made timely completion of this thesis possible. Financial support towards fieldwork was generously provided by PATTEC and for this I am grateful to Dr. Pamela Olet, the PATTEC Country Co-ordinator, for the support.

It is also worth mentioning that my University supervisors, Prof. Simiyu Wandibba and Dr. Salome Bukachi, were always available for me. Their indefatigable support through prioritization of my work and their enquiries about my progress enabled me to complete this work in time. I, therefore, cannot thank them enough.

I cannot also fail to acknowledge Dr. Lawrence Godia whose encouragement made me develop sufficient energy to pursue this study. I also acknowledge my other colleagues at TRC, including Mr. Tony Ogolla, for assisting in data collection and entry, Michael Musembi for data collection and drawing of maps and Ms. Cecilia Wambui for tirelessly availing sleeping sickness records at TRC whenever I needed them.



Lastly, I acknowledge my family, my wife Florence, my son Eric and my daughters Elsie, Diana and Whitney for their endurance during periods when I was expected to be with them but in pursuit of the timely completion of this thesis I was elsewhere.

Abstract

This study was designed to investigate access barriers to formal health services among communities in Teso district, one of the traditionally known human trypanosomiasis (HAT) or sleeping sickness foci in western Kenya. The focus of the study was on the National Sleeping Sickness Referral Hospital (NSSRH) based at Alupe. The study was undertaken between March and June 2010 in four divisions of Teso District, namely, Chakol, Amukura, Amagoro and Ang'urai. Three questions that centred around an establishment of people's knowledge and attitude towards sleeping sickness, treatment procedure and the hospital; the factors that influence health seeking behaviour of the people living in the research site; and whether formal health providers in the study site offered referral advice to potential sleeping sickness patients formed research questions that the study sought to answer. The overall objective of the study was to assess barriers to formal health services offered at the National Sleeping Sickness Referral Hospital. A combination of disease theory and the health belief model guided the study.

Data were collected through secondary sources (journal articles, books, theses, published and unpublished reports), structured interviews, focus group discussions, key informant interviews and direct observation. The study employed purposive sampling to establish the villages where research activities were undertaken. In total, 400 respondents were interviewed and 8 focus group discussions were held.



The findings indicate that there are socio-cultural and demographic barriers that may hinder access to services offered at NSSRH and formal health services in general within the district. The barriers include social stigma associated with the NSSRH, the disease and the treatment process; lack of knowledge about the epidemiology of sleeping sickness, the location and functions of NSSRH among community members; ethnicity; and the existence of a multiplicity of healthcare options, both formal and informal, within the research site. Long distance to health facilities was also indicated by respondents as a determinant of their utilization of health services. The health infrastructure also presented an access barrier to formal health service provision through centralization of the NSSRH, diagnostic and treatment procedure of sleeping sickness, and the quality of services exhibited through harassment of healthcare-seekers by providers and/or long queues of healthcare-seekers at the health centres.

The study concludes that access barriers to services offered at the NSSRH and formal health services, within Teso district in general, exist. The study, therefore, recommends continuous sensitization of the community and non-HAT formal health attendants within the district about the disease and the services offered at the NSSRH to increase hospital visibility. The study also recommends capacity building of health facilities in all the divisions traditionally affected by sleeping sickness in western Kenya and beyond to aid in diagnosis of the disease. An improvement of diagnostic technologies for HAT at the NSSRH to enhance compliance and confidence of the community members for the hospital and its services is also recommended.

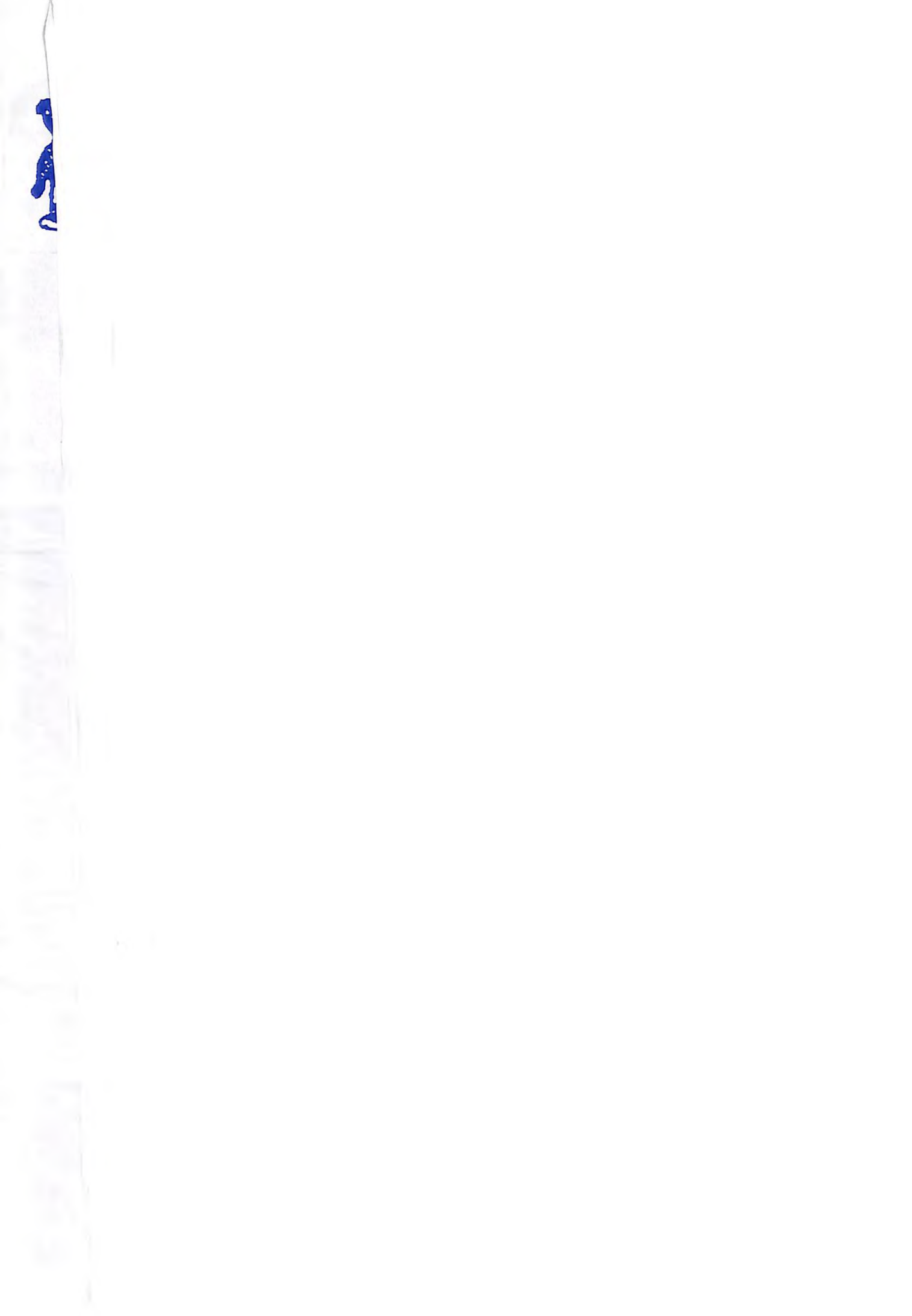


List of Acronyms and Abbreviations

| | |
|--------|--|
| AIDS | Acquired Immune-deficiency Syndrome |
| DDT | Dichlorodiphenyltrichloroethane |
| DMO | District Medical Officer |
| DT | Disease Theory |
| EANETT | East African Network for Trypanosomiasis |
| FAO | Food and Agriculture Organisation |
| FGD | Focus Group Discussion |
| FHI | Family Health International |
| GIS | Geographical Information System |
| GOK | Government of Kenya |
| GPS | Global Positioning System |
| HAT | Human African Trypanosomiasis |
| HBM | Health Belief Model |
| HIV | Human Immunodeficiency Virus |
| IAEA | International Atomic Energy Agency |
| KARI | Kenya Agricultural Research Institute |
| KEMRI | Kenya Medical Research Institute |
| KETRI | Kenya Trypanosomiasis Research Institute |
| KI | Key Informant |
| MOH | Medical Officer of Health |
| MSF | Medicine Sans Frontiers |



| | |
|----------|--|
| NSSRH | National Sleeping Sickness Referral Hospital |
| NALIRI | National Livestock Research Institute |
| NDVI | Normalised Difference Vegetation Index |
| OAU/IBAR | Organisation of African Unity/Inter-African Bureau for Animal Resources |
| ORS | Oral Re-hydration Salts |
| PAAT | Programme Against African Trypanosomiasis |
| PATTEC | Pan-African Tsetse and Trypanosomiasis Eradication Campaign |
| PCA | Principal Component Analysis |
| RTIs | Respiratory Tract Infections |
| T&T | Tsetse and Trypanosomiasis |
| TRC | Trypanosomiasis Research Centre |
| USPHS | United States Public Health Services |
| UTRO | Uganda Trypanosomiasis Research Organisation |
| WHO | World Health Organisation |



CHAPTER ONE

BACKGROUND TO THE STUDY

1.1 Introduction

Trypanosomiasis is a devastating disease that affects both humans and animals in sub-Saharan Africa. The disease is transmitted by the tsetse fly, *Glossina spp.*, and adversely affects human health through sleeping sickness and constraints livestock production through *nagana*. Human African Trypanosomiasis (HAT) or sleeping sickness is one of the diseases categorised by the World Health Organisation (WHO) among the world's most neglected diseases affecting poor populations in remote rural areas of Africa (WHO, 2002; Lutumba *et al.*, 2007). The disease impedes livelihood strategies available to an estimated 60 million people residing in 36 African countries (Bukachi *et al.*, 2005; Ng'ayo, 2005; WHO, 2002).

The parasite causing sleeping sickness, the trypanosome, is transmitted to humans through the bite of an infected tsetse fly. According to WHO (1998), the disease is restricted to tropical sub-Saharan Africa and occurs in two forms, a chronic form caused by *Trypanosoma brucei gambiense* (*Tbg*) and an acute form caused by *Trypanosoma brucei rhodesiensis* (*Tbr*). The chronic form (*Tb gambiense*) is found in West and Central Africa while the acute form (*Tb rhodesiense*) occurs in East and Southern Africa. Inhabiting the vast savannah across sub-Saharan Africa, tsetse flies come into contact with humans, wild



animals, cattle and other domestic animals, all of which act as reservoirs for the parasite.

The prevalence of the disease differs within and between countries. According to WHO (2010), in the last 10 years, over 70% of reported cases occurred in the Democratic Republic of Congo (DRC). In 2008 and 2009, the DRC and the Central African Republic declared over 1000 new cases per year. Other countries such as Angola, Chad, Sudan and Uganda declared between 100 and 1000 new cases per year. On the other hand, countries such as Cameroon, Congo, Côte d'Ivoire, Equatorial Guinea, Gabon, Guinea, Kenya, Malawi, Nigeria, United Republic of Tanzania, Zambia and Zimbabwe reported less than 100 new cases per year (WHO, 2010).

Regional focus indicates that in East Africa, the disease is found in selected areas of the three countries (Kenya, Uganda and Tanzania). In Uganda, the disease is found in Busoga in the South-east and Arua in the North-west (Picozzi *et al.*, 2005). In Tanzania, the disease is found in areas surrounding the Serengeti National Park (Sindato *et al.*, 2008), while in Kenya it is endemic in four districts bordering Uganda, namely, Busia, Bungoma, Teso, and Suba.

1.2 Disease Morbidity in Kenya

Sleeping sickness has been a problem for the health service system in Kenya since 1900 with the peak of the disease burden being felt during the outbreak of

1954 where more than 450 people were infected with the disease (Figure 1.1). Historically, the trend of sleeping sickness has been rising and dropping at different times. However, from the year 1990, there has been a drop in numbers of sleeping sickness patients treated at the hospital. For example, records show that 95 HAT patients were diagnosed and treated for the disease in 1990. The same records also indicate that the figures went down to 22 cases in 2002 and only one case was reported in 2006 (Fig. 1.1) with an additional case detected in 2009. A point worth noting is that the records further indicate that virtually all patients reported at the institution when they were in the second stage of the disease (Unpublished KETRI sleeping sickness hospital reports). Conversely, on the Ugandan side of the border, barely 10 kilometres away from the NSSRH, health centres have continued to register a comparatively higher number of cases. For example, in 2002, WHO estimated that Uganda continued to report 200 cases annually (WHO, 2002).

Sleeping sickness manifests itself in two stages. The first stage presents non-specific symptoms such as headache, fever, sweating, and general body weakness. If treatment is not given, the parasite invades the infected person's central nervous system thus setting in motion the second stage. This second stage is characterized by such symptoms as anxiety, increased sleepiness, insomnia (lack of sleep at night), drowsiness and uncontrollable urge to sleep during the day (MSF, 2004; WHO, 2004; ADAM, 2005; Health-Cares, 2005).

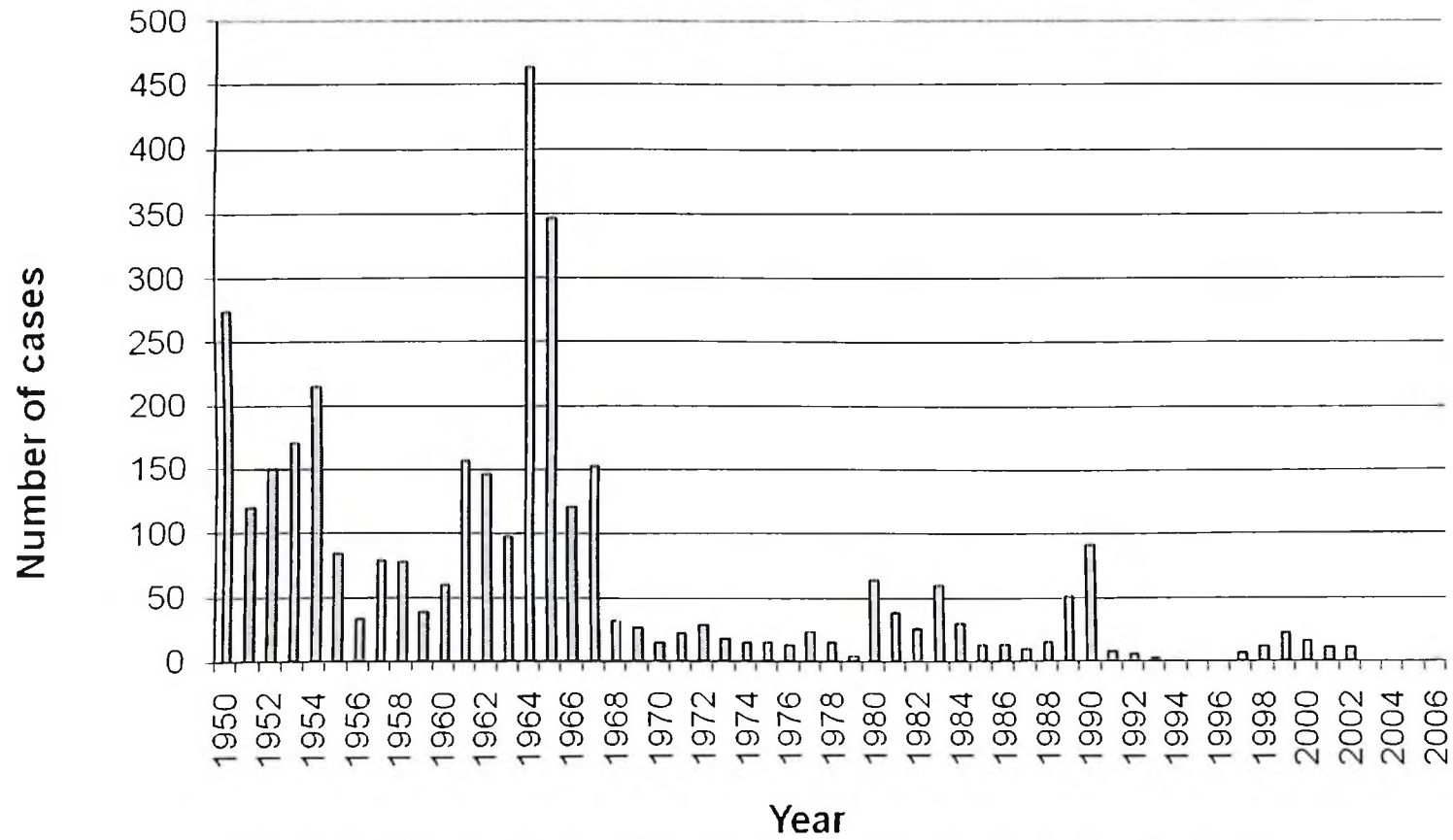


Figure 1.1: Sleeping Sickness Trends in Kenya 1950-2006

Source: Unpublished KETRI sleeping sickness hospital reports.

Diagnosis of sleeping sickness relies on detecting parasites in the person's blood or lymph nodes. If initial diagnosis is positive, it is followed by a lumbar puncture, a painful and potentially dangerous process, needed to determine whether the parasites have crossed over to the central nervous system (second stage of the disease). Determination of whether the patient is in the second stage is necessary because the medicine used to treat second stage disease (Melarsoprol®) is very toxic and may have fatal secondary effects. Thus, treatment of the disease requires that the medicines are administered to only those patients who need them (MSF, 2004; Thomas, 2004; Kuzoe, 2001).

The non-specific nature of symptoms presented by sleeping sickness patients makes it necessary for diagnosis and treatment of the disease to be carried out at specialized health facilities and by experienced personnel. In Kenya, there is only one specialized health institution, the National Sleeping Sickness Referral Hospital (NSSRH) based at Alupe that is mandated to provide health services to sleeping sickness patients. Situational analysis of the disease in the country is, therefore, mainly premised on hospital admissions.



However, Kenyan patients sometimes cross over to Uganda Trypanosomiasis Research Organization (now the National Livestock Research Institute [NALIRI]), a hospital in Uganda near Tororo town that serves sleeping sickness patients. A cross-border survey in 1998 indicated that 27 sleeping sickness patients from Kenya were treated at the institution in that year (Unpublished KETRI sleeping sickness hospital reports).

1.3 Indicators of Sleeping Sickness

In sleeping sickness-endemic areas, the presence of tsetse flies, movement of people and animals within and out of the areas, as well as detection of trypanosomes in livestock and other domestic animals would indicate a risk of disease occurrence within the human population. This is particularly so when there is animal and/or human movement (potential disease reservoirs) in and out of sites characterised by comparatively higher disease prevalence as presented by the Kenya-Uganda situation. Between the two countries, cross-border trade in livestock and human movement particularly at un-official crossing points is common.

Apart from detection of trypanosomes in animal blood samples, domestic animals such as dogs with corneal opacity may also indicate a rise in human-infective trypanosomes within the population. A study by Matete (2003) in Busia and Teso districts in Kenya, revealed the presence of dogs with corneal opacity



within the population in the area and some yielded human-infective trypanosomes in their blood samples. This observation may indicate low level presence of sleeping sickness among communities on the Kenyan side of the border, a common characteristic of neglected diseases. The temporal decline in admissions and treatment of sleeping sickness patients at the Kenyan sleeping sickness hospital could, thus, be due to the presence of access barriers to health services offered at the hospital.

The World Health Organization estimated that out of 60 million people at risk of acquiring the disease in 1999, only 3 to 4 million were either actively screened or had access to a health centre with the appropriate diagnostic and treatment capabilities (WHO, 2001:89). On the other hand, studies by Odiit *et al.* (2004) and Bukachi *et al.* (2009) in South-eastern Uganda and Western Kenya, respectively, established the presence of inappropriate diagnosis of sleeping sickness amongst health providers. The study by Odiit *et al.* (2004) revealed that at first presentation, most (72.3%) of the patients were diagnosed and treated for malaria and that only 22.6% of the patients were referred to NALIRI hospital for treatment. The study further found that most of the patients (67.2%) that took part in the study at first thought they had malaria while the rest suspected AIDS.

According to Mbulamberi (1989) and Okia *et al.* (1994), sleeping sickness is likely to be highly under-reported as outbreaks tend to occur mainly among the rural poor and during civil strife when control measures for the disease are



difficult to apply. At the end of the 1990s, WHO (1998:7) estimated that there were approximately 300 000–500 000 new infections of both forms of sleeping sickness per year but that only 45 000 were reported. A study by Odiit *et al.* (2005:845) in Eastern Uganda projected that in every one reported sleeping sickness infected person in the village, there are 12 others that are unreported. These observations indicate a high level of under-detection of sleeping sickness in affected areas (Odiit *et al.*, 2005:840).

In many areas, sleeping sickness is mainly detected by passive case finding, with patients presenting at a health facility for treatment and diagnosis based on microscopic detection of trypanosomes (WHO, 1998). According to Cattand and De Raadt (1991:805), microscopy as a diagnostic tool for sleeping sickness is characterized by low sensitivity. Odiit *et al.* (2005:841) add that in a village setting, effective detection of sleeping sickness through passive surveillance calls for appropriate knowledge of the disease and the specialized treatment facility by the concerned community members. However, due to under-detection, estimating the true prevalence of the disease based on microscopy and passive surveillance is difficult (Odiit *et al.*, 2005:840).

1.4 Statement of the Problem

The number of sleeping sickness admissions at the NSSRH has been diminishing over the years. This has led to changes in control strategies aimed at managing the disease within affected communities in Kenya. Ordinarily, during

times of disease outbreaks, active surveillance, a strategy that entails officers from the hospital going to the community to establish disease status using various diagnostic tests, was frequently used. With dwindling sleeping sickness admissions at the NSSRH, passive surveillance, a strategy that requires people who suspect sleeping sickness to present themselves to health facilities for testing and treatment, has been depended upon for disease control.

However, the occurrence of sleeping sickness in Kenya is faced with two contradictory observations. On one side, there is an observation of diminishing numbers of sleeping sickness patients served at the country's sleeping sickness hospital (NSSRH). This may indicate that authorities have successfully controlled the disease, putting the country on the verge of eliminating sleeping sickness as a public health problem in Kenya. Indeed this triggered discussions over the possibility of declaring Kenya sleeping sickness free. On the other hand, reports as a result of field surveys in the period when there were diminishing sleeping sickness patient admissions at the NSSRH indicate presence of tsetse flies, the disease vector. Reports from the livestock department in the district have also indicated that livestock trypanosomiasis is still one of the major diseases affecting livestock production in the area. Livestock, wild and other domestic animals act as reservoirs for sleeping sickness. Likewise, studies by Matete (2003) in the district also isolated sleeping sickness-causing trypanosomes in dogs with corneal opacity. This isolation of sleeping sickness-causing trypanosomes in dogs in the research site, the proximity of the site to Uganda



where comparatively more cases were reported, treatment of 27 Kenyan sleeping sickness patients in the Ugandan health facility (NALIRI Hospital) in 1998, and the diagnosis and treatment of a sleeping sickness patient in the district in 2009 indicates that the disease is in circulation within the population although in low prevalent rates. The occurrence of diseases in low prevalence rates is a common characteristic of neglected diseases (WHO, 2004).

Studies have shown that the occurrence of a single sleeping sickness patient in a community indicates presence of more patients within the population (Odiit *et al.*, 2005). Therefore, the observation of reported low numbers of patients served at the NSSRH makes it logical to assume that there are more infected people within the population. If this is the case, there could be factors that hinder people from presenting to the NSSRH for sleeping sickness diagnosis and treatment. Unpublished reports at the Trypanosomiasis Research Centre, an institution that manages the NSSRH, indicate that little attention has been given to the influence of anthropological factors on sleeping sickness management. Based on the contradictory observations therefore, this study assumes that communities in Kenya likely face social, economic and/or geographical barriers to accessing formal sleeping sickness healthcare. This study was, therefore, designed to answer the following questions:

1. What are the people's knowledge of and attitude towards sleeping sickness, its treatment procedure and the NSSR hospital?



2. What factors influence the health seeking behaviour of the people living in Teso district?
3. To what extent does referral advice or lack of it by health providers influence utilization of services offered at the sleeping sickness hospital by people living in Teso district?

1.5 Study Objectives

1.5.1 General Objective

To assess access barriers to formal health services offered at the National Sleeping Sickness Referral Hospital (NSSRH) based at Alupe in Teso District, western Kenya.

1.5.2 Specific Objectives

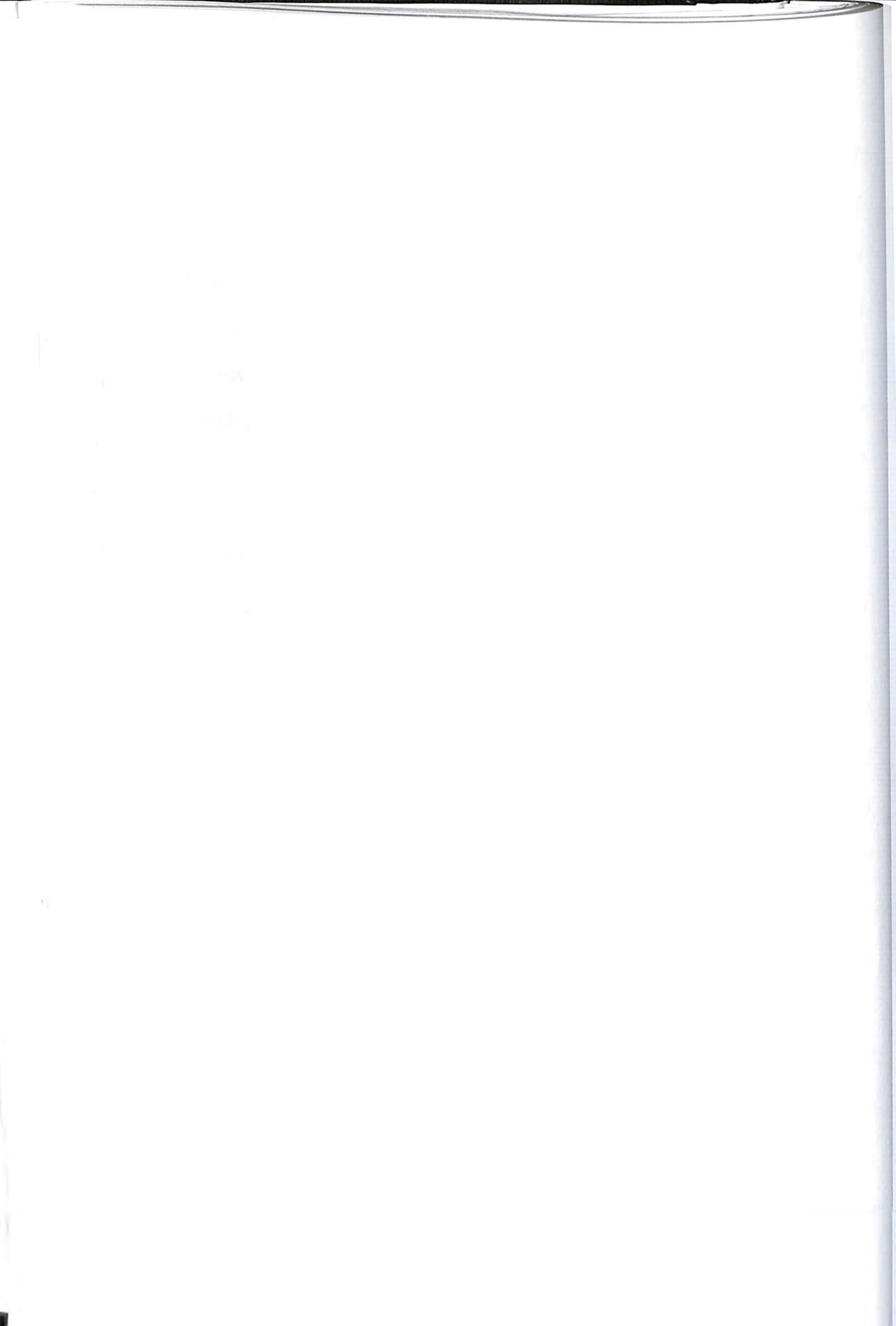
1. To examine people's knowledge and attitude to, sleeping sickness, its treatment and the NSSR hospital.
2. To determine the factors that influence health-seeking behaviour of people living in Teso district.
3. To establish the extent to which formal health providers offer referral advice to people living within Teso district.



1.6 Rationale of the Study

This study provides valuable information about knowledge levels of people living in Teso district relating to sleeping sickness, the NSSRH and their overall perception of the disease and hospital. An establishment of this knowledge is important because it points out barriers that may negatively affect disease control strategies. Knowledge about this kind of barriers is also important in pointing out areas that need corrective action through community sensitisation during disease control activities.

Whereas passive surveillance is a method of choice to detect and treat diseases such as sleeping sickness that are characterised by low morbidity compared to diseases such as malaria (Odiit *et al.*, 2005:841), there are fundamental prerequisites that need to be fulfilled before successful operationalization of this ideological structure. The basic assumption is that people's health seeking behaviour and the referral system in the health provision infrastructure work synergistically in favour of passive surveillance. However, because knowledge about if, how and when formal health providers offer referral services to community members in the research site was lacking, this made it important that such information is established. Understanding people's health-seeking behaviour and determinants for the behaviour is helpful to formal health providers in understanding their clients better and thus put in place mechanisms that may surmount any barriers that would otherwise have prevented people from seeking



proven effective formal health services. This would make effective control of health problems such as sleeping sickness in the country achievable.

The findings should also offer an additional explanation as to why virtually all those admitted at the sleeping sickness hospital have always been in the late stage of the disease. The findings also shed more light on the reasons why patients cross the international border to Uganda to search for sleeping sickness health services.

Apart from providing information that can contribute to the desired effective management of sleeping sickness, this study's findings also makes important contributions to the enrichment of anthropological theory relating to the local people's health-seeking behaviour. The generated anthropological information also provides valuable input in the debate about the status of sleeping sickness in Kenya.

1.7 Assumptions of the Study

The following three assumptions guided the research.

1. The people of Teso District have basic knowledge of sleeping sickness but have negative attitude towards its treatment procedures and the Sleeping Sickness hospital.



2. Perceived disease causality determine the health-seeking behaviour of residents of Teso District.
3. People living within Teso district do not receive appropriate referral advice from formal health providers within the district.

1.8 Scope and Limitations of the Study

In Kenya, the traditional foci for sleeping sickness and the catchment area for the sleeping sickness referral hospital based at Alupe extend beyond the administrative boundaries of Teso district. The other foci include areas in districts such as Suba, Bungoma and Busia. This study's coverage was restricted to the four divisions of the larger Teso district (Now South and North Teso districts) and did not extend to the other known traditional foci areas because these were not relevant to the research problem at hand.

This study was anthropological in nature. Therefore, details such as obtaining samples from local inhabitants to establish presence of trypanosomes in the blood was not carried out.

Language was also a barrier. This was because the study design required that there was direct face to face interview with respondents. However, this limitation was surmounted through recruiting and training of research assistants who were native speakers.



In the structured questionnaire, some questions such as enquiries about whether any member(s) of their families had ever suffered from sleeping sickness required them (respondents) to exercise their recall capability. The researcher took cognisance of the fact that there was a possibility of getting inaccurate information due to recall period. To surmount this methodological hurdle, the researcher also used other methods such as focus group discussions and key informant interviews for triangulation purposes.



1.9 Definition of Terms

Barriers

Any factor whether financial, environmental, social, cultural or infrastructural that may prevent people from utilizing services at the National Sleeping Sickness Referral Hospital (NSSRH) at Alupe.

Formal/biomedical Health Services

Health services offered at health institutions within the research site. The services offered here are biomedical in nature and include diagnosis, treatment and referral services.

Illness

This stands for culturally specific perception of loss of health. In broad terms, it may be viewed as a sociological definition of disease. In this study, illness results from pathogenic and /or humanistic agents.

Health

As defined by the World Health Organization, health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. This definition was also adopted by this study.



Tradition Medical Practitioners

People involved in the provision of traditional medical services based on non-western principles. The services here include use of herbal and other non-modern substances and procedures to cure disease. In the research site they include the *musebe* people.

Health Seeking Behaviour

This refers to all the actions taken and options used by community members perceived to be ill in their endeavour to restore and/or maintain their state of health. The actions include use of biomedical health services and/or traditional medical practitioners.

1
2
3

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter presents a review of literature relating to sleeping sickness. It focuses on the disease, its causative agent and the general impact of trypanosomiasis on human communities and their livestock. The historical perspective of HAT in Kenya and literature on health seeking behaviour and the determinants of the behaviour in affected communities is also presented. The chapter further explores some of the theoretical perspectives that explain observable health seeking behaviour in different communities and ends with a discussion of the theoretical framework which guided the study.

2.2 Sleeping Sickness

Human African Trypanosomiasis (HAT) or sleeping sickness is a vector-borne disease caused by the parasite *Trypanosoma brucei* (*Tb*). In East Africa, the parasite that causes HAT is *T.b. rhodesiense* while in West Africa the parasite mainly responsible for sleeping sickness is *T. b. gambiense*. This disease is a major public health problem in sub-Saharan Africa where it affects mainly the rural poor (Lutumba *et al.*, 2007). The disease occurs only in sub-Saharan Africa, in regions where the tsetse fly (vector) is found. However, in Kenya, for unknown reasons, there are many areas, such as North-Eastern, Eastern and Coast Provinces where tsetse is found but sleeping sickness is not. The rural



populations that live in such environments and depend on them for agriculture, fishing, animal husbandry or hunting are the most exposed, along with their livestock, to the tsetse bite.

Sleeping sickness affects remote and rural areas where health systems are least effective, or non-existent. The disease spreads with socio-economic problems such as political instability, displacement of populations, war and poverty. It develops in foci whose sizes can range from a village to an entire region. Within a given focus, the intensity of the disease can vary considerably from one village to the next (WHO, 2001; Bukachi, 2007).

The World Health Organisation estimated that in the affected areas of Africa, about 300,000 people were infected with sleeping sickness in 2004 and over 60,000 people die from the disease every year (MSF, 2004). The parasite causing sleeping sickness is transmitted to humans through the bite of infected tsetse flies. Tsetse flies, humans, cattle, other domestic and wild animals act as reservoirs for the parasites (MSF, 2004; WHO, 2004).

When a person is infected, sleeping sickness progresses in stages. The non-specificity in symptoms of the first stage makes it difficult for non-specialised personnel to diagnose the disease. However, when proper diagnosis is done, this stage is relatively easy to treat. If no treatment is given, the parasites cross over to the infected person's central nervous system and the second stage sets in.

10

This can be as early as a few weeks or as late as several years after infection (MSF, 2004:2). If no treatment is done, the patient ultimately dies.

Prevalence of sleeping sickness in an area is likely to be driven by different environmental, climatic and social factors associated with the presence and density of tsetse flies (Berrang-Ford *et al.*, 2006; Rogers and Randolph, 1993). Courtin *et al.* (2005) add that the introduction of the parasite in an area, the presence of reservoir host species and the frequency of human-fly contact also contribute to the prevalence rate of the disease.

Spatial analysis and geographic information systems (GIS) have been applied increasingly to the understanding of infectious disease epidemiology in recent years. This has also included the analysis of sleeping sickness (Fevre *et al.*, 2001; Courtin *et al.*, 2005; Zoller *et al.*, 2008), animal trypanosomiasis (Hendrickx *et al.*, 2000) and tsetse distribution data (Rogers and Randolph, 1993). However, according to Odiit *et al.* (2006:355), the factors that control the distribution of the disease within small areas are poorly understood, though this knowledge would be of practical use for the targeting of control efforts and the prevention of further spread. Previous studies have linked the distribution of sleeping sickness in Uganda with proximity to areas of swamp and low population densities (Zoller *et al.*, 2008). In addition, several studies have examined the distribution of the tsetse fly, the disease vector, with a number of environmental variables found to have significant correlations with their



distribution. These factors include the distribution of green vegetation cover (Normalized Difference Vegetation Index [NDVI]), humidity, temperature, rainfall and elevation (Rogers and Randolph, 1993; Robinson *et al.*, 1997).

Batchelor *et al.* (2009:9) observe that there was an increased risk of sleeping sickness in villages closer to livestock markets than in villages farther away. This suggests that the spread of the disease may result from the continued movement of untreated cattle. The distribution of specialized health facilities for management of sleeping sickness may also affect disease distribution. According to Odiit *et al.* (2004:342), studies have shown that levels of geographical accessibility to treatment facilities have an effect on the observed spatial distribution of sleeping sickness. Thus, a smaller number of cases has been reported from areas which are farther from the treatment centres. Other factors contributing to the distribution of sleeping sickness include movement of untreated livestock from trypanosomiasis affected areas to comparatively less affected areas (Fevre *et al.*, 2001:627).

In many areas, despite reinforced policy regarding the treatment of livestock for trypanosomes prior to movement from endemic areas, because of some factors, little input towards fulfillment of policy direction seems to be done (Wendo, 2002). The stringent implementation of regulations requiring the treatment of cattle prior to sale at livestock markets should be a priority for affected areas. Tsetse control efforts may be more efficiently targeted to areas surrounding livestock markets to



prevent the establishment of transmission in previously unaffected areas (Batchelor *et al.*, 2009).

2.3 Disease Management and Control

2.3.1 Disease Management

Management of sleeping sickness is carried out through diagnosis and treatment. Diagnosis of the disease relies on detecting parasites in the person's blood or lymph nodes. If the initial diagnosis is positive, it is followed by a lumbar puncture, a painful and potentially dangerous manoeuvre needed to determine whether the disease has reached its second stage. However, according to MSF (2004:2), the current diagnostic methods are difficult to use particularly in resource-poor settings as obtaining accurate results requires highly skilled staff.

Because of this difficulty, many sleeping sickness-infected people go undiagnosed and die from the disease unreported. According to Odiit *et al.* (2005:846), it is estimated that approximately 85% of the patients who die undiagnosed do enter the health system at some stage, and that one-third of those that do enter the health system die undiagnosed. It would thus be expected that less-developed areas would have a high rate of under-detection, and hence higher disease-related mortality, than areas with close proximity to specialized health facilities.

Handwritten blue ink markings, possibly a signature or initials, located at the top left edge of the page.

However, according to Malele *et al.* (2006:84), most health facilities in Third World countries have inadequate capacity in human resource and diagnostic services. Finding malarial parasites in the blood of a patient with sleeping sickness is not unusual, and can mislead clinicians, diverting their attention from the diagnosis of trypanosomiasis and other haemoparasites.

The non-specific nature of symptoms makes it imperative that effort is made to distinguish sleeping sickness from other infections such as malaria, tuberculosis, HIV infection, leishmaniasis, toxoplasmosis, hookworm infection, typhoid, and viral encephalitis (Atouguia and Kennedy, 2000:346). This is because all the above diseases have body weakness, wasting and fever as symptoms. Atouguia and Kennedy (2000:352) further observe that anti-malarial treatment may actually reduce the fever due to sleeping sickness, thus confounding and delaying the correct diagnosis. In most cases, sleeping sickness and malaria co-exist in the affected environments. This may partly explain the reasons for the delay in the confirmatory diagnosis of sleeping sickness cases (Sindato *et al.*, 2008:179). Environmental conditions, infrastructural and socio-cultural barriers may also affect the effectiveness of disease control programmes. WHO estimates that current sleeping sickness control activities reach only 10% of persons at risk (Lutumba *et al.*, 2005:248).

Once parasites are detected in an individual's system, the next step will be staging of the disease. Staging involves performance of lumbar puncture (spinal



tap) to establish if the disease parasites have crossed over to the central nervous system.

The presence of the trypanosomes in the central nervous system (in the cerebral-spinal fluid) indicates that the patient is in the second stage of the disease. The first stage is represented by restriction of the parasites in the blood. After determining the stage of the disease, treatment is commenced. The treatment of sleeping sickness involves the use of chemotherapy. The drugs used in the treatment of sleeping sickness are stage specific. According to WHO (2004) and MSF (2004), first stage sleeping sickness can be treated with two existing drugs, Pentamidine® and Suramine®. These drugs were developed in the 1920s and 1940s, respectively. Suramin® is used to treat sleeping sickness caused by *Tb rhodesiense*. This drug has severe side effects and the treatment course takes five weeks to complete. Pentamidine®, used against *T.b. gambiense*, is usually well tolerated but must be injected in muscles (MSF, 2004; WHO, 2007).

Most infected people only seek treatment when the disease has already advanced to the second stage (Unpublished KETRI Reports). The most common treatment at this stage against both parasites is the use of Melarsoprol® (Thomas, 2004:4). Introduced in 1949, Melarsoprol® is so painful when injected and so toxic that it kills one in every twenty patients receiving it (MSF, 2004:2). Furthermore, the drug is becoming less effective. In some areas, such as Omugo

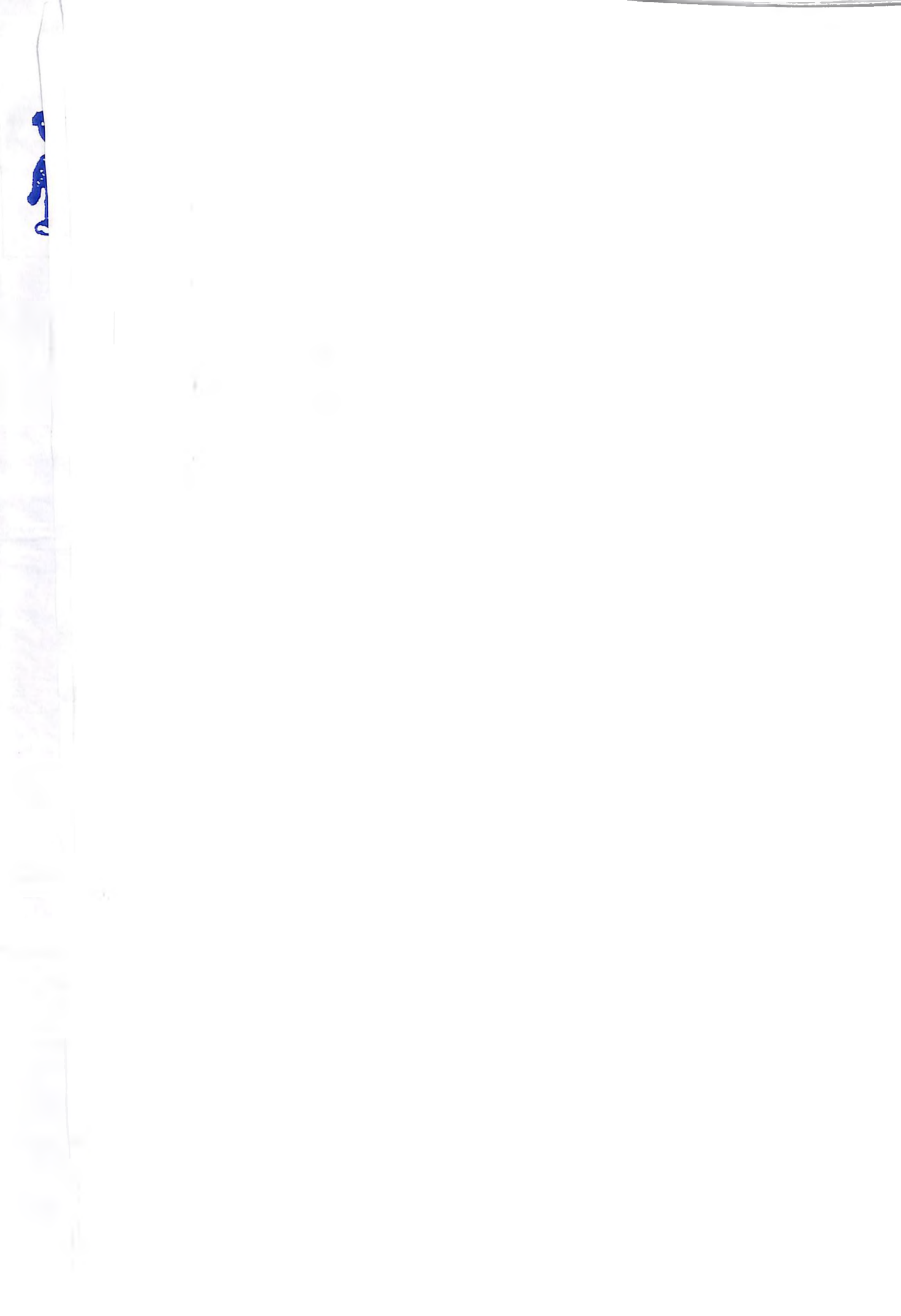


in Uganda and Ibbra in Southern Sudan, in addition to its harmful side effects, the drug has also been found to have a failure rate of up to 30% of patients treated (MSF, 2004:2).

According to Fe`vre *et al.* (2001) and Welburn *et al.* (2001), there is need to improve surveillance of sleeping sickness. Strategies that improve both passive and active case findings should be operationalized. These should also include increased awareness among the affected communities and, most importantly, health workers, as well as a commitment of more resources by authorities for health services at the local level. Given the high mortality that characterizes this zoonotic disease during outbreaks, preventive measures such as chemotherapy of the livestock trypanosomiasis can greatly reduce the risk of outbreaks occurring in sleeping sickness endemic areas like eastern Uganda and western Kenya (Wendo, 2002). Wendo (2002) adds that these areas have predominantly been characterized by both livestock production and cultivation of land for consumption and commercial purposes.

2.3.2 Disease Control

Control of sleeping sickness largely depends on vector control and disease treatment in livestock. Livestock and wild animals act as reservoirs and sustain the disease in communities. According to Thumbi *et al.* (2010:2), an estimated 45-50 million cattle are at risk of infection in Kenya, with an estimated economic loss of up to US\$ 1.3 billion in cattle production.



Records relating to livestock trypanosomiasis at the Teso District Zoologist's (DZ) office indicate that all the divisions within the district reported presence of the disease in livestock in the first quarter of 2010 (Figure 2.1). However, the District Zoologist noted that the livestock trypanosomiasis cases were on a reducing trend compared to the preceding years. According to the Teso District Livestock Production Officer (DLPO), the reduced monthly figures for reported livestock trypanosomiasis cases was due to encouragement of farmers by the veterinary and livestock production offices to use community crush pens and utilization of acaricides that were used to control both tsetse and ticks in livestock. However, according to reports at the District Zoologist's office, in 2010, the district had at least 100 trypanosomiasis reported cases every month. The zoologist indicated that the most affected division in the district was Angurai with 262 reported cases while the least affected was Amukura division with 96 cases (Figure 2.1).

Handwritten blue ink markings on the left margin.

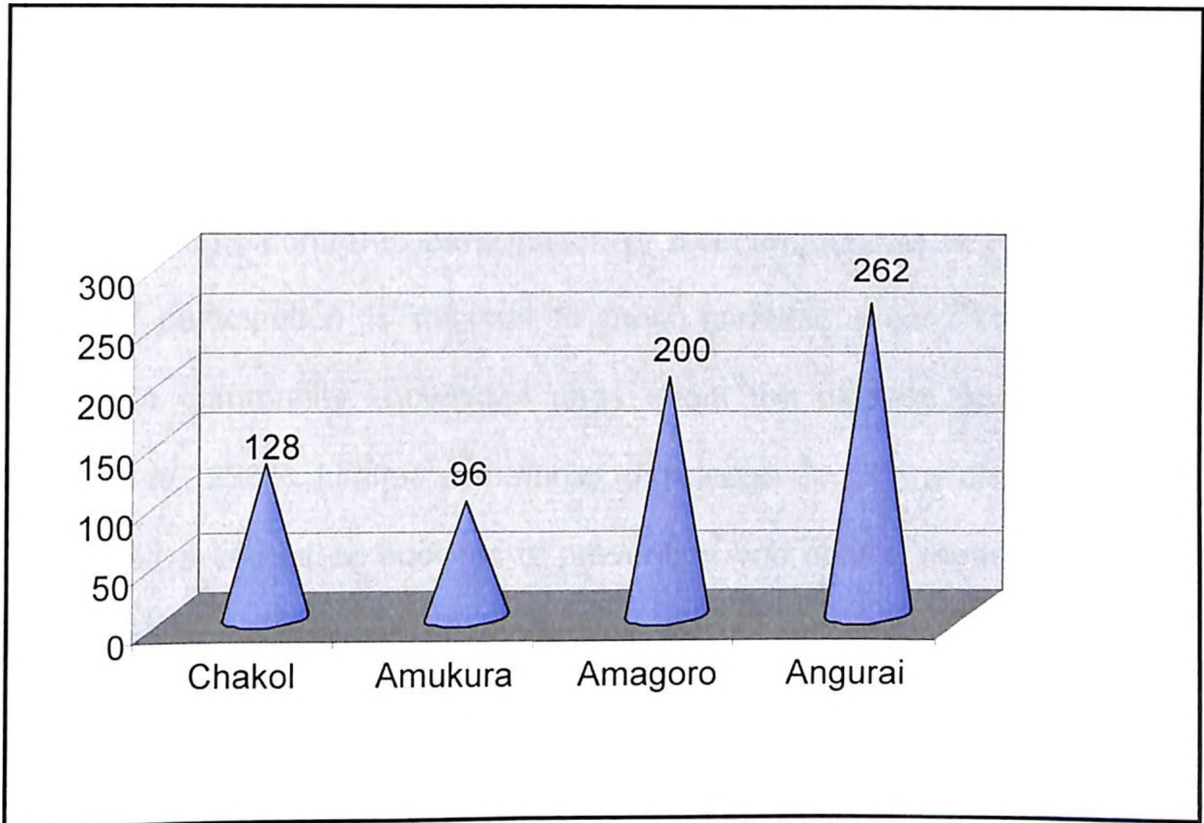
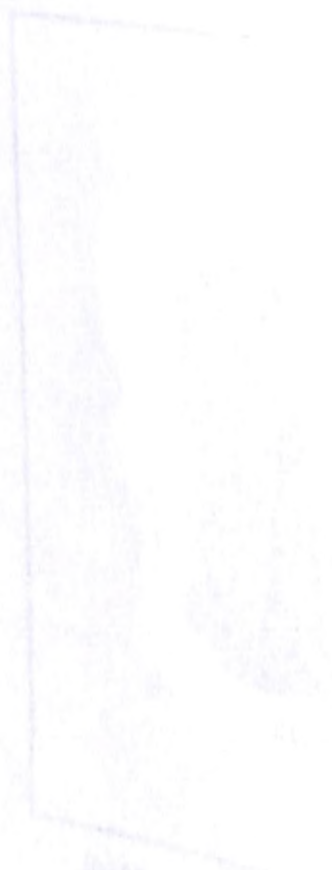


Figure 2.1: Livestock Trypanosomiasis Cases in Teso District (April 2010).
Source: District Livestock Office.

The disease also has public health implications and on this, Schofield and Kabayo (2008) and Madanitsa *et al.* (2009), state that its public health importance has led to attempts to control the disease nationally and regionally with initiatives such as the Pan Africa Tsetse and Trypanosomiasis Eradication Programme (PATTEC) and the East African Network for Trypanosomiasis (EANETT). These initiatives have supported active surveillance amongst human populations and general tsetse and trypanosomiasis (T&T) control activities in affected areas.

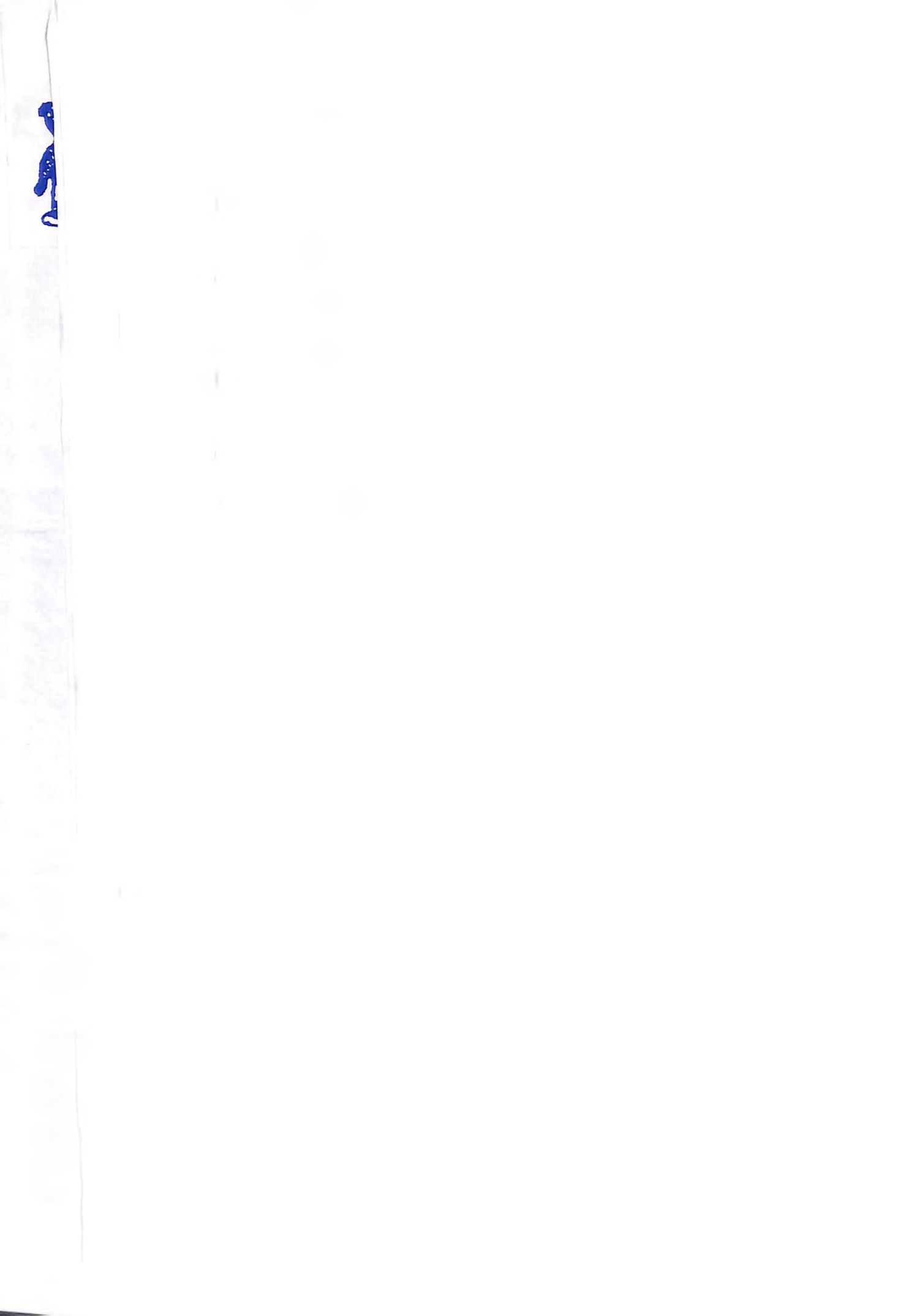


Faint text or a label located directly below the rectangular diagram.

A series of faint, illegible lines of text or a list, positioned in the lower middle section of the page.

According to Kuzoe and Schofield (2004:12), control measures for sleeping sickness include continuous surveillance of the population at risk, treatment of infected people and suppression of vector density using insecticide impregnated traps and targets. Along with this, an equally important aspect in tsetse and sleeping sickness control is participation of the communities at risk. However, community participation is minimal in most endemic areas. This has been attributed to community knowledge gaps about the disease and the vectors (Mboera *et al.*, 2005). Limited community knowledge about any disease not only has a negative impact on success of prevention and control measures but also on health seeking behaviour (Kinung'hi *et al.*, 2006:170).

In Malawi, Madanitsa *et al.* (2009:22) found that sleeping sickness cases tended to cluster in close proximity to animal reservoirs such as game parks. This is also consistent with findings of Kaare *et al.* (2007). Madanitsa *et al.* (2009:24) further observed that men were affected more than women. This could be attributed to greater exposure of men to the parasite because of the nature of the activities that they engage in. These activities include poaching, honey gathering and encroachment on the game reserve to clear land for tobacco farming, which is a major economic activity in the northern region of Malawi. It is within the same vein that the greater proportions of cases are adults owing to activities that bring them into contact with the infected vectors.



2.4 Impact of Trypanosomiasis

Trypanosomiasis is a disease of major economic importance due its effect on both humans and their domestic animals, especially cattle. According to Mulumba (2003) and Abenga *et al.* (2003), the disease is responsible for three million livestock deaths and 55,000 people deaths in Africa annually. Geerts and Holmes 1998 (quoted in Samdi *et al.*, (2010:47) further estimate that about 35 million doses of trypanocidal drugs are administered to livestock annually for curative and chemoprophylaxis in Africa.

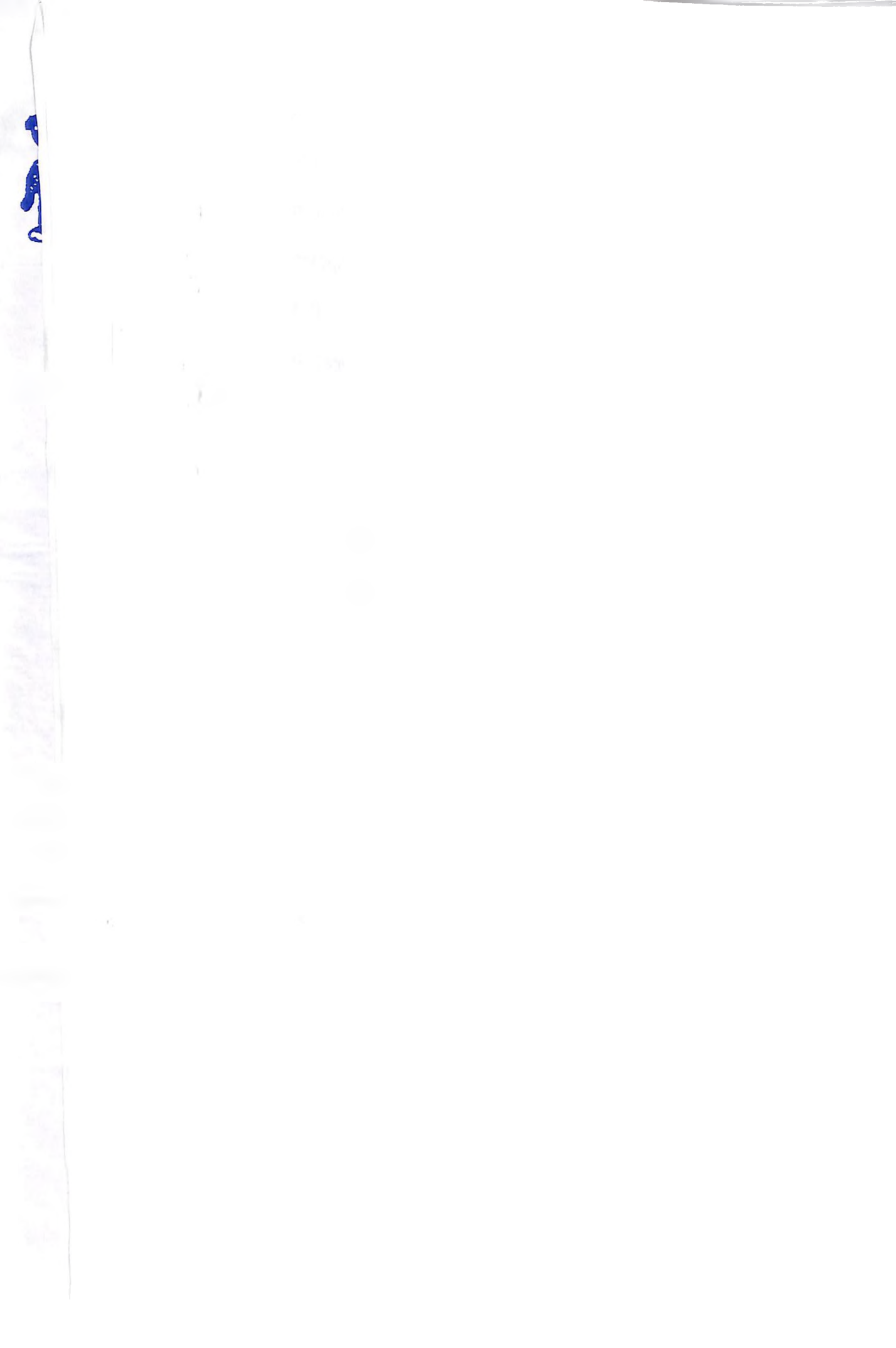
An outbreak of trypanosomiasis causes large losses in livestock numbers. People are also forced to leave tsetse infested areas to less affected areas. This leads to changes in settlement patterns and increases population density of the destination areas (Swallow, 2000; WHO, 1998; Samdi *et al.*, 2010). For example, an outbreak of bovine trypanosomiasis in Lere district of Kaduna, Northern Nigeria, led to livestock deaths and migration of the semi-nomadic Fulani people from the area (Abenga *et al.*, 2003:109).

In the case of sleeping sickness, the disease reduces productivity of the affected people. Family members who take care of the ill abandon their normal routine work and affected school-going children may also drop out of school and assume the responsibilities of more mature members of the community. This may sustain illiteracy rates and levels of poverty in the affected communities (WHO, 1998:43).



The effects of poor health also go far beyond physical pain and suffering. As a result of poor health, learning is compromised, returns to human capital diminish, and environments for entrepreneurial and productive activities are constrained (World Bank, 1994:15). According to Bukachi (2007:31), poor health imposes immense economic costs on individuals, households and society at large. It is evident that better health can contribute positively to economic outcomes in Africa.

If left untreated, sleeping sickness leads to death. The problems associated with this disease, at times transcend treatment. Besides long hospitalization during treatment, some patients suffer life-long disease side effects such as reduced libidinal energy and mental disturbances. The long hospitalization may also negatively affect agricultural-based economies because the affected population may be unable to work (Kuzoe, 2001; WHO, 1998). Patients may also develop functional incapacities that increase their dependence on other community members. Moreover, time and money spent in search of cure may be a serious drain of the family's resources. At community and family levels, mental confusion, personality and behavioural changes which often result when the trypanosomes enter the central nervous system (late stage of the disease), may lead to divorce and break-up in homes. This may also present unfavourable social environment for bringing up of children as well as lead to stigmatization of the patient and the family. In some cases, such people become mentally



disturbed, suicidal and violent. They may, therefore, constitute a danger to themselves and the community (Kuzoe, 2001; Bukachi, 2007).

According to Aroke *et al.* (1998:833), studies in Uganda have observed that sleeping sickness has adverse impacts on the functioning of households. These impacts include increased poverty and decline in agricultural activities, often leading to famine or lack of basic food security. In addition, the researchers involved in the studies noted that the disease caused disruption of children's education and led to reversal of gender roles and obligations (Aroke *et al.*, 1998:834).

An epidemic of sleeping sickness creates a climate of panic that finally makes the survivors abandon fertile land and their homes. Sleeping sickness also creates social problems that completely change relationships and even cultural values. Fear is aggravated by traditional beliefs that sickness and death are the result of witchcraft, religious influences or wrong doing in the family. For example, in the Niger Delta in Nigeria HAT is regarded as a contagious disease. In this case a person suspected of suffering from the disease is stigmatized, isolated and put into quarantine (Airauhi *et al.*, 1999; WHO, 1998). This may increase loneliness and suicidal tendencies amongst sleeping sickness suspects.

2.5 History of Sleeping Sickness in Kenya

Initial researchers who preoccupied themselves with the study of sleeping sickness believed that the disease was a problem restricted to the Busoga area of Uganda. However, Christy (1903, quoted in Welde, 1989:1), believes that sleeping sickness extended across the Kenya-Uganda border in 1901 and spread beyond Kisumu into South Nyanza and progressed into Tanzania.

In 1904, the authorities in Kenya, under the leadership of Dr. Wiggins, then the Medical Officer of Health (MOH) in Kisumu, had the desire to understand the epidemiology of the disease. The causative agent of sleeping sickness was at the time still only a speculation (Welde, 1989:3). At the beginning of his fieldwork, together with his team, Dr Wiggins failed to detect the disease in people in Karachuonyo. However, farther south at Homa Bay, sleeping sickness cases were found in every village. Tsetse flies and sleeping sickness were found in South Nyanza along the Lake Victoria shore line at Gembe, Rangwe, Utegi Karungu and Kadem Point. Disease prevalence and the fly population were particularly heavy at Kadem Point near the mouth of river Kuja (Welde, 1989:3).

On Rusinga Island, Dr. Wiggins found a few sleeping sickness cases. In Central Nyanza, on Magera Island, Dr. Wiggins learned from a local chief that about 500 inhabitants had died from the disease leading to abandonment of the area. Farther north, at Sio Port and Yala, Dr. Wiggins found a high prevalence of

sleeping sickness, a large population of tsetse flies and a shoreline with very heavy vegetation. At Nzalagobe Hill, flies were numerous around villages where most of the inhabitants were infected with two or three deaths daily (Wellde, 1989:3). Dr. Wiggin's visit to these areas confirmed the association between tsetse and sleeping sickness. This associated link propelled the colonial authorities to put in place measures to control the disease and the vector (Wellde, 1989).

Control of sleeping sickness started in 1909 with the signing of the Anglo-German Sleeping Sickness Agreement. The agreement was designed to prevent movement of populations across the Kenya-Tanganyika border. This was followed by construction of an isolation and treatment camp at Kanyamkago. By about 1912, the epidemic appeared to have receded and the sleeping sickness camp was abandoned (Kenya Government, 1912, quoted in Wellde, 1989:4).

However, in 1917, a report indicated a re-emergence of sleeping sickness along Sondu and Awach rivers and at Gembe in South Nyanza where the District Medical Officer (DMO) advised on bush clearing and increased agricultural activities to destroy the tsetse habitats. The areas were later classified as unfit for human habitation due to tsetse infestation and proclaimed a prohibited zone under the Native Authority Ordinance and many people were moved to other regions (Kenya Government, 1940, quoted in Wellde, 1989:4).

In the 1940s, control of sleeping sickness saw the introduction of increased tsetse control using insecticides. Initially DDT® was used but later Dieldrex® was found to be more effective in tsetse control. The insecticide was sprayed in the affected riverine areas and lakeshores. Early in the 1950s, it was found that a majority of areas targeted had experienced effective tsetse control (Glover, 1962, quoted in Welde, 1989:6). However, reinvasion of cleared areas by tsetse flies was found in 1959. It, therefore, became apparent that for sustained tsetse control, constant vigilance and treatment of re-infested areas was necessary. Tsetse control operations with the application of Dieldrex® continued in the early 1980s with activities concentrated in Lambwe Valley (Waema, 1984, quoted in Welde, 1989:7). This concentration of tsetse activities witnessed effective control of sleeping sickness in the region at the time (Welde, 1989:7).

However, there was re-emergence of sleeping sickness in the country in the late 1990s. This saw a total of 95 patients admitted at the sleeping sickness referral hospital at Alupe (Unpublished hospital reports). Thereafter, the number of recorded cases has been marked by fluctuation (Figure 2.2).

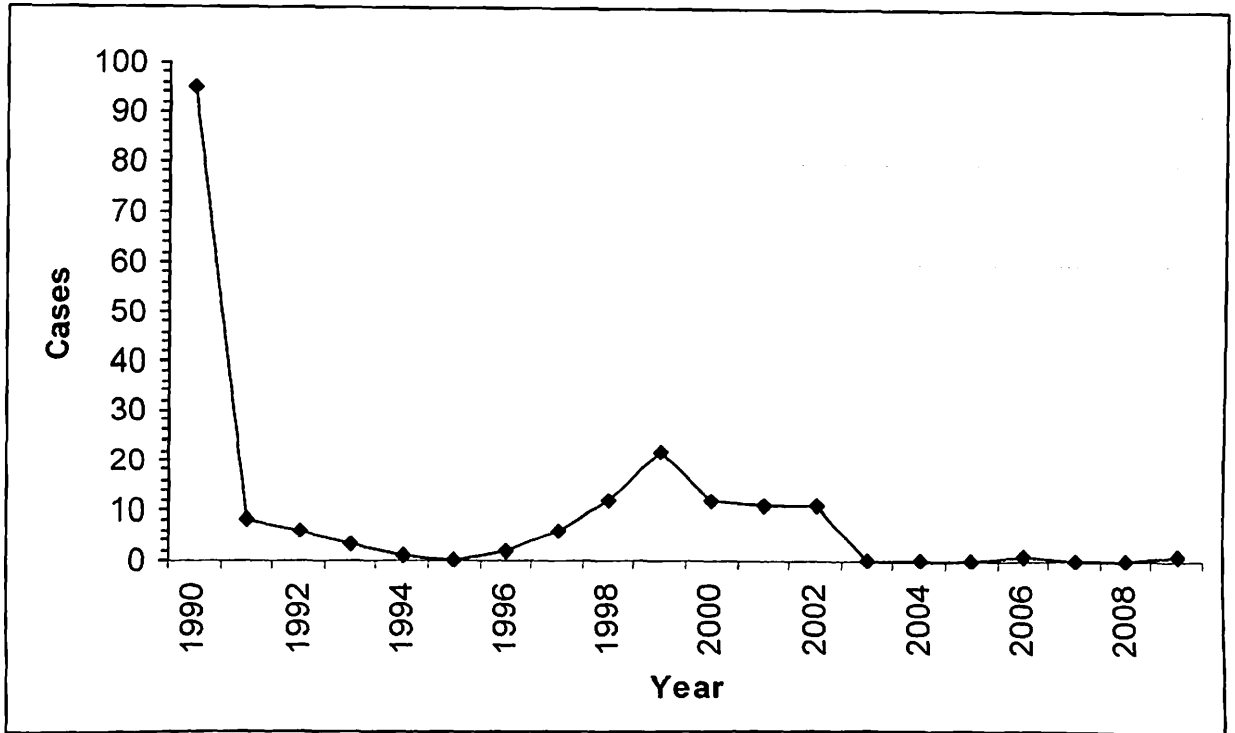


Figure 2.2: Sleeping Sickness Cases Treated at NSSR (1990-2010)

Source: Unpublished Hospital Data

2.6 Perceptions of Disease and Health-seeking Behaviour

Across cultures worldwide, the way people define and respond to illness is learned and varies from one society to another. In different cultures, similar symptoms may be attributed to different causes and, as a result, different communities view and treat their illnesses in varied ways (Logan, 1978:159). Ward *et al.* (1997:23) argue that people's beliefs about the cause of an illness influence where and how patients from the community seek health services.

According to Nyamwaya (1986a) and Whyte and Kariuki (1997), the Luo of western Kenya believe that chronic wasting and debility in an individual is caused by a ritual impurity locally known as *chira*. *Chira* is believed to be caused by individuals not adhering to the community's cultural norms. Some of the reasons blamed for *chira* include: a man having sex with the wife of a living brother, a breastfeeding mother meeting a woman whose child has just passed away, a man having sexual relationship with a woman who is sexually related to his son/sons, an unmarried girl sitting or sleeping on her parents bed and a man neglecting his senior wives in favour of the younger wives (Wanjala, 2000:6). Illnesses perceived to be caused by *chira* may therefore not be treated at formal health centres. In this case the affected people are more likely to seek for health services from traditional medical providers.

Among the Banyole of Uganda, when a person is unjustly or mistakenly killed by a relative, he or she becomes a spirit called *omuhieeno* (Whyte, 1997:132). *Omuheeno* is believed to retaliate against the killer by causing diseases and, ultimately, death to his or her children down through generations. According to these people, the protection of children from this kind of illnesses can only be done through the use of amulets. In such a case, therefore, people are less likely to go to formal health providers for health services.

Apart from disease causality theories, people's perceptions about disease identity and the ultimate reaction from the other community members to the

disease influences health seeking behaviour of the affected individuals. According to Bukachi (2007), sleeping sickness is sometimes erroneously attributed to HIV/AIDS or witchcraft. This causes the patients to be stigmatized and may lead to adverse social and economic effects on HAT affected households. The wrongful association of HAT to HIV/AIDS or witchcraft may also lead to delay in seeking treatment (Bukachi 2007:166).

Perception of the seriousness of an illness by community members may also influence their health-seeking behaviour. Nichter (1991, quoted in Helman, 1994:366) points out that in some communities in the Philippines, diarrhoea associated with dysentery may be considered more serious than ordinary diarrhoea. Fever and pain, not blood in the stool, were seen as the reasons for going to hospital for treatment. However, in Sri Lanka, bloody diarrhoea is associated with 'heat' trapped in the body and such an illness is treated by ingesting 'cooling substances'. Some people, therefore, refuse antibiotics as they look at them as dangerous heating agents. In contrast, others refuse to use oral re-hydration salts (ORS) for watery diarrhoea because cultural beliefs dictate drying of the watery stool during diarrhoeal episodes. However, even in cases where there is general agreement about hospitals being the only capable sources of effective health services, people also exhibit preference for some health facilities to others. Some of the factors that determine people's choice of health facilities include perceived quality of service, distance to the health

facilities from the people's homesteads and the cost of health services (Wanjiru, 2011:440).

2.7.1 Factors Influencing Patients' Choice of Health Facilities

The choice of where an individual goes for health services is largely dependent upon decisive conclusions made by the concerned person. Many factors have been observed by researchers as having an influence on decisions about which health facilities to go to in the event of an illness. Top on the list of factors is the cost of health services offered. In rural areas where most of the people are poor, the cost of services has been noted as the greatest single determining factor. According to Collins *et al.* (1996:61), poor people are more sensitive to service cost changes and the income of poor households strongly influences the choice of their health provider.

Some researchers have observed that user fees introduced by many African governments during the 1980s led to a decline in public hospital attendance. For example, in Tanzania, studies carried out by Hussein and Mujinja (1997:749) in hospitals noted that utilisation of outpatient services in government-owned hospitals in Dar es Salaam declined by more than 50% following the introduction of user charges. In Ghana, the scheme resulted in a drop in attendance at health facilities, especially in the rural areas and one of the reasons given was the high cost of care (Asenso-Okyere, 1995:87).

Kenya introduced user-fees in public health facilities as a cost-sharing programme in 1989. The authorities in the Ministry of Health noted that the introduction of this programme was followed by an average reduction in utilisation of outpatient services by 27% at provincial hospitals, 45% at district hospitals and 33% at health centres (Collins *et al.*, 1996:52).

Many researchers have found an association between cost of health services and attendance to health services particularly for outpatient services. Litvack and Bodart (1993) for Cameroon, Lavy and Germain (1994) for Ghana, Gertler and Van der Gaag (1990) for Cote d'Ivoire and Ngugi (1999) for Kenya, all found that the introduction of user fees reduced the usage of public health services particularly among the poor.

Mwabu *et al.* (1994) and Hutchinson (2001), however, found a strong association between utilisation of health services and distance. They found that those households that were far from health facilities were less likely to use the facilities often compared to those that were located close to the facilities. Hutchinson's (2001:428) survey among Ugandan households found that for every kilometre travelled to the health unit, usage fell by approximately 1%.

The choice of the facility where a patient is taken for treatment is largely made in the household by parents, guardians or relatives. However, at times, patients make decisions about where to go for health services. This happens particularly

when the patients are decision-makers within their respective households (Furuta and Salway, 2006:24).

Apart from household decisions, factors related to health infrastructure such as distance to the health facilities from the household, quality of service offered by the facilities and hospital charges influence facility choice and attendance. However, a study by Egunjobi (2002:265) in Nigeria established that personal factors such as connections with hospital staff, religion and income levels of the affected patients also determine which hospital or health facility to go for health services. King'ola (2010:63) adds that other factors such as gender roles, more particularly the many roles played by women in households, and lack of awareness about the services offered by health facilities negatively influenced utilization of health services by women in Kilome, Makueni (now Mukaa) District.

2.8 Theoretical Perspectives on Disease and Health-seeking Behaviour

Communities have different ways of approaching health, disease and misfortune. In the event of illness or misfortune, particularly when faced with uncertainty relating to cause, family members engage in activities aimed at getting answers about the causative agent(s) and the mechanisms of restoration to what is perceived to be normalcy. In most cases, conclusions made influence the health seeking and maintenance behaviour (Venkatraju and Prasad, 2010:27).

Health-seeking behaviour studies acknowledge that health control tools, where they exist, remain greatly inadequately used. Understanding human behaviour is a prerequisite to changing behaviour and improving health practices (Hausmann-Muela *et al.*, 2003). Experts in health interventions and health policy have become increasingly aware about the influence of human behavioural factors in quality health care provision. In order to respond to community perspectives and needs, health systems need to adapt their strategies, taking into account the findings from behavioural studies (Hausmann-Muela *et al.*, 2003:3). Researchers in the area of health seeking behaviour have utilized theories and models to focus their studies. Some of these models and theories are reviewed below.

2.8.1 The Health Care Utilisation Model

This model was proposed by Andersen (1968). The gist of the model is treatment selection. The model includes both material and structural factors, which influence choice of treatment options. The model identifies, in a logical sequence, three clusters or categories of factors which can influence health seeking behaviour. These factors are predisposing, enabling and need factors.

i. Predisposing factors

These include factors such as age, gender, religion, prior knowledge about disease and general attitude towards health services from the option in

consideration. For an individual to utilize health services, they must be aware of the existence of the services, the social environment in which they live (gender, religion, possession of formal education), must be permissive to the health action and must have positive attitude towards the offered health services (Andersen 1968, cited in Hausmann-Muela *et al.*, 2003:12)

ii.Enabling factors

Utilization of a health system is dependent on factors that facilitate accessibility of the offered services to targeted individuals. These factors include availability of the services to be offered and resources to enable health service seekers to access the rendered services (Andersen 1968, cited in Hausmann-Muela *et al.*, 2003:12).

iii.Need factors

These include perception factors. For an individual to utilize health services related to a particular health condition, factors such as perception of severity, total number of sick days, total number of days in bed and days missed from work or school, among other factors, influence health seeking behaviour (Andersen 1968, cited in Hausmann-Muela *et al.*, 2003:12)

The model was specifically developed to investigate the use of biomedical health services. The use of this model has, however, been extended to include studies on other health care sectors such as traditional medicine and domestic treatments (Weller *et al.*, 1997). Figure 2.3 presents a combination of factors that influence health seeking behaviour.

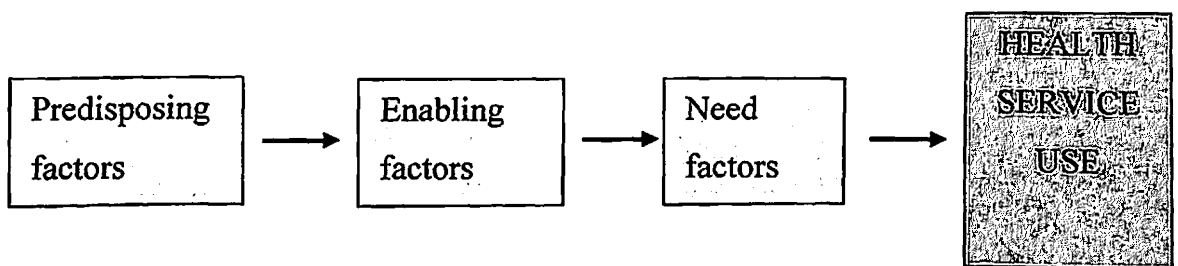


Figure 2.3: Anderson, 1968's Steps in Health Care Utilization Model
(Source: Hausmann-Muela *et al.*, 2003:12)

Whereas the model acknowledges perception about disease to be an important determinant of choice of health care option, it does not address perception about the treatment procedure or institution, factors that may influence one's utilization of a health service provision option. The model is also silent on the individuals' knowledge about disease and seems to give more weight to the social environment as determinants for health care choices. Finally, the model does not address disease causality and its influence on health seeking behaviour. The model did not, therefore, fully address the areas that the project sought to cover.

2.8.2 The Pathway Model

This model was developed by Janzen (1978) and focuses on pathways followed by patients while seeking health restoration in an event of illness. Starting with recognition of symptoms, the model centres on the path that people follow in their search for health services. The model situates the patient at the centre of a social group, 'significant others' that plays an important role in disease management and establishment of the treatment option to be visited (Fig. 2.3).

According to Janzen (1978, quoted in Hausmann-Muela *et al.*, 2003:15) 'significant others' are part of the 'therapy management group', which is key to understanding decision-making in therapeutic processes. However, Hausmann-Muela *et al.* (2003:15) are of the opinion that the emphasis on 'significant others' as key to understanding therapeutic decisions in communities stresses the pivotal role of extended groups of relatives and friends in illness negotiation and management and challenges the role played by the individual in health management.

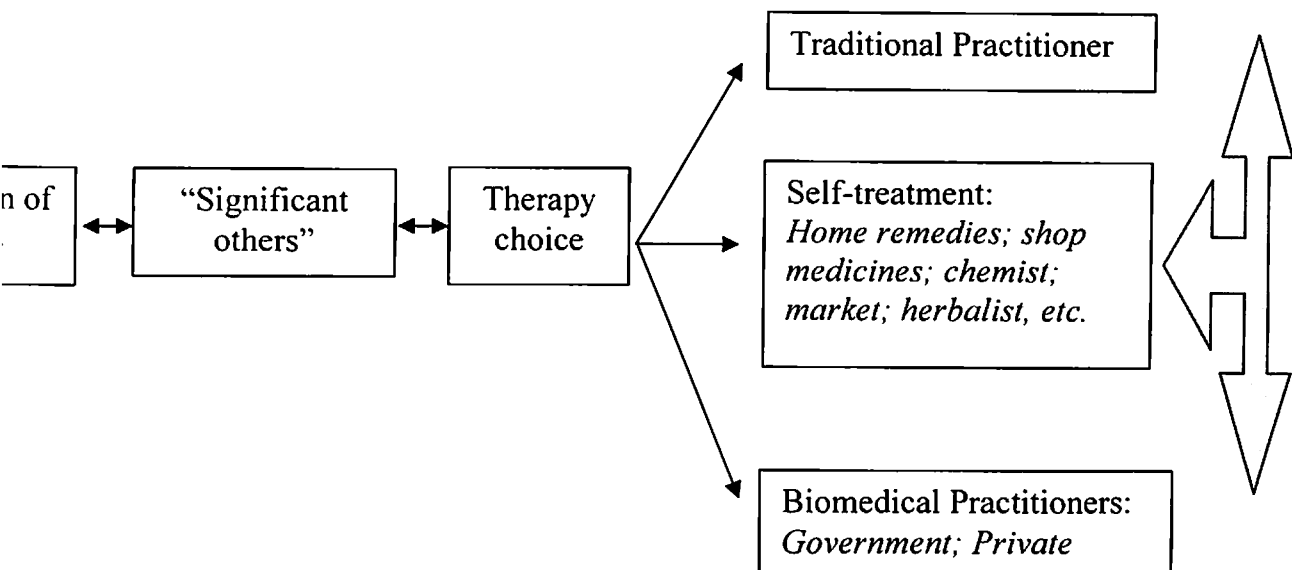


Figure 2.4: Janzen's Pathway Model (Janzen, 1978, presented in Hausmann-Muela *et al.*, 2003:15). The grey arrow indicates that people can move from one sector to another.

This model overlooks the influence of past disease experiences on individuals' health seeking behaviour. The individual perception about disease, treatment and health facilities is not recognized as a role player in an individual's health seeking behaviour. The individual is not also seen as a decision-maker in health care choices but the social grouping in which he or she belongs. Therefore, the pathway model does not fully address all the areas that the project sought to cover.

2.8.3 Social Learning Theory

Social learning theory was proposed by Bandura (1977). The theory looks at behaviour as being shaped by events within the environment and views the

individual as an active participant in his or her behaviour, interpreting events and selecting courses of action based on past experience

However, according to Rosenstock *et al.* (1988:176), the theory does not acknowledge an individual's perception of disease or health provider as an important determinant of health seeking behaviour. It does not also address cues to action within the health provision infrastructure such as referral services or health related advertisements within the environment that may influence health seeking behaviour. The theory concentrates on past experiences. Therefore, the social learning theory did not provide an appropriate framework for the study.

2.9 Theoretical Framework

To answer the research questions this study utilized two theoretical frameworks, namely, the health belief model (HBM) and the disease theory (DT).

2.9.1 Health Belief Model (HBM)

The health belief model is a psychological model that attempts to explain and predict health behaviours by focusing on the attitudes and beliefs of individuals. The model was developed as part of an effort by social psychologists in the United States Public Health Service (USPHS) to explain observed poor public participation in health screening and prevention programmes particularly during the free and conveniently located tuberculosis project (FHI, 2004:2). Since then, the HBM has been adapted to explore a variety of health behaviours, including

sexual risk behaviours and the transmission of HIV/AIDS. According to Rosenstock *et al.* (1994:14), the key variables of the HBM include perceived threat, perceived benefits, perceived barriers and cues to action.

The perceived threat consists of perceived susceptibility (one's subjective perception of risk of contracting a health condition) and perceived severity (the feelings concerning the seriousness of contracting an illness or the consequences of leaving it untreated-including both medical and social consequences). Perceived benefits include the believed effectiveness of strategies designed to reduce the threat of illness. On the other hand, perceived barriers constitute the potential negative consequences that may result from taking particular health actions, including physical, psychological and financial demands. Finally, cues to action include events, either bodily such as disease symptoms, or publicity that motivate people to take action (FHI, 2004; Eisen *et al.*, 1992).

2.9.2 Disease Theory (DT)

Disease theory was conceptualised by Foster and Anderson (1978). The theory deals with causality, the explanations given by people to account for the loss of health. Explanations such as breach of taboos, an upset in the hot-cold balance within the body, failure of a person's immunological defences against pathogenic agents such as germs and viruses or the work of a sensate agent who may be a supernatural being (a deity or a god), a non-human being (such as ghost,

ancestor or evil-spirit) or a human-being (a witch or a sorcerer) are, therefore, found in a people's disease theory. The main tenet of the disease theory is that the people's ideological standpoint about causality of a particular health disorder influences their health seeking behaviour (Foster and Anderson, 1978:37).

The subject matter of explaining illness, its causes and how to go about curing it is, therefore, found in the disease theory of any particular community. According to Foster and Anderson (1978:42), the disease theory dictates where and from whom to seek treatment. For example, if an illness is defined as due to an intrusion of an object by a sorcerer, extraction of the object is essential to return the patient to health. In Western medicine, if a laboratory analysis indicates a pathogenic infection, then an appropriate antibiotic is prescribed by a physician. Studies by Wanjala (2003) and Whyte (1997) amongst the Luo of Kenya and the Banyole of Uganda respectively reinforces the ideas by Foster and Anderson (1978).

This theory, therefore, focuses on people's beliefs about the nature of health, the perceived causes of illness and the approaches used for restoration and protection of health. The disease theory has been utilized by other scholars such as Maithya (1992) in his investigation of the awareness and management of mental illness among Babukusu of Bungoma District and Wanjala (2000) in his research on perceptions of diarrhoea in children under five years of age among the Luo of Bondo District in Western Kenya.

2.10 Relevance of the Theories to the Study

This study was conceptualised with the basic assumption that there are barriers within the community that prevent potential sleeping sickness patients from seeking formal health services at the sleeping sickness hospital. The health belief model addressed issues related to perception of threat, seriousness and cost (including financial, social and geographical) of sleeping sickness by the people living in the research site. The model also focussed on the existence of any supportive programmes within the community that influenced community members to seek for health services from the sleeping sickness hospital. On the other hand, the disease theory addressed issues related to disease causality among people living in the research site. A combination of the two theories, therefore, provided the framework within which this study was mapped (See Figure 2.5).

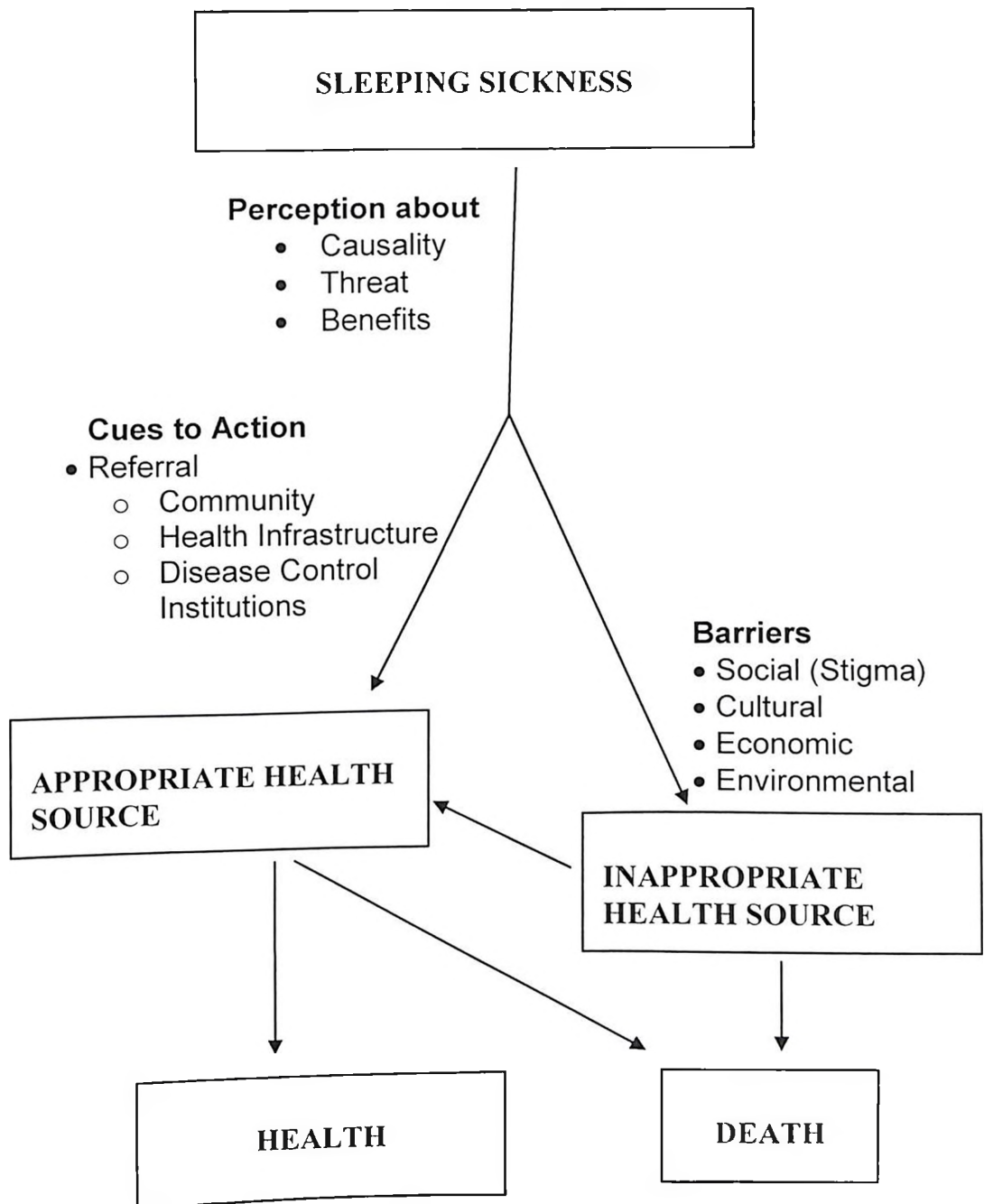


Figure 2.5: Diagrammatic Representation of the Conceptual Framework
 Source: Adapted from Foster and Anderson (1978).

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter describes the methodology used in the study. The study site is described with focus on administrative boundaries, health infrastructure and the people. Emphasis is put on the people's cultural aspects relevant to the study. The research design involving study population and unit of analysis, sampling design, the scope and limitations of the study and strategies employed to overcome the limitations is also presented. The chapter concludes with a presentation of the data collection methods, data analysis techniques and the measures put in place to fulfil ethical requirements during and after the fieldwork.

3.2 Study Site

3.2.1 Location and Physical Features

Teso district is one of the 19 districts that make up Western Province. The district is bordered by Bungoma South district to the East, Bungoma West district to the North-east, Busia district to the South and the Republic of Uganda to the West (Fig. 3.1). The district lies between latitudes 0° and $0^{\circ} 32'$ North and longitudes $34^{\circ} 01'$ and $34^{\circ} 07'$ East. It has an approximate area of 553 km^2 with a permanent water surface area of 137 km^2 which increases during the wet season when the low lying swampland along river courses floods (GoK, 2002:4). All the

rivers in the district are part of the Lake Victoria basin drainage system (Angus, 1996).

Most parts of Teso district receive between 1,270 mm and 1,790 mm mean annual rainfall, though some parts of the district may receive an evenly distributed rainfall of up to 2,000mm. About 50% of the annual rainfall occurs during the long rains season with peaks between late March and late May while 25% falls during the short rains with peaks in August and October. A dry spell with scattered rains occurs in December to February (GoK, 2002:4).

Temperatures for the whole district are more or less homogeneous. The annual mean maximum temperature ranges between 26°C and 30°C while the mean minimum temperature ranges between 14°C and 22°C (GoK, 2002:6).

The district's altitude ranges from 1,300 metres above sea level in the south to an average of 1,500 metres above sea level in the central and northern parts. The land is suitable for both food and cash crops (GoK, 2002:4). The main staple foods grown in the district are maize, cassava, millet, sorghum, beans, groundnuts, sweet potatoes and bananas. The crops are consumed at subsistence level but at times they are sold, thereby serving the dual purpose of food and cash crop (Angus, 1996:76).

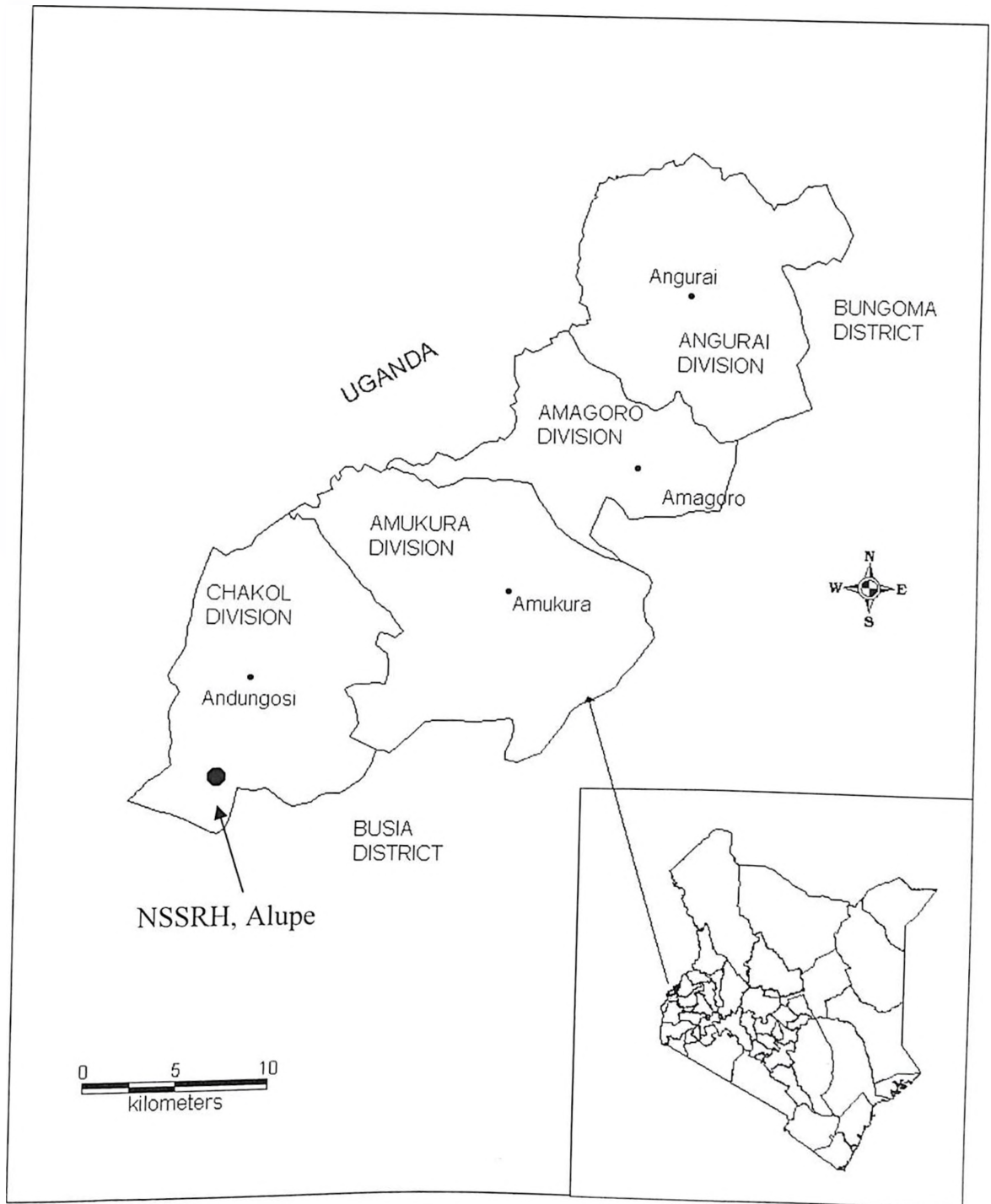


Figure 3.1: Map of Teso District showing administrative divisions and the location of NSSRH, Alupe.
 (Map drawn by Mr. Musembi Kikwae, GIS section, KARI-TRC)

3.2.2 Administrative Divisions

Teso District is divided into four administrative divisions that include Amagoro, Angurai, Amukura and Chakol (Figure 3.1). The district is further sub-divided into thirty locations and eighty-two sub-locations (Table 3.1 below). In 2009 the district had a population of 255,871 people. Chakol division, with a population of 76,388 was comparatively more populated while Amagoro division, with a population of 58,207 people, was the least populated. Amukura division had a population of 61,536 people while Angurai had a population of 59,740 people (GoK, 2010).

However, as far as population density is concerned, Chakol and Amagoro divisions were comparatively more densely populated with population densities of 543 and 510 people per square kilometre, respectively. Amukura division, with a population density of 387 people per square kilometre, was the least populated (GoK, 2010).

Table 3. 1: Administrative Units in Teso District

| Division* | Area km² | Locations | Sublocations |
|------------------|----------------------------|------------------|---------------------|
| Amagoro | 114 | 9 | 21 |
| Amukura | 155 | 7 | 20 |
| Angurai | 149 | 8 | 23 |
| Chakol | 135 | 6 | 18 |
| Total | 553 | 30 | 82 |

Source: GoK (2009:3)

* The process of sub-division of the district is on-going. Amagoro and Angurai are to be based in North Teso with its headquarters in Amagoro Town while Chakol and Amukura are to be based in South Teso with its headquarters in Amukura Town. With completion of the sub-division, new administrative units may be created.

3.2.3 Religion

The Iteso practise religions of conversion (Christianity and Islam) as well as their traditional religion. These people knew of the existence of God, whom they called different names. The names that were used to refer to God were *Nakasuban* (creator), *Akuj* (one in the sky), *Apaap* (great father) and *Ejokit* - the good one (Akong'a and Ekeya, 1986:28).

During times of need or crises such as epidemics, barrenness or drought, communal prayers and sacrifices were offered. The prayers were led by a diviner (*Imurwon*). The Iteso attributed misfortune to causes other than God. The

causes and remedies for individual misfortunes were sought through divination. Most diagnosis always points to witchcraft, breach of taboos and omission of rites. Besides diagnosis, an *Imurwon* (plural, *Imuruok*) prayed for blessings over people, officiated at the trial of a suspected criminal and performed ritual cursing, *ilami*, whose result was misfortune and illness to the victim (Akong'a and Ekeya, 1986:29).

3.2.4 Health, Belief Systems and Status

Among the Iteso, diseases are grouped into two categories, namely, those diseases that are best treated at home and those that require hospital treatment for effective recovery of the patient. Diseases such as leprosy (*emulo*), scabies (*chup*), measles (*ekuwam*) and epilepsy (*imataula*,) are believed to be best treated at home while diseases such as diarrhoea are believed to be effectively treated at the hospital. Such beliefs affect the actions taken when a person falls sick (Nyamwaya, 1986b:89).

The occurrence of illness in an individual in this community is blamed on factors that include natural, supernatural and humanistic. If improper funeral rights are performed on a dead family member, it is believed that the displeased spirits will hound the living members of the family, causing them illness. The healing process in such cases involves performing rituals by a diviner to please the affected spirits. The rituals (*epunyas*) involve exhuming the afflicting ancestor's bones, placing them under a specific tree and subjecting them to libations of food

and drink. To prevent ancestors from causing illnesses, *epunyas* should be performed about ten years or less after death. Another ritual known as *eworo* is performed when an illness is believed to be caused by humanistic causes and the healing process is set in motion when an animal is slaughtered and villagers invited to eat the meat (Nyamwaya, 1986b:98).

The most prevalent diseases in Teso district are malaria and respiratory tract infections (RTIs). However, the greatest challenge in the district is posed by HIV infections with a prevalence rate of 5.1 per cent. The district has a total of 18 health facilities – 2 Sub-district hospitals, 4 Health Centres, 11 Dispensaries, and 1 Nursing home. There are 16 private clinics in the district, the average distance to the nearest health facilities being 5 km (GoK, 2009: 18).

3.2.5 Education

The District educational statistics in 2008 indicated that at pre-primary level, total enrolment for both boys and girls stood at 12,100 pupils with negligible dropout rate. There were a total of 66,524 pupils enrolled in primary schools consisting of 33,027 boys and 33,497 girls (GoK, 2010). In 2009, there were a total of 124 primary schools in the district (GoK, 2009: 19).

In 2008, the number of students attending secondary education in the district was 7,543 consisting of 4,288 boys and 3,255 girls (GoK, 2010). There were a total of 23 secondary schools in the district (GoK, 2009: 19). However, statistics indicate

that at primary level, the enrolment of girls is higher than that of boys. However at secondary school enrolment, the number of boys is higher than that of girls (GoK, 2009:30). This disparity in enrolment between boys and girls at secondary level may be explained by the preference for boys by parents, early marriages and teenage pregnancies (GoK, 2009:30). According to Akong'a and Ekeya (1986:32), women among the Iteso were not supposed to excel in areas considered to be the domain of men. This domain included leadership positions, academic excellence, economic independence and inheritance of property. This cultural expectation for women to occupy subordinate position to men and the high cost of education may explain the comparatively low average attendance in secondary schools for girls in the district. GoK (2010:119) indicates that the number of males who had never attended formal school in the district in 2009 was 13,327 as opposed to 19,983 females (Table 3.2).

Table 3.2: Population by Sex, Highest Level of Education Attained and Division

| Divisions* | Never Attended | | Pre-Primary | | Primary | | Secondary | | Tertiary | | University | |
|---------------------|----------------|---------------|--------------|--------------|---------------|---------------|---------------|---------------|--------------|--------------|------------|------------|
| | Male | Female | Male | Female | Male | Female | Male | Female | Male | Female | Male | Female |
| Chakol and Amukura | 8261 | 12412 | 5186 | 5256 | 35112 | 38005 | 7947 | 6200 | 1284 | 1135 | 502 | 272 |
| Amagoro and Angurai | 5066 | 7571 | 4438 | 4356 | 29804 | 33581 | 9372 | 7127 | 1155 | 998 | 406 | 181 |
| Total | 13,327 | 19,983 | 9,624 | 9,612 | 64,916 | 71,586 | 17,319 | 13,327 | 2,439 | 2,133 | 908 | 453 |

Source: GoK (2010:119)

3.3 Research Design

This study was cross-sectional in nature and both qualitative and quantitative methods of data collection were employed. The study was structured into three phases with frequent visits to the research site to undertake activities aimed at answering research questions and emerging issues.

During Phase one, the survey instrument was pre-tested in Samia district, a neighbouring district to the research site. This was done to ensure that the interviews are carried out with ease and that responses from respondents are maximised. The pre-testing exercise was followed by structured interviews in Teso district. Also, during this phase, establishment of households belonging to former sleeping sickness patients and/or their relatives was done to lay down the groundwork for case studies.

Phase two involved conducting of in-depth interviews. The participants in in-depth interviews were former sleeping sickness patients and/or their relatives. The other activity conducted in this phase was key informant interviews. The participants in these interviews included sleeping sickness hospital staff, officers from the ministry of livestock within the district, local administrators (chiefs) and other people considered to be knowledgeable about sleeping sickness.

Phase three involved conducting focus group discussions. During this time, answers to emerging issues in preceding activities such as why people from the

district sought treatment from Uganda and the status of referral service by formal health providers were given. This activity also provided the framework through which triangulation of information from various respondents was made possible.

Data from the survey were analyzed using descriptive statistics and the results presented in the form of tables of frequencies and percentages. Cross-tabulation of important variables to the study was also undertaken. Other analysis tools such as principal component analysis (PCA) were also utilized to establish meaningful interactions between variables. On the other hand, data collected during focus group discussions, key informant and in-depth interviews were analyzed through content analysis and presented in form of verbatim quotes.

3.4 Study Population and Unit of Analysis

The study population included all households within the four divisions of Teso district. The household constituted the unit of analysis since decisions about when and where to go for healthcare in the event of illness were made within the household.


Within the household, adults 18 and above years old were approached to participate in the research and provide answers to the research instruments. The focus on adults is because they can comprehend their experiences with the disease better than children.

3.5 Sample Size and Sampling Strategy

A multi-stage sampling strategy involving purposive and simple random sampling techniques was utilized in this study to get the desired information. Purposive sampling was adopted to get the villages from where research activities were undertaken. Villages that were sampled included Apatit and Obekai (from Amukura division), Ikapolok and Totokakile (Amagoro division), Obuchun and Amaase (Andungosi division), and Katotoi and Ademoru (Angurai division) [Figure 3.3]. This sampling technique was used because former sleeping sickness patients served at the NSSRH hailed from these villages.

To get the number of households from where respondents were obtained, the researcher utilized Raosoft® (2004), an internet-based resource for sample size calculation (<http://www.raosoft.com/samplesize.html>). The required variables to enable computation of the representative household sample included the margin of error, confidence level and the total number of households in Teso district. Because the total number of households was unknown at the time, given the dynamic nature of residential construction, the total number of households was taken to be 20,000. The above variables were, therefore, inserted into the table provided by Raosoft® (2004) and the calculation of the minimum representative sample reached at 384 households (Table 3.3). For easy workability, however, the researcher took his working sample size to be 400.

Table 3.3: Raosoft Sample Size Calculation

|  Raosoft® | | |
|---|------------------------------------|--|
| What margin of error can you accept? (5% is a common choice) | <input type="text" value="5"/> % | The margin of error is the amount of error that you can tolerate. If 90% of respondents answer yes, while 10% answer no, you may be able to tolerate a larger amount of error than if the respondents are split 50-50 or 45-55. Lower margin of error requires a larger sample size. |
| What confidence level do you need? (Typical choices are 90%, 95%, or 99%) | <input type="text" value="95"/> % | The confidence level is the amount of uncertainty you can tolerate. Suppose that you have 20 yes-no questions in your survey. With a confidence level of 95%, you would expect that for one of the questions (1 in 20), the percentage of people who answer yes would be more than the margin of error away from the true answer. The true answer is the percentage you would get if you exhaustively interviewed everyone. Higher confidence level requires a larger sample size. |
| What is the population size? If you don't know, use 20000 | <input type="text" value="20000"/> | How many people are there to choose your random sample from? The sample size doesn't change much for populations larger than 20,000. |
| What is the response distribution? (Leave this as 50%) | <input type="text" value="50"/> % | For each question, what do you expect the results will be? If the sample is skewed highly one way or the other, the population probably is, too. If you don't know, use 50%, which give the largest sample size. See below under |
| Your recommended sample size is | 384 | This is the minimum recommended size of your survey. If you create a sample of this many people and get responses from everyone, you're more likely to get a correct answer than you would from a large sample where only a small percentage of the sample responds to your survey. |

Source: Raosoft® (2004) (<http://www.raosoft.com/samplesize.html>)

To get to the individual households where the questionnaire was administered, the researcher approached local administrators (chiefs) who, with the assistance of respective village headmen, provided lists of households for the above

villages. The lists constituted sampling frames for the households. Thereafter, simple random sampling was employed to get a maximum of 50 households from each of the above villages. The actual operationalization of the simple random sampling procedure involved assigning numbers to the provided households. The numbers were then written on pieces of paper (a single number on each piece of paper). The papers were then folded and dropped in a box. Thereafter, four research assistants were asked to pick the pieces of paper with numbers representing individual households from the box in turns till a count of 50 was reached. The 50 randomly picked numbers were then correlated with the list to give the 50 randomly sampled households per sampled village. In total, therefore, 400 households were targeted for questionnaire administration in the district. Each of the sampled 400 households provided a respondent for interviews.

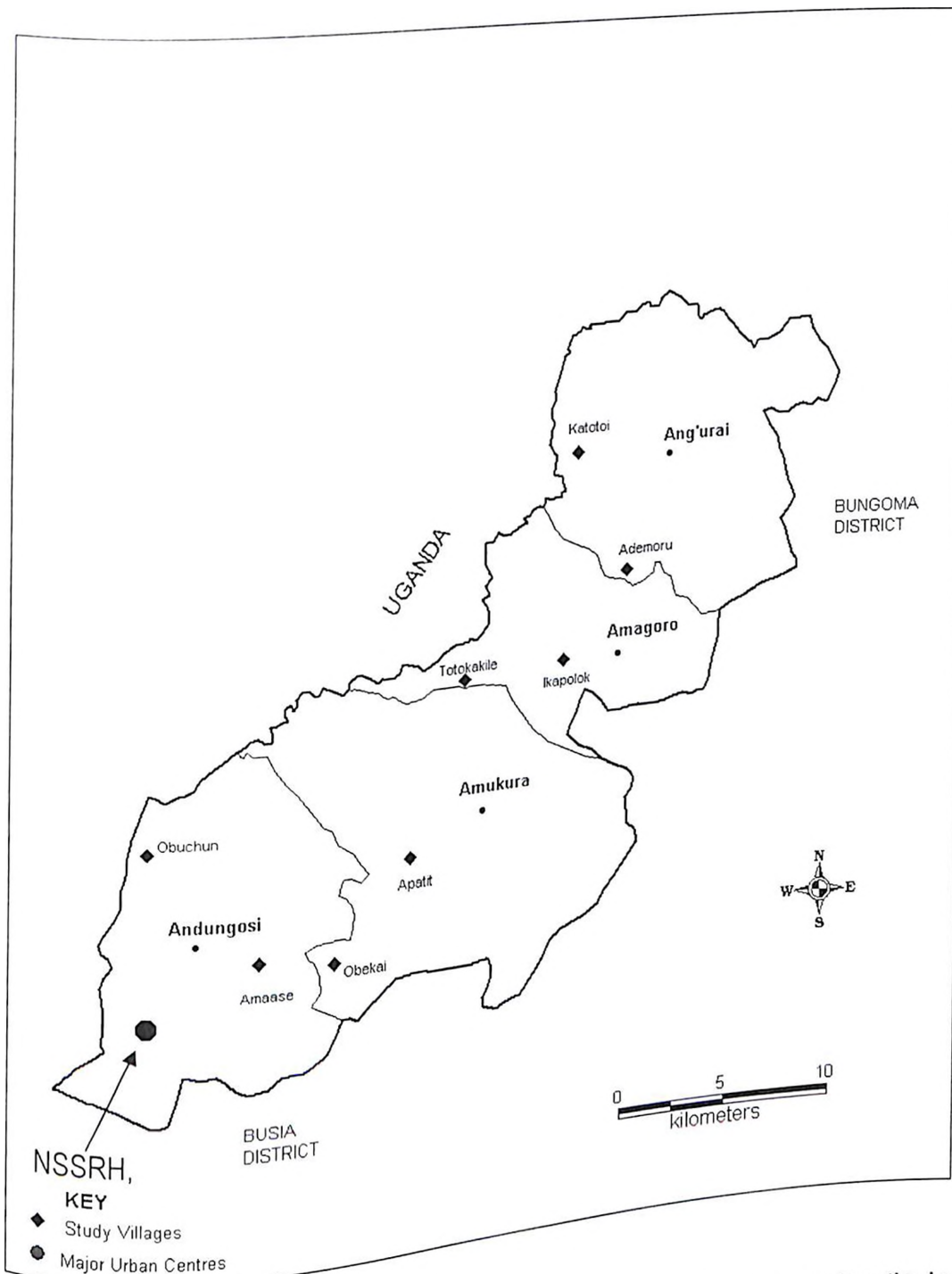


Figure 3.3: Map of Teso District showing sampled study Villages indicating the location of NSSRH
(Map drawn by Mr. Musembi Kikwae, GIS section, KARI-TRC)

3.6 Methods of Data Collection

3.6.1 Structured Interviews

During the survey, face-to-face interviews were conducted with the help of a structured questionnaire (Appendix 1). The questionnaire was composed of open-ended questions. This questionnaire design was necessitated by the researcher's desire to give respondents the framework in which to provide unrestricted but moderated information on the variables in question. This activity was used to get initial insights into the community and information about the general area of interest, including knowledge levels of sleeping sickness and the National Sleeping Sickness Referral Hospital at Alupe; determination of people's health seeking behaviour in relation to sleeping sickness; establishment of the existence of referral services among health provision agents; and determination of people's prioritisation of sleeping sickness management and control. The information obtained at this stage was, therefore, used as a basis for other research methods such as key informant interviews and focus group discussions.

3.6.2 In-depth Interviews

Case histories were conducted with former sleeping sickness patients or their close relatives to get their experiences with the disease during and after periods of illness. Retrospective interviews were conducted to establish if the former patients encountered stigmatization from people they interacted with during the times of illness and after. Their experiences with hospital attendants in the district

in terms of whether they were referred to the NSSRH and the ultimate path they followed in their endeavour for health restoration were also sought.

Information on location of the former sleeping sickness patients and/or their relatives was obtained from the sleeping sickness hospital. A total of 50 former sleeping sickness patients were purposively selected for interview from a list provided by officers from the National Sleeping Sickness Referral Hospital. A criterion for inclusion was the availability of the sleeping sickness survivors, or their relatives. However, during the fieldwork only 43 former sleeping sickness patients were traced. The researcher, therefore, employed snowballing that yielded the seven additional former sleeping sickness patients and/or their relatives within the research site. In-depth interviews were particularly important because they illuminated the health-seeking behaviour of people who were once affected by sleeping sickness either as victims or relatives of the patients.

Extrapolative explanations as to why a majority of sleeping sickness patients presented themselves at the sleeping sickness hospital while in the second stage of the disease was established through the case histories. A checklist of themes (Appendix 2) was used to conduct the interviews.

3.6.3 Key Informant Interviews

Key informant interviews were carried out to get in-depth information about the topic in question and also authenticate information obtained through the survey.

The key informants were those people considered knowledgeable about sleeping sickness and health seeking behaviour in general either through training or experience as a result of having interacted with sleeping sickness patients. Therefore, the key informants included local administrators (chiefs and village headmen) and sleeping sickness hospital staff. The major objective of this method was to provide in-depth information about the path followed by sleeping sickness patients before they ultimately reach the sleeping sickness hospital for treatment. The information that was obtained during the survey was also authenticated during key informant interviews. A total of 10 key informants were interviewed. A key informant interview guide (Appendix 3) was used to conduct the interviews.

3.6.4 Focus Group Discussions

Focus group discussions were used to authenticate and complement information obtained through the survey and to fill any gaps observed from the findings. Each focus group discussion was composed of twelve discussants. The participants in the discussions were purposively sampled from community members believed by the researcher to be knowledgeable about the subject under discussion. The discussions were conducted with the help of a focus group discussion guide (Appendix 4). A total of eight focus group discussions were held, four with women and four with men. This method provided additional qualitative data to enrich the quantitative information collected during the survey. The inclusion/exclusion criterion was the period of residence in the research site. An

individual who had resided in the research site since the 1980s qualified to be included in the focus group discussions. The 1980s was the period when the sleeping sickness problem was a among major human health concerns for authorities involved in disease control in the district and so whoever had resided in the district since then was deemed to be knowledgeable about the disease.

3.6.5 Secondary Sources

Secondary data were obtained from already collected and published data by researchers who were involved in work on similar or related topics to the research. Sources of secondary data were, but not restricted, to copies of theses, published books, published articles in journals, sleeping sickness hospital reports, news prints and internet materials. The collection of this kind of data was a continuous exercise throughout the study.

3.7 Data Processing and Analysis

Data obtained from key informant interviews and focus group discussions were coded using *Open Code 2.0* computer programme and analysed through content analysis. Presentation was by description of reality as provided. In-depth interviews were analysed and presented by verbatim quotations of the information provided by informants in retrospect. On the other hand, data obtained from the survey were coded, entered into the computer and analysed by descriptive statistics using *SPSS 12.0* computer programme and findings presented in tables of frequencies and percentages. Cross-tabulations were

done in instances where comparison of variables was seen to be necessary. Principal component analysis (PCA) was also used to establish significant determinants of the health-seeking behaviour of the study subjects.

3.8 Ethical Considerations

This project received clearance from the Kenya Medical Research Institute, a national research institution with the mandate to carry out research related to human health in Kenya (Appendix 5). As far as participation in the research activity was concerned, the consent of respondents was sought before commencement of interviews. Evidence for acceptance of participation was by appending of one's signature on the consent-seeking section of the questionnaire. Full explanation about the purpose of the research activity and expectations of the researchers from respondents, however, took precedence. The study ensured a high degree of privacy and confidentiality from the data collection stage to storage. During data collection, the survey instruments only indicated codes instead of respondents' names for identification. A separate note book was used to record the identities of the codes. This was done to ensure that only the researcher understood the identity and location of respondents just in case a revisit for clarification of issues was needed.

CHAPTER FOUR

KNOWLEDGE AND PERCEPTIONS OF SLEEPING SICKNESS

4.1 Introduction

This chapter presents findings on knowledge and perceptions of sleeping sickness and the NSSRH by residents of Teso district. The chapter begins with a presentation of the socio-demographic characteristics of the respondents, their economic activities and distances from (respondents') residences to major access roads. Thereafter, highlights of the respondents' knowledge of sleeping sickness, the symptoms associated with the disease and their knowledge of the National Sleeping Sickness Referral Hospital are presented. The social cost of the disease and the respondents' perceptions of the treatment process are also highlighted.

4.2 Socio-Demographic and Environmental Characteristics

The respondents for this study were drawn from the four divisions of Teso district. The socio-demographic and environmental factors in focus are age of respondents, level of formal education attained, economic activities and distance from homesteads to major access roads.

4.2.1 Age and Sex

The youngest respondent was 18 years of age while the oldest was 82 years old. The respondents' modal age was 40 years.

As far as the sex of respondents was concerned, over half, 57.5% (230), were female while 42.5% (170) were male.

4.2.2 Educational status

Literacy was gauged by the ability to read and write in Kiswahili, English and Ateso, the local language. Multiple responses indicated that more than half (57.3%, 229) of the respondents, could not read or write in Kiswahili, 50% (200) could neither read nor write in English and an equal proportion of respondents (50% or 200) could not read or write in Ateso, the local language. Regarding the level of formal education, 61% (243), of the respondents had primary level of education though with variations in the highest level attained. Slightly over a third, 36.6% (146) of the respondents had taken between 6 and 8 years of formal schooling (had gone up to upper primary level of education). Only a few respondents, 1.5% (6) had attained post-secondary level of education, to either university or other post-secondary institutions, that is, completed 14 years of formal education. A focus on the educational status of respondents across divisions revealed that Amukura and Angurai had a comparatively high proportion of respondents who had completed secondary school. The counts for those who had completed secondary education stood at 13% (N=100) and 12% (N=100), respectively, from the two divisions.

Across all divisions, however, the modal range of years taken for formal education by respondents was between 6 and 8 years (upper primary level of

education). Those without any formal education across all the divisions constituted 18.8% (75) of respondents with Amukura and Amagoro divisions having the highest number of respondents without formal education. The divisional data relating to the educational level attained indicated that Amukura and Amagoro divisions each had 24% (24) of respondents without any formal education (see Figure 4.1).

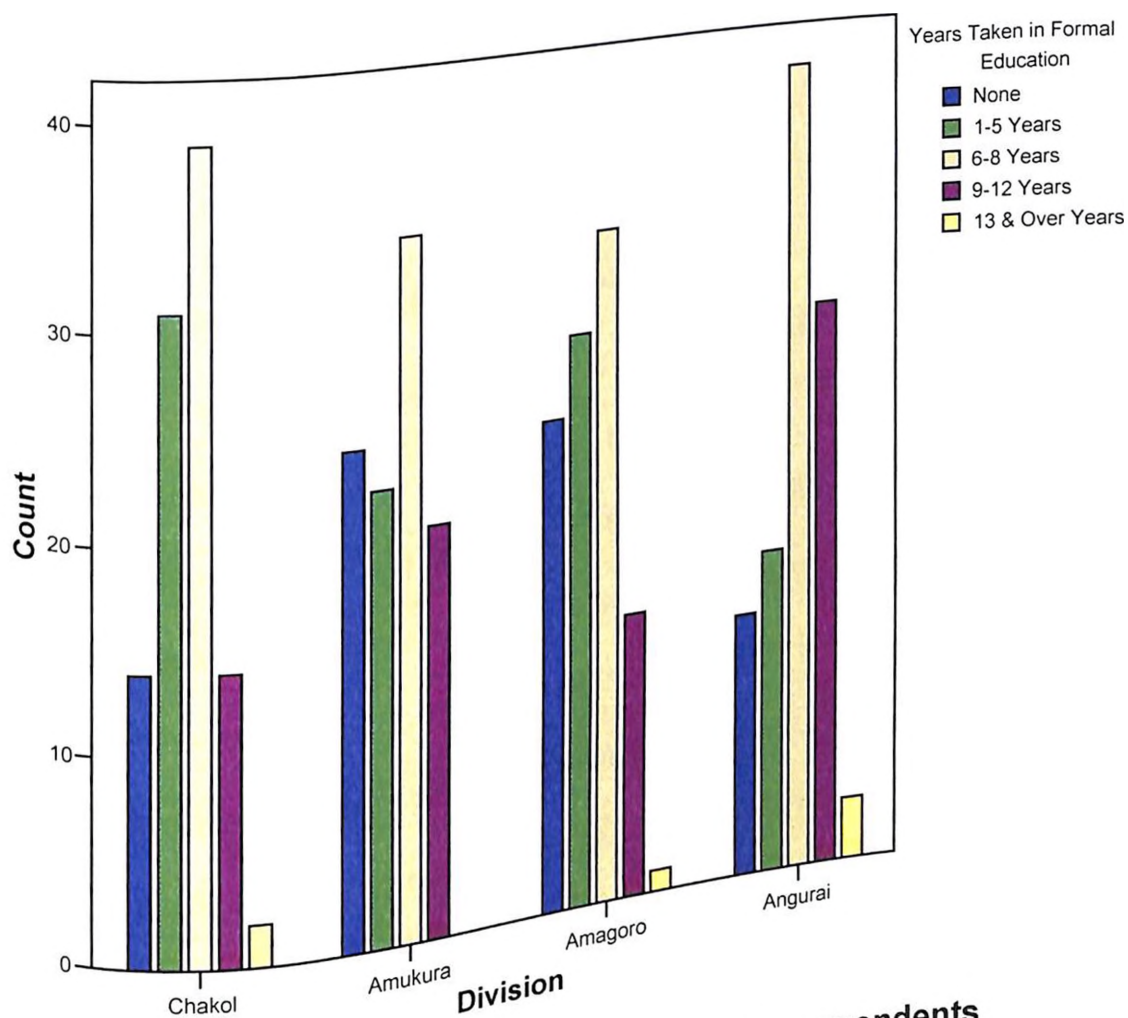


Figure 4.1: Duration taken in formal education by respondents

4.2.3 Economic Activities

As far as economic activities are concerned, results indicate that a majority 90.5% (362) of respondents were engaged in small scale-farming, and mainly subsistence farmers. A total of 7.3% (29) of the respondents were engaged in business while 2.3% (9) were teachers by profession. Those who engaged in business activities sold agricultural produce such as cereals, fruits and other merchandise obtained from Uganda and some within the Kenyan borders. Regarding accessibility to households, most of the respondents, 93.7% (386), resided 1-5 kilometres from major access roads, either all-weather or murrum roads.

4.3 Knowledge of Sleeping Sickness

Results indicate that most of the respondents from the research site were knowledgeable about the association between the tsetse bite and sleeping sickness. A majority of the respondents, 77.2% (309), positively linked tsetse (*echuchut/ekamonit*) bite with sleeping sickness transmission. However, a small number of respondents, 12.8% (51), did not have any knowledge about either the cause or the transmitting agent of the disease. Generally, in all divisions, 22.8% (91) of the respondents did not correctly identify the transmitting agent for sleeping sickness (Table 4.1).

Table 4.1: Knowledge of sleeping sickness transmitting agent

| Cause/Transmitting Agent | Frequency | Percentage |
|---------------------------------|------------------|-------------------|
| Tsetse bite | 309 | 77.2 |
| Don't know | 51 | 12.8 |
| Mosquito bite | 13 | 3.3 |
| Stress | 2 | 0.5 |
| Witchcraft | 25 | 6.2 |
| Total | 400 | 100 |

Whereas a majority of respondents rightfully associated sleeping sickness with the tsetse bite, divisional data indicate that Amagoro and Angurai divisions had the highest number of respondents who out rightly indicated that they did not know the cause of sleeping sickness. These constituted 17% and 18% (N=100) of respondents from the two divisions, respectively. Other causes given by respondents across the divisions included witchcraft, mosquito bite and the body condition of individuals such as stress (Table 4.2).

Table 4.2: Knowledge of sleeping sickness cause by division

| Division | Tsetse bite | Indicated sleeping sickness cause | | | | Divisional Total |
|----------|-------------|-----------------------------------|------------|------------|--------|------------------|
| | | Mosquito Bite | Witchcraft | Don't Know | Stress | |
| Chakol | 88(88%) | 4(4%) | 1(1%) | 7(7%) | 0(0%) | 100(100%) |
| Amukura | 80(80%) | 3(3%) | 8(8%) | 9(9%) | 0(0%) | 100(100%) |
| Amagoro | 76(76%) | 0(0%) | 5(5%) | 17(17%) | 2(2%) | 100(100%) |
| Angurai | 65(65%) | 6(6%) | 11(11%) | 18(18%) | 0(0%) | 100(100%) |

This study did not, however, find a significant relationship between the respondent's age and knowledge about the sleeping sickness cause or transmitting agent ($P\text{-Value} > 0.05$). Likewise, the study did not find any significant difference between gender (male and female) relating to knowledge about the cause of the disease.

4.3.1 Symptoms Associated with Sleeping Sickness

Results indicate that a majority of the respondents, 57.3% (229), associated sleepiness with sleeping sickness. In fact, the local Iteso name for the disease is *adeka na kajo/mongota* which literally translates to "disease of sleep". Other symptoms of sleeping sickness mentioned by respondents and discussants in focus group discussions included headache, body wasting and fever. However, 11.8% (47) of the respondents did not have any idea about the symptoms of sleeping sickness (Table 4.3).

Table 4.3: Knowledge about symptoms of HAT

| Symptom mentioned | Frequency | Percentage* |
|-----------------------|-----------|-------------|
| Sleepiness | 229 | 57.3 |
| Headache | 101 | 25.3 |
| Body wasting/weakness | 172 | 43.0 |
| Fever | 112 | 28 |
| Other | 122 | 30.5 |
| Don't know | 47 | 11.8 |

*Sum of the % more than 100 as this was a multiple response question

Amongst the 'other' symptoms were swelling of feet and psychological instability of the infected individuals. However, information from key informants indicated that psychological problems, irritability, abortion and low libidinal energy were both consequences and symptoms of the disease.

On symptoms associated with sleeping sickness, former sleeping sickness patients and 39.8% (159) of the respondents talked about the disease from their personal experiences or those of close family members. A former sleeping sickness patient from Obuchun village of Chakol division summarized her personal experience with sleeping sickness symptoms as follows:

In the early stages I would feel very cold and always wanted to be in the sun. My appetite for food also went very low and I became very slim like somebody with AIDS. People actually ran away from me. I later started feeling too sleepy every time and my stomach and legs

started to swell. I even aborted my pregnancy. I also became easily irritated and violent. I was then taken to the National Sleeping Sickness Referral Hospital where I was diagnosed with sleeping sickness and treated. I took about five weeks in the hospital (A 35-year old female former sleeping sickness patient from Obuchun village).

4.3.2 Knowledge of Predisposing Behaviour to Sleeping Sickness

Knowledge about predisposing behaviour for the disease showed that less than a half of the respondents, 46.3% (185), reported that going or working in bushy areas was a risk factor for sleeping sickness. A total of 32.3% (129) of the respondents thought that going to the river either to fetch water for domestic use, bathing or washing clothes were behaviour that predisposed an individual to tsetse bites and, ultimately, sleeping sickness infection. A small proportion of respondents, 3% (12), also associated colour with predisposition to tsetse bites. The colour, black, was particularly singled out as an attractant to tsetse flies. Participants in the focus group discussions held in Amukura and Chakol divisions were unanimous that putting on black clothes or herding black animals enhanced one's susceptibility to tsetse bites. However, 12.6% (51) of the respondents from all the divisions did not have any knowledge of the sleeping sickness predisposing behaviour (Table 4.4).

Table 4.4: Knowledge of predisposing behaviour to sleeping sickness

| Behaviour | Frequency | Percentage (%) |
|--------------------------------|------------|----------------|
| Going to the river | 135 | 33.5 |
| Working in bushy places | 196 | 49.1 |
| Putting on black clothes | 6 | 1.6 |
| Herding black animals | 6 | 1.6 |
| Working near grazing livestock | 6 | 1.6 |
| Don't know | 51 | 12.6 |
| Total | 400 | 100 |

4.3.3 Knowledge of Sleeping Sickness Treatment

Generally, most, 88.8% (355), of the respondents reported that the disease could be treated. Information about the most suitable option for treatment of the disease was, however, not unanimous. Whereas a majority, 89.5% (358), of the respondents indicated that the disease could be treated in formal or biomedical health facilities (hospitals, clinics and dispensaries), 4% (16) thought the disease could be treated through traditional medical practitioners. A total of 3.5% (14) respondents were of the opinion that the way to restore health from sleeping sickness was through spiritual means and hence prayers were sufficient. However, a few, 3% (12), of the respondents did not have any idea about which option(s) to utilize for sleeping sickness treatment.

4.3.4 Awareness of the National Sleeping Sickness Referral Hospital

When community knowledge of the NSSRH was tested, 47.5% (190) of the respondents indicated that they knew the location of the National Sleeping Sickness Referral Hospital and rightfully pointed out that it was the institution where the disease could be treated in Kenya. However, 28.2% (114) did not know of any sleeping sickness treatment institution in Kenya and beyond. Those who did not know about the NSSRH at Alupe thought that any government hospital and other biomedical health facilities such as mission and private hospitals could treat sleeping sickness. There were, however, a few respondents, 3.5% (14), who thought the disease could only be treated at UTRO, Uganda and not anywhere in Kenya (Fig. 4.2).

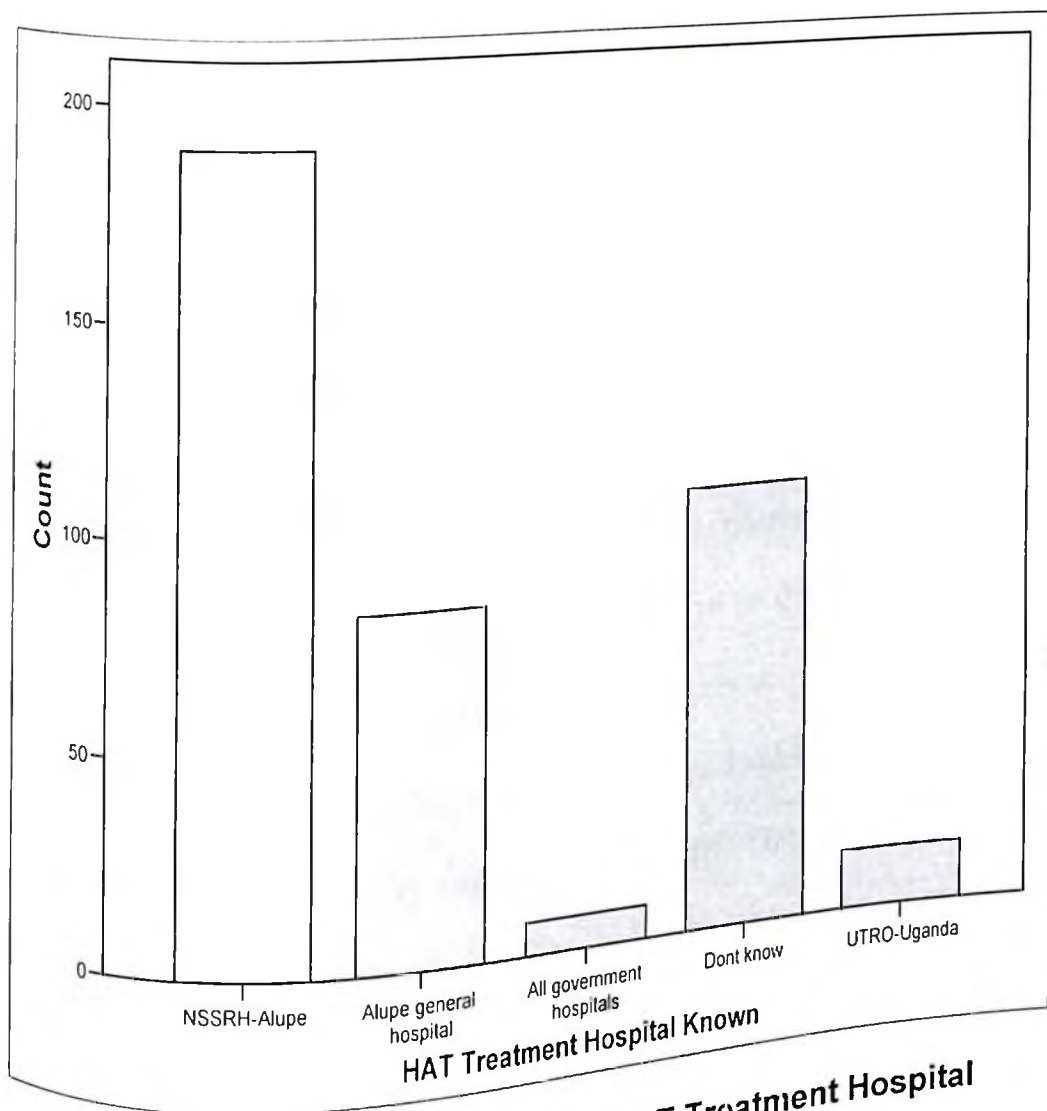


Figure 4.2: Knowledge of any HAT Treatment Hospital

A key informant was of the opinion that in matters relating to treatment of sleeping sickness, UTRO has been known more than the NSSRH, Alupe over time. According to the informant, the comparatively lower cost charged for health services in Uganda as compared to health institutions in Kenya has led many people from Teso district to continue utilizing services from UTRO and St. Anthony Hospital at Tororo, Uganda. However, the general view relating to knowledge about the Kenyan sleeping sickness hospital indicated that slightly

more than a half, 52.5% (210), of the respondents did not have any knowledge about the NSSRH.

Disaggregated data about knowledge of sleeping sickness hospital across divisions indicated that a majority, 69% (N=100), of the respondents from Amukura division were knowledgeable about the NSSRH as the centre where sleeping sickness could be treated in the country. The least number, 30% (N=100), of respondents, who had knowledge of the hospital were from Angurai division. The division (Angurai) also had, comparatively, the highest number of respondents, 35% (N=100), who out rightly indicated that they did not know where to go for sleeping sickness treatment. This lack of knowledge may be attributed to insufficient sensitization activities about the disease and hospital in the division. The highest number of respondents, 12(12% N=100), who knew UTRO as the centre for sleeping sickness treatment was from Chakol division (Table 4.5).

Table 4.5: Knowledge of where to get treatment for sleeping sickness

| Division | Name of Sleeping sickness hospital known | | | | | |
|------------------------|--|------------------------|--------------------------|----------|------------|-------------|
| | NSSRH-Alupe | Alupe general hospital | All government hospitals | Other | Don't know | UTRO-Uganda |
| Chakol | 49(49%) | 14(14%) | 0(0%) | 0(0%) | 25(25%) | 12(12%) |
| Amukura | 69 (69%) | 17(17%) | 0(0%) | 0(0%) | 14(14%) | 0(0%) |
| Amagoro | 42(42%) | 24(24%) | 3(3%) | 0(0%) | 30(30%) | 1(1%) |
| Angurai | 30(30%) | 28(28%) | 5(5%) | 1(1%) | 35(35%) | 1(1%) |
| Frequency Total | 190 | 83 | 8 | 1 | 104 | 14 |

However, some informants stated that some community members were knowledgeable about the NSSRH facility but they preferred UTRO and other health facilities in Uganda for sleeping sickness treatment. This is reflected in the following excerpt of responses from one FGD:

With us, we know UTRO as the only sleeping sickness hospital. Although we have heard about Alupe for treatment of the disease, we know that Alupe deals mostly with leprosy. Also, when you are sick, you do not go far for treatment. Alupe is too far from us and UTRO is closer here. The UTRO hospital is also cheaper and attendants are kind to us because we speak the same language. We explain our situations in Kiteso (local language) and they understand us better than hospital workers at Alupe. Services there (UTRO) are also faster. When samples are taken to UTRO hospital, workers sometimes come to our village and bring results while we are in our homes. When we go to UTRO for treatment, we identify ourselves as Ugandans. This is because, many people from this village have land and homes across the border in Uganda (Female FGD, Obuchun village, Chakol division).

Similar views were also reflected in focus group discussions held in the other divisions in the district.

4.4 Community Experiences with Sleeping Sickness

Out of the 400 community members interviewed, 39.8% (159) had an experience with sleeping sickness, either having suffered from it themselves or member(s) of

their respective families. Disaggregated results from divisions indicated that the highest number of respondents who had had an experience with sleeping sickness, 35.8% (57), hailed from Chakol division. A total of 27% (43) of respondents whose family member(s) or themselves had suffered from the disease were from Amukura division. On the other hand, the least number of respondents, 15% (25), who had experienced the disease were from Angurai division.

Generally, slightly more than a third, 36.5% (146), of the respondents from all the divisions indicated that they learned that what they or their relative(s) were suffering from was sleeping sickness from the hospital staff who attended to them. However, 3% (12) indicated that they learned about their condition and the reason for their suffering from their friends, relatives and/or local administrators. At the time of this fieldwork in 2010, one sleeping sickness patient from Obekai village of Amukura division, was still undergoing treatment and observation. The patient had previously had an experience of the disease in her household. Her husband had died from sleeping sickness in the late 90s. This is what she had to say about her experience with the disease and the treatment:

I was bitten by the fly in 2009 while here in my compound. I killed the fly and even showed my daughter. I did not know that the bite would subject me to a lot of suffering. After about two weeks, I started feeling ill. I went to our local hospital at Amukura and was treated for malaria but my condition did not improve. I went back to the hospital and was treated for typhoid. I sold all my three cows to get money for

the treatment. All the treatment that I got seemed not to help me. Later people, including myself, started thinking that I had been bewitched. Some villagers even said that I had contracted HIV/AIDS. Later, my son remembered that my late husband had similar symptoms before he died while undergoing treatment at the National Sleeping Sickness Referral Hospital. We opted to try the hospital for my treatment. There, the initial diagnosis indicated that I was negative for sleeping sickness and was told to go back home. I had actually given up to fate when I saw people from the hospital again here at home. They informed me that they wanted to do more tests. They took me to the hospital and took my blood samples again. I was later informed that I was positive with sleeping sickness and that they had to perform lumbar puncture on me. The painful lumbar puncture was performed and thereafter, I was put on treatment (A 50-year old female former sleeping sickness patient from Obekai village, Amukura division).

4.4.1 Perception of the Treatment Process

Results indicate that respondents had varied opinions about the sleeping sickness treatment process. Some of the disease diagnosis and treatment issues raised by key informants and respondents that may affect utilization of formal health services include:

i) Blood samples utilized for other undisclosed purposes

As far as giving blood samples for analysis was concerned, whereas a majority, 97.2% (389), of the respondents indicated that they would freely give their samples to any research team interested in establishing their pathogenic status,

2.8% (11) indicated that they would not co-operate. Those who stated that they would not willingly give their blood samples feared that the samples would be subjected to HIV tests without their consent. The respondents who held the above view were from Chakol and Angurai divisions. However, a key informant (chief) from Apatit village, Amukura division indicated that when blood samples were taken from the villages, some community members always discouraged the willing participants in the exercise because they believed that the blood samples would be used for other purposes. This is how the informant put it:

Sometimes people come and mobilize community members to get their blood samples. However, some are never seen in the villages again. It is, therefore, understandable when people think their blood samples are taken for other purposes other than to the community members' benefit. Some people think that those who take blood from people are devil worshipers. When those who come in government vehicles tell villagers that they want to take blood samples, many people always believe that the sole objective of their visit is to analyse the samples to get the number of people who have HIV (A 45-year informant from Apatit village).

ii) Painful diagnosis procedure and adverse impact after recovery

Regarding the diagnostic procedure for sleeping sickness, 68.5% (274) of the respondents indicated that they did not know about lumbar puncture. However, the respondents who knew about the process, 31.5% (126), had varied opinions about the process. Whereas 62.7% (N=126) of the respondents who knew about

lumbar puncture were of the opinion that the procedure would not deter them from seeking formal sleeping sickness healthcare, 37.3% (N=126) indicated that lumbar puncture would prevent them from going to hospital for treatment. The reasons that these respondents gave included the fact that the procedure was too painful and that they could not tolerate the pain if the process was repeated again on them. On this basis, 7.5% (30) of the respondents from all the four divisions asserted that they would not advise any sleeping sickness suspect to go to the sleeping sickness hospital for treatment. Some indepth interviews yielded information about negative impacts of sleeping sickness after treatment.

On this treatment of sleeping sickness and its impact, a former sleeping sickness patient had the following to say:

I was sick in 2000 and treated at the NSSRH. During treatment, lumbar puncture was performed on me six times. The process was very painful. As a result of the disease or lumbar puncture process, I have continued to suffer the consequences. As from the year 2000, my back still pains and I cannot work in the field for long hours. I also suffer from reduced libido. My first wife ran away from me because I could not perform my matrimonial responsibilities to her satisfaction. I cannot bear to see another person going through what I go through. If my condition is as a result of sleeping sickness treatment, it is better to suffer the consequences of the disease without the treatment (A 38-year male former sleeping sickness patient from Amaase village, Chakol division).

iii) The long treatment period taken during treatment

A male key informant indicated that treatment for sleeping sickness took between six and eight weeks in the hospital. Twenty per cent of the respondents who had experienced the disease (N=159) were of the opinion that the period was too long to be away from home. Focus group discussion participants in Obuchun and Amaase villages were unanimous that the period was very long particularly if the victim is the bread winner for the family.

iv) Death of a patient while undergoing treatment

The outcome of treatment of sleeping sickness was of concern to community members. Asked about whether they had any reservations about treatment of sleeping sickness at the NSSRH, 2% (8) of the respondents, who also doubled up as respondents who had experienced the disease in their families, indicated that their patients died while undergoing treatment thus they developed fear for the treatment process. The NSSRH records, however, indicated that out of the 35 sleeping sickness patients served at the hospital between 2000 and 2006, five patients died from the disease while undergoing treatment or shortly after treatment while at home.

4.4.2 Community Attitude towards Sleeping Sickness Patients

The former sleeping sickness patients and key informants indicated that prior to getting appropriate treatment for the disease, either at the NSSRH or at UTRO

Hospital in Uganda, they (former HAT patients) moved from one hospital to another in search of health services. At community level, because of the apparent lack of being healed as a result of treatment in various formal health centres, 67.6% (129), of the former sleeping sickness patients or respondents whose relatives had been affected indicated that some members of the community, including their relatives, thought they (sleeping sickness patients) had contracted HIV/AIDS. Ten (5.2%) respondents observed that other community members thought that their illness was due to humanistic (witchcraft) or supernatural causes (Table 4.6).

Table 4.6 : Initial Perceptions of Sleeping Sickness by Community Members

| Illness Perception | Frequency | Percentage |
|--------------------|------------|------------|
| HIV/AIDS | 129 | 67.6% |
| Malaria | 52 | 27.2% |
| Witchcraft | 10 | 5.2% |
| Total | 191 | 100 |

During the time of illness, a majority of the affected respondents, 79.8% (N=159), indicated that they experienced social stigma from the other community members. They, therefore, formed targets for village gossip and avoidance. According to an informant, the stigmatization continued long after treatment as even after realization that the disease was not bewitchment or HIV/AIDS, some

members of the community looked at the former patients as being abnormal or unable to function as their former selves. This observation was also supported by former sleeping sickness patients who took part in focus group discussions. The discussants further observed that they suffered low libido and/or psychological problems. According to these sleeping sickness survivors, the other community members thought that these experience of low libido and/or psychological problems that they encountered during and after disease treatment were permanent.

On stigmatization about the disease, a former sleeping sickness patient had the following to say about his experiences with the disease:

When I was sick, some people thought it was AIDS or witchcraft. This is because, I was not responding to treatment from local dispensaries and other health facilities. Many of my former friends and relatives ran away from me. Some relatives gave me herbal medicine and food. However, others talked so negatively about the disease and me. I was so weak and many people pointed fingers at me and said unpleasant words. Because of the community's conclusion that mine was a case of HIV/AIDS, some people were saying that my family members should not waste their time and money by going to other hospitals that I was going to die anyway. I was, therefore, left unattended even by close relatives. Later, my brother who had heard about NSSRH took me there where I was diagnosed positive for sleeping sickness and put on treatment. Even with the diagnosis and commencement of treatment, some

community members still could not believe that it was not AIDS. They said that doctors talked about sleeping sickness as another way of communicating HIV/AIDS status to confirmed cases (A 45-year old male former sleeping sickness patient from Apatit village, Amukura division).

Another informant from Angurai division who had suffered from sleeping sickness and was treated at the NSSRH added that during treatment, some community members thought that they were confirmed HIV positive cases and were on anti-retroviral (ARV) treatment. The former sleeping sickness patient observed that many people ran away from him including his church members.

CHAPTER FIVE

HEALTH-SEEKING BEHAVIOUR

5.1 Introduction

This chapter presents the health-seeking behaviour of people residing in Teso district. The chapter begins by highlighting the sources of healthcare and thereafter, factors that determine the utilization of health services amongst the community members are presented.

5.2 Sources of Healthcare

In the event of illness, findings indicate that people from the research site utilize various healthcare options. These options range from utilization of formal (biomedical) health provision sources such as pharmaceutical outlets (chemists), clinics, dispensaries and hospitals either in the country or across the international borders to Uganda. Traditional medicine and prayers were also utilized as sources of healthcare. However, respondents utilized the available options at different stages of illness. For example, during the onset of illness, 68% (272) of the respondents indicated that they utilized chemists. However, a key informant stated that in the event of illness, the local people evaluated their own conditions, were assisted by attendants in the pharmaceutical shops (chemists), their friends or relatives and/or based their disease diagnosis and remedial measures on past

experiences with the various illnesses that affected them individually, their relatives, or their friends.

After purchases from chemists/pharmacists, 64.4% (257) of the respondents indicated that they went to local dispensaries for treatment as a second source of healthcare. However, on this disease progression path, the findings indicate that after hospital utilization, the population that crossed to Uganda, stayed at home, sought traditional medicine or looked upon supernatural intervention through Prayer(s) increased (Table 5.1).

However, the findings also indicate that the least popular healthcare choice for the people residing in the research site were private health facilities. According to a key informant, the cost of healthcare offered by these health facilities was a deterrent to their utilization as it was viewed to be expensive.

Table 5.1: Respondents' utilization of the various healthcare options/sources

| Disease | Healthcare source | | | | | | | |
|------------------------------|-------------------|-------------------|-------------------|----------|-------------------|----------------|----------------------|----------|
| | Chemists | Dispensary | Hospital | Uganda | Stay at home | Private Clinic | Traditional Medicine | Prayers |
| Onset | 272(68%) | 91(22.7%) | 8(2.0%) | 0(0%) | 14(3.6%) | 0(0%) | 5(1.3%) | 10(2.4%) |
| 2nd Source | 23(5.7%) | 257(64.4%) | 97(24.3%) | 2(0.4%) | 13(3.2%) | 3(0.8%) | 5(1.2%) | 0(0%) |
| 3rd Source | 0(0%) | 23(5.7%) | 292(72.9%) | 34(8.5%) | 38(9.7%) | 2(0.4%) | 5(1.2%) | 6(1.6%) |
| 4th Source | 0(0%) | 2(0.4%) | 120(30%) | 52(13%) | 125(31.3%) | 0(0%) | 72(18%) | 29(7.3%) |

*Sum of the % more than 100 as this was a multiple response question

5.3 Determinants of Health Seeking Behaviour

Results indicate that the health-seeking behaviour of people in the research site was determined by cost of the offered health services, distance to health facilities, perception of the cause of illness, persistence or state of illness and other factors that were mainly related to the health infrastructure in the research site. These health infrastructure-related factors included staffing levels, ethnic backgrounds of facility staff, personal etiquette of health attendants, fear of HIV test and historical factors.

i) Cost of Health Services

Research findings indicate that the cost of services offered by health providers affected the people's health-seeking behaviour. According to key informants, most community members utilized health services from sources they perceived to be affordable. The informants were also of the view that patients shunned services from facilities or health provisions options that they believed were expensive in regard to the health services offered. This was also reflected in the preference of one formal health facility (chemist, clinic or hospital) over another. According to respondents, the high cost of health services charged at some hospitals acted as a deterrent to use of available health services. For instance, 52.5% (210) of the respondents indicated that the cost of treatment would negatively influence their choice of health facilities.

In all the four divisions of the research site, hospital charges were significantly associated with the factors that would deter community members from seeking hospital treatment (P -value < 0.05). In regard to divisions, 86% (86) of respondents from Chakol division, 65% (65) from Amukura, 75% (75) from Amagoro and 61% (61) of the respondents from Angurai division were of the view that high hospital charges would prevent community members from hospital treatment.

ii) Distance to Health Facilities from Households

Distance from place of residence to a health facility was stated by 21.5% (86) of respondents as being a determining factor for choice of health facility from where to seek healthcare (Table 5.2). This distance determinism was also reflected in respondents' explanations about why community members went to Uganda for health services. A total of 11% (44) of the respondents reportedly went to Uganda for health services because the health facilities in Uganda were geographically near their homes and also comparatively cheaper in cost of the services offered as opposed to facilities in Kenya.

This study also found a significant association between distance to hospital and the tendency to utilize health services by community members within the research site (P -value < 0.05). Chakol, Amukura and Amagoro divisions had 9%, 23% and 14% of the respondents, respectively, who cited distance as a factor that would prevent a community member from going to a health facility for

treatment. Conversely, Angurai division with 40% had the biggest proportion of respondents stating that distance would prevent one from accessing hospital treatment. Katotoi village of Angurai division where the research activities were carried out is 40 km away from the NSSRH, Alupe but shares a boundary with Uganda on its west. On the other hand, the village is 15 km from Kocholia sub-District Hospital (Amagoro division). The distance from Amukura and Amagoro to the NSSRH is 20 km and 30 km, respectively.

iii) Causality of Illness

The nature of illness determined people's health-seeking behaviour. The results indicate that 237(59.3%) of the respondents were of the view that different healthcare options handle different illnesses and that the ability of healthcare options to treat illnesses influenced utilization of the options. The respondents expressed the view that the community's theories about disease causality influenced health-seeking behaviour. According to a key informant, who doubled up as a local administrator (chief), an illness that was defined as resulting from humanistic causes was taken to a traditional medical practitioner for health restoration. The key informant was of the view that illnesses resulting from personalistic causes would not respond to biomedical treatment.

Regarding utilization of health facilities, respondents were of the view that different health facilities have different levels of reputation regarding the expertise to treat illnesses. A total of 8.3% (33) of respondents from all the four divisions of

the research site indicated that the ability of facilities to treat particular illnesses influenced their choices to go to a health facility for treatment and other health services.

iv) Stigma

Study findings also indicate that social stigma associated with illnesses influenced health-seeking behaviour. When faced with a disease that was defined by community members as resulting from immoral or deviant behaviour, community members would avoid going to health facilities for healthcare. This is because they were fearful of either being exposed to other community members or being victims of ridicule from hospital officers. Results indicate that 1% (4) of the respondents thought that fear of being tested for HIV/AIDS may bar community members from seeking hospital services, particularly in where blood samples were required.

v) Persistence of Illness

The findings indicate that if illness persisted, people sought health services from various healthcare options within Teso district and beyond. An analysis of the health seeking behaviour patterns of the community in the research site indicated that with the advent of illness, 68% (272) of the respondents utilized the local drug stores (chemists/pharmacists). With persistence of illness, the results indicate that there was an increase in the population that went to traditional medical practitioners and spiritual healing. A total of 45.8% (183) of the respondents

believed that traditional medical practitioners were the best option for health restoration, while 18.8% (75) resorted to supernatural intervention (prayers) for health restoration in times when persistence of illness was encountered. The results also revealed that when there was unsuccessful treatment of illness in Kenya, 3.5% (14) of the respondents indicated that they crossed over to Uganda for health services (Figure 5.1).

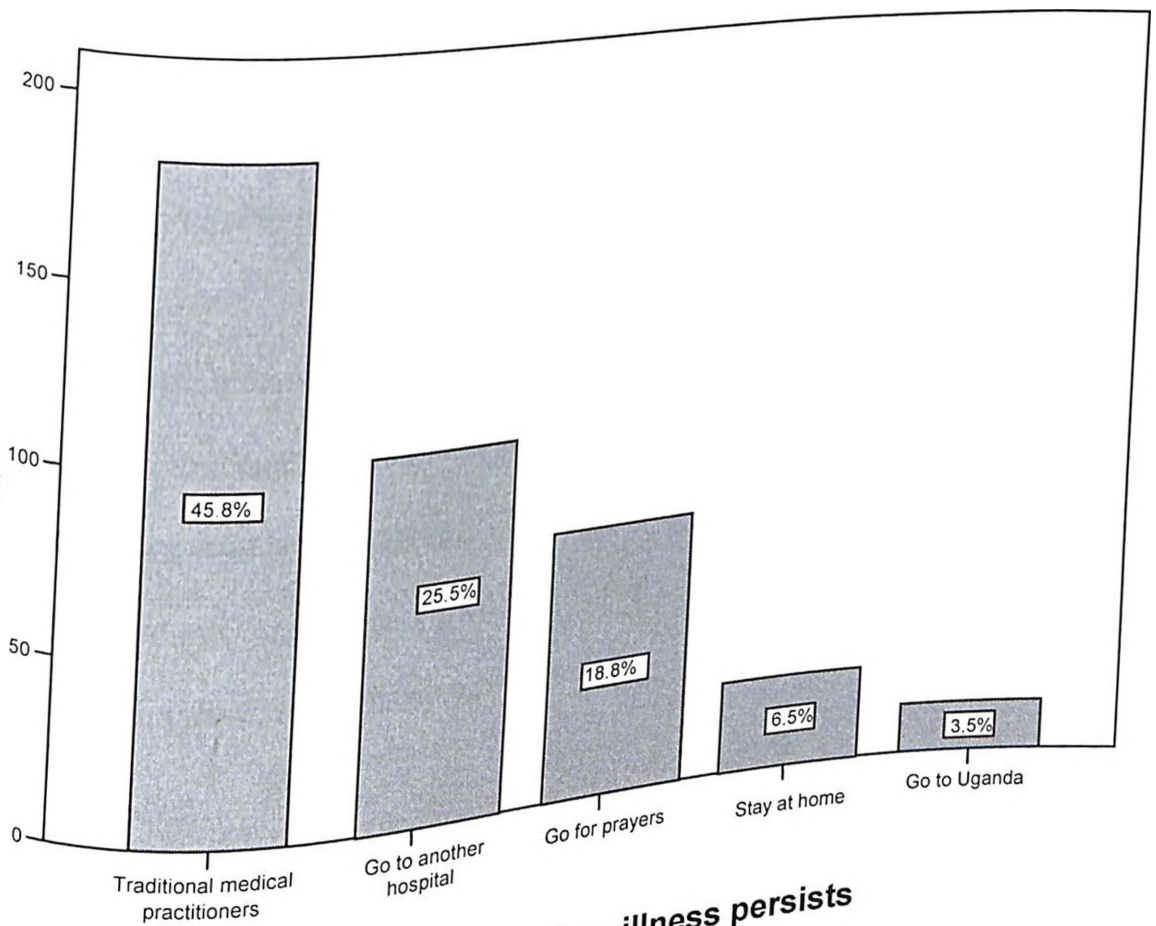


Figure 5.1: Where people go when illness persists

When asked why some people from the community visited traditional medical practitioners, a majority (75%) of the respondents reported that some diseases could not be treated by biomedical means. This influenced the people's utilization of alternative options, particularly when they defined the illness as having been caused by humanistic or supernatural causes.

The other reasons given by respondents for going to traditional medical practitioners for health services included the fact that the traditional medical practitioners were easily available and accessible, they were cheaper, and that they had solutions to many health problems unlike the biomedical service providers. Thirty-one per cent of the respondents reported that traditional medical practitioners could also tell in cases where there was a humanistic cause to illness and hence enabled timely access to appropriate health solutions. On this basis the respondents believed that traditional medical practitioners are better than any other healthcare option (Table 5.2). These ideas were also reflected during the key informant interviews and focus group discussions. This is what a key informant (chief) had to say on the subject:

Traditional medical practitioners live with us in the villages and understand and respect our cultural dictates. When they are approached for health services, their diagnosis is wide as it also includes cases of witchcraft, supernatural causes and also can tell when natural causes are involved. The traditional medical practitioners will either prescribe herbal remedies where natural causes are involved or give directions about the protective

charms or sacrifices involved for health restoration in the event of personalistic causes. The cost of services is also manageable as one may be needed to part with only a chicken (A 40-year old female local administrator from Amukura division).

Table 5.2: Reasons for utilization of traditional medical practitioners

| Reason | Frequency | Percentage |
|--|------------|------------|
| | 183 | 45.6 |
| Some diseases cannot be treated by biomedicine | 124 | 31 |
| It is better than any other option | 38 | 9.6 |
| To find out if there is a human cause to illness | 20 | 5 |
| They are easily accessible | 19 | 4.8 |
| No alternative option | 16 | 4 |
| They are cheaper compared to biomedical services | | 100 |
| Total | 400 | |

vi) Quality of Services Offered

A total of 10.3% (41) of the respondents indicated that long queues or slow services at the service centres determined their utilization of particular health facilities for health services (Table 5.3). Observation during the fieldwork

revealed that in many health facilities, particularly public ones, there were long queues by people and/or patients seeking for services at the facilities. According to a local administrator in Katotoi village and discussants in practically all focus group discussions, at times, some patients seeking for health services are turned away till the following day due to staff shortage at health facilities within the district.

On the performance of health facilities in the district, a key informant had the following to say:

In many health facilities in this district, treatment is done without laboratory diagnosis. They just give drugs or ask the patients to go and buy the drugs from chemists. At times, it is difficult to get services because providers start serving patients late and leave early. The providers are also few. Because of the long queues, some providers harass patients. Many people, therefore, go to St. Anthony's Hospital and the UTRO Hospital in Uganda for treatment. The facilities in Uganda don't charge a lot of money and they give us drugs. In hospitals in this district (Teso, Kenya), including Alupe Hospital, you are asked to buy almost everything including needles, syringes, drugs and even gloves for doctors' use. In Tororo, a patient also explains his/her problems in Ateso and we feel treated compassionately in Uganda than in the health facilities in Kenya (A 50-year old male village elder from Katotoi village, Angurai division).

Table 5. 3: Determinants of choice of healthcare among the available healthcare options

| Determining factor | Frequency | Percentage |
|------------------------------------|------------------|-------------------|
| Cost of treatment | 210 | 52.5 |
| Distance from residence | 86 | 21.5 |
| Poor services from providers | 41 | 10.3 |
| Nature or ability to treat illness | 33 | 8.2 |
| Lack of laboratory services | 4 | 1 |
| Fear of HIV/AIDS test | 4 | 1 |
| Other** | 12 | 5.5 |
| Total | 400 | 100 |

** Included among 'other' were availability of drugs, presence of a known person in the health facilities, waiting time before services at the facilities and presence of a health provider or staff member from one's own ethnic group at the target health facility.

A focus on divisions also revealed that in all the divisions, the cost of treatment and distance to health facilities ranked highly amongst the factors that determined health-seeking behaviour in the community (Figure 5.2).

Table 5. 3: Determinants of choice of healthcare among the available healthcare options

| Determining factor | Frequency | Percentage |
|------------------------------------|------------|------------|
| Cost of treatment | 210 | 52.5 |
| Distance from residence | 86 | 21.5 |
| Poor services from providers | 41 | 10.3 |
| Nature or ability to treat illness | 33 | 8.2 |
| Lack of laboratory services | 4 | 1 |
| Fear of HIV/AIDS test | 4 | 1 |
| Other** | 4 | 5.5 |
| Total | 400 | 100 |

** Included among 'other' were availability of drugs, presence of a known person in the health facilities, waiting time before services at the facilities and presence of a health provider or staff member from one's own ethnic group at the target health facility.

A focus on divisions also revealed that in all the divisions, the cost of treatment and distance to health facilities ranked highly amongst the factors that determined health-seeking behaviour in the community (Figure 5.2).

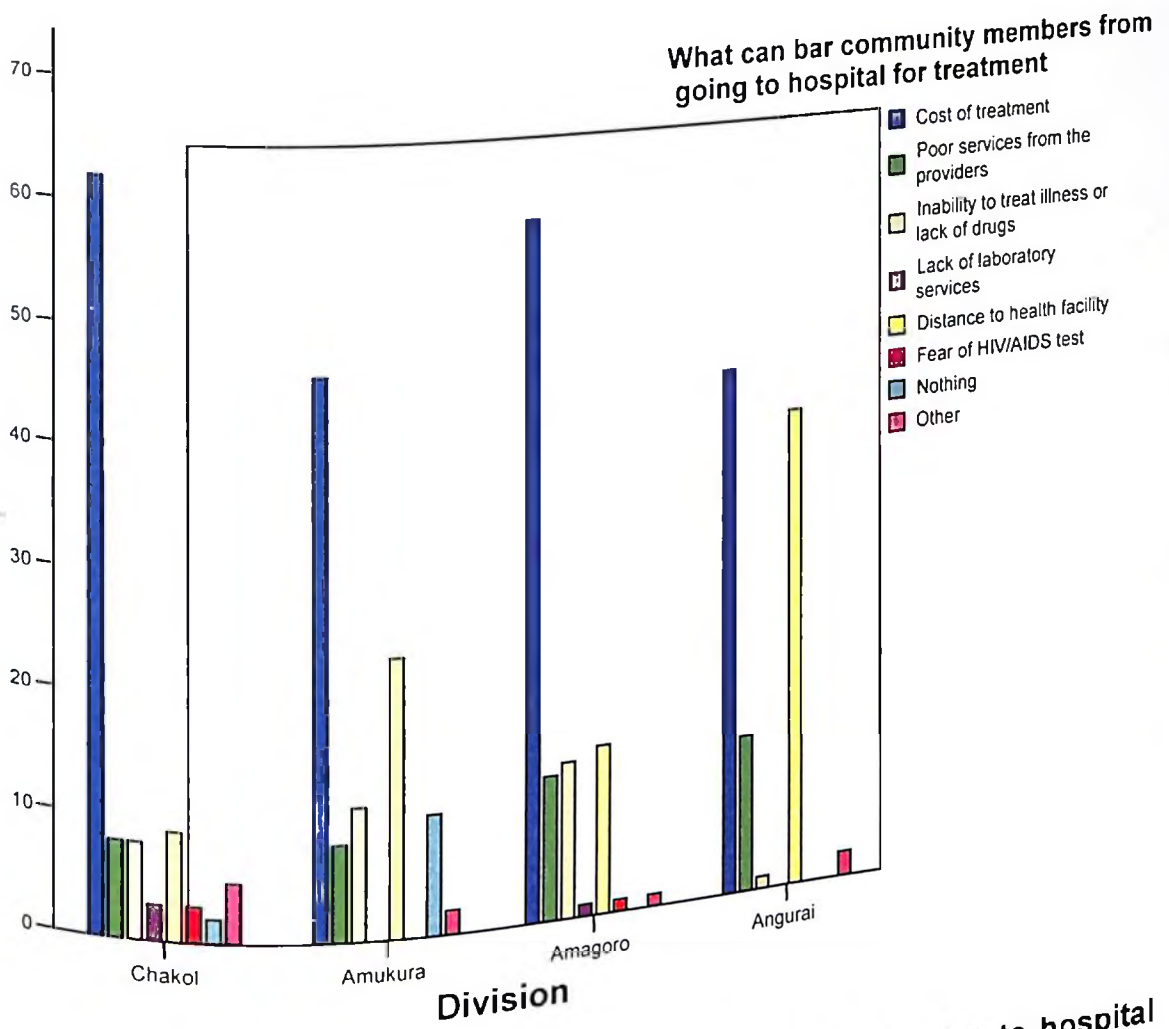
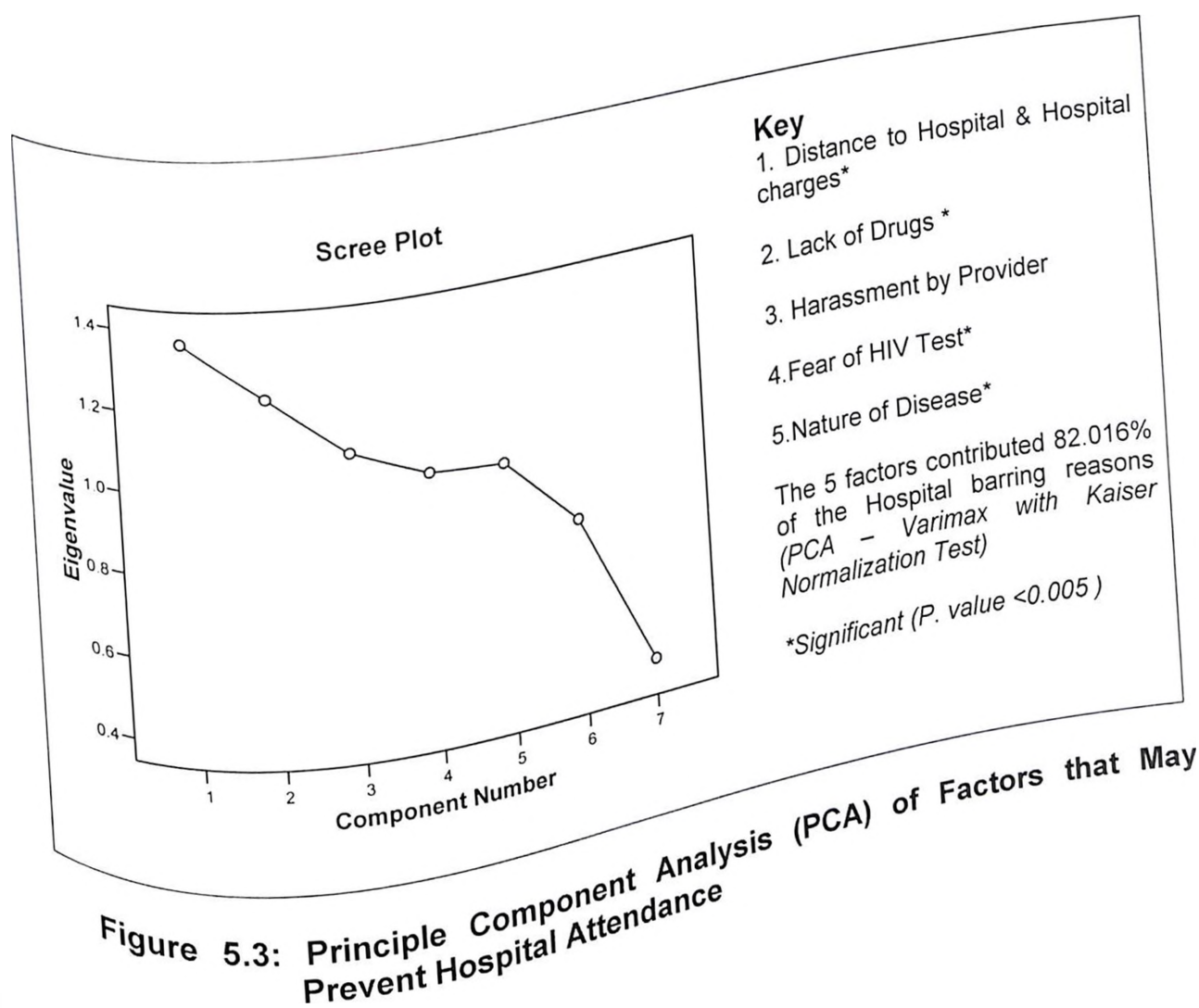


Figure 5.2: Factors that may prevent people from going to hospital for health services by division

A further analysis of the factors that would act as an impediment to people utilizing hospital health services using principal component analysis (PCA-Varimax with Kaiser Normalization Test) revealed that distance to hospital and hospital charges, lack of drugs in the health facilities, harassment/poor services by providers including long queues waiting for services, fear of being tested for HIV/AIDS and nature of illness constituted 82% of the factors that may prevent the communities living in Teso District from going to particular hospitals for the

services (Figure 5.3). Of these factors, high hospital charges (cost of treatment), distance to hospital, availability of drugs in the facilities and nature of illness had a significant contribution to the factors that determined respondents' choices of particular health facilities or health options over others in the district (P-value <0.05). The furthest point in Angurai division to the NSSRH is approximately 50 km away.



vii) Ethnicity

Ethnic composition of officers working at health facilities was mentioned by 15% of respondents as among factors that may deter them from utilization of services from particular facilities. Communication and cultural understanding were the main determinants for the ethnic consideration by the community. The following excerpt from an interview with a key informant exemplifies the local people's preference of healthcare workers from their own communities to attend to their health needs as opposed to workers from other ethnic groups:

...it is natural for people to go to hospitals where the doctor comes from the same ethnic group as them. Here people prefer to utilize services where the doctor is from Teso community. This is because it is easier to explain oneself in the local language than in Kiswahili or English. Because of that we prefer to go to UTRO or St. Anthony hospitals in Tororo, Uganda, to going to Alupe for treatment. Sometimes doctors from other ethnic groups are harsh to those seeking for health services (A 50 year old male village elder from Katotoi village, Ang'urai division).

viii) Historical Factors

Historical factors emanating from the fact that UTRO (formerly East African Trypanosomiasis Research Organization - EATRO) was the institution where sleeping sickness was treated in Kenya and Uganda influenced local people's health seeking behaviour. This is particularly when there was suspicion about the cause of illness being sleeping sickness infection. Alupe, where the NSSRH is

situated was associated with diseases such as leprosy. According to a village elder from Obekai village, Amukura division, leprosy is a stigmatised disease among the Iteso as it is considered to be caused by a curse. This is how the key informant put it:

...many of us in Teso district always knew that in case of sleeping sickness UTRO is the only known treatment centre. Alupe, where NSSRH is located was known to be a sanctuary for people suffering from illnesses resulting from curses and other bad diseases like leprosy. Therefore many people from this community did not want to be associated with Alupe. Some people still hold that view today. (A 65 year old male village elder from Obekai village).

CHAPTER SIX

REFERRAL SERVICES

6.1 Introduction

This chapter presents information about personal accounts of interactions of former sleeping sickness patients with formal health providers within Teso district. Information relating to provision of referral services by the formal health providers to community members in the district is also presented. The chapter also highlights impediments to intra community provision of referral advice to sleeping sickness suspects specifically targeting the National Sleeping Sickness Referral Hospital.

6.2 Interaction between Health Providers and Former Patients

A focus on interaction between formal health providers and former sleeping sickness patients in the district revealed that at first presentation to the health facilities, a majority of the respondents, 80% (N=159), who had had an experience with sleeping sickness either directly or indirectly were treated for malaria and/or typhoid fever. People who had had an experience with the disease indicated that at the time of illness, drugs were changed for the same disease in subsequent visits to the health facilities. According to a female former sleeping sickness patient from Katotoi village, Angurai division, persistence of malaria-like symptoms after treatment was met with the conclusion that what the particular individual was suffering from was a strain of malaria that is resistant to

common anti-malarial drugs. This, according to the former patient, led some formal health providers to prescribe and administer the quinine injection.

The following excerpt from an interview with another former sleeping sickness patient summarizes experiences of the interaction between patients and formal health providers in the research site:

In the hospitals here, a sick person is exposed to a lot of suffering in the course of search for treatment. There are not enough personnel to handle large numbers of patients and thus this forces people to make long queues as they wait for treatment. In some cases, patients are not served and are told to report back the following day. This makes people avoid these health facilities. In some cases, particularly when malaria conditions become persistent, the hospital attendants just change drugs. One may be given Fansidar®, Metakelfin® or Coatem® during initial visits and later with continued persistence of the malarial signs, quinine injection is administered as the end resort. In most cases, diagnosis and treatment of the disease is done on the basis patients' described signs and feelings (45-year male old key informant from Amukura division).

6.3 Provision of Referral Services by Health Providers

A majority of respondents, 66.8% (267), indicated that referral services, particularly to the National Sleeping Sickness Referral Hospital, were not offered by formal health providers within the research site. According to the respondents and key informants, this was particularly if community members presented themselves to health facilities with malaria-like conditions, one of the initial symptoms of sleeping sickness. The findings indicate that 66.8% of the respondents received medication on the basis of symptoms presented. With symptoms such as fever, body weakness and lack of appetite, most of the respondents were treated for malaria and typhoid fever.

As far as offering of referral services by non-HAT formal health practitioners is concerned, 33.2% (133) of the respondents indicated that they had been referred to other health facilities during their last illness. According to the respondents, such referrals were informed by the necessity for laboratory diagnosis and in case of emergency cases such as people involved in accidents. The findings reveal that most of the referrals were made to health facilities with laboratory services or to sub-district hospitals such as Alupe and Amagoro.

The respondents who had been referred observed that the referral services were offered by health providers but after varied numbers of visits to their health facilities. Whereas about a third of the respondents, 30% (41), indicated that referrals were done after the first visit, that is, done on the second visit to their

local health facility, about one-fifth of respondents, 17% (22), stated that they were referred after the fourth visit to the facility (Figure 6.1).

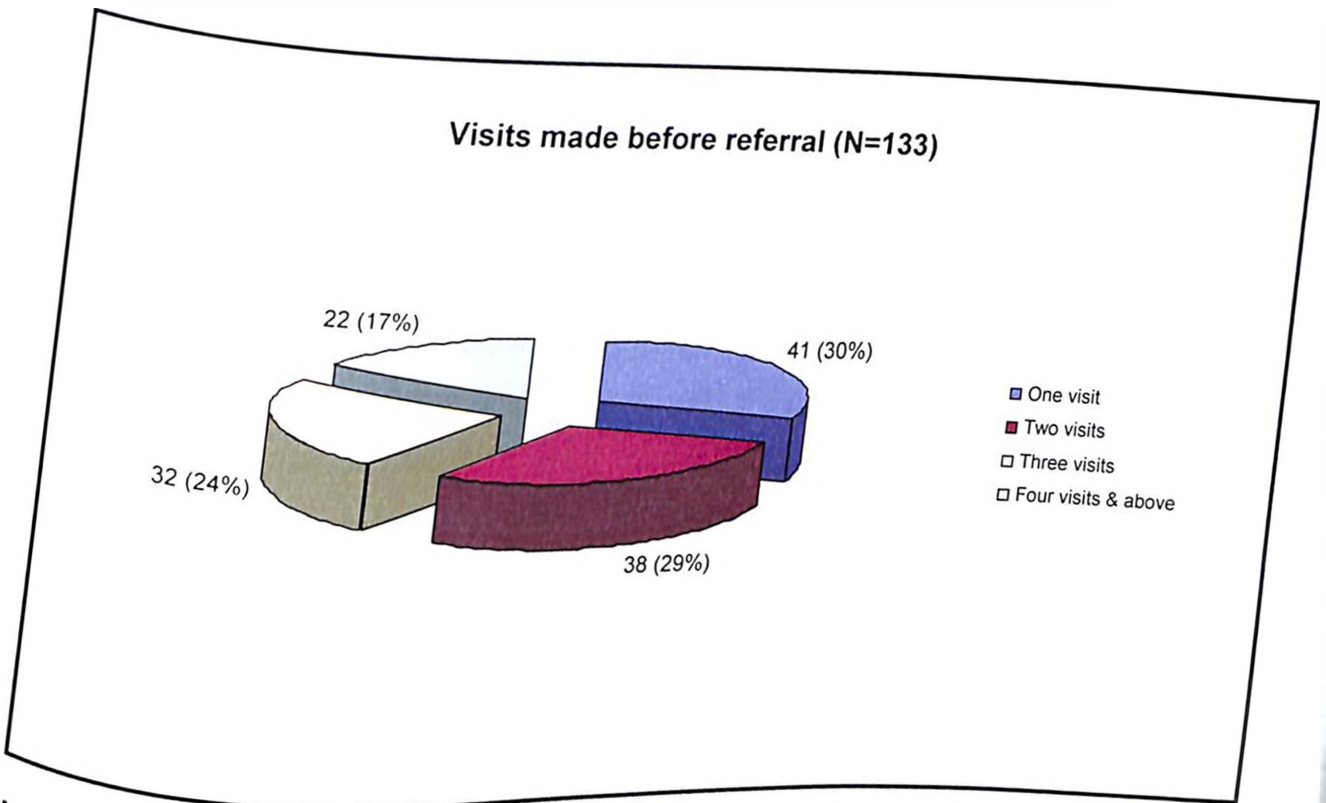


Figure 6.1: Number of visits made by respondents before referral service is given.

According to former sleeping sickness patients, whenever patients were referred to the health facilities with laboratory facilities, most of them were given recommendations for treatment of malaria and/or typhoid. Some of those who were found to be negative for both typhoid and malaria were advised by either family members or some formal medical providers to look for alternative medicine, notably traditional medicine.

For those who were not referred, 66.8% (267) indicated that the formal health providers in the area only changed their prescribed drugs on subsequent visits. After the fourth visit, some respondents indicated that they were advised to try traditional medicine. This is how a 52-year old female former sleeping sickness patient put it:

I had taken approximately two years in my marriage when I became ill in 1988. I initially thought I had malaria. I first used traditional herbal medicine to treat as I always did. However, this time, I did not get better. After deliberations with my husband, we decided to go to Amukura Health Centre for treatment. I was given drugs for malaria on the first and second visits. On the third visit, I was tested and treated for typhoid but my condition appeared to worsen. When I was taken back again, the health officer who handled me advised that my illness required a 'cultural solution'. Back home, my husband invited the Musebe people (Traditional medical practitioners who are believed to possess and use supernatural powers to exorcise malevolent spirits in an individual). We gave them a goat and two cockerels. However, things still did not work. Later, a villager who worked with the National Sleeping Sickness Referral Hospital came and advised us to go to the NSSRH for tests. I had initially resisted because I had developed dislike for hospital drugs. Reluctantly, we decided to try the hospital. When tests were carried out, I was found to be positive with sleeping sickness and put on treatment regime for two months. However, back pains that resulted from lumbar puncture have persisted to date. I cannot work in the field for long hours as I used to do before the treatment (A 52-year old female former sleeping sickness patient from Apatit village, Amukura division).

The above information was also corroborated by data generated during focus group discussions where participants indicated that formal health providers (from clinics and dispensaries) gave referral services when a patient presented at the health facilities when in a very bad state. In such a case, the patient was referred to Alupe Sub-District Hospital even before treatment.

According to a male key informant from the NSSRH, provision of referral services by non-HAT formal health providers in Teso and the surrounding districts is important for the success of passive surveillance and the ultimate control of sleeping sickness in the area. According to the informant, early referrals lead patients to access correct diagnosis and appropriate treatment early. The key informant had the following to say regarding provision of referral services by other formal health providers within the district:

Health centres are not sending in patients for screening. We rarely get referrals. Although a few people come for tests we expect many referrals. This passive surveillance is not a strong structural approach to get sleeping sickness patients. We need to have active surveillance to be able to know about our sleeping sickness situation in the country with certainty (An Officer at the NSSRH).

The NSSRH records indicate that a total of 24 individuals had been referred from health facilities in the district between 2006 and 2011, a majority (21) being referred from Alupe sub-District Hospital. According to an officer at the NSSRH,

the referrals were made when the individuals under observation appeared to be sleepy.

6.4 Impediments to Intra-community Referrals to the NSSRH

i) Diagnosis of HAT at the NSSRH

Interviews with former sleeping sickness patients from Obuchun and Amaase villages indicated that they had been referred to the National Sleeping Sickness Referral Hospital by their local administrators (chiefs) but they pointed out that while at the hospital, they were screened and found negative for sleeping sickness. However, these informants observed that their illnesses persisted and when they went to Tororo (UTRO Hospital, Uganda), they were diagnosed with the disease. This, according to these former patients, made them have more confidence in the UTRO hospital as opposed to the National Sleeping Sickness Referral Hospital. This is how one of them described his health-seeking movement:

I was infected with sleeping sickness in 1998. Because during that year many people from our village were affected, the local chief came to my homestead and asked that I go for test at 'Alupe ya Juu' (NSSRH). He had initially been moving in the villages with some National Sleeping Sickness Referral Hospital field officers in their sleeping sickness sensitization campaigns. When I went there, my blood sample was taken and later I was informed that everything was fine. However, I was convinced by my conscience and the way I felt that I was ill. Back home, my relative who worked

in Tororo, Uganda, came and informed me to try UTRO Hospital. When I went there, I was diagnosed with sleeping sickness and admitted for three weeks. Without the decision to go to UTRO, I would be long dead (60-year old male former sleeping sickness patient from Amaase Village, Chakol Division).

An interview with an officer at the sleeping sickness hospital on the surveillance and diagnosis procedure indicated that surveillance of sleeping sickness in the sleeping sickness foci in the country mainly depended on passive surveillance. When sleeping sickness suspects went to the hospital and their blood samples taken, the buffy coat technique (BCT) – a diagnostic procedure involving spinning of blood samples in a centrifuge to separate blood components followed by microscopic observations - was used to determine the disease status of the samples. According to the hospital informant, this technique worked better when there was a heavy parasite load (many trypanosomes) in the samples as this enhanced their being observed through the microscope. However, in cases where there is a small number of trypanosomes in the blood samples, the informant added that it required multiplication of the parasites through inoculation in mice (injecting mice with some sample parts and trypanosomes, if any, allowed to multiply) before observation by microscopy. The sleeping sickness hospital informant indicated that compared to the UTRO hospital, the NSSRH did not have a mice colony of its own and, therefore, the laboratory technicians at the hospital carried out their observations mainly through the buffy coat technique and microscopy. The informant further stated that this diagnosis method had low

sensitivity and thus for success in diagnosis of sleeping sickness it is necessary to build up a mice colony to aid in disease diagnosis and research. The hospital informant also added that for human health, analysis of the blood samples should involve utilization of other molecular methods such as polymerase chain reaction (PCR) that were available and better for reliable results, but are not used at the hospital for the purpose.

ii) Multiplicity of Roles by the NSSRH Officers

A male key informant from Obuchun village of Chakol division recalled that in the 1980s and 1990s, KETRI had a high visibility within the villages. According to him, the organization was involved in a lot of active surveillance activities and transported cases that they found within the villages to the sleeping sickness hospital for management at their own cost. However, the key informant observed that in the early 2000s, sleeping sickness cases dwindled and the community members saw the officers who formerly engaged in trypanosomiasis activities switch to agricultural activities such as the promotion of cassava and potato varieties within the villages. This, according to the informant, made the community members who knew about the hospital start having doubts about the capacity of the hospital to manage human illness. The end result of these doubts is that the desire by the community to refer sleeping sickness suspects to the National Sleeping Sickness Referral Hospital was impeded.

The following excerpt from a key informant in Amukura gives an indication of the prevailing views of the communities about KETRI and the NSSRH:

A suspicion about a single case of sleeping sickness in the villages would lead to KETRI sending very many research scientists to the villages to get animal and people's blood samples for analysis. The officers from the hospital worked well with local administrators and members of the local community. These days, the vehicle that used to come for patients and control of the disease in livestock is seen in the villages with officers with the mission to promote cassava breeds and poultry farming. This makes us doubt the capability of the hospital to handle sleeping sickness as the officers are now involved in other activities unrelated to the control of the disease. The active doctors we used to know are also not at the hospital (50 year-old male key informant from Amukura).

According to an officer from the NSSRH, there was a transition in the early 2000s that led to the merging of KETRI with Kenya Agricultural Research Institute (KARI). KETRI was the parent institution that managed the activities of the sleeping sickness hospital. The officer was of the opinion that the merger led to the transfer its functions and staff to KARI. According to the officer, this transition also culminated into reduced funding for tsetse and trypanosomiasis (T&T) control activities, particularly active surveillance for sleeping sickness in the district.

On the transition from KETRI to KARI and the reduced number of sleeping sickness patients in Kenya, a key informant summarized his opinion and experiences about the disease as follows:

In the period from late 80s to around 2002, the hospital used to carry out active surveillance with increased community advocacy activities. However, since KETRI was taken over by KARI in 2003, we have had virtually no funds for tsetse and trypanosomiasis field activities. We have also observed increasing perception from the community members that the hospital and its entire staff were transformed into dealing with crops as opposed to human and livestock health. Therefore, because of the current situation and the fact that we currently have one sleeping sickness case, we believe the disease is in circulation in the district but at low levels. Passive surveillance is not working well for us as people are not presenting themselves to our hospital for screening as expected. We need to carry out spot checks periodically in villages particularly in our traditional hot spots. We also get referrals but not so many. We also think people avoid us because they think we screen for HIV without their consent. Our visibility in the community is diminishing (An Officer from the National Sleeping Sickness Referral Hospital).

iii) Absence of structures to enhance visibility of the NSSRH

As far as structures to enhance community sensitization about the disease and the NSSRH in the district were concerned, direct observation in the four divisions of the district revealed that there were no structures in the district to enhance the community members' voluntary screening for sleeping sickness whenever they

(the local people) encountered possible symptoms. The structures of interest here included permanent billboards and graffiti like what the government and non-governmental organizations have put up in the case of HIV/AIDS or malaria control. Likewise, there were no observed structures to increase visibility of the NSSRH to the community. Instead what was observed were the long queues of community members at formal health service facilities (hospitals and dispensaries) seeking for health services. This lack of structures to enhance visibility of the hospital in the community reduces the chances for community members to have knowledge about the hospital hence diminishing the possibility for effective referral of possible sleeping sickness cases to the NSSRH from other community members.

CHAPTER SEVEN

DISCUSSION AND CONCLUSION

7.1 Introduction

This chapter discusses community knowledge about sleeping sickness and the National Sleeping Sickness Referral Hospital in relation to access to formal sleeping sickness health services. The chapter also focuses on the people's health-seeking behaviour and determinants of the behaviour and elucidates the impact of the behaviour on access to sleeping sickness healthcare. Lastly, the chapter discusses provision of referral services both at the community and formal health provider levels in Teso district.

7.2 Effects of Knowledge of HAT and the NSSRH on Access to HAT

Services

The results indicate that a majority of the respondents were knowledgeable about the transmitting agent for sleeping sickness. However, a few (16.7%) of them across the research site did not associate sleeping sickness with tsetse fly bites and the associated predisposing behaviour for the disease. Instead, other factors such as witchcraft, mosquito bites and stress were blamed for the disease. Foster and Anderson (1978) are of the view that different cultures have varied explanations relating to cause and/or spread of illness and the rationale for different options for the healthcare sought. Some illnesses may be defined as

resulting from personal or human factors while others may be viewed as having their roots in supernatural and/or natural causes. According to Venkatraju and Prasad (2010), objective knowledge of any disease epidemiology by both scientific and local communities is important in attaining effective control of the target disease.

Insufficient or conflicting knowledge between biomedicine and folk theories about either the transmitting agent in case of vector-borne diseases or inappropriate information about the cause and/or the treatment centre may lead to unsuccessful disease control by implementing agencies. This may happen if agencies for disease control use biomedical approaches as guiding principles in contradiction to the local communities' epidemiological theories. The perspectives taken by the different communities towards explanation for illness have a bearing on the individual health-seeking behaviour of the affected people and the ultimate disease control by concerned authorities (Venkatraju and Prasad, 2010:27). The existence of alternative disease theories relating to sleeping sickness, as opposed to biomedical standpoint, is also consistent with findings by Bukachi (2007) in her study on sleeping sickness in western Kenya.

Results indicate that some respondents attributed the cause of sleeping sickness to witchcraft, a fact that is inconsistent with the biomedical view about the epidemiology of the disease. The people who defined sleeping sickness as resulting from witchcraft would avoid biomedical health facilities while those who

held the view that the disease is transmitted by mosquitoes would go to any other (non-HAT) health facilities within their reach for health restoration. This inappropriate orientation in knowledge constitutes an access barrier to the services offered at the National Sleeping Sickness Referral Hospital as the patients would either report to the HAT hospital for proper diagnosis and treatment late or will suffer in the course of searching for health and die undiagnosed. The existence of a diversity of views on the causes of an illness renders the control and management of disease by established formal health management units an uphill task. This is because community members will have different mechanisms relating to health restoration and management (Toé *et al.*, 2009).

The existence of diversity of explanations about the cause and spread of illness is not peculiar to the people of Teso District. Toé *et al.* (2009), in their study on malaria and bed net usage in Burkina Faso, found the existence of different explanations relating to the cause of malaria among target populations. In their study, they found that the occurrence of malaria was attributed to many factors and mosquito bite, a bio-medically accepted link to malaria transmission, was regarded by community members as only one of a number of causes for the disease. They also concluded that some measures taken by the communities to prevent malaria were manifested in ways unrelated to mosquitoes. The adoption of bed net usage was, therefore, linked to beliefs around the causes of malaria. People who defined the mosquito bite as a lesser cause for malaria, therefore,

did not see the use of bed nets as a mechanism to control the disease with the seriousness that it deserved in the malaria-prone areas (Toé *et al.*, 2009:7)

The study results reveal that 12.8% of respondents had no knowledge of either the cause or transmitting agent for sleeping sickness. The results also indicate that 11.8% of the respondents did not have any knowledge of the symptoms associated with the disease. Lack of knowledge about the cause and/or spreading mechanisms of a disease constitutes an access barrier to formal health services offered at specialized health facilities. This is because the target population may try to find healthcare elsewhere as opposed to the health facilities where appropriate and effective health services are offered. In the case of sleeping sickness in Teso district, the lack of knowledge about the disease amongst the population may see HAT patients seeking for health services from other non-HAT hospital facilities as opposed to the National Sleeping Sickness Referral Hospital. In such a scenario, dependence on passive surveillance in control of the disease becomes an uphill task. According to Venkatraju and Prasad (2010:21), success of passive surveillance largely depends on the affected communities' awareness of the disease and their ability to recognize the early signs.

In many areas of developing countries, limited knowledge of wellness and illness affect accessibility of health services to the target community members (Karim, 1987). According to Hunter and Sultana (1992:1393), besides limited knowledge

of illness and wellness, cultural prescriptions and community perceptions about a health service provider have an influence on the effectiveness of the available health services. It is, therefore, important to understand the influence of these factors of health seeking behaviour of the population and the factors driving this behaviour (Shaikh and Hatcher, 2004:50).

Cultural beliefs and practices often lead to self-care, home remedies and consultation with traditional healers in rural communities. These factors result in delay in treatment seeking and are more common amongst women, not only for their own health but also their children's illnesses (Nakagawa, 2001:28; Karim *et al.*, 2007: 331). Family size, educational status and occupation of the head of the family are also associated with health seeking behaviour besides age, gender and marital status (Nyamongo, 2002; Yip *et al.*, 1998: 318).

Regarding the symptoms of sleeping sickness, results indicate that 57.3% of the respondents associated sleepiness with the disease. This association of sleeping sickness with sleep as a symptom of the disease by a large proportion of respondents may also explain delayed seeking of appropriate diagnosis and ultimate treatment of the disease. The National Sleeping Sickness Referral Hospital records indicated that a majority of sleeping sickness patients previously presented themselves to the hospital while in the second stage of the disease. This may be because sleepiness exhibited by sleeping sickness patients comes in the second stage of the disease and, therefore, implies that patients will seek

for health from the sleeping sickness hospital when the sleepiness symptom is exhibited. According to MSF (2004:2), treatment of sleeping sickness at the second stage of the disease is more difficult due to the toxicity of the drugs involved. Therefore, people who present at the sleeping sickness facilities when in this stage may have bad experiences with the treatment procedure or even witnessed death of patients, a fact that can easily discourage people from taking HAT patients to the facilities for services. The pain associated with the lumbar puncture may also act to keep away potential sleeping sickness patients from the specialized health facilities.

Whereas a majority (89.5%) of the respondents indicated that the disease could be treated through biomedical means, 52.5% of them did not have any knowledge about the NSSRH. Those who did not have knowledge about the hospital thought the disease could be treated at any other government hospital, or by traditional medical practitioners and/or spiritual means. People who think that an illness can be treated through other means as opposed to biomedical means, are more likely not to use the health services offered at formal health facilities including the sleeping sickness hospital. The population with such an ideological standpoint may also not benefit from referral services from other biomedical facilities (non-HAT health facilities) that should, in an ideal case, refer patients to specialised health facilities such as the sleeping sickness hospital when they get to their respective facilities.

The study results indicate that, in general, 3.5% of the respondents did not recognize the National Sleeping Sickness Referral Hospital as a centre for treatment of sleeping sickness. Such people believed that the disease could only be treated at UTRO Hospital at Tororo in Uganda. This knowledge about the Ugandan hospital may have emanated from the historical knowledge about UTRO Hospital being the only treatment centre for sleeping sickness in East Africa from colonial days to the break-up of the East African Community (EAC) in 1979. This historical attachment to UTRO Hospital among the residents of the research site, therefore, constituted an access barrier to the HAT health services offered at the NSSRH as suspicions about the disease would see potential patients presenting for treatment in Uganda.

The results also indicate that the treatment process of sleeping sickness involves getting blood samples from patients and if found positive with trypanosomes in the blood, lumbar puncture is performed. According to 7.5% of the respondents and former sleeping sickness patients, the lumbar puncture is a painful procedure. MSF (2004), Thomas (2004) and Kuzoe (2001) report that the lumbar puncture procedure is not only painful but also dangerous. The pain associated with the lumbar puncture may prevent patients from utilizing the health services offered at health facilities specialized in the diagnosis and treatment of sleeping sickness including the National Sleeping Sickness Referral Hospital.

In addition, the results also indicate that 2.8% of respondents feared that utilization of health facilities where blood samples are taken would lead to their samples being examined for HIV against their wish. This fear of the HIV/AIDS test is among the important factors that may prevent people in Teso District from going to hospital for the treatment of HAT. The fear of giving blood samples because of the possible screening for HIV was also reported by Kamara *et al.* (1994:31) in their study in Busia and Teso districts. Because diagnosis of human trypanosomiasis involves use of blood samples from suspected patients, this may discourage potential patients from going to the NSSRH for diagnosis and ultimate treatment in case of HAT patients.

Results further indicate that the community stigmatized sleeping sickness patients and often associated their condition with HIV infection and/or mental illness or low libidinal energy and eventual infertility. The fact that one of the symptoms for sleeping sickness is body wasting, a condition also associated with HIV/AIDS, an individual who contracts sleeping sickness may also experience the same stigma associated with AIDS victims. An individual who experiences body wasting may, therefore, avoid going for diagnosis at formal health facilities for fear of being found HIV/AIDS positive. This stigma attached to body wasting serves to derail the appropriate diagnosis and early treatment and may account for late diagnosis and treatment of the disease as indicated in the findings from the KETRI unpublished Sleeping Sickness Referral Hospital reports.

The social stigma associated with sleeping sickness and/or its treatment may also bar people from going to specialized health facilities for formal diagnosis and treatment. According to Weiss (2008:1), stigma is an important social determinant of the effectiveness of disease control through its effect on help-seeking and treatment adherence. Weiss (2008:1) further observes that the impact of stigma is not readily accounted for in the epidemiological data that characterize the defined burden of disease. Instead, stigma imposes what has been termed a 'hidden burden' to patients and communities. Therefore, for effective control of health problems particularly in rural communities, recognition of the serious impact of stigma and its elimination by agencies working in the affected areas must be prioritized.

Perry and Donini-Lenhoff (2010:225) argue that stigmatization prevents people with disease from seeking care, engenders fear of those who have disease, causes prejudice against entire groups or communities and, in some cases, has led to violence against the stigmatized group. Nsagha *et al.* (2001) and Waxler (1981) add that stigmatization can lead to the affected person being rejected and excluded from society. Cheung *et al.* (2006:1918) conclude that for effective control of infectious diseases, more effort should be placed in strategically changing the attributions made by the public towards infectious diseases. In so doing, the public would develop more acceptable attitudes towards disease and the affected individuals. They add that for preventive programmes of infectious diseases to be effective, their associated stigma must be actively addressed.

Nsagha *et al.* (2001:42) observe that clinicians working in developing countries should, therefore, be prepared for the challenges of providing care to diverse populations through a deeper understanding of what past caregivers and patients have encountered when disease and discrimination intersected.

The research results indicate that sleeping sickness is associated with witchcraft and permanent mental illness, conditions that lead to finger pointing and desertion. This is consistent with the findings of Bukachi (2007) who reports that there is stigmatization and avoidance of former sleeping sickness patients who experience reduced libido and mental illness, conditions associated by communities with sleeping sickness infection or treatment. According to Bukachi (2007:84), sleeping sickness stigmatization was not limited to people external to the family but also existed within the family through avoidance and neglect. This may make potential sleeping sickness patients shun the diagnosis and treatment centre (NSSRH) for fear of being associated with the disease.

The apparent side effects of either the disease or the treatment process such as psychological disturbances and/or low libidinal energy may also negatively affect utilization of the services offered at the National Sleeping Sickness Referral Hospital. This is because people may fear to encounter these experiences and/or become the focus of village gossip and finger pointing.

7.3 Health-seeking Behaviour and Access to HAT Formal Health Services

Study results indicate that the community members within the research site were exposed to a variety of healthcare options from which to seek for health when illness occurred. The options ranged from traditional medical practitioners, biomedical sources of health (including chemists/pharmaceutical outlets, clinics, dispensaries and hospitals run by religious organizations, government or private bodies). This finding is consistent with those of Bukachi *et al.* (2009) who found that a majority of community members utilized more than one source of healthcare with most using self-treatment through over-the-counter drugs. This utilization of drugs from chemists/pharmaceutical outlets were described by Kleinman (1980:65) as belonging to the popular sector of healthcare and utilized by society as the initial step towards health restoration. Similar findings were also reported by Amuyunzu-Nyamongo and Nyamongo (2006) and Miguel *et al.* (1998) in their studies on malaria in Kenya and the Philippines, respectively. Utilization of health services from the popular sector may serve to increase the period with which proper diagnosis of illnesses that require specialized attention is done. This may also be compounded in cases where the agents for health provision in the popular sector are not adequately knowledgeable about the disease in question in relation to symptoms and/or suitable health facilities for treatment of the disease as is the case with sleeping sickness.

Unpublished reports by KETRI indicate that most of the attendants in the health facilities within the district including chemists/pharmaceutical outlets were not knowledgeable about sleeping sickness and the National Sleeping Sickness Referral Hospital. Study findings suggest that, initially, most of the former sleeping sickness patients were treated for malaria and/or typhoid fever before they found their way to the sleeping sickness hospital either through referral by the NSSRH employee, local administrator or past experiences with the disease in the family or neighbourhood. This finding about lack of knowledge of sleeping sickness and the hospital by non-HAT formal health providers within the district implies that in the event of sleeping sickness, the affected member(s) may have difficulty in trying to get appropriate treatment option. Similar sentiments were expressed by Durrheim *et al.* (1999 quoted in McCombie, 2002:339) based on their study on malaria in South Africa.

The multiplicity of health care options in the research site implies that depending on the community's theories about disease causality, people would move from one healthcare option to another or favour particular health options over others. This movement is informed by what the people perceive to be the most appropriate option for healthcare.

As in most of Africa, health care in Kenya is pluralistic. The context of health-seeking in the country, therefore, reflects a great diversity. Western biomedicine, faith healing, patent medicine shops and traditional medicine co-exist, and care-

seekers choose among these options to meet their health needs (Izugbara *et al.*, 2009:37). On the onset of illness, results indicate that 68% of respondents utilized chemists/pharmaceutical outlets and when there is disease persistence, 64.4% of respondents went to local dispensaries and, subsequently, to local hospitals. Ayodele *et al.* (2002:331), in their study on health-seeking behaviour in Nigeria, however, found that community members first utilized home remedies and only went to the hospital when cases became severe.

Wandwalo and Morkve (2000) and Anorlu *et al.* (2004) in their studies on tuberculosis in Tanzania and cervical cancer in Nigeria, respectively, found that a majority of the patients first sought treatment at a hospital and a few either treated themselves at home by buying medicine from a nearby drug shop or were attended to by a local traditional healer. Therefore, patients delayed to present to hospital because they spent longer periods seeking treatment from traditional healers, profit making or private hospitals or delayed due to poor referral systems. This caused their financial resources to be wasted, at times, without getting proper treatment. As far as sleeping sickness is concerned, this multiplicity of healthcare options in the research site and the patient mobility within the options partly explains the late stage reporting of the disease to the NSSRH by a majority of the treated patients.

The study results also indicate that sleeping sickness is difficult to diagnose by simple microscopy and requires experienced personnel. The difficulty in

detecting trypanosomes in patients may constitute a problem in the success of trypanosomiasis control programmes as patients may remain untreated and hence serve as reservoirs for the disease for the other community members (Kyombadde *et al.*, 2000:120). Improper diagnosis that culminates into inappropriate treatment of the disease may serve to obscure sleeping sickness-related morbidities and mortalities and hence act as an access barrier to formal health services offered at the sleeping sickness hospital or lead to late reporting of cases.

This study also found that after hospital treatment without success, the population that crossed over to Uganda, stayed at home to wait for any eventualities and the ones that utilized traditional medicine and prayers, increased. This scenario means that the chances of people going to the National Sleeping Sickness Referral Hospital for health services is further diminished by disease persistence as biomedicine will have been seen to have failed and those who cross to Uganda, if found to have the disease, may be registered as Ugandan cases. This is especially so because, as suggested by key informants, when community members from Teso district on the Kenyan side of the border crossed over to Uganda in search of health services, they identified themselves as Ugandans. This concealing of nationality is done possibly to avoid extra charges that may be charged by hospital authorities in Ugandan health facilities for non-Ugandans. The fact that the inhabitants of the area across the border are

predominantly Iteso, distinguishing a Kenyan Iteso from a Ugandan one is an uphill task.

7.4 Determinants of Health-seeking Behaviour and Access to Services at NSSRH

Results indicate that 52.5% of respondents and key informants were of the view that the cost of services offered by health facilities in Teso district may deter the local people from utilization of the offered health services. There was a general view among respondents that the cost of health services was higher in Kenya as compared to the amount charged by the Ugandan health facilities. According to the respondents and key informants, this made some people go to Uganda for health services as opposed to Kenya. The group that goes to Ugandan health facilities for services because of the perceived high cost of health services in Kenya may, therefore, include some Kenyan sleeping sickness cases.

Whereas the National Sleeping Sickness Referral Hospital does not charge for activities related to sleeping sickness disease diagnosis and management, the charging of outpatient services for other diseases such as malaria and typhoid fever serves to classify the hospital with other non-HAT health facilities that charge for health services within the country. This may lead to avoidance of the hospital by those who look at the services offered as expensive. Lawson (2004:20) observed that although income is strongly associated with increased health care demand in the western world, the impact of introduction of user fees

on healthcare demand in developing countries resulted in undesirable effects. There was reduction of the population that utilized health services where the user fees had been introduced with women more affected than men.

Uzochukwu and Onwujekwe (2004), in their study on the introduction of user fees in the provision of health services in Nigeria, concluded that access to care is generally reduced especially during the early stages of implementation. On user fees and its impact on hospital service utilization, Asenso-Okyere (1995) observed that the introduction of user fees in health in Ghana resulted in a drop in attendance at health facilities, especially in rural areas. The reason given for this drop was the high cost of care. Mbugua *et al.* (1995) also observed that in Kenya there was a drop of 42% in attendance for curative services at health centres in Kibwezi district due to the introduction of cost sharing program in patients' facilities after the authorities introduced user fees in medical services (Hussein and Mujinja, 1997:753). Lawson (2004:20) observed that abolition of cost sharing in healthcare in Uganda coincided with an increase in demand for government provided health care.

According to Onwujekwe *et al.* (2000), the cost of health care is a hindrance to many health care seekers, leading them to look at alternative providers for healthcare. The alternative health providers have included drug peddlers and pharmaceutical shop operators. These operators provide services which are closer to the people and may be cheaper in the short run than services from

regular health care providers because of non-payment of consultation fees and transport expenses. The alternative health providers offer treatment for common ailments like fever, diarrhoea, headache and stomach-ache (Asenso-Okyere *et al.*, 1998:185).

The charging of user fees has also led to patients engaging in self-treatment. According to Deressa *et al.* (2003), McCombie (2002) and Gomes *et al.* (1998), self-treatment lowers the cost of treatment and is more common for illness episodes that are not considered severe. However, potential dangers such as over-dosing and problems of disease resistance to common drugs exist in self-treatment (Gomes *et al.*, 1998). According to Asenso-Okyere *et al.* (1998:186), poverty not only excludes people from the benefits of health care system but also restricts them from participating in decisions that affect their health, resulting in greater health inequalities.

Apart from the determinism of cost of healthcare to utilization of health services, results also indicated that distance from the place of residence by the local people to the location of health centres also influenced the tendency of people to utilize health services from the health facilities. In the event of illness, people indicated that they sought health services from facilities that were closer to their homesteads. The results suggested that 11% of respondents crossed over to Uganda in search of health services because they considered Ugandan health facilities geographically near to them. This determinism of distance on access to health services is not peculiar to the people in the research site. According to

Lawson (2004:20), demand analysis for healthcare in Uganda suggests that the distance travelled to health centres is important in developing countries as far as access to healthcare is concerned. He concludes that the use of more localized health institutions that offer a higher level of care may be a feasible alternative to centralized units which cater for large numbers of people and that policies aimed at lowering travel costs would have a positive impact towards access of healthcare to community members.

In many developing countries, the effect of distance on service use becomes stronger when combined with the dearth of transportation and with poor roads. This state of affairs contributes towards increased costs of visits to health facilities (Daniels, 2000:743). Availability of transport, physical distance of the facility and the time taken to reach the facility undoubtedly influence the health seeking-behaviour and the utilization of health services (Noorali *et al.*, 1999:195). According to D'Souza (2003), the distance separating patients and clients from the nearest health facility is an important barrier to use, particularly in rural areas. The long distance has even been a disincentive to seek care especially in case of women who would need somebody to accompany them. As a result, the factor of distance gets strongly adhered to other factors such as availability of transport, total cost of one round trip and women's restricted mobility (D'Souza, 2003:138).

According to Anorlu *et al.* (2004), people who live far from hospitals have a higher chance of delaying going to hospital compared to those living close to

hospitals particularly if the area in focus is characterized by poor transport infrastructure. Delay to present to hospital is, therefore, associated with how accessible the hospitals are. It is, thus, necessary to recommend that governments, particularly in developing countries, should try to take health care closer to the people. This is particularly important for communities in rural areas who make the majority of the population and who form the bulk of the workforce for these countries.

The centralization of specialized health facilities may also affect utilization of the offered services. This is particularly so in cases where the centralized health facilities serve patients from far-off distances. The location of the National Sleeping Sickness Referral Hospital at Alupe, without other health facilities with the capacity to diagnose sleeping sickness in the district, may affect utilization of the health services offered at the hospital. Disaggregated divisional results from Teso district indicate that 23% and 40% of respondents from Amukura and Angurai divisions, respectively, were of the view that distance to health facilities would deter them from going to hospital for health services. Non-attendance at health facilities because of distance affects utilization of specialized sleeping sickness healthcare. In cases where other formal health providers (non-HAT providers/facilities) are located far from the people, the distance may discourage people from seeking health services from the facilities. Therefore, referral services from such biomedical facilities to specialised health facilities such as the NSSRH may not be accessed. Perception of the sleeping

sickness hospital as being far from peoples' homesteads may also lead to people not accessing the HAT services due the long distances involved. Referred cases may also fail to honour referrals to the hospital in the event that they are discouraged by long distances.

The results indicate that community members from the research site had a multiplicity of explanatory theories for disease causation. In general, these theories explained illness as resulting from humanistic, supernatural and naturalistic causes. Six point two per cent of the respondents associated sleeping sickness with witchcraft. According to Ward *et al.* (1997:21), cultural practices and beliefs shape people's access to healthcare. Therefore, in case disease causality is attributed to either humanistic or supernatural causes, consideration for biomedical facilities and services is not feasible.

Warsame *et al.* (2007:6) are of the view that local beliefs regarding aetiology of illnesses strongly influence health-seeking patterns. For instance, caregivers are likely to consult traditional healers when they believe that illness is due to witchcraft. According to Stuyft *et al.* (1996) and Perez-Cuevas (1996), cultural practices and beliefs affect awareness and recognition of severity of illness, availability and acceptability of health services. Geissler *et al.* (2000:1778) add that in rural communities, cultural beliefs and practices have been prevalent regardless of age, socio-economic statuses of families and level of education. WHO (2008, quoted in Chibwana *et al.*, 2009) advises that in many developing

countries, governments and disease control agencies should develop interest in traditional healers as the healers provide an opportunity for collaboration between the traditional and the formal health system in increasing prompt access to effective biomedical treatment for many health problems common in these countries.

Historically, traditional healers have often been thought of as being harmful in disease treatment and prevention since they appear to delay patients from accessing appropriate treatment. However, in Tanzania, the World Health Organization (2008, quoted in Chibwana *et al.*, 2009) notes that the involvement of traditional healers led to an improvement of early referral and prompt treatment for children with severe malaria. Deliberate efforts should, therefore, be made to incorporate and train traditional healers in disease control either as community dispensers of drugs or to counsel caregivers regarding the need for appropriate and early referral to a health facility (WHO, 2008, quoted in Chibwana *et al.*, 2009). In Kenya, there have not been clear policy guidelines aimed at achieving co-operation between traditional medical practitioners (TMP) and bio-medically oriented hospital officers. This state of affairs does not offer a framework where the possibility of community members who perceive sleeping sickness to be caused by humanistic factors other than transmitted by tsetse flies can be taken care of at the NSSRH through referral from the sensitized traditional medical practitioners.

This study established that when faced with disease persistence, some community members crossed over to Uganda, stayed at home to wait for eventualities or utilized traditional medicine, while others resorted to spiritual healing by way of prayers. The crossing over to Uganda for health services and utilization of alternative health services implies that the chances for this group of people to utilize the health services from the NSSRH are remote. These findings indicate that in the event of an illness, community members who crossed over to Uganda, utilized alternative sources and those that stayed at home increased when the disease persisted even after seeking treatment at formal health facilities.

Study findings also suggest that a majority of respondents had trust in traditional medicine within the district. This could indicate that in the event of sleeping sickness, some patients would utilize traditional medicine and other available healthcare options apart from the sleeping sickness hospital hence go unreported.

According to key informants, Alupe is associated with the management of leprosy, a stigmatized disease. The Iteso believe that leprosy results from a curse and the victims need to be avoided. The association of Alupe with leprosy may, therefore, act as an access barrier to the HAT services offered at the NSSRH as the hospital is also situated in the same location. Historically, treatment of sleeping sickness was associated with UTRO. Therefore, suspicion

of sleeping sickness amongst community members in Teso District would lead to some affected people shunning treatment at NSSRH and instead cross over to UTRO.

7.5 Interactions between Patients and Formal Health Providers in the District

The study found that most former sleeping sickness patients were first treated for malaria and later typhoid or treated for the two diseases when they went to the health facilities before they ultimately got to the NSSRH or UTRO for treatment. According to respondents and key informants, the non-HAT formal health providers changed the drugs for them to treat malaria and/or typhoid fever during subsequent visits. This treatment of one or the two diseases by non-HAT biomedical practitioners instead of proper diagnosis of sleeping sickness may delay the appropriate treatment and management of the disease and increase the transaction cost involved in health restoration among the community members. The lack of referral services by formal health attendants in the research site exacerbates the problem of increased transaction cost. A combination of inappropriate diagnosis and treatment and the lack of referral services from formal health attendants may explain why former sleeping sickness patients reported to HAT facilities while at the second stage of the disease. According to Snow *et al.* (1992:238), referral networks are the mechanisms by which self-regulation and quality enhancement take place in healthcare delivery systems.

Infrastructural shortcomings in the health sector within the district such as inadequate staffing levels and lack of sufficient health-related supplies such as essential medicines for treatment of common diseases affect utilization of formal health services provided by health facilities within the district. Because of these infrastructural shortcomings, particularly inadequate staffing levels, long queues of health service seekers at health facilities were observed. This observation was also made by Mugunieri and Wanjala (2007:6) in their study on the interaction of hospital attendants and community members during malaria treatment in Teso district. They observed that patients seeking treatment, particularly in government outpatient hospitals, waited the longest (average of 3 hours) before obtaining treatment. The waiting time was significantly higher in government outpatient than in all the other categories of health facilities in the district. According to Gilson *et al.* (1994:775), insensitive hospital staff and long waiting lines are some of the features that limit patients' utilization of some facilities. The long queues may also make people avoid the health facilities. Avoidance of health facilities may render referral services from these facilities to the NSSRH inaccessible.

Study results indicate that some former sleeping sickness patients were found to be negative for sleeping sickness when they visited the National Sleeping Sickness Referral Hospital for screening. However, when they crossed over to Uganda (UTRO Hospital), they tested positive for the disease. Therefore,

potential sleeping sickness patients with the above experience may lose confidence in the NSSRH's diagnostic outcomes and shun the hospital in favour of other health facilities in Uganda. This state of affairs may act as an access barrier to the health services offered at the NSSRH.

An interview with the NSSRH staff responsible for the screening of sleeping sickness indicated that the technology used for screening the blood samples for the disease-causing pathogens (trypanosomes) at the sleeping sickness hospital (microscopy without inoculation in mice to enhance observation of parasites, if positive) had low sensitivity and hence the need to operationalize utilization of other more specific and sensitive methods. According to Andaleeb (2000) and Meng *et al.* (2000), client-perceived quality of services and confidence in the health provider affect the health service utilization. Kinung'hi *et al.* (2006:171) are of the idea that lack of satisfactory surveillance and suitable diagnostic techniques for sleeping sickness may lead to cases being easily mistaken for febrile diseases like malaria and other diseases prevalent in many sleeping sickness endemic areas. The poor surveillance system, inadequate diagnostic technologies, coupled with low incidences and the sporadic nature of the disease, make it difficult to identify cases of sleeping sickness (Malele *et al.*, 2006).

Results indicate that the sleeping sickness hospital utilized the buffy coat technique and observation of samples in the microscope to diagnose

trypanosomes in the collected samples. This method was described by a key informant from the sleeping sickness hospital as characterized with low sensitivity. The use of methods with low sensitivity in the screening of human trypanosomiasis in the area may account for the perception among the locals that the Ugandan health facilities are better providers of specialized health services than the Kenyan sleeping sickness hospital and hence constitute an access barrier to health services offered at the NSSRH. According to Cox *et al.* (2005:27), Polymerase Chain Reaction (PCR) diagnostic method overcomes the low sensitivity limitations of many parasitological techniques. Njiru *et al.* (2005:187) are of the opinion that PCR assays able to detect all pathogenic trypanosome species in a single reaction have been developed. These reduce the costs of screening a sample from an endemic area by up to five times, and have been suggested as suitable for large-scale epidemiological studies (Thumbi *et al.*, 2010:2).

Reduced active surveillance and community sensitization activities in the area by the NSSRH staff may also act as an access barrier to the services offered at the hospital. This is because the low knowledge about the hospital and its location by a majority of respondents in the district may affect hospital attendance. Uzochukwu *et al.* (2004:17) note that the decision as to where to seek health care depends upon many factors including the availability of a provider within the community, reputation of the provider, perceived quality of the services and

community knowledge about the health facility that provides the required health services.

As far as sensitization about the hospital and sleeping sickness is concerned, the results indicated that structures to enhance sensitization and visibility among the population in the district were also non-existent. Messages to facilitate recognition of the disease and hospital were not observed. This did not give the needed direction to community members to access health services at the hospital in times of need. The lack of sensitization of the traditionally affected communities about the hospital and disease within Teso district may act as an access barrier to formal sleeping sickness health services offered at the National Sleeping Sickness Referral Hospital (See Fig. 7.1 below).

The admission by the district zoologist about the presence of livestock trypanosomiasis in the district (animals acted as reservoirs to sleeping sickness) and testimonies of a respondent who was still undergoing observation after being treated of sleeping sickness, may reinforce the view that sleeping sickness as a neglected disease is still in circulation within the research site albeit at low levels.

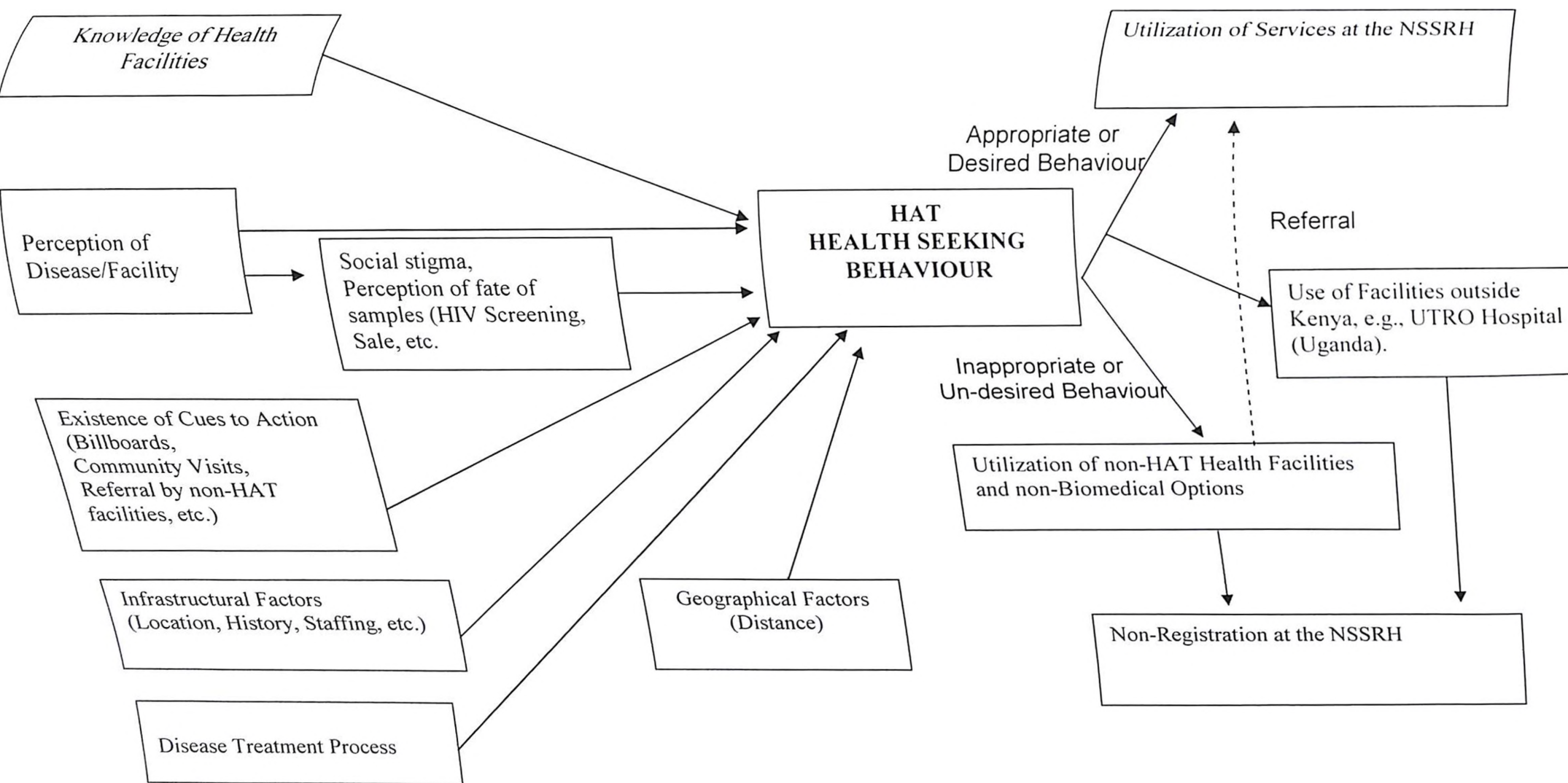


Fig. 7.1: Summary of Determinants of Health Seeking Behaviour and their Impact on Utilization of Health Services offered at the National Sleeping Sickness Referral Hospital (NSSRH).

7.6 Conclusion

This study sought to establish whether there were access barriers to formal health services offered at the National Sleeping Sickness Referral Hospital based at Alupe, Teso District, Kenya. The study concludes that a majority of community members were knowledgeable about the link between the tsetse bite and sleeping sickness. However, the population as a whole had a multiplicity of explanations for the causes of sleeping sickness. This multiplicity of causes involved bio-medically sound transmission theory of tsetse-bites on one hand, and community explanatory theories involving witchcraft, mosquito-bite and stress associated with socio-economic conditions on the other. This multiplicity of explanations about causality hinders some members who believe in causes other than tsetse bites from seeking formal health services offered at the NSSRH. This is because, knowledge about the cause of disease would influence the health-seeking behaviour of the concerned members.

Whereas a majority of respondents were knowledgeable about the transmitting agent (tsetse fly) of sleeping sickness, there was no commensurate knowledge for the sleeping sickness hospital amongst the population in terms of location and the services offered. Lack of knowledge by a few members of the community about the National Sleeping Sickness Referral Hospital constitutes an access barrier to the sleeping sickness services offered at the hospital. This is because, in case of sleeping sickness,

the affected community members would not know where to seek appropriate treatment on their own.

The association of sleeping sickness with sleep as a symptom of the disease amongst a greater majority of the local people implies that the symptom (sleep) has to be observed before conclusion about the disease can be made. This association of the disease with sleep may explain late reporting to the sleeping sickness hospital by patients served by the hospital in the past.

The association of sleeping sickness with HIV/AIDS, witchcraft (particularly when disease persistence was experienced), mental illness and sexual dysfunction through reduced libidinal energy also led to community stigmatization of the disease. The overt stigmatization was observed by patients through finger pointing, ridicule and avoidance by other community members. This stigmatization influenced people's health seeking behaviour.

The treatment process of the disease, particularly, the performance of the lumbar puncture was seen as a painful and dangerous process by both the physicians who performed the procedure and the patients that had undergone the process. This perception of the lumbar puncture as a painful and dangerous process by the community constituted an access barrier to formal sleeping sickness health services.

Likewise, some people's association of blood samples given during diagnosis of sleeping sickness with unauthorized HIV/AIDS screening and/or other

purposes such as sale or devil-worshipping practices, served to deter some potential sleeping sickness patients from utilizing sleeping sickness biomedical services. The existence of social stigma associated with the disease and the treatment process may affect utilization of HAT services at the National Sleeping Sickness Referral Hospital and hence act as an access barrier to formal health services offered at the hospital.

In the event of illness, the people from the research site first utilized chemists (pharmaceutical shop outlets) and later, as a second stage utilized dispensaries and, subsequently, established health facilities such as mission or government hospitals. When there was persistence of illness, results indicate that the population that crossed over to Uganda for health services (in the biomedical facilities), the ones that resorted to alternative means (traditional medicine and supernatural/religious means) and those that resigned and stayed home to wait for eventualities increased. Therefore, in case of sleeping sickness in the population, without referral after utilization of the non-HAT health facilities (both biomedical and alternative), the population that cross to Uganda and those that utilize non-HAT health options may not be registered at the NSSRH as patients in Kenya. This suggests that existence of a multiplicity of healthcare options in Kenya serves either to deter potential sleeping sickness patients from going for diagnosis and treatment of the disease early or prevent the potential sleeping sickness patients from utilization of services from the sleeping sickness hospital. This may lead to late reporting for disease diagnosis and treatment or undiagnosed deaths of disease victims.

The cost of health services has been documented to have a negative impact on the overall utilization of health services from health facilities. The argument by respondents that the high cost charged for health services may deter residents from utilization of the services at health facilities in the district reinforces this point. This deterrence may hinder the people from accessing referral services from these facilities. Referral service provision is necessary to access health services particularly for diseases such as sleeping sickness that need highly specialized health facilities for successful disease management. Avoidance of health facilities in the district may lead people from Teso district to miss out on referral services that, in essence, should be offered by these health facilities in case of sleeping sickness infection.

Although the NSSRH does not charge for services related to sleeping sickness, the charging of out-patient services by the hospital for other diseases such as malaria and typhoid may discourage the possible sleeping sickness patients from going there for tests. These charges may also make community members cross over to Uganda for services because of the perceived comparatively lower charges for services at health facilities there. The crossing over to Uganda by the local people further pushes the possibility of utilization of health services from National Sleeping Sickness Referral Hospital to be a remote possibility.

The absence of referral services by health facilities within the research site, particularly for illnesses whose symptoms are also mimicked by sleeping

sickness, also acts as an access barrier to formal health services offered at the sleeping sickness hospital. This is because a lot of valuable time is lost during health-seeking and may lead either to late reporting or death from sleeping sickness.

Reduced surveillance for the disease by the NSSRH officers due to shortage of financial resources may also have had negative impact on the quest to enhance visibility of the hospital and its services to the community members within the district.

The non-specific nature of symptoms associated with sleeping sickness influences people to spend highly in terms of financial resources and time as they move from one health option to another and from one non-HAT health facility to another. This non-specific nature of the disease associated symptoms also acts as an access barrier to formal sleeping sickness health services offered at the NSSRH as it may lead to patients giving up on biomedical health facilities including the sleeping sickness hospital or may lead to patients accessing the appropriate health services late or encounter death in the process of health-seeking.

The centralization of the National Sleeping Sickness Referral Hospital at Alupe without any outposts in the far off divisions such as Angurai and Amagoro negatively affects utilization of sleeping sickness health services offered at the hospital. This is because of the long distances involved.

Distance was reported by respondents and researchers working on health-seeking behaviour as a deterrent to access to health services.

The existence of a multiplicity of explanatory theories for disease causation also acts as a deterrent to the sleeping sickness health services offered at the NSSRH. This is because some of the people perceived sleeping sickness to be caused by humanistic and supernatural causes. Therefore, actions taken with guidelines from such ideological perspectives do not envision utilization of biomedical services but traditional medical practices and/or religious solutions. This hinders utilization of services from biomedical sources including the sleeping sickness hospital.

This study also found that amongst some members of the population, historical factors such as the association of Alupe, where the NSSRH is situated, with management of diseases such as leprosy that were considered by the community as 'bad diseases' led to institutional stigmatization as anybody with leprosy was considered a cursed individual who had to be secluded.

The association of the Uganda Trypanosomiasis Research Organization (UTRO) Hospital with treatment of sleeping sickness coupled with geographical factors, notably distance to the NSSRH from peoples' homesteads, acts as an access barrier to the services offered at the National Sleeping Sickness Referral Hospital. This is particularly so for people who

reside far from the NSSRH (such as in Angurai and Amagoro divisions) but comparatively closer to the UTRO Hospital.

Microscopy without the use of other methods such as PCR for diagnosis of sleeping sickness constitutes methods with low sensitivity. The use of diagnostic methods with low sensitivity and specificity as far as sleeping sickness is concerned by the NSSRH personnel also acted to further deter potential sleeping sickness patients from utilization of the sleeping sickness services offered at the hospital. This is because it is easy to miss on cases deserving sleeping sickness treatment at the hospital. The community's establishment of better diagnostic capabilities in other institutions such as UTRO in Uganda may lead to shunning of the Kenyan sleeping sickness hospital for such facilities across the border. Indeed, some former sleeping sickness patients indicated that they tested negative for sleeping sickness at the NSSRH but when they crossed over to UTRO Hospital in Uganda were diagnosed with and treated for the disease. The diagnostic techniques utilized at the hospital, therefore, acts as a barrier to utilization of services offered at the sleeping sickness hospital.

7.6.1 Recommendations

1. This study recommends sensitization of the population and the formal health providers within Teso district to increase awareness of the disease and visibility of the sleeping sickness hospital and the offered services. The study farther recommends the development of diagnostic aid for health attendants to enhance appropriate and early referral to the HAT hospital in time of need.
2. The study recommends capacity building of some health facilities from divisions like Angurai and Amagoro that are located far from the National Sleeping Sickness Referral Hospital to act as satellite centres for the hospital to enhance early reporting and diagnosis. This may be achieved through private-public partnership. Other areas whose populations remain at risk for sleeping sickness contraction in the country such as Lambwe Valley, Busia and Bungoma districts should also be targeted for HAT satellite health facilities. These centres will act as sensors for the disease within the target areas whenever the disease occurs.
3. The study recommends use of better diagnostic technologies such as PCR and inoculation in laboratory mice to improve the chances of HAT diagnosis.

4. The study also recommends further research within Teso district to document peoples' mobility patterns particularly to areas in Uganda and beyond where the risk for disease contraction is comparatively high. This will be important to illuminate the level and seasonality of risk for contracting sleeping sickness.

References

- Abenga, J.N., F.N.C. Enwezor, F.A.G. Lawani, C. Ezebuoro, J. Sule and K.M. David 2003. Prevalence of Trypanosomiasis in Trade Cattle at Slaughter in Kaduna. *Nigerian Journal for Parasitology*, 23: 107-110.
- ADAM 2005. *Medical Encyclopaedia: Sleeping Sickness*. Available at <http://www.nlm.gov/medlineplus/ency/article/001362>. Retrieval Date: 5/10/2006.
- Airauhi L., E.I. Unuigbe and C.E. Okaka 1999. Human African Trypanosomosis: Knowledge, Attitude and Beliefs in a Focus in The Niger Delta of Nigeria. *Paper presented at The 25th Meeting of ISCTRC, 13th –17th September, Mombasa, Kenya.*
- Akong'a, J. and Ekeya, B. 1986. Religion and Belief Systems. In *Busia District Socio-cultural Profile*, pp. 25-40. G.S Were (Ed). Nairobi: GOK and Institute of African Studies, University of Nairobi.
- Amuyunzu-Nyamongo, M. and Nyamongo, I. K. (2006) Health-seeking Behaviour of Mothers of Under-five-year Old Children in the Slum Communities of Nairobi, Kenya. *Anthropology and Medicine*, 13 (1): 25 – 40.

Andaleeb, S. S. 2000. Public and Private Hospitals in Bangladesh: Service Quality and Predictors of Hospital Choice. *Health Policy Plan*, 15: 95-102.

Andersen, R. 1968. *A behavioral Model of Families' Use of Health Services*. Research Series No. 25. Chicago, IL: Center for Health Administration Studies, University of Chicago.

Angus, S.D. 1996. *The Epidemiology of Trypanosomiasis in Village Livestock in an Endemic Sleeping Sickness Area of Western Kenya*. Unpublished PhD Thesis, Faculty of Veterinary Medicine, University of Glasgow, UK.

Anorlu, R.I., C.O. Orakwue, L. Oyeneyin and O.O. Abudu. 2004. Late Presentation of Patients with Cervical Cancer to a Tertiary Hospital in Lagos: What is Responsible? *European Journal for Gynaecology and Oncology*, 25(6): 729-732.

Aroke, A., T. Asonganyi, and E. Mbonda 1998. Influence of Past History of Gambian Sleeping Sickness on Physical Growth, Sexual Maturity and Academic Performance of Children in Fontem, Cameroon. *Annals of Tropical Medicine and Parasitology*, 92 (8): 829-835.

Asenso-Okyere, W.K. 1995. Financing Healthcare in Ghana. *World Health Forum*, 16:86-91.

Asenso-Okyere, W., A. Anum, I. Osei-Akoto and A. Adukonu. 1998: Cost Recovery in Ghana: Are there any Changes in Health-seeking Behaviour? *Health Policy and Planning*, 13 (2):181-188.

Atouguia, J.L.M. and P.G.E. Kennedy 2000. Neurological Aspects of Human African Trypanosomiasis. In *Infectious Diseases of the Nervous System*, pp.321-372 Davis L.E & P.G.E. Kennedy (Eds.); Oxford: Butterworth- Heinemann.

Ayodele, S. J. 2002. The Yoruba Cultural Construction of Health and Illness. *Nordic Journal of African Studies*, 11(3): 322-335.

Bandura, A. 1977. *Social Learning Theory*. New York: General Learning Press.

Bartchelor, N.A., P.M., Atkinson, P.W., Gething, K., Picozzi, E.M., Fevre, and S.C. Welburn 2009. Spatial Predictions of Rhodesian Human African Trypanosomiasis (Sleeping Sickness) Prevalence in Kaberamaido and Tokolo, Two Newly Affected Districts of Uganda. *PLoS. Neglected Tropical Diseases* 3(12): 1-11. e563. doi:10.1371/journal.pntd.0000563. Available at: <http://www.plosntds.org/article/info:doi/10.1371/journal.pntd.0000563>. Retrieval Date: 15/3/2010.

Berrang-Ford, L., O. Berke, L. Abdelrahman, D. Waltner-Toews and J. McDermott 2006. Spatial analysis of Sleeping Sickness, Southeastern Uganda, 1970–2003. *Emerging Infectious Diseases*, 12: 813–820.

Bukachi, S.A. 2007. *Socio-economic and Cultural Impacts of Human African Trypanosomiasis and Coping Strategies of Households in the Busoga Focus*. Unpl. PhD. Thesis, Institute of African Studies, University of Nairobi.

Bukachi, S. A., S. Wandibba, and I. K. Nyamongo (2009). The Treatment Pathways Followed by Cases of Human African Trypanosomiasis in Western Kenya and Eastern Uganda. *Annals of Tropical Medicine and Parasitology*, 103 (3): 211-220.

Bukachi, S.A., S. O. Nyamwaro, G. O. Matete, and J. W. Karuga 2005. Capacity of Community-Based Organisations to Disseminate Sleeping Sickness Information. *East African Medical Journal*, 82 (8): 409-413.

Cattand, P. and De Raadt, P. 1991. Laboratory Diagnosis of Trypanosomiasis. *Clinics in Laboratory Medicine*, 11: 899–908.

Cheung, R., W. Mak, J. Woo, F. Cheung and D. Lee 2006. Comparative Stigma of HIV/ AIDS, SARS, and Tuberculosis in Hong Kong. *Social Science and Medicine*, 63:1912-1922.

Chibwana, A. I., D. P Mathanga, J. Chinkhumba and C. H. Campbell. 2009. Socio-cultural Predictors of Health-seeking Behaviour for Febrile Under-five Children in Mwanza-Neno District, Malawi. *Malaria Journal*, 2009, 8:219 doi: 10.1186/1475-2875-8-219. Available at <http://www.malariajournal.com/content/8/1/219>. Retrieval Date: 20/12/2011.

Collins, D., J.D. Quick, S.N. Musau, K. Kraushaar, and I.M. Hussein 1996. The Fall and Rise of Cost-sharing in Kenya: The Impact of Phased Implementation. *Health Policy Plan*, 11(1):52-63.

Courtin, F., V. Jamonneau, E. Oke, B. Coulibaly and Y. Oswald 2005. Towards Understanding the Presence/Absence of Human African Trypanosomiasis in a Focus of Cote d'Ivoire: A spatial Analysis of the Pathogenic System. *International Journal for Health Geographics*, 4: 27.

Cox, A., A. Tilley, F. McOdimba, J. Fyfe, M. Eisler, G. Hide and S. Welburn 2005. A PCR-based Assay for Detection and Differentiation of African Trypanosome Species in Blood. *Experimental Parasitology*, 111(1):24-29.

- D'Souza R. M. 2003. Role of Health-seeking Behaviour in Child Mortality in the Slums of Karachi, Pakistan. *Journal for Bio-social Sciences*, 35: 131–144.
- Daniels, N. 2000. Benchmarks of Fairness for Healthcare Reform: A Policy Tool for Developing Countries. *Bulletin of the World Health Organization*, 78: 740–750.
- Deressa, W., A. Ali and F. Enqusellassie. 2003 Self-treatment of Malaria in Rural Communities, Butajira, Southern Ethiopia. *Bulletin of the World Health Organization*, 81:261-268.
- Diack, A., A.K. Maloo and A.S. Peregrine, 1998. Effects of Multiple Treatments of Cattle with Diminazene on Infectivity of Drug Resistance to *T. congolense* for *Glossina morsitans centralis*. *Revue d'elevage et de Medecine Veterinaire des Pays Tropicaux.*, 51(3): 211-218.
- Egunjobi, L. 2002 *Factors Influencing Choice of Hospitals: A Case Study of the Northern Part of Oyo State, Nigeria*. Ibadan: Nigerian Institute of Social and Economic Research.
- Eisen, M., G.L. Zellman, and L. M. Alister 1992. A Health Belief Model-Social Learning Theory Approach to Adolescents' Fertility Control:

Findings from a Controlled Field Trial. *Health Education Quarterly*,
19 (2): 249-262.

Family Health International (FHI) 2004. *Behaviour Change : A Summary of Four
Major Theories*. Available at
<http://www2.fhi.org/en/aids/aidscap/aidspubs/behres/bcr4theo.html>
11/12/2004 Retrieval Date: 8/04/2007.

Fèvre, E.M., P. G. Coleman, M. Odiit, J.W. Magona, S.C. Welburn and M.E.J.
Woolhouse 2001. The Origins of a New *Trypanosoma brucei*
rhodesiense Sleeping Sickness Outbreak in Eastern Uganda.
Lancet, 358: 625-628.

Foster, G. M. and Anderson, B.G. 1978. *Medical Anthropology*. Toronto: John
Wiley & Sons.

Furuta, M. and Salway, S. 2006. Women's Position within the Household as a
Determinant of Maternal Health Care Use in Nepal. *International
Family Planning Perspectives*, 32(1):17-27

Geerts, S. and Holmes, P.H. 1998. *Drugs Management and Parasite
Resistance in Bovine Trypanosomiasis in Africa*. PAAT Technical
and Scientific series 1. Rome: FAO.

- Geissler, P.W., K. Nokes, R.J Prince, R. O. Achieng', J. Aagaard-Hansen and J.H. Ouma 2000. Children and Medicines: Self-treatment of Common Illnesses among Luo School Children in Western Kenya. *Social Science and Medicine*, 50: 1771–1783.
- Gertler, P., and Van der Gaag, J. 1990. *Willingness to Pay for Medical Care: Evidence from Two Developing Countries*. Baltimore, MD: Johns Hopkins University Press.
- Gilson, L., M. Alilio and K. Heggenhougen 1994. Community Satisfaction with Primary Healthcare Services: An Evaluation Undertaken in the Morogoro Region of Tanzania. *Social Science and Medicine*, 39(6): 767-780.
- Gomes, M., S. Wayling and L. Pang 1998. Interventions to Improve the Use of Antimalarias in South-east Asia: An Overview. *Bulletin of the World Health Organization*, 76(1):9-20.
- Good, C.M. 1987. *Ethnomedical Systems in Africa*. New York: The Guilford Press.
- Government of Kenya. 2002. *Teso District Development Plan, 2002-2008*. Nairobi: Government Printer.
- Government of Kenya. 2009. *Teso District Development Plan, 2008-2012*. Nairobi: Government Printer.

Government of Kenya. 2010. *Population and Housing Census (2009)*, Vol. 1.
Nairobi: Government Printer.

Hausmann-Muela, S., J. M. Ribera, and I. Nyamongo 2003. *Health-seeking Behaviour and the Health System Response*. Disease Control Priorities Project Working Paper No. 14. London: London School of Hygiene and Tropical Medicine.

Health-Cares 2005. *Symptoms of Sleeping Sickness*. Available at
<http://neurology.health-cares.net/sleeping-sickness-symptoms.php>.
Retrieval Date: 8/01/2007.

Helman, G. 1994. *Culture, Health and Illness*, 3rd edition. London:
Butterworth-Heinemann,

Hendrickx, G., A. Napala, J.H.W. Slingenbergh, R. De Deken and J. Vercruysse (2000). The Spatial Pattern of Trypanosomosis Prevalence Predicted with the Aid of Satellite Imagery. *Parasitology*, 120:121–134. Available at
<http://www.plosntds.org/article/info:doi/10.1371/journal.pntd.000023>
7. Retrieval Date: 2/8/2011.

- Hunter, P., and F. Sultana 1992. Health-seeking Behaviour and the Meaning of Medications in Balochistan, Pakistan. *Social Science and Medicine*, 34: 1385–1397.
- Hussein, A.K. and Mjinja, P.G. 1997. Impact of User Charges on Government Health Facilities in Tanzania. *East African Medical Journal*, 74(12): 751-757.
- Hutchinson, P. 2001. Combating Illness. In *Uganda's Recovery : The Role of Farms, Firms and Government*, pp.407-444. R. Ritva and G. Collier (Eds). Washington, D.C.: The World Bank.
- Izugbara, C., A. Ezeh and J. Fotso 2009. The Persistence and Challenges of Homebirths: Perspectives of Traditional Birth Attendants in Urban Kenya. *Health Policy and Planning*, 24:36–45.
- Janzen, J.M. 1978. *The Quest for Therapy in Lower Zaire*. Berkeley, CA: University of California Press.
- Kaare, M.T., K. Picozzi, T. Mlengeya, E. M. Fe`vreb, L. Mellau, , M. M. Mtambo, S. Cleaveland, and S. Welburn, (2007) Sleeping sickness—A Re-emerging Disease in the Serengeti? *Travel Medicine and Infectious Disease* 5, 117–124.

Kamara, D.W., B.M. Swallow and J.J. Curry 1994. Assessment of the Socio-economic Factors Affecting Implementation of Community-based Tsetse Control in Busia, Kenya. KETRI, Nairobi.

Karim, M. S. 1987. *Socio-economic, Demographic and Health Situation in Thatta District. Karachi: Aga Khan University.*

Karim, F., A. Islam, A.M.R. Chowdhury, E. Johansson and V. K. Diwan. 2007. Gender Differences in Delays in Diagnosis and Treatment of Tuberculosis. *Health Policy and Planning*, 22:329-334

Keay, R.W.J. 1953. *An Outline of Nigerian Vegetation*, 2nd ed., Lagos: Government Printer.

King'ola, R.M. 2010. *An Investigation into the Factors Determining the Utilization of Antenatal Care Services in Kilome Division, Eastern Kenya.* Unpl. Masters Thesis, Institute of Anthropology, Gender and African Studies, University of Nairobi.

Kinung'hi, S.M., I.I. Malele, S.N. Kibona, L.E. Matemba, J.K. Sahani, C. Kishamawe and T.D. Mlengeya 2006. Knowledge, Attitudes and Practices on Tsetse and Sleeping Sickness Among Communities Living in and Around Serengeti National Park, Tanzania. *Tanzania Health Research Bulletin*, 8 (3):168-172.

Kleinman, A. 1980. *Patients and Healers in the Context of Culture*. Berkeley, CA: University of California Press.

Kuzoe, F.A.S. 2001. A Position Paper on African Trypanosomiasis. Paper Presented at the *Scientific Working Group Meeting on African Trypanosomiasis, 4 -8 June, 2001*, Ouagadougou, Burkina Faso.

Kuzoe, F.A. and C. J. Schofield 2004. Strategic Review of Traps and Targets for Tsetse and African Trypanosomiasis Control. Available at <http://apps.who.int/tdr-research-publications/strategic-traps-targets-tsetse/PDF/tsetse>. Retrieval Date: 29/7/2011.

Kyombadde J.W., J.C.K.'Enyaru, E. Matovu, M. Odiit and F. Carasco 2000. Detection of Trypanosomes in Suspected Sleeping Sickness Patients in Uganda Using the Polymerase Chain Reaction (PCR). *Bulletin of the World Health Organization*, 78(1):119-124.

Lavy, V. and Germain, J. 1994. *Quality and Cost in Healthcare Choice in Developing Countries*. Living Standards Measurement Study Paper No. 105. Washington, D.C.: The World Bank.

Lawson, D. 2004. Determinants of Health-seeking Behaviour in Uganda – Is it Just Income and User Fees that are Important? Manchester, University of Manchester.

- Litvack, J. and Bodart, C. 1993. User Fees Plus Quality Equals Improved Access to Healthcare: Results of a Field Experiment in Cameroon. *Social Science and Medicine*, 37:369-383.
- Logan, M. H. 1978. *Health and the Human Condition: Perspectives on Medical Anthropology*. North Scituaat, CA: Duxbury Press.
- Lutumba, P., E. Makiyenya, A. Show, F. Meheus, and M. Boelaert. 2007. Human African Trypanosomiasis in a Rural Community, Democratic Republic of Congo. *Emerging Infectious Diseases*, 13(2): 248-254. Available at www.cdc.gov/eid. Retrieval Date: 5/10/2009.
- Lutumba P, J. Robays, C. Miaka, V. Kande, D. Molisho and J. Declercq 2005. Trypanosomiasis Control in the Democratic Republic of Congo, 1993-2003. *Emerging Infectious Diseases*, 11:1382-1388.
- Madanitsa, M., J. Chisi and B. Ngwira 2009. The Epidemiology of Trypanosomiasis in Rumphu District, Malawi: A Ten Year Retrospective Study. *Malawi Medical Journal*, 21(1):22 – 27.
- Maithya, H. M. 1992. *The Awareness and Management of Mental Illness among the Babukusu of Bungoma District*. Unpublished M. A. Thesis, Institute of African Studies, University of Nairobi.

Malele, I.I., S.N. Kibona, L.E. Matemba, K. Sahani, J. Swilla, C.D. Mwalimu, B.K. Mayala, E. Kimaro, C. Msumary, and R.B. Kalinga 2006. Human African Trypanosomiasis and Challenges to its Control in Urambo, Kasulu and Kibondo Districts, Western Tanzania. *Tanzania Health Research Bulletin*, 8:80-85.

Matete, G.O. 2003. Occurrence, Clinical Manifestation and Epidemiological Implications of Naturally Occurring Canine Trypanosomiasis in Western Kenya. *Onderstepoort Journal of Veterinary Research*, 70:317-323.

Mbeche, I. 2004. *Research Design, Data Collection and Analysis: A Training Manual*, pp 61-70. P. Ngau (Ed). Nairobi: UNCRD.

Mboera, L.E.G., S.F. Rumisha, K.P. Senkoro, B.K. Mayala, E.H. Shayo and W. N. Kisinza 2005. *Research on Knowledge Systems: Determination of Strategies and Approaches for a Successful Improvement of Gaps for Health Knowledge in Tanzania*. Technical Report, National Institute for Medical Research, Dar-es-Salaam, Tanzania.

Mbugua K. J., G. H. Bloom and M.M. Segall 1995. Impact of User Fees on Vulnerable Groups: The Case of Kibwezi in Rural Kenya. *Social Science and Medicine*, 41:828-835.

- Mbulamberi, D.B. (1989). Possible Causes Leading to an Epidemic Outbreak of Sleeping Sickness: Facts and Hypotheses. *Annales de la Sociéte Belge de Médecine Tropicale* 69(Suppl. 1):173-179.
- McCombie, S.C. 2002. Self-treatment for Malaria: The Evidence and Methodological Issues. *Health Policy and Planning*, 17(4): 333-344.
- Meng , Q., X. Liu and J. Shi. 2000. Comparing the Services and Quality of Private and Public Clinics in Rural China. *Health Policy Plan.* 15: 349-356.
- Miguel, C.A., L. Manderson and M.A. Lansang 1998. Patterns of Treatment for Malaria in Tayabas, The Philippines: Implications for Control. *Tropical Medicine and Internal Health.* 3(5):413-421.
- MSF 2004 *Sleeping Sickness or Human African Trypanosomiasis*. Available at [www.access med-msf.org](http://www.access-med-msf.org). (Retrieval Date: 5/10/2006).
- Mugunieri, G.L. and K.B. Wanjala. 2007. Does the Conduct of Malaria Treatment Agents Predispose Service Users to High Transaction Costs? Evidence from Kenya. A WHO/TDR. Project Report (Project No. TDR ID A50772).

Mulumba, K. 2003. *Socio-economic and Agricultural Factors in the Research and Control of Trypanosomiasis*. PAAT Technical and Scientific Series 4. Rome: FAO.

Mwabu, G.M., M. Ashworth and A. Nyamete 1994. Quality of Medical Care and Choice of Medical Treatment in Kenya: An Empirical Analysis. *Journal of Human Resources*, 28(4): 838-862.

Nakagawa, Y.M. 2001. Gender Difference in Delays to Diagnosis and Healthcare-seeking Behavior in a Rural Area of Nepal. *Int J Tuberc Lung Dis*, 5: 24-31.

Ng'ayo, M.O. 2005. Detection of Trypanosomiasis in Small Ruminants and Pigs in Western Kenya: Important Reservoir in Epidemiology of Sleeping Sickness? *Kineto Plastid Biology and Disease*, 14 (5): 1475-9292. Available at <http://www.kineto-plastids.com/content/4/1/5>. (Retrieval Date: 5/10/2006).

Ngugi, R. 1999. *Health-seeking Behaviour in the Reform Process for Rural Households: The Case of Mwea Division, Kirinyaga District, Kenya*. African Economic Research Consortium Paper No. 95. Nairobi, Kenya: The World Bank.

Njiru, Z.K., C. S. Guya, J. Crowther, J.M. Kiragu, R.C. Thompson and A.M. Davila 2005. The Use of ITS1 rDNA PCR in Detecting Pathogenic African Trypanosomes. *Parasitology Research*, 95(3):186-192.

Noorali, R., L. M. Stephen, and H. Rahber 1999. Does Use of Government Service Depend on Distance from the Health Facility? *Health Policy Plan*, 14: 191-197.

Nsagha, D.S., A. Z.Bissek and S.M. Nsagha 2001. Social Stigma as an Epidemiological Determinant for Leprosy Elimination in Cameroon. *Journal for Public Health in Africa*, 2: 38-44.

Nyamongo, I. K. 2002. Healthcare Switching Behaviour of Malaria Patients in a Kenyan Rural Community. *Social Science and Medicine*, 54: 377-386.

Nyamwaya, D. 1986a. Medicine and Health. In *South Nyanza District Socio-cultural Profile*, pp. 101-111. G.S. Were, B.E Kipkorir and E.O. Ayiemba (Eds.). Nairobi: GOK and Institute of African Studies, University of Nairobi.

Nyamwaya, D. 1986b. Medicine and Health. In *Busia District Socio-cultural Profile*, pp. 101-113. G.S. Were (Ed.). Nairobi: GOK and Institute of African Studies, University of Nairobi.



Study in Five Malaria Holo-endemic Communities. *Health Policy*, 54: 143-159.

Perez-Cuevas, R. 1996. Mother's Health-seeking Behavior in Acute Diarrhea in Tlaxcala, Mexico. *Journal of Diarrhoeal Disease Research*, 14: 260-268.

Perry, P.M. and F. Donini-Lenhoff 2010. Stigmatization Complicates Infectious Disease Management. *Virtual Mentor*, 12 (3): 225-230.

Picozzi, K., E.M. Ferre, M. Odiit, M. Carrington, M.C. Eisler, I. Moudlin and S.C. Welburn 2005. Sleeping sickness in Uganda: A Thin Line Between Two Fatal Diseases. *British Medical Journal*, 331: 1238-1241.

Raosoft, 2004. Sample Size Calculators. Available at <http://www.raosoft.com/samplesize.html>. Retrieval Date: 4/6/2007.

Robinson, T. D., J. Rogers, and J.F. Chapman 1997. Mapping Tsetse Habitat Suitability in Common Fly Belt of Southern Africa Using Multi-variant Analysis of Climate and Remotely Sensed Vegetation Data. *Medical Veterinary Entomology*, 11:235-245.

Rogers, D.J., Randolph, S.E. 1993. Distribution of Tsetse and Ticks in Africa - Past, Present and Future. *Parasitology Today*, 9: 266-271.

Rosenstock, I., V. Strecher, and M. Becker 1988. Social Learning Theory and the Health Belief Model. *Health Education Quarterly*, 15(2):175-183.

Rosenstock, I., V. Strecher, and M. Becker 1994. The Health Belief Model and HIV Risk Behaviour Change. In *Preventing AIDS: Theories and Methods of Behavioral Interventions*, pp. 5-24. R. J. DiClemente and J.L. Paterson (Eds.). New York: Plenum Press.

Samdi, S.M., J.N. A. Abenga, M.K. Attahir, B.M. Haruna, A.O. Wayo, H.M. Fajinmi, A.O. Sumayin, J.Z. Usman, H. Hussaina, J.E. Muhammad, R.P. Ovbagbedia and R.A. Abdullahi 2010. Impact of Trypanosomosis on Food Security in Nigeria: A Review. *International Journal of Animal and Veterinary Advances*, 2(2): 47-50.

Schofield C.J. and J. P. Kabayo 2008. Trypanosomiasis Vector Control in Africa and Latin America. *Parasites and Vectors*, 1(1):1-24.

Shaikh, T.B. and J. Hatcher 2004. Health-seeking Behaviour and Health Service Utilization in Pakistan: Challenging the Policy Makers. *Journal of Public Health*, 27(1): 49-54.

Sindato, C., S.N. Kibona, G.M. Nkya, T.J. Mbilu, C. Manga, J.S. Kaboya and F. Rawille 2008. Challenges in the Diagnosis and Management of

- Sleeping Sickness in Tanzania: A Case Report. *Tanzania Journal of Health Research*, 10 (3):177-181.
- Snow, R.W., N. Peshu, D. Foster, H. Mwenesi and K. Marsh 1992. The Role of Shops in the Treatment and Prevention of Childhood Malaria on the Coast of Kenya. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 86(3): 237-239.
- Stuyft P.V., S.C. Sorenson, E. Delgado and E. Bocaletti 1996. Health-seeking Behavior for Child Illness in Rural Guatemala. *Tropical Medicine and International Health*; 1: 161-170.
- Swallow, B.M. 2000. *Impact of Trypanosomiasis on African Agriculture*, Vol. 2. PAAT Technical and Scientific Series. Rome: FAO.
- Thomas, S.L. 2004. *African Sleeping Sickness*. Boston, MA: Boston College.
- Thumbi, S.M., J.O. Jung'a, R.O. Mosi, and F.A. McOdimba 2010. Spatial Distribution of African Animal Trypanosomiasis in Suba and Teso Districts in Western Kenya. Available at: <http://www.biomedcentral.com/1756-0500/3/6>. Retrieval Date: 17/10/2010.
- Toé, L. P., O. Skovmand, K. R. Dabiré, A. Diabaté, Y. Diallo, T. R. Guiguemdé, J. Marie, C. Doannio, M. Akogbeto, T. Baldet and M. E. Gruénais. 2009. Decreased Motivation in the Use of Insecticide-

treated Nets in a Malaria Endemic Area in Burkina Faso. *Malaria Journal* 2009, 8:175. Available at <http://www.malariajournal.com/content/8/1/175> .Retrieval Date: 7/12/2011.

Uzochukwu, S.C. and Onwujekwe, O.E. 2004. Socio-economic Differences and Health-seeking Behaviour for the Diagnosis and Treatment of Malaria: A Case Study of Four Local Government Areas Operating the Bamako Initiative Programme in South-east Nigeria. Enugu, University of Nigeria.

Venkatraju, B and S. Prasad 2010. Beliefs of Patients about the Causes of Tuberculosis in Rural Andhra Pradesh. *International Journal of Nursing and Midwifery*, 2(2):21-27.

Wandwalo, E.R. and O. Morkve 2000. Delay in Tuberculosis Case-finding and Treatment in Mwanza, Tanzania. *The International Journal of Tuberculosis and Lung Disease*, 4 (2): 133-138.

Wanjala, K. 2000. *Perception of Diarrhoea in Children under Five Years of Age among the Luo of Western Kenya*. Unpl. Masters Thesis, Institute of African Studies, University of Nairobi.

Wanjala, K. 2003. *Challenges Faced by Western-Trained Paediatricians working in Developing Countries: The Case of Paediatrics*



Diarrhoea among the Luo of Bondo District, Western Kenya. *MILA* (NS), 5: 30-37.

Wanjiru, L. M. 2011. Factors that Influence Choice of Healthcare Provider Options for Malaria in Mwea Irrigation Scheme. *International Journal of Current Research* 3(12):434-441.

Ward, H., E. M. Thierry and C. Thomas 1997. Health-seeking Behaviour and the Control of Sexually Transmitted Disease. *Health Policy and Planning*, 12(1): 19-28.

Warsame M, O. Kimbute, Z. Machinda, P. Ruddy, and M. Melkisedick 2007. Recognition, Perceptions and Treatment Practices for Severe Malaria in Rural Tanzania: Implications for Accessing Rectal Artesunate as a Pre-Referral. *PLoS ONE* 2(1): e149. doi:10.1371/journal.pone.0000149.

Waxler, N. E. 1981. Learning to be a Leper: A Case Study in the Social Construction of Illness. In *Social Contexts of Health, Illness, and Patient Care*, pp. 169-194 E.G. Mishler. Amarasingham, S. T. Hauser, R. Liem, and S. D. Osherson (Eds). Cambridge: Cambridge University Press.

Weiss, G. M. 2008. Stigma and the Social Burden of Neglected Tropical Diseases. *PLOS. Neglected Tropical Diseases*, Vol.2/Issue5/e237.

Available at:

<http://www.plosntds.org/article/info:doi/10.1371/journal.pntd.000023>

7. Retrieval Date: 2/8/2011.

Welburn, S.C., E.M. Fèvre, P.G. Coleman, M. Odiit, and I. Maudlin 2001.

Sleeping Sickness: A Tale of Two Diseases. *Trends in Parasitology*

17:19–24.

Wellde, B. T., D. A. Chumo, D. Waema, M. J. Reardon and D. H. Smith 1989.

A History of Sleeping Sickness in Kenya. *Annals of Tropical*

Medicine and Parasitology, 83(1): 1-11.

Weller, S.C., T.R. Ruebush and R.E. Klein 1997. Predicting Treatment-seeking

Behaviour in Guatemala: A Comparison of the Health Services

Research and Decision-Theoretic Approaches. *Medical*

Anthropology Quarterly, 11(2):224-245.

Wendo, C. 2002. Uganda Revises Cattle Treatment to Protect Humans from

Sleeping Sickness. *Lancet*, 359:239-240.

WHO 1998. *Control and Surveillance of African Trypanosomiasis*. WHO
Technical Report Series, 881. Geneva: WHO.

WHO 2001. *WHO Drug Information*, 15(2):95-145. Available at <http://apps.who.int/medicinedocs/pdf/s2288e/pdf>. Retrieval Date: 8/04/2007.

WHO 2002. *Programme to Eliminate Sleeping Sickness: Building a Global Alliance*. Geneva, Switzerland: WHO.

WHO 2004. *Trypanosomiasis*. Available at <http://www-micro-msb.le.ac.uk/index.html>. Retrieval Date: 8/04/2007.

WHO 2007. *African Trypanosomiasis (Sleeping Sickness)*. Available at <http://www.who.int/mediacentre/factsheet/fs259/en/>. Retrieval Date: 18/06/2008.

WHO 2010. *African Trypanosomiasis (Sleeping Sickness)*. Available at <http://www.who.int/mediacentre/factsheet/fs259/en/>. Retrieval Date: 22/11/2010.

Whyte, S. R. and Kariuki, W. P. 1997. Malnutrition and Gender Relations in Western Kenya. In *African Families and the Crisis of Social Change*, pp. 135-153. T. Weiner, C. Bradley and P. Kilbride (Eds.). London: Bervin and Garvey.

Whyte, S. R. 1997. *Questioning Misfortune: The Pragmatics of Uncertainty in Eastern Uganda*. Cambridge: Cambridge University Press.

- Wooff, W. R. 1969. A Review of Current Tsetse Control in Uganda. *Transactions of the Royal Society of Tropical Medicine and Hygiene*, 63: 125-126.
- World Bank 1994. *Development in Practice: Better Health in Africa: Experience and Lessons Learned*. Washington, D.C: The World Bank.
- Yip, W.C., H. Wang and Y. Liu. 1998 Determinants of Choice of Medical Provider: A Case Study in Rural China. *Health Policy Plan*, 13:311-322.
- Zoller T., E. M. Fevre, S. C. Welburn, M. Odiit and P.G. Coleman. 2008. Analysis of Risk Factors for *T. brucei rhodesiense* Sleeping Sickness within Villages in South-east Uganda. *Biomedical Central Infectious Diseases*, 8: 88-92.

Appendix 1: Questionnaire

Consent

My name is Kennedy Wanjala, a student at IAGAS, University of Nairobi and an employee of KARI-TRC. I am doing research on sleeping sickness, which I think is common in this area. This questionnaire seeks to get information from you about your knowledge and perception of, and experiences with sleeping sickness. The purpose of this activity is to establish the existence of any access barriers to the sleeping sickness hospital. The information so obtained will be used for educational purposes and may also be used by authorities to address existing barriers to formal health services offered at the sleeping sickness hospital. The information you provide will be treated **confidentially**. If you accept to participate, please sign here.....

A. Background Information

Name of Enumerator..... Respondent Code.....

Division..... Village.....

1. Education level of the respondent

.....

2. Sex of the respondent

.....

3. Relationship to the household head

.....

4. Occupation of the respondent

.....

11. Where can sleeping sickness be treated?

12. Do you know of any specialized sleeping sickness hospital in Kenya?

13. If 'Yes' in Q12 above, what is the name of the hospital?

14. Have you or any of your relatives ever suffered from sleeping sickness?

15. If "Yes" in Q 14 above, where did you or your relative go for treatment

16. If "Yes" in Q14 above, did you or the relative get better?

17. Did you or the relative recover fully?



26. If 'Yes', how much were you charged?

27. Would you willingly give your blood samples for laboratory tests to establish presence of sleeping sickness?

28. Do you know about the lumbar puncture?

29. If YES for Q28 above, can the process deter you from seeking hospital health services?

30. Would you advise somebody you suspect of having sleeping sickness to go to the KETRI Alupe sleeping sickness hospital for treatment?

31. If No for Q30 above why would you not recommend the person to the hospital?

C. Health-seeking behaviour

32. In this community, what would prevent one from going to hospital for treatment?

33. Do some people from this community go for treatment in Uganda?

34. If 'Yes' in Q 34 above why do they go to Uganda for treatment and not Kenya?

35. Which diseases make people go to Uganda for treatment?

36. When you are sick, where do you normally go for treatment?

| Onset of illness | 2. Place | 3 Place | 4 Place | 5 Place |
|------------------|----------|---------|---------|---------|
| | | | | |

37. Where do members of this community go when they have persistent illness (after having attended local health centres)

38. Why do you go for treatment in the place mentioned above?

39. Apart from the formal health services, do we have traditional medical practitioners in this area?

40. Why do some people visit traditional medical practitioners?

41. **Why** would you prefer to go to one place for treatment to another?

42. Do people in this community fear being tested for diseases especially where blood or other samples are taken?

43. If 'Yes' in Q 41 above, why do they fear?

D. Performance of Health Provision Agents

44. The last time you or your family member was sick, where did you go for treatment?

45. If you went to the health centre, how many times did you go for treatment at the facility with same symptoms?

46. If you went to the facility with the same symptoms more than once, were you or your relative referred to another health facility for further treatment?

47. If 'Yes' where were you or your relative referred to?

48. What were you given as the reason for referral?

49. Did you go to the hospital where you were referred?

50. If **NO** to **Q48** above, why didn't you go to the hospital?

51. Did you get better after referral and treatment?

52. What is your assessment of the health provider, was he/she friendly?
.....

53. How do you rate the services offered by formal health providers in this area?
.....

54. How far is your home to the nearby health facility?

55. Can distance bar you from going to the health centre for treatment?
.....

56. Apart from clinics and dispensaries, do you have any other health facilities that serve people in this area?
.....

57. If 'Yes', who are they?
.....

58. How do you compare traditional medical practitioners with modern medical practitioners?
.....
.....
.....
.....

Appendix 2: In-depth Interview Guide

1. When did you/your relative suffer from sleeping sickness?
2. What made you conclude that it was sleeping sickness?
3. Were you/your relative referred to TRC (KETRI) Sleeping sickness Referral Hospital or how did you/your relative get there for treatment?
4. How long did it take you/your relative to get well and go back home?
5. What do you think about services offered at the TRC (KETRI) Sleeping Sickness Referral Hospital?
6. Would you recommend any other patient to go for treatment at the hospital for sleeping sickness services?
7. Why do some people from this area go for health services in Uganda?
8. Why do you think there are no sleeping sickness cases admitted at the TRC (KETRI) Sleeping Sickness Referral Hospital in the recent past?
9. Is there any social stigma associated with sleeping sickness or the sleeping sickness hospital in this community?

Appendix 3: Key Informant Interview Guide for Sleeping Sickness Hospital Staff

1. The last case of sleeping sickness admitted to this hospital was in 2006. Why do you think we have not had any new admissions since then?

2. There is an indication that the disease is no longer a problem in Kenya. What is your personal view on this?

3. From your past interaction with sleeping sickness patients, is there anything that would deter patients from seeking health services offered at this hospital?

4. What is your personal evaluation of passive surveillance; do you think it is working well for the hospital and the population?

5. From your interaction with UTRO hospital officers, why do you think Uganda has recorded more sleeping sickness patients than Kenya?

6. Do people from the community come to this hospital for sleeping sickness tests?

Appendix 4: Themes for Focus Group Discussions (FGDs)

1. Knowledge of sleeping sickness (Cause, transmitting agent, predisposing behaviour, symptoms)
2. Knowledge of the sleeping sickness treatment centre (KARI-TRC [KETRI] Sleeping sickness Referral Hospital).
3. Health-seeking behaviour of the people in the research site (Onset of illness and persistence).
4. Determinants of health-seeking behaviour.
5. Reasons why there are no sleeping sickness cases admitted at the TRC (KETRI) Sleeping Sickness Referral Hospital in the recent past.
6. Is there any social stigma associated with sleeping sickness or the sleeping sickness hospital amongst the community members?

Appendix 5: Ethical Clearance



KENYA MEDICAL RESEARCH INSTITUTE

P.O. Box 54840-00200 NAIROBI Kenya
Tel: (254) (020) 2722541, 2713349, 0722-205901, 0733-400003. Fax: (254) (020) 2720030
E-mail: direction@kemri.org, info@kemri.org, Website: www.kemri.org

KEMRI/RES/7/3/1

MARCH 28, 2008

FROM: SECRETARY, KEMRI/National Ethical Review Committee
THRO: Lawrence M Godiah
TO: Mr. Kennedy W Barasa (KARI/TRC)
Principal Investigator
RE: Access barriers to Formal health Services: Focus on the sleeping sickness hospital in Western Kenya

Dear Sir,

This is to inform you that during the 153rd meeting of KEMRI/National Ethical Review Committee held on 16th APRIL 2008, the above study was reviewed.

The Committee notes that you intend to understand people's health seeking behaviour, you will do this using a variety of methods including Key Informant interviews, Focus group Discussions, case histories and mapping of health facilities.

Due consideration has been given to ethical issues and the study is granted approval from today the 17th APRIL 2008 to APRIL 16th 2009.

Please note that any changes to the research study must be reported to the Scientific Steering Committee and to the Ethical Review Committee prior to implementation. This includes changes to research design, equipment, personnel, funding or procedures that could introduce new or more than minimum risk to research participants.

Kindly remit the translated informed consent documents and Questionnaire to the secretariat for our records.

Respectfully,

R. C. Kithinji
R. C. Kithinji,
For: Secretary,
KEMRI/NATIONAL ETHICAL REVIEW COMMITTEE