

**SOCIO-ECONOMIC AND CULTURAL IMPACTS OF HUMAN AFRICAN
TRYPANOSOMIASIS AND COPING STRATEGIES OF HOUSEHOLDS
IN THE BUSOGA FOCUS**

By

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**A Thesis Submitted to the Institute of Anthropology, Gender and African
Studies in Fulfilment of the Requirements for the Degree of Doctor of
Philosophy of the University of Nairobi**

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DECLARATION

I declare that this thesis is my original work and has not been presented anywhere else for a degree.

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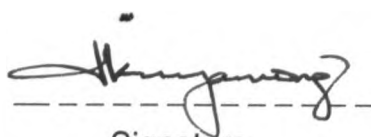


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DEDICATION

To my father John Peter Ouko, my husband, Michael, and children, Rebecca and David for the sacrifices they have made to make me achieve the best.

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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency Virus
LIRI	Livestock Health Research Institute
KETRI	Kenya Trypanosomiasis Research Institute
SS	Sleeping Sickness
HAT	Human African Trypanosomiasis
CNS	Central Nervous System
MOF	Ministry of Finance and Economic Development
GOK	Government of Kenya
WHO	World Health Organisation
HSB	Health Seeking Behaviour
DALYs	Disability-adjusted Life Years
SSA	Sub-Saharan Africa
QOL	Quality of Life
FGDs	Focus Group Discussions
IDIs	Indepth interviews
IAGAS	Institute of Anthropology, Gender and African Studies
OTC	Over-the-counter
DRC	Democratic Republic of Congo
STDs	Sexually Transmitted Diseases
SIs	Structured Interviews
KETRI	Kenya Trypanosomiasis Research Institute
LIRI	Livestock Health Research Institute
Tb	Trypanosoma brucei

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ABSTRACT

This study was designed to investigate the socio-economic and cultural impacts of Human African Trypanosimiasis (HAT) and the coping strategies of households in the Busoga focus. Fieldwork for the study was conducted in Busia, Teso and Bungoma districts of western Kenya, and Busia and Teso districts of southeast Uganda between January 2004 and June 2005. The main assumptions that guided the study were: health-seeking behaviour (HSB) perpetuates the impacts of HAT on affected individuals and households; HAT disrupts the social functioning of households; and HAT affects the economic base of affected households.

Data was obtained through: review of hospital records; structured interviews; key informant interviews; in-depth interviews and focus group discussions. Purposive sampling was used to obtain the sample size of 481 from both HAT and non HAT respondents. The quantitative data obtained through structured interviews was analyzed using descriptive statistics and presented in the form of frequency and percentage tables. On the other hand, the qualitative data, obtained through review of hospital records, key informant interviews, in-depth interviews and focus group discussions, was analyzed according to emerging themes using a grounded theory approach and presented in the form of case studies, excerpts and quotes.

The main findings of this study indicate that delayed diagnosis of HAT led to severe somatic effects on the patients. The findings also reveal that the mental effects of HAT are pronounced among young patients who subsequently face difficulties fitting back into the community. Households affected by HAT experience increased financial burden as a result of seeking treatment from much different health service providers. The median time lag for

starting HAT treatment was between three and four months and much of this time lag is attributable to the health service provider's failure to diagnose HAT. The disease was also sometimes erroneously attributed to HIV/AIDS or witchcraft, causing patients to be stigmatized, delay seeking treatment or to seek treatment from wrong sources.

The findings also show that HAT disrupts the normal functioning of affected households. This is manifest through conflicts within marriages, families and the community and reversal of roles, which increased the burden and responsibilities of women and children. On the socio-economic front, the study reveals that HAT impoverishes households through re-allocation of household resources to meet the increased financial expenses for seeking treatment and care. Other economic impacts were school drop-outs, school absenteeism, reduced productivity and increased funeral and burial expenses.

This study therefore recommends the instituting of continuous, concerted inter-border measures to reduce the incidences of HAT. In line with this, it is necessary to put in place strategies for effective case finding of HAT at an early stage of HAT. This can be achieved by building the capacity of primary health care personnel to diagnose HAT and to increase their awareness about the same. Similarly, people at risk of HAT should be empowered with relevant information to help them recognize the symptoms of the disease early. Finally the study recommends the establishment of strategies that would assist HAT patients to be integrated back into the community. This study contributes rich information on the socio-economic and cultural impacts of HAT that can be used by policy makers and programme implementers to make informed decisions that will help abate the impacts of HAT, as well as give HAT the attention and priority it deserves, considering that it is one of the neglected diseases. Additionally, this study reveals that diseases like HAT are an important chain in the cycle of poverty.

CHAPTER ONE

INTRODUCTION

1.1 Background to the study

In many countries in Africa, there are a number of diseases that afflict people, which have both a socio-economic and cultural perspective. These conditions have been there for a considerably long period and the ability often to institute sustainable treatment measures is in many instances shrouded in the “mystery” that is often associated with these diseases. What is sometimes more worrisome is the inadequate or, in some cases, the absence of a comprehensive people-centred and participatory health policy management of the disease. One of these infections is Human African Trypanosomiasis (HAT) or sleeping sickness (SS).

Human African trypanosomiasis is a parasitic infection transmitted by the tsetse fly to humans. Its initial symptoms are swollen lymph nodes, fever, severe headache, muscle and joint pains and itching. Eventually, the disease affects the central nervous system causing severe neurological disorders, and if left untreated, it invariably causes the death of the infected person (Kuzoe, 1993). The disease is re-emerging after near elimination in the early 1960s (Hide, 1999; WHO, 2001a). By the end of the last century, an estimated 55 million people in 36 African countries were considered to be at risk of the disease (WHO, 2000a). Kuzoe (1993) estimated that there were about 20,000 to 25,000 new cases of HAT per year in the 1980s, which rose to more than 300,000 persons in 1995 (Ekwanzala, 1995). In 1999, the burden of HAT was estimated at 66,000 deaths and 2 million disability-adjusted life years (DALYS) lost (WHO, 2000a), although

only 45,000 new cases were reported in 1999. However, the actual number of people affected is probably ten times greater than what is reported (Shaw *et al.*, 2001; WHO, 2001b). It is a major public health problem in sub-Saharan Africa (SSA) and is responsible for a considerable degree of morbidity and mortality in countries where it is endemic. The impact of HAT in terms of public health lies not in the annual incidence, but in its potential for the development of explosive epidemics causing thousands of deaths. If incidence alone is considered, the disease appears as a minor health problem compared with other parasitic diseases like malaria and helminthic infections. However, because of its severity, a single case in a family will affect all members (Kuzoe, 1989).

Depending on the parasite involved, HAT takes two forms. One is caused by *Trypanosoma brucei rhodesiense* that is dominantly found in the Southern and Eastern Africa regions. The other form is caused by *Trypanosoma brucei gambiense* mostly found in Central and Western Africa (Jordan, 1986; WHO, 2001a). The disease develops in two stages: early and late stage. The symptoms of the early stage of HAT are non-specific and include nausea, fever and lethargy. In the late stage, the disease affects the central nervous system (CNS), causing severe neurological disorders and invariably leads to death if not treated. Although some countries experience low prevalence of HAT, the disease is considered a major public health threat because of the potential danger of epidemics, serious disease symptoms, high mortality, and high cost of bringing an epidemic under control (Hide, 1999; Shaw *et al.*, 2001).

The key to effective management of HAT is early detection and its treatment. Cattand *et al.* (2001) opine that the spread of HAT can be effectively prevented by regular surveillance of the population at risk, including diagnosis and treatment, and in certain areas, by controlling the tsetse fly population. This is something that is not easy to achieve in many rural areas of Africa, where early symptoms of HAT are easily confused with those of other common diseases such as malaria and influenza (Jordan, 1986). Thus, in a region where there are competing demands for resource allocation, the impact of the disease on the people is immense.

If untreated, HAT causes biological damage and leads inexorably to death. If treated late, it can leave major, irreversible sequel; and since patients must stay in bed or in hospital for a long time, they are unable to work. People develop functional incapacities that increase their dependence. Manifestations of HAT are varied and these depend on the stage of the disease. Mental disturbances are one of the manifestations of a late stage case of HAT (WHO, 2001b:3). These disturbances can lead to stigmatization of both the patient and the family. In women, HAT causes abortion, sterility and gynaecological disorders such as amenorrhoea, which lead to stigmatization. Infected women also risk giving birth to a congenitally infected child. Finally in children, HAT can retard physical growth and intellectual development (WHO, 1998).

Outbreaks not only affect families but also place a major burden on the whole community by reducing the labour force, interrupting agricultural activities, disrupting the local economy and jeopardizing food security (Kuzoe, 1989). The disease tends to affect economically active people who are, for the most part, the mainstay of families. The resulting burden on the extended family is heavy, not only because infected individuals become unproductive but also because close relatives have to spend time taking them for treatment and looking after them. Time and money spent in search of a cure may be a serious drain on the family's resources (Shaw *et al.*, 2001; WHO, 1998). The disease often strikes several members of the same family, which makes mutual support difficult. HAT is therefore a threat to the survival of families and to the education of children (Shaw, 1999).

An endemic situation can rapidly become epidemic. Epidemics are usually identified by a sudden increase in transmission and the number of patients reporting to treatment centres or identified during surveys (Kuzoe, 2001). Epidemics are often associated with ecological changes in the tsetse biotope, including environmental changes and population movements, all of which foster the transmission and spread of the disease. These changes often remain unperceived by communities and public health authorities (WHO, 1998).

In social terms, the large numbers of cases and the high mortality rates are sources of conflict and tension in villages. An epidemic creates a climate of panic that finally makes the survivors abandon fertile land and their homes. In some areas, epidemics have caused entire villages to disappear (Kuzoe, 1993)

Health seeking behaviour (HSB) is greatly influenced by cultural practices and traditions. For example, local explanations of HAT causality or any other disease is embedded in beliefs (these can be in the form of superstitions, magic/witchcraft, myths, taboos and religion) and thus a core determinant of the kind of treatment and place where treatment will be sought. Cultural aspects are thus of central importance for the understanding and devising of appropriate interventions in the health sector. Otherwise, if appropriate interventions are not in place, the HAT pandemic will continue and in turn perpetuate its adverse impacts on affected communities as they struggle to cope with the disease. The cultural aspects of this study will include community perceptions of HAT, social relationships and interaction, social structures within the family, gender and gender roles and HSB.

In terms of social aspects, when a community strongly holds a negative concept of a disease, this can negatively influence the social relations and the moral identity of those afflicted by the disease and also efforts to control it in general. Human African trypanosomiasis also creates social problems that completely change relationships and even cultural values. The social isolation and consequences of disease include divorce, loss or threat of losing jobs, pity and avoidance. Usually, people living in endemic areas are well able to identify the disease, at least in its advanced stage. Fear is aggravated by traditional beliefs that sickness and death are the result of witchcraft, religious influences or wrong doing in the family. In demographic terms, HAT causes sterility and abortion and

thus reduces the reproductive capacity of the population. The combined effects of higher mortality, lower birth rate and migration result in the depopulation of entire areas, as observed at the beginning of the 20th century. Although the disease becomes sporadic when an epidemic regresses, it takes the affected population a long time to recover and regenerate (WHO, 1998).

Problems of limited budgetary allocations on diseases like this one by Governments in the face of the HIV/AIDS pandemic has also adversely affected the treatment and management of HAT leading to socio-economic and cultural impacts. To make matters worse, a number of health professionals in many African countries despise working in rural environments where HAT is endemic due to low levels of motivation, hence compounding the problem even more.

However, little empirical evidence is available on the extent of these impacts. In this study, therefore, an investigation into the socio-economic and cultural impacts of HAT as well as the coping mechanisms employed by the communities in the Busoga focus¹ was initiated and undertaken.

1.2 The People

1.2.1 The Abaluyia

The Abaluyia like many Bantu in Kenya are not a fully homogeneous people even though they are clearly distinct from the surrounding ethnic groups. They are a group of about 16 major sub-ethnic groups who have diverse historical roots, which have led to numerous variations in their dialects, customs and

¹ The Busoga Focus consists of the districts in southeastern Uganda and continues into some parts of western Kenya namely, Busia, Bungoma and Teso districts. In total, the area currently is about

practices. In spite of their diverse origins, they speak mutually intelligible Luyia dialects and share many cultural characteristics (Wagner, 1949; Were, 1967). Different theories have been posited on the origin of the Abaluyia. However, what is evident is that when the Abaluyia settled in Western Kenya, they came into contact with various groups such as Iteso, Kalenjin, Masaai and Batwa and intermarried and borrowed from these other groups. This explains the variations in dialect and customs among the Abaluyia (Ogutu, 1985).

The individual family constitutes the basic social group, in their kinship structure, that co-operates most widely and intensely in the activities of everyday life. Each member contributes to the economic maintenance of the family group by performing tasks, which are assigned to him or her by the traditional rules of the division of labour, on the basis of age and gender. However, this traditional division of labour has changed. The shift from economic self-sufficiency within the traditional family to dependence on the market economy has affected both the division of labour and social cohesion. The continuous influx into major towns in search of employment by men has not only affected social cohesion as a result of separation in family lives, but has also increased women's responsibilities besides their traditional ones.

A family consists of husband, wife and unmarried children. Married sons continue to live with their parents until they set up homesteads of their own, which they usually do after the birth of one or several children. Until then marriage, being mutually patrilocal, the young wife of a married son becomes a

member of the family, her exact position in it being defined by formal rules of conduct with regard to each family member.

The Abaluyia are patrilineal and therefore an individual becomes a member of his father's clan by birth. A clan therefore comprises all persons who trace their descent in paternal line to a common ancestor and who, on that ground, form a community of interests, refrain from intermarrying, and traditionally inhabited a common stretch of land. A significant manifestation of clan solidarity is the observance of taboos on a clan-basis (Wagner, 1949). Marriage is an important institution and traditionally serves to legitimize children. The extended family is widespread and this is probably due to its adaptive role, especially in providing the organisational basis for pooling productive resources, particularly land and labour.

In all the Luyia sub-groups, wide ranges of ritual ceremonies were used as a means of incorporating the young into the more adult groups. There were also feasts and festivals commemorating particular events that were meant to achieve the same end. There were initiation ceremonies, ceremonies connected with clan taboos, establishing the legitimacy of marriage or birth, deaths, war, harvest, religion and magic (Sifuna, 1985). The age group system seems to be common to a majority of the Luyia sub-groups that practise traditional circumcision. Some groups have, however, abandoned the system due to the influence of Christianity. Others do not practise circumcision, probably due to influence from their neighbouring non-Luyia-ethnic groups like the Luo and the Iteso.

Respect for elders (often meaning males who are not necessarily old), old people, aging parents and an ancestor is a strong value in sub-Saharan African cultures. The more senior a person is in years, or kinship status, the more respect that person should receive from juniors (Cattel, 1993). Furthermore, old men are highly respected as potential troublesome spirits because their curse is said to be efficacious (Wagner, 1949). Even though roles and functions of elders are changing in form over time, they are still strong. Many people are still very cautious about angering/openly questioning the opinions of more senior elders because of continuing beliefs about the power of the curse. A study carried out among the Tiriki in western Kenya (Sangree, 1997), shows that seniority, even though it has lost much of its traditional religious significance in recent decades, remains an important status-ascribing principle in every Kenyan ethnic group. As a status conferring principle it is an important cultural norm that has strongly influenced and shall continue in the future to influence the individual, nuclear and extended family choices of not only the Tiriki, but other Kenyan ethnic groups as well, as they respond and accommodate to a changing world.

1.2.2 *The Teso*

The Iteso belong to the plains section of the Nilotes who, in Kenya, include the Turkana. They are also part of a wider community of the Iteso living in eastern Uganda around Tororo thus making a continuum along the Kenya-Uganda border. Another section of Iteso lives in North-western Uganda in Teso district (Simiyu, 1989). They spring ultimately from a common origin with the Karamojong and Turkana and, like them, speak an Eastern (Plains) Nilotic

language. They have a strong pastoral tradition like other Nilotes but claim to have already been farmers before they left Karamoja (Soper and Kapule, 1986).

The Iteso live according to clans, even though the need to sell and buy land has mixed up the clans. They are patrilineal and, after marriage, residence is patrilocal. On marrying, a woman is incorporated into her husband's clan and observes its taboos. The clans are for the most part exogamous (Ekeya, 1984). Members observing the same clan *etale*, taboos, are understood to be blood relatives and do not intermarry. The basic production unit is the polygynous household, within which the individual wives and their children form largely independent sub-units for daily activities. The division of labour is based mainly on age and sex though there are tasks in which everyone shares (Ekeya and Akong'a, 1989).

Marriage is one of the most fundamental of social customs because men and women were brought up with the aim of becoming parents. Marriage was a cross-clan affair and when a young man married, his entire clan participated in his marriage. Birth, initiation, marriage and death are all natural stages in the life of an individual. The Iteso did not have elaborate initiation ceremonies like circumcision, though young men had a staged fight in which they demonstrated physical strength and courage. The community celebrated their coming of age in a ceremony called *ekimwogor* in which a group of boys born at the same time, *aturi*, in a neighbourhood got together and a bull was slaughtered for them accompanied by much drinking and dancing. This ceremony and many others

are no longer performed partly due to influence from neighbouring ethnic groups and the changing times (Ekeya and Akong'a, 1989).

1.2.3 Cultural factors predisposing the two communities to HAT

The cultural aspects of the communities in the Busoga focus are important because they influence many areas of people's lives including their beliefs, behaviour, perceptions, attitudes, all of which may have important implications for health and health care. It is therefore important to always place health and disease in the cultural context of communities. For example, within the Busoga focus, it is important to understand the world view of the communities living there, the way they organize themselves socio-economically and culturally and how these predispose them to disease. These communities engage in various socio-economic activities that may expose them to risk of HAT infection. Activities such as livestock keeping, farming, fishing, charcoal burning, fetching firewood/water in the bushes and along the rivers are common among these communities and have been identified (Smith *et al.*, 1998) as some of the risk factors for HAT infection. Furthermore, division of labour is done along age and sex and thus some of these activities since they are male dominated may expose more males than females to HAT and also more youthful than elderly people. In addition, in these communities livestock are kept for socio-cultural and economic purposes such as paying of bride price, milk for sale and household consumption and also for slaughter during ceremonies such as funeral and burials. Fevre and colleagues (2005) identified cattle as reservoirs of HAT and may therefore play a role in its spread. In addition to the above, the common practice by these

communities of keeping domestic animals close to their dwellings may also be a contributory factor to the spread of HAT.

Communities' world view about health and disease also affects their aetiology of certain diseases and thus influences their organization and utilization of modern and traditional medical care. It is therefore important to study all cultural aspects of the communities as they relate to the prevalence and spread of HAT in the Busoga focus.

1.3 Problem Statement

HAT is a major public health problem in SSA that is not only responsible for a considerable degree of morbidity and mortality in countries where it is endemic, but is also beginning to reverse the gains attained in both the health and development sector. The socio-economic and cultural underpinnings of this disease have by and large had insurmountable implications on those affected. Left untreated, the final outcome of the disease for the patient is death, but equally insidious is its effect on households, communities and quality of life resulting from the debilitating symptoms.

On the economic front, the effects of the disease are costly for young and developing economies, which also rely heavily on agriculture as the greatest employer of the populace, with about 80% of the population relying on agriculture (GOK, 2001a). Kenya has since independence relied heavily on the agricultural sector as the base for economic growth, employment creation, and foreign exchange generation. The sector is also a major source of the country's food

security, both of which are of primary concern to the government. About 80% of the country's population live in rural areas and depend on agriculture for their livelihood (Kenya 1999). Kuzoe (2001) states that some affected countries have agriculture-based economies and workers on cocoa and coffee plantations are at risk of contracting the disease and consequently labour force is reduced.

HAT disrupts normal family life, reduces household labour, causes abortion and sterility and gynaecological disorders which lead to stigmatization, reduces productivity of its patients and causes loss of income and time in terms of hospital bills and transport costs (Hide, 1999; WHO, 1998). Epidemics have serious social and economic consequences, which far outweigh the cost of maintaining surveillance. During epidemics, large proportions of communities are affected with great loss of life and untold human suffering. Studies in Uganda have demonstrated that HAT had an adverse impact on the functioning of households. These included increased poverty, decline in agricultural activities often leading to famine or lack of basic food security, disruption of children's education and generally reversal of role obligations, which more often than not enhance women's and children's burdens. The debilitating nature of the disease also poses more problems for women who may be stigmatised and /or rejected by their spouses even after recuperation (Kuzoe, 2001).

African communities are often known to have close-knit social ties and relationships, often along the bonds of the extended family. However, with the resurgence of HAT, these relationships are often thrown in disarray, especially

on the affected individuals and households alike. Such incidences of stigma with subsequent isolation and marginalization have often affected the personality worth and self-esteem of those affected, with subsequent disintegration of the once closely knit family fabric unit. Mental confusion, personality and behaviour changes, which often characterize the central nervous system (CNS) involvement in late stage of the disease, may lead to divorce and break up in homes and present unfavourable climate for bringing up children. In some cases such people become mentally disturbed, suicidal and violent and constitute danger to themselves and the community (Kuzoe, 2001). The situation has also been made worse by the inability of communities, in HAT endemic areas, to critically understand the disease, its treatment and general health implications but have often relied on stereotypes about the disease².

The impacts of HAT are quite immense and if proper and sustainable control measures are not put in place, the disease can impact negatively on the human and economic development of the country. Thus this study sought to answer the following questions:

1. How does health seeking behaviour perpetuate the impacts of HAT in the Busoga focus?
2. To what extent does HAT affect the normal social functioning of HAT affected households in the study area?

² The low levels of awareness of the disease, its transmission and management have made people simply treat HAT as a cursed incurable disease that they do not want to be associated with.

3. How does HAT affect the economic base of HAT affected households in the study area?

1.4 Objectives of the Study

1.4.1 Overall Objective

The study's overall objective was to establish the socio-economic and cultural impacts of HAT and the coping strategies of households in the Busoga focus

1.4.2 Specific Objectives

- 1 To assess the effects of health seeking behaviour in relation to HAT on affected individuals and households.
- 2 To determine the extent to which HAT affects the normal social functioning of HAT affected households.
- 3 To establish the economic impacts of HAT on households.

1.5 Rationale of the Study

This study aimed to generate detailed social science evidence for prevention, care and mitigation of the impact of the HAT epidemic on individuals, families and communities. The objective was to inform tailoring of policies, programmes and interventions to the social, developmental, cultural and economic contexts within which modern-day communities in endemic areas live. Improved human health will translate into improved community welfare through increased productivity and therefore reduce poverty, leading to better rural livelihoods.

Many HAT endemic countries in Africa tend to experience similar socio-economic aspects such as competing demands for resource allocations, which preclude adequate surveillance and control infrastructure. Since they also tend to have

similar health systems, the findings may be used to address some of these problems in other HAT endemic regions.

Disease epidemics are not only a threat to the health status of a nation, but also have detrimental consequences on sustainable development (Browne, 2001; Lambo, 2000; Okorosobo, 2000). Sessional Paper No. 10 of 1965 and successive development plans in Kenya, indicate that human health is one of the fundamental basic needs that require full attention from the Government and is an essential prerequisite for the overall economic and social development. Accordingly, to improve human health is to improve the general economy of the country, which subsequently leads to poverty reduction. This will in turn be useful in re-engineering the study on a disease that is slowly being forgotten in the face of other competing diseases like malaria and HIV/AIDS. In spite of the hitherto stated position, the socio-economic and cultural effects of HAT have not been adequately researched on, yet it is on the strength of these impacts that policies and control programmes are formulated.

Biomedical scientists have for a long time mainly placed emphasis on the clinical aspects of disease, yet the behavioural aspects are equally important in enabling the health practitioners to understand how the disease affects the patient's relationships within the family and community at large. The kind of information generated from this study can help health practitioners know whom, where and how to target their interventions, against disease, in order to achieve success in disease control.

An understanding of the effects of HAT and the coping strategies could provide information, which can be used by health policy makers to prioritize health problems. Similarly, health providers will be able to better understand how people contextualize themselves when faced with a particular health problem and thus position themselves to provide better services. The findings from this study should help us to understand how people and families cope with HAT and to treat them with a humane face. It is anticipated that findings and the conclusions thereof that have emanated from this study will be useful in the abatement of the consequences of HAT among the communities living in HAT endemic foci.

1.6 Scope and Limitations of the Study

This study was undertaken within the precincts of Busia, Bungoma and Teso districts of Western Kenya and Busia and Tororo districts of South-eastern Uganda because they are a continuation of the same tsetse fly belt. Although the issues investigated had also affected other areas in Kenya and Uganda, the coverage of these areas were not possible due to logistical problems. HAT has impacts, which go beyond the national and regional borders but these were beyond the scope of this study. Instead the study concentrated on the socio-economic and cultural impacts of HAT at the individual, household and community levels within the selected districts.

This study was anthropological in approach and its emphasis was on the field of medical anthropology, where impacts of HAT were seen as being affected by people's perceptions of the illness and the coping strategies employed to manage it. While there was an obvious link to other disciplines, no attempts

were made to push the study to the other domains. For instance, no laboratory tests were carried out to determine who has contracted HAT.

Some of the information sought was also quite sensitive and this could have limited the quality of information obtained from the field. Throughout the study, respondents were assured of the confidentiality of the information they were giving. Another possible limitation to the study was tracing some HAT patients. This is because some had relocated or died. In such cases, where possible, guardians who took care of the patient at the time of illness were interviewed.

1.7 Organisation of the Thesis

This thesis is organized in eight chapters. This current chapter has dealt with the background information on HAT, basic information on the people in the study area as well as a description of the research problem. The research questions, objectives and the scope and limitations of the study are also presented. In Chapter two, literature relevant to the study is reviewed and the theory used to guide the study articulated and linked to the study. The main assumptions and operational definitions of key terms are outlined. The research methodology is presented in chapter three while the findings of the study are covered in chapters four, five and six. Chapter seven presents the discussion of the findings of the study whilst chapter eight summarizes the findings and generates conclusions and recommendations from the findings.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

In this chapter, literature pertaining to the study topic is reviewed in order to have an overall understanding of the effects of HAT. The conceptual model that guided the study is also described and the hypotheses and operational definitions of variables presented.

2.2 Human African Trypanosomiasis

Human African Trypanosomiasis is caused by protozoan parasites of the *Trypanosoma* species and occurs in 36 African countries between latitudes 14^o North and 29^o South (de Atouguia and Kennedy, 2000). The disease, which had been virtually eliminated in the 1960s, has returned with a vengeance, mainly because of deterioration in control activities, severe disruptions of health services, and population movements into high-risk areas (WHO, 2001a). Since 1999, the spread of HAT to areas previously free of the disease has caused serious concern (WHO, 2001c). It is estimated that 60 million people are at risk of contracting the disease (WHO, 1986; WHO, 2002). Together, these 36 countries report only about 25,000 new cases of the disease to WHO annually. However, this is an obvious underestimate attributed to poor reporting, difficulty in diagnosing the disease and poor accessibility of the affected areas. WHO estimates that 300,000 to 500,000 persons are currently infected (WHO, 2001a). The true figure is currently estimated to exceed 300,000 new cases annually.

The reported annual incidence of human cases has increased year after year (Kuzoe, 1993).

The history of HAT has been characterized by waves of epidemics, resurgence and outbreaks. Nevertheless, HAT was brought practically under control in the early 1950s in West and Central Africa, mainly through vector control but its true incidence has recently been increasing rapidly (Cattand and de Raadt, 1991; Kuzoe, 1993). Social and political changes, failure of national health authorities to give due attention to HAT control, civil and political unrest, lack of adequate resources, and competing national health priorities, have resulted in epidemics and resurgence of many old foci of the disease, and the appearance of new ones (Kuzoe, 1993).

HAT is transmitted to humans through the bite of the tsetse fly. The disease occurs in two forms: *Tb gambiense* and *Tb rhodesiense*. *Trypanosoma brucei*, and the role of the tsetse fly (*Glossina spp.*) as its vector was identified in game animals in Zululand by David Bruce two centuries ago. Later, morphologically identical trypanosomes were identified in the blood of a European from The Gambia, West Africa, and transmission by riverine tsetse was confirmed. The disease was called Gambian trypanosomiasis and the parasite, *T. gambiense*. In 1908, a severe rapidly fatal trypanosomal infection was identified in the Luangwa valley, Zambia (Former Rhodesia). This led to the description of *Rhodesiense* trypanosomiasis due to *T. rhodesiense* (*T.b. rhodesiense*) (Mbulamberi, 1989). Both forms evolve into a central nervous system infection

and, without treatment, cause death. *Tb rhodesiense* causes an acute infection lasting from a few weeks to a few months. This form of the disease prevails in Eastern and Southern Africa. On the other hand, infections of *Tb gambiense* are chronic, lasting for years, with a latent period which may be several years long before the patient shows any major clinical signs (WHO, 2001b; Cattand *et al.*, 2001). However, when symptoms do appear, the disease is already in an advanced stage (WHO, 2001b). Infections of *Tb gambiense* are typically found in Western and Central Africa (WHO, 1998).

The early stage main clinical signs are high fever, weakness and headache, joint pains and itching. Gradually, the initial symptoms become more pronounced and other manifestations appear, such as anaemia and cardiovascular and kidney disorders. Later, when the parasites invade the CNS, the disease takes a dramatic turn. The patient's behaviour changes; he or she can no longer concentrate and becomes indifferent to or is exasperated by everything. Sudden and completely unpredictable mood changes become increasingly frequent. The patient is then overcome by extreme torpor, insomnia and exhaustion, leading to a deep coma and death (WHO, 1996).

Until very recently, treatment prospects have been bleak and the treatment has presented serious problems for the medical personnel mainly due to toxicity of the available drugs and the need to hospitalize patients during treatment. Extensive and careful nursing (including supplementation of the diet) and regular follow-ups to check for relapse are also essential (Molyneux and Ashford, 1983).

Available medicines are expensive to manufacture and administer. While some are well tolerated, others, used in the neurological phase, are so dangerous that fatal complications are common. In addition, problems of drug resistance have been reported in a growing number of countries (WHO, 2001a:3)

2.3 Culture and Health

According to Tylor (1958:1): *“Culture is that complex whole which includes knowledge, beliefs, art, morals, law, customs and any other capabilities and habits acquired by man as a member of society”*. On the other hand, Keesing and Keesing (1968:20) define culture as *“The totality of learned socially transmitted behavior”*. From these two definitions one can infer that culture is a set of guidelines which individuals inherit as members of a particular society, and which tells them how to view the world, how to experience it emotionally and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment. A cultural background, therefore, has an important influence on many aspects of people's lives, including their beliefs, behaviour, perceptions, emotions, attitudes to pain and other forms of misfortune, all of which may have important implications for health and health care (Helman, 2007).

An important point in understanding the role of culture is that it must always be seen in its particular context. This context is made up of historical, economic, social, political and geographical elements. It may, therefore, be impossible to isolate 'pure' cultural beliefs and behaviour from the social and economic contexts in which they occur (Helman, 1984). It is in view of this that this study

attempted to establish the socio-economic and cultural consequences of HAT to find out how they influence health seeking behaviour (HSB), and vice versa. The study concentrated on the kind of behaviour that is related to health and disease. The health and disease of humans and of the community in which they live depend upon the interaction with the physical, biological and social environments. Cultural factors have an impact upon the pattern of health and disease in the community and they play a role in the etiology of certain diseases (Elissen, 1991). These factors also play an important role in the organization and utilization of modern and traditional medical care. In addition, the pattern of interaction between health workers and their clients is influenced by their socio-cultural and economic backgrounds.

The success of preventive and promotive action programmes largely depend upon their acceptability and this is related to cultural norms and values (Abdullah, 1984). An investigation carried out in Machakos District with the aim of finding out what mothers believe about measles and diarrhoea and what they do when their children contract these diseases, revealed that perceived etiological notions about these diseases influenced the beliefs held and this led to their being classified among "God's diseases" (Maina, 1978). This classification influenced an adherence to traditional practices as well as the acceptability to seek modern care.

Maina (1978) argues that social and cultural factors influence many aspects of health and disease. These factors do not only affect patterns of morbidity and mortality, but also the utilization of therapeutic options. Suchman (1963, quoted

in Maina 1978:139) asserts that social factors determine the response of society and the individual to many health problems. The meaning of illness, its perception and definition, as well as behavioural responses to illness are basic factors influencing the reactions of the public to public health programmes. This implies that the existence and role of beliefs and practices, which are part of the culture of a particular population, should be taken into account when designing measures and programmes aimed at improving the health situation in that population (Manyeneng, 1980).

According to Van Luijk (1974), the study of how and why people behave the way they do in relation to health problems is important in order to get a better insight into the social process in a community. It is also important in understanding why people accept or reject certain "modern" medical activities. The way in which people deal with illness is closely related to their ideas about cause and etiology and these vary from one society to another (Kaendi, 1995; Sindiga, 1995).

Explanatory models provide explanations for the etiology, symptoms, physiological changes, natural history and treatment of the illness. On this basis, patients choose what seems to be the appropriate source of advice and treatment for their condition (Helman, 1984). For instance, illnesses such as colds, are treated by relatives; supernatural illnesses (such as 'spirit'-possession) by sacred folk healers; while 'natural' illnesses by physicians - especially if they are very severe. If, for example, the ill-health is ascribed to divine punishment for a moral transgression, then "prayer and repentance, not penicillin, cure sin" (Snow, 1978). In this way, sick people frequently utilize several different types of

healers at the same time or in sequence (Helman, 2007; Nyamwaya, 1992; Sindiga, 1995).

Many African communities categorize disease and illness according to cause. This, in turn, may influence therapy seeking and selecting behaviour. Patients will go to biomedical facilities when their families, friends or neighbours or even themselves believe that an illness is naturalistic. On the other hand, they will turn to traditional healers when they conceive an illness to be caused by human-induced forces. However, when faced with actual illnesses, patients in the African context have been observed to be quite flexible, sometimes combining a number of systems for the same episode of illness (Sindiga, 1995; Nyamwaya, 1992).

Foster (1978) has observed that non-western medical systems possessed two categories of disease causation, that is, personalistic and naturalistic. Correlated with the personalistic category is the belief that disease is due to the active purposeful intervention of an agent who may be human or non-human. Diseases under this category included the uncommon conditions, which members of a community cannot comprehend, such as conditions that lead to deliriums, malignant growths and elephantiasis. Under the natural category, diseases are believed to stem from such natural forces or conditions as cold, heat, wind and dampness. These diseases included everyday complaints such as fever, the common cold and diseases of children, the aged and expectant mothers (World Bank, 1994).

2.4 Role of Beliefs in Health and Illness in the Busoga Focus

Disease is a universal phenomenon and so are responses aimed at maintaining or restoring health. The Abasamia recognize the fact that poisoning, snake-bites, “mind” and physical degeneration cause illness, *obulwaye*. However, at other times, they attempt to explain the particularity of an illness, here they resort to identifying things like witchcraft, violation of food and moral taboos, and the evil eye, *obusara*. Spirits, *ebikhieno*, especially *emisebe*, ancestor spirits, are also given as ‘causes’ of certain disease conditions. The Iteso and Abasamia and Babukusu categorize diseases into those that are treated best at home and those that are best handled in the hospital (Nyamwaya, 1986; Kiragu, 1989).

Among the Iteso leprosy (*emulo*), scabies (*chup*), measles (*ekuan*), and epilepsy (*imatuala*), are believed to be illnesses for home treatment. Among the Abasamia, *ebikhieno* (spirits), *esikerete* (measles), *obokengi* (malnutrition), sorcery, infertility and madness are believed to be best dealt with by using traditional medicine. Such beliefs affect the actions taken when a person falls sick, although other factors like level of education and religion also influence coping mechanisms to illnesses. Among the two ethnic groups, leprosy patients traditionally led very miserable lives. They were isolated and lived alone in rough shelters with no human contact. When a leprosy patient died, the shelter he lived in was burned together with the body (Nyamwaya, 1986).

2.4.1 Indigenous Health Practices in the Busoga Focus

Several measures are taken by the Abasamia, the Babukusu and the Iteso to prevent the occurrence of illness. Some people have acquired health education

through schools, churches and the mass media and take modern preventive measures such as proper nutrition and personal hygiene. However, some people still observe traditional food habits and moral taboos as ways of preventing diseases (Kiragu, 1989; Nyamwaya, 1986).

The Abasamia believe, for example, that marasmus is a symptom of *ekhira* (malnutrition), and is caused by adultery committed by the husband. The Iteso believe that improper funeral rites can cause illness, so the *epunyas* (rituals), are performed to prevent such illness. Young children especially are given herbal concoctions to prevent illness. Various rituals and prayers at the family level are performed to prevent diseases believed to have social and spiritual origins (Kiragu, 1986; Nyamwaya, 1986).

Among the Bukusu are the *kimisambwa*, a group of diseases associated with a curse passed down in families and clans. They are treated traditionally by healers who possess "prophetic" powers to trace down the origin of the problem, recovery based mainly on the principles of 'faith healing'. Victims of *kimisambwa* have behavioural maladjustment and have been mistaken for lunatic or mentally ill persons (Kiragu, 1986). Among the Babukusu, there are traditional clothes and ornaments like metal rings, worn by both men and women to correct certain diseases which modern medicine is not able to treat and cure.

Most adults are expected to know herbal remedies for common ailments. However, *abalesi* (general term for healers) in Olusamia and *muruk* in Ateso know more specialized cures. In fact, most illnesses are treated at home before

the hospital is visited. Many people in these communities believe in and utilize various forms of traditional medicine as a complement to the existing modern health facilities. Wide varieties of healers exist among the ethnic groups and are similar. Some indigenous healers usually refer their patients to other healers or even to hospital.

The Bukusu people have several rituals, which are supposed to be performed, failure of which may lead to illness. There are specialists, among them diviners, medicine men, traditional birth attendants, religious healers and sacrificial priests, who must be without failures or blemishes and wield a lot of mystical powers. They are often consulted by people and help solve some of the health problems. Illnesses which require their attention include sudden and violent illness, repeated bad dreams in the course of which a patient suffers from appearance of the spirits of the dead, as well as hallucinations and many others (Wagner, 1949). A diviner would be consulted to know the cause and the appropriate treatment.

2.4.2 *Psycho-social Medicine in the Busoga Focus*

The three ethnic groups know that social, spiritual and psychological factors can cause illness in human beings. All the groups recognize mental illness and believe that certain psychosocial problems can lead to physical illnesses. Among the Bukusu people, etiological concepts of mental illness are multiple, ranging from social to physical. They include, among others, witchcraft (*bulosi*), broken taboos (*kimisilo*), failure to offer sacrifices to the ancestors (*bakuka*), inheritance (*kimisambwa*), curse (*khuchuba*), attacks from evil spirits (*bisieno*), accidents, organic illnesses such as malaria, and chemical imbalance in the brain. Most

people prefer traditional healers (Maithya, 1992). They further attribute some mental illness to anti-social behaviour of some members of the community such as sorcerers and witches, while failure to perform certain ceremonies is equally an important cause (Wagner, 1949).

To prevent illness, which may be caused or aggravated by social, spiritual or psychological factors, measures are taken to ensure that people are in harmony with one another and ancestral spirits. However, social disharmony does occur and the ancestors get annoyed. To prevent negative consequences following social and/or spiritual disharmony, various rituals and ceremonies are performed and these seem to have a cathartic effect on both the affected individuals and the community as a whole (Nyamwaya, 1986).

The Samia people have a wide variety of therapeutic rituals, which they perform to eradicate illnesses of social and spiritual causation. Apart from just the effect from physical symptoms, these rituals are performed to effect complete healing, which is perceived to include both the cure of biological disease and the removal of the social and spiritual forces thought to be involved in illness. These people also consider it necessary to perform therapeutic rituals during the management of an episode of illness, which is thought to involve in its etiology forces such as the curse, oath, evil (human) wishes or malevolent spirits (Nyamwaya, 1986).

Proponents of psychomatic medicine suggest that the rituals have a placebo effect on the patients, thereby contributing to physiological recovery. However, the rituals are also important in the community's coping with the social, spiritual

and psychological disruptions, which are occasioned by illness. Therefore, though the ritual performed may leave the patient with the disease uncured, it serves the function of enabling the community to make sense of a painful experience – illness caused by disease (Nyamwaya, 1986).

Among the Iteso, the diviners, of whom there are more than four types, play a very big role in psychosocial medicine by psycho-diagnosing social problems, most of which have mystical origins. When an Etesot suspects that an illness is due to human/spiritual causes, he/she visits the various diviners who have esoteric knowledge, which enables them to label the condition. The diviners usually advise what course of action is to be taken. The fact that a problem has been defined and labelled in itself brings much psychological satisfaction to the victim. Most diagnoses point to quarrels, breach of taboo, omission of rites and general ritual impurity as the causes of various illnesses. The two ethnic communities utilize both hospital therapy and traditional rituals in complementary fashion (Nyamwaya, 1986).

2.5 Socio-economic and Cultural Aspects of Disease

The effects of poor health 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. And, in view of the demonstrated importance of human capital to economic progress, it comes as little surprise that no country has attained a high level of economic development with a population crippled by high infant and maternal mortality,

pervasive illness of its work force, and low life expectancy (World Bank, 1994). 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.

Health is not merely the absence of illness, but a state of optimum capacity of an individual for the effective performance of the roles and tasks for which he has been socialised (Fako, 1980:119). Therefore, illness is undesirable to society because its abundance may reduce the number of fully functioning members who are required in many aspects of the development of society. It is therefore in the interest of society to control or minimise illness. For an individual, illness is a state of disturbance in the normal functioning of the total human being. It interferes with the normal patterns of interaction. In a family, illness of a member creates somewhat different emotional relationships among family members. It puts a strain on them and may create an emotional environment, which may complicate the patient's emotional adjustment (Fako, 1980).

Diseases such as onchocerciasis and malaria are location-specific and have been shown to discourage settlement on, and development of, fertile land. Trypanosomosis has made one-third of Africa unsuitable for cattle raising, which in turn has aggravated protein deficiency problems. Malaria and trypanosomosis are inhibiting migration and resettlement of new lands in Uganda (World Bank, 1994).

2.5.1 Socio-economic Impacts of HAT

The socio-economic and cultural impacts of HAT are often underestimated. If left untreated, HAT causes biological damage and leads inexorably to death; and if treated, it can still leave major irreversible conditions. Some affected countries have agricultural-based economies and workers on cocoa and coffee plantations are at risk of contracting the disease and consequently labour force is reduced. This is because patients must stay in bed/in hospital for a long time and thus are unable to work (Kuzoe, 2001; WHO, 1998). Patients develop functional incapacities that increase their dependence. Time and money spent in search of a cure may be a serious drain on the family's resources. At community and family levels, mental confusion, personality and behaviour changes, which often characterize central nervous system involvement in late stage disease, may lead to divorce and break-up in homes. This may also present unfavourable climate 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 and constitute danger to themselves and the community (Kuzoe, 2001).

In Central Africa, there are important problems regarding treatment, particularly the severe social consequences of long-term hospitalisation. There are important behavioural factors contributing to risk of death from sleeping sickness, such as negative attitudes towards hospital treatment, which often lead to absconding and incomplete treatment (Kuzoe, 2001). Low level of awareness concerning the disease can also create an obstacle to effective treatment and control of the disease, thus perpetuating the adverse impacts on the community.

In the Santchou focus of Cameroon, 40.5% of the study population did not know that tsetse flies are the vectors of SS and instead suggested other modes of transmission such as heredity and sexual relations (Touko *et al.*, 1997). In Chad it was reported that populations of non-infected villagers treat those of infected villages with disdain and expel from the village anyone recognised as ill (Ngar-Ndigoum, 1997).

Studies in Uganda have demonstrated that HAT had adverse impacts on the functioning of households. These impacts included increased poverty and decline in agricultural activities often leading to famine or lack of basic food security. In addition, the impacts caused disruption of children's education and generally reversal of role obligations, which more often than not enhances women and children's burdens. The debilitating nature of the disease also poses more problems for women who may be stigmatised and /or rejected by their spouses even after recuperation. This is because SS causes abortion, sterility and gynaecological disorders such as amenorrhea. This reduces the reproductive capacity of the populations. Infected women also risk giving birth to a congenitally infected child. Aroke *et al.* (1998) have reported that past history of *Tb gambiense* SS in children had influence on physical growth, intellectual development and attainment of sexual maturity.

In social terms, the large numbers of cases and the high mortality rates are sources of conflict and tension in villages; an epidemic 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 Niger Delta in Nigeria HAT is regarded as a “disease of mourning” that is passed on by physical contact; people suspected of passing on the disease are frequently isolated or put into quarantine (Airauhi *et al.*, 1999; WHO, 1998).

2.5.2 Socio-economic and Cultural Impacts of Mental and Behavioural Disorders

Many communities in Zimbabwe believe that mental illness is caused by witchcraft. This belief exists in most African cultures, for instance, anxiety is expressed as fear for failure in procreation, in dreams and complaints about witchcraft (Nyati and Sebit, 2002). Mental and behavioural disorders have a large impact on individuals, families and communities. Individuals suffer the distressing symptoms of disorders. They also suffer because they are unable to participate in work and leisure activities, often as a result of the disorder and discrimination.

Victims and their relatives may be denied their right of association and life partners as they are feared and avoided (Maithya, 1992). They worry about not being able to shoulder their responsibilities towards family and friends, and are fearful of being a burden to others (WHO, 1997). Maithya (1992) asserts that when young people suffer from these psychiatric disturbances their education is adversely affected or even impaired due, partly, to school absenteeism. When

an adult member(s) of a family is/are afflicted their productivity is lowered. Time is also lost through repeated hospital visits where the problem may be vaguely presented as other physical illnesses such as abdominal problems and headaches.

The victims' families are required not only to provide for physical and emotional support, but also to bear the negative impact of stigma and discrimination. The burden on families ranges from economic difficulties to emotional reactions to the illness, the stress of coping with disturbed behaviour, the disruption of household routine and the restriction of social activities (WHO, 1997). Expenses for the treatment of mental illness often are borne by the family either because insurance is unavailable or because mental disorders are not covered by the insurance. In addition to the direct burden, lost opportunities have to be taken into account. Families in which one member is suffering from a mental disorder make a number of adjustments and compromises that prevent other members of the family from achieving their full potential in work, social relationships and leisure (Gallagher and Mechanic, 1996). Families often have to set aside a major part of their time to look after the mentally ill relative, and suffer economic and social deprivation because he/she is not fully productive. There is also the constant fear that recurrence of illness may cause sudden and unexpected disruption of the lives of family members. Family relationships are strained endangering marriage stability that may result in divorce. Thus, social costs to the family in terms of disrupted organisations and family life are irreparable (Maithya, 1992).

The impact of mental disorders on communities is large and manifold. There is the cost of providing care, the loss of productivity, and some legal problems. The economic impact of mental disorders is wide-ranging, long lasting and huge. These disorders impose a range of costs on individuals, families and communities as a whole. Part of this economic burden is obvious and measurable, while part is almost impossible to measure. Among the measurable components of the economic burden are health and social service needs, lost employment and reduced productivity, impact on families and caregivers, levels of crime and public safety and the negative impact of premature mortality. Low treatment costs (because of lack of treatment) may actually increase the indirect costs by increasing the duration of untreated disorders and associated disability (Chisholm *et al.*, 2000).

Mental and behavioural disorders cause massive disruption in the lives of those who are affected and their families. Although the whole range of unhappiness and suffering is not measurable, one of the methods to assess its impact is by using the quality of life (QOL) instrument (Lehman *et al.*, 1998). A number of studies have reported on the QOL of individuals with mental disorders concluding that the negative impact is not only substantial but sustained (UK700 Group, 1999). It has been shown that the quality of life continues to be poor even after recovery from mental disorders as a result of social factors that include continued stigma and discrimination. A recent study clearly demonstrated that unmet basic social and functioning needs were the largest predictors of poor quality of life among individuals with severe mental disorders (UK700 Group, 1999). The

impact on QOL is not limited to severe mental disorders, for anxiety and panic disorders also have a major effect, in particular with regard to psychological functioning.

From the foregoing review of literature it is evident that disease affects more than just the physical aspect of a person. Its effects go beyond the individual to the family and society at large. It is also clear from the above literature, that traditional beliefs about cause and aetiology of disease still influence, to a great extent, the HSB of people and their attitudes to disease, especially in the rural areas. Thus, there is need to study the traditional beliefs about cause and aetiology of HAT, so as to help in understanding the attitude and behaviour/practices of people as regards the disease. However, most studies done have exclusively focused on cultural aspects and how they influence HSB but have not gone further to establish how HSB perpetuates the impacts of disease on the infected and the affected. Similarly, a number of studies have looked at the impacts of different diseases but there is a dearth of in-depth information and analysis on socio-economic and cultural impacts of HAT especially at different levels that is at the individual, household and community level. Yet it is on the strength of these that policies and control programmes are formulated. Since there are gaps in knowledge about the detailed impact of HAT, this study has endeavoured to fill some of the gaps and provide the relevant literature.

2.6 Theoretical Framework

A number of formulations have been designed in an attempt to account for health behaviour. Disease not only involves the body, it also affects people's social relationships, self-image and behaviour. The socio-psychological aspects of illness are related in part to the bio-physiological manifestations of disease but are also independent of them (Oyaya, 1993). The health belief model (HBM) has frequently been used in the analysis of health related behaviour. Three modes of behaviour have been incorporated in HBM. These include health behaviour, illness behaviour and sick role behaviour (Becker, 1974, quoted in Oyaya, 1993:27). Although this study is health-related, it looked beyond these three modes of behaviour and studied the impacts of disease not only on the individual but the family and community as a whole. The theory of cultural materialism was thus identified as a suitable theory that would incorporate impacts of disease, to guide this study. From the foregoing review of literature it is evident that disease affects more than just the physical aspect of a person. Its effects go beyond the individual to the family and society at large. From the foregoing review of literature it is evident that disease affects more than just the physical aspect of a person. Its effects go beyond the individual to the family and society at large.

2.6.1 Cultural Materialism

Cultural materialism is an anthropological paradigm founded upon, but not constrained by, Marxist materialistic thought. It was developed by Marvin Harris who believed that modes of production and material conditions determine culture (Harris, 1979). Cultural materialists study technology, environment, and economic factors. They believe that these material constraints are the primary

cause of cultural variation. They divide cultural traits into three categories: the infrastructure, structure and superstructure (Lett, 1997).

The infrastructure constitutes the interface between nature in the form of unalterable physical, chemical, biological, and psychological constraints, on the one hand, and culture, on the other (Harris, 1995:68). The structure is the basic social organization of the culture; it consists of the ways the society is organized to produce, distribute, and consume goods and services at both the domestic and political levels. The superstructure comprises the set values and beliefs that add meaning to life by providing emotional, intellectual, and aesthetic satisfactions (Harris, 1995:68). The fundamental theoretical principle of cultural materialism is that of infrastructural determinism, which holds that particular forms of infrastructure give rise to particular forms of superstructure (Lett, 1997). The cultural materialist model of society asserts that all three levels (infrastructure, structure and superstructure) are in a continuous dynamic state and that there are significant and predictable relationships between them. The model suggests that changes in a society's infrastructure are primarily the result of changes in a human population's relationship to its environment (Lett, 1997).

The theory of cultural materialism can be conceptualized as shown in Fig. 2.1.

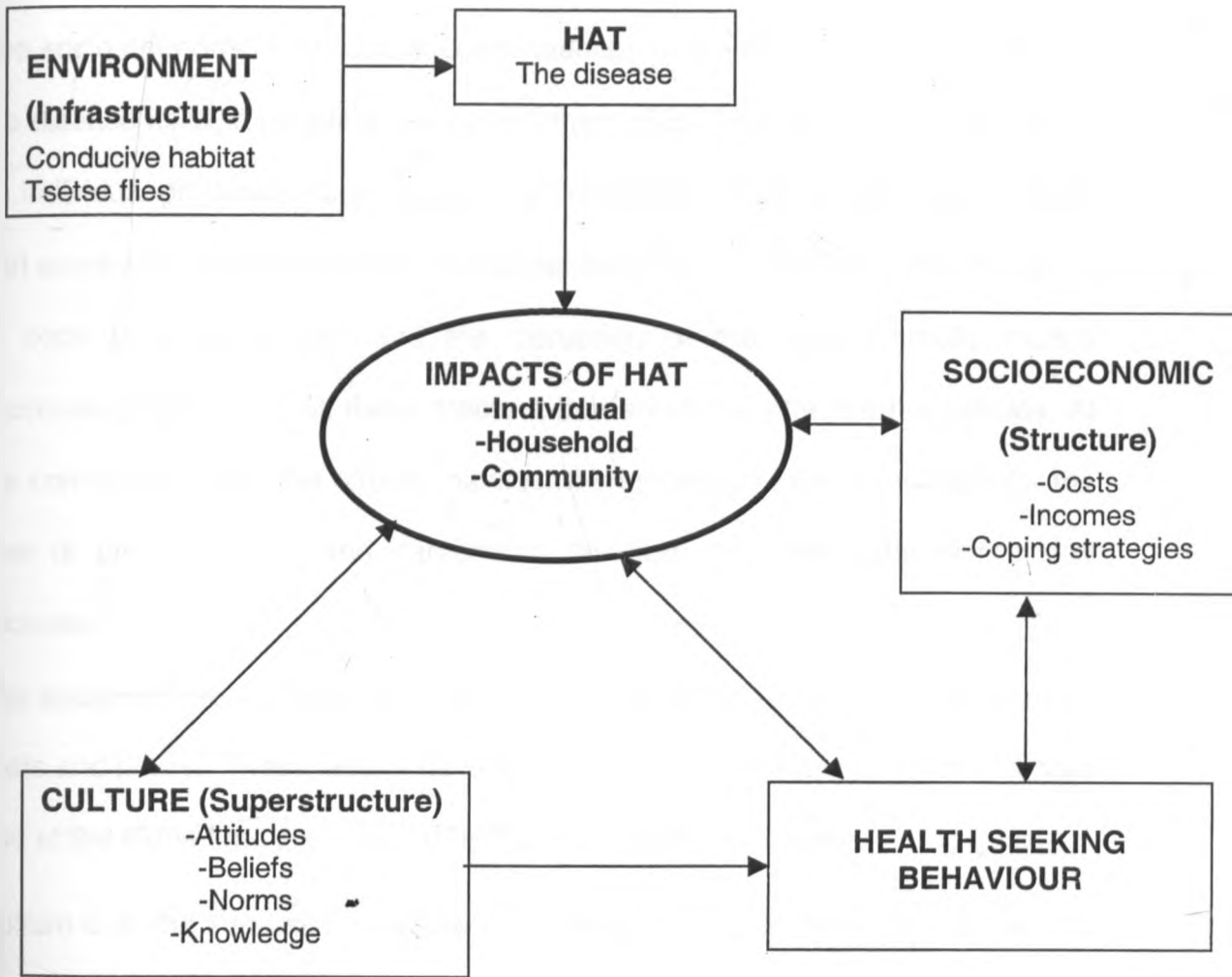


Fig. 2.1: Conceptual model of cultural materialism

2.6.2. Relevance of Cultural Materialism to the Study

Cultural materialists divide culture into three categories: the infrastructure, structure and superstructure. In relation to this study, the environment is at the infrastructure level. In this case, weather, conducive habitat for tsetse flies and

an increase in the flies, which are infected with the parasite that causes HAT, comprise the environment. When these flies bite a person, they cause the disease in humans and once a human is infected, the effects of the disease begin.

The socio-economic and cultural consequences of the disease are as a result of the disease itself, a people's culture and their HSB. The disease directly affects an individual physically causing pain and discomfort. This, in turn, causes social and economic consequences to the household in terms of money and time spent to cope with the illness, and the disruption of the patient's daily routine chores/engagements. All these create a burden on the affected households. At the community level, the effects manifest themselves in loss of productivity, the cost of providing care and damage to the fiber of entire communities and societies.

The structural level is characterized by socioeconomic factors such as income, costs and policy. These factors have an effect on the impacts of HAT at all levels and at the same time are affected by the impacts of the disease.

Culture is at the superstructure level. It comes into play in that it affects the way people define and interpret diseases (in this case HAT) and shapes their attitudes, beliefs, norms and knowledge concerning HAT. Culture therefore has an important influence on many aspects of people's lives including their beliefs, behaviour, perceptions, emotions, attitudes to pain and other forms of misfortune, all of which are important implications for health and health care (Helman, 1984). Therefore, depending on the community's beliefs of HAT, stigmatisation and

rejection by spouses and community members is bound to occur, thus aggravating the consequences of the disease.

Culture also affects the HSB in terms of coping strategies of the individual or community to seek relief from HAT. Different communities have different coping strategies. Fabrega (1975:969, as quoted in Johnson and Sargent, 1990:118) implied that members of different cultures think about disease and organize themselves towards treatment and the social organisation of treatment itself. The way in which people deal with illness, is closely related to their ideas about cause and etiology, which varies from one society to another (Kaendi, 1995; Sindiga, 1995; Stevenson, 1987). Therefore, an individual's beliefs and knowledge about the cause and etiology of HAT is bound to influence his/her coping reactions.

2.7 Assumptions

Following the research problem highlighted the objectives set and the subsequent review of literature, the following assumptions were formulated: -

1. Health seeking behaviour perpetuates the impacts of HAT on the individual and household.
2. HAT disrupts the social functioning of households.
3. HAT negatively affects the economic base of individuals and households.

2.8 Operational Definition of Key Terms

Human African Trypanosomiasis (HAT): is defined in this study as the human disease transmitted by the tsetse fly.

Health Seeking Behaviour: this refers to all the action taken and options used by HAT patients and their households when seeking treatment.

Impacts of HAT: this was measured as a combination of socio-economic and cultural effects that the individual faced when suffering from HAT

Economic base: this was measured as a combination of income/productive time lost in either patient-care or seeking treatment.

Social functioning: this referred to the ways the household distributes and organizes daily responsibilities and roles in order to function as a unit

Individual: this was measured as a person having been infected HAT.

Household: this was measured as a group of persons who normally live and eat together, whether or not they are consaguineals (related by blood) or affines (related by marriage) and who share a common source of food.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter is divided into four sections, namely: description of the research area, sampling design, methods of data collection and data analysis.

3.2 The Research Site

This study was carried out in the Busoga focus, which is shown in Map3.1 by the number 1. This focus consists of Busia, Teso and Bungoma districts of western Kenya and Tororo and Busia districts of southeast Uganda.

3.3 Ecological Profile of Tsetse and the Busoga Focus

3.3.1 Ecology of Tsetse

Tsetse flies are haematophagous—dependant on blood sucking to derive nutrients. Different species of *Glossina* have different preferences for the source of their blood meal with some specifically preferring human blood and are therefore important vectors of the disease in human populations. Both male and female flies feed on blood and are both vectors of the parasites. The distribution of African trypanosomiasis is completely linked to the range of its vector, the tsetse fly. Due to the tsetse fly's climatic restrictions the disease is restricted between the 14th latitude north and the 29th latitude south on the African continent. There are 29 species and subspecies of tsetse, divided into three groups with contrasting ecological and behavioural characteristics. First, the **Morsitans** group of tsetse is found mainly in savannah woodlands across sub-Saharan Africa. These species are highly

mobile and use a combination of visual and olfactory stimuli to locate their hosts. The group includes the more important vectors of animal trypanosomiasis such as *G. pallidipes*, *G. morsitans* subsp., *G. longipennis* and *G. austeni*. Second, the **Palpalis** group comprises species found mainly in riverine woodland of west and central Africa. Species from this group are generally less mobile, being confined to their riverine habitats, and use visual cues, rather than olfactory ones, to locate their hosts. The group includes important vectors of human sleeping sickness such as *G. fuscipes* and *G. palpalis* subsp. Third, the **Fusca** group comprises species typically found in humid forests. Species from this group are generally considered to be less important as a vector, largely because their natural habitat is less used by livestock and people. Nonetheless, some species (e.g., *G. brevipalpis*) have been implicated as significant vectors of animal trypanosomiasis (Torr *et al.*, 2007).

Tsetse flies thrive well at humid temperatures of 25-26⁰C. Their breeding sites in East Africa are dry sandy beaches, under the shade of dense vegetations, under leaf litter in thickets/forests or under lantana or Euphorbia hedges. Most activity of the tsetse is in the early to mid morning and in the late afternoon (Pollock, 1982). In West, and Central Africa, HAT is transmitted by riverine species of tsetse fly (*palpalis* group), which require sustained levels of humidity and prefer dense riverine habitats. These tsetse flies feed preferentially on man, especially where man-fly contact is high, such as water collection and bathing points and river crossings. For the riverine species of tsetse flies, man provides the reservoir of infection, although wild and domestic animals may play a minor role

in particular foci. However, in East Africa, the epidemiology is different in that *T. b. rhodesiense* is transmitted by *G. fuscipes fuscipes* and domestic cattle are the main reservoir (Mbulamberi, 2001).

3.3.2 Ecology of the Busoga Focus

The Busoga focus in southeastern Uganda and western Kenya has long been an important focus of human sleeping sickness. The topography is characterized by a gently undulating slope dropping only 110 m in the 100 km from Lake Victoria to Lake Kyogo. The terrain is a vast network of slow-moving or stagnant streams overgrown with marsh and dense forest. Wild game is no longer abundant in this region, although bushbuck and antelope are occasionally seen; reptiles such as the monitor lizard are plentiful. Domestic cattle, pigs, goats, and dogs are found near to homesteads. The population density varies between 12 and 300 people per km² and agriculture is now mainly subsistence despite the presence of a large cotton-growing cash crop industry prior to 1971. Coffee and subsistence crops are grown on small plots close to homesteads. The old cotton plantations, with their heavy use of insecticides, were poor tsetse fly habitats, but the coffee plantations provide a good habitat for tsetse flies.

The Busoga focus has an undulating terrain consisting of hills intersected by numerous valleys. Several river systems, which drain into Lake Victoria, harbour *Glossina fuscipes*, which is an important vector of HAT, whereas the hills harbour *Glossina pallidipes*, which are excellent vectors for animal trypanosomosis.

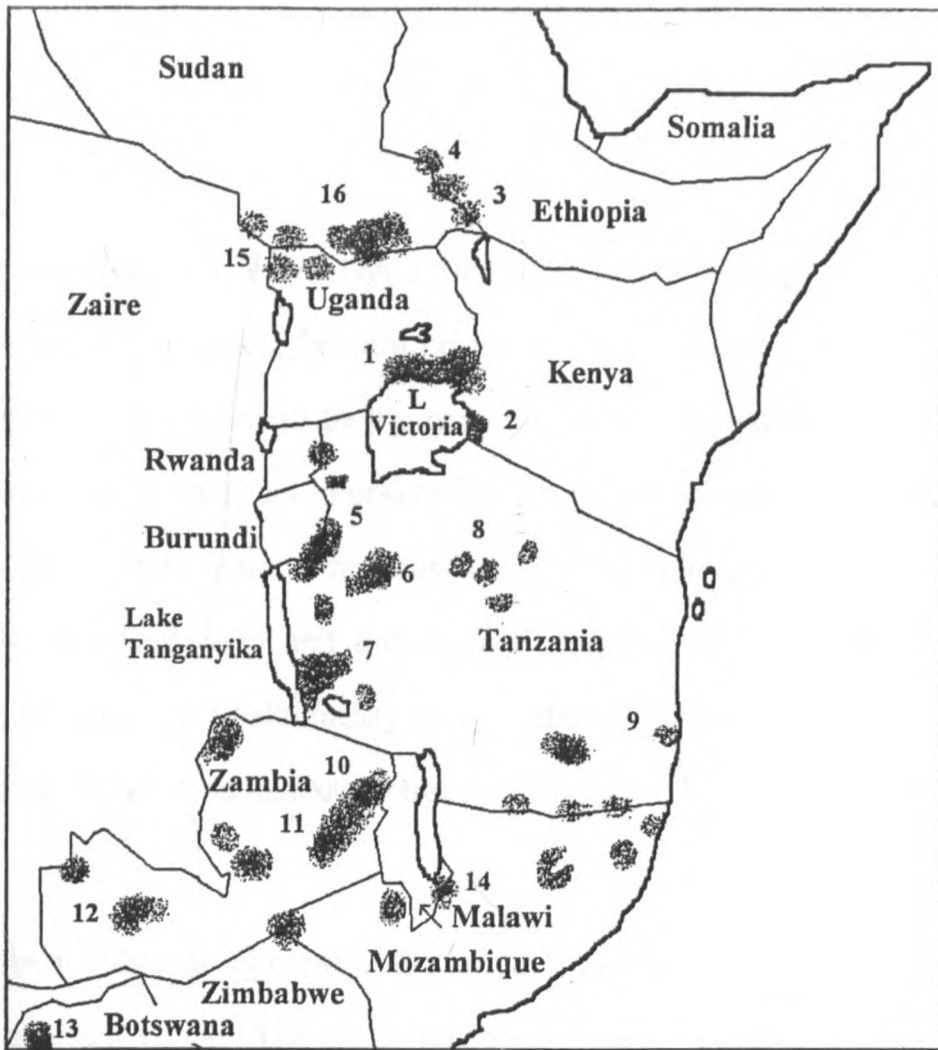
The vegetation in the uncultivated land the area is mainly composed of savannah grassland interspersed with *Lantana camara* bush and *Digithonia spp*, which

form good habitats for tsetse flies. Thick forests and swamps are found along the rivers and streams, which form suitable habitats for *Glossina fuscipes*, a riverine tsetse species that is the main one infesting the areas (Okoth *et al.*, 1991). However, *Glossina pallidipes* is scanty in the area (Magona *et al.*, 1998).

3.3.3 Busia District, Kenya

Busia district, which covers an area of 1,261 km², falls within the Lake Victoria Basin. The altitude varies from 1,130m above sea level on the shores of Lake Victoria to 1,373m above sea level in the central parts. Its mean annual rainfall is 1,500mm. The long rains start in March and continue into May, while the short rains start in August and continue into October. The dry spells are from November through February and June to August. Annual mean maximum temperature ranges between 26⁰C and 30⁰C while the annual mean minimum temperature varies from 14⁰C to 18⁰C. The district is in the Low Midland (LM) zone and is divided into four agro-ecological zones (Kenya, 2001a).

Busia district is divided into six administrative divisions, namely, Budalangi, Butula, Funyula, Matayos, Nambale and Township. The divisions are further divided into 30 locations and 99 sub-locations (Kenya, 2001a). In 1999, the district had a population of 405,388 people of whom 183,514 were the labour force. There are 81,697 households with an average size of 4.5 people. The monthly average household income is 5,141.8 Kenyan shillings (Kenya, 2001a).



Map 3.1: Human Sleeping Sickness Foci in Eastern Africa (Hide, 1999)
 (The area marked as 1 represents the Busoga Focus)

Economic activities: Agriculture is the main economic activity in the district. Almost every household practices some form of agriculture, mainly subsistence farming. Approximately 81.1% of the population works in the agricultural sector. Other economic activities include cross-border trade, fishing and other forms of businesses. The district has two cropping seasons. The main crops grown during the long rains include maize, beans, sorghum, finger-millet and tobacco. Cotton, groundnuts and sweet potatoes are mainly grown during the short rains.

The major livestock species found in the district are cattle, mainly the local zebu with a few improved stock, poultry, sheep, goats and pigs.

Health facilities: The district has a total of 28 health facilities out of which two are government hospitals, five are private nursing homes, 17 are dispensaries and health centres manned by the government and the remaining 4 are either private or mission hospitals. Funyula division is well served with health facilities with a total of eight medical facilities, followed by Nambale with six, Township with five, and Budalangi and Butula each with four health facilities. Matayos division has only one health facility (Kenya, 2001a). The average distance to the nearest health facility is four kilometres.

The level of utilization of most of the health facilities in the district has reduced over the recent years. The major reason is that the government, through the Kenya Finland Primary Health Care Programme, has trained a number of community-based health workers (CBHWs) who are treating patients right at their doorsteps hence reducing the number of patients going to various health centres. In addition, although the introduction of user charges has improved the services offered by these facilities, it has also reduced patient visits to the facilities since some families cannot afford to pay the fees (Kenya, 2001a).

3.3.4 Teso District, Kenya

Teso district is bordered by Bungoma district to the North and South, Busia District to the South and the Republic of Uganda to the West. It has an

approximate area of 559 km². The altitude ranges from 1,300m above sea level in the South to an average of 1,500m in the Central and Northern parts. The annual mean maximum temperature ranges between 26⁰C and 30⁰C while the mean minimum temperature ranges from 14⁰C to 22⁰C. Most parts of the district receive between 1,270mm and 1,790mm mean annual rainfall, though some parts of the district may receive an evenly distributed rainfall of up to 2,000mm. The long rains start in March and continue into May, while the short rains start in August and continue into October. The dry spells are from November through February and June to August (Kenya, 2001b).

The district is divided into four administrative divisions, namely, Amagoro, Angurai, Amukura and Chakol, which are further sub-divided into 30 locations and 82 sub-locations. According to the 1999 census, the district had a human population of 197,395 persons. Chakol division has the highest population density of 427 persons per square kilometre while Amukura has the least with 287 persons per square kilometre. The population density is fairly distributed except in Amukura division where there are large tracts of swampy and marshy areas. There are 38,258 households with an average size of 4.7 people in a household. There are two main rivers in the district, Malaba and Malakisi, with their origin in Mt. Elgon. Numerous streams, most of which are seasonal, originate from the marshy hill bottoms. Marshy swamps are common features in lowlands of the district. Most of them are found in Kwangamor, Kamuriai and Kamolo. These swamps are under-utilised, thus reducing the area of land under

farming. Therefore, there is need to reclaim these vast wetlands mentioned above to improve the productivity of the district (Kenya, 2001b).

Economic activities: The district has an agricultural land capacity of 44,000 hectares on which to produce crop and livestock products. Of the total arable land 27,000 hectares are under cultivation. Livestock farming is one of the major activities in the area. Crops like maize, cotton, potatoes and tobacco are grown in this area (Kenya, 2001b). Sixty-five per cent of the population works in the agricultural sector.

Health facilities: The district has a total of 13 health facilities consisting of one district hospital, four dispensaries, three sub-district hospitals, four health centres and one health unit. The average distance to the nearest health facility is 5km. The KETRI-Alupe Sleeping Sickness Referral Hospital, which is the only HAT referral hospital in Kenya, is situated in this district (Kenya, 2001b).

3.3.5 Bungoma District, Kenya

Bungoma is situated on the southern slopes of Mt. Elgon and is bordered by Uganda to the North-west, Mt. Elgon district to the North, Trans Nzoia district to the North-east, Kakamega district to the East, Lugari district to the South-east and Busia district to the West.

The district has an altitude ranging from 1,000m to 1,500m above sea level. Climatically, the temperatures vary between a mean maximum of 22^oC and 30^oC. Rainfall varies according to altitude while the annual rainfall ranges between 1,270 and 1,780mm per annum. The long rains start in March and continue into

May, while the short rains start in August and continue into October. The dry spells are from November through February and June to August. There are several major rivers that run through the district to either Lake Victoria or L. Kyoga in Uganda: These are Malakisi, Lwakhakha, Khalaba, Chwele, Kimilili, Kuywa, Nzoia and Sio (Kenya, 2001c). According to the 1999 human census, the district had a total population of 704,148 people and 174,838 households.

Economic activities: The district lies in an agriculturally high potential zone with mixed crop and animal production (Kenya, 2001c). Agriculture accounts for over 75% of the local employment. Apart from livestock rearing, the local people also grow both cash and food crops such as maize, coffee, sugarcane, vegetables, sunflower, wheat, beans, tobacco, bananas, millet and potatoes. That agriculture plays a central role in the district's socio-economic life is largely due to the favourable climatic and soil conditions. Out of a total land area of 307,400 hectares, 135,323 hectares are high potential while 97,267 hectares are medium potential. Furthermore, 70% of agricultural land in the district (232,590 hectares) consists of small-holdings of an average size of less than 10 hectares each (Kenya, 2001c).

Health facilities: Health services in the district are provided by three main agencies: Ministry of Health, non-governmental organizations, and mission and other private owners. The district has five hospitals, 14 health centres, 20 dispensaries and six nursing homes. Like elsewhere in Kenya, health services are inadequate in terms of personnel, equipment, drugs and other facilities. Some health facilities are inaccessible whereas in some cases they are not

available altogether. The average distance to the nearest health facility is four kilometres (Kenya, 2001c).

3.3.6 Tororo and Busia Districts, Uganda

Tororo and Busia districts are located in eastern Uganda at the border with Kenya. The two districts cover an area of approximately 3,500 square kilometers. According to the 1991 population census projections for 1998, the human population in these two districts was 628,000 with 95% of the population living in the rural areas (MOF). The population is a mixture of the Nilotic and Bantu ethno-linguistic groups.

Southeastern Uganda is drained by the river Nile and its tributaries between lakes Victoria and Kyoga. The two districts, Busia and Tororo are separated by River Malaba and there are several streams running from Mt.Elgon in the east into lakes Kyoga and Victoria. The climate has two distinct wet (September to November and March to May) and dry (June to August and December to February) seasons. There is a growing pressure on land with people encroaching on the swamps. The riverine species *G.f. fuscipes* is considered to be the main vector for HAT (Okoth, 1986).

Economic activities: The population is composed mainly of subsistence farmers some of whom keep livestock. The main occupation is small-scale mixed farming with subsistence growing of food crops and livestock rearing. Farmers rear cattle, goats, pigs, sheep and poultry. The crops grown include maize, millet, groundnuts, cassava, sweet potatoes and rice.

Health facilities: In Tororo district, there are four hospitals, seven health centres and several private clinics. Two of these hospitals treat HAT, although all of the hospitals and three health centres are equipped to diagnose the disease. Drugs for the treatment of HAT are provided free of charge by WHO to the ministry of health (MOH). The MOH is the sole supplier of these drugs and they can only be administered in prescribed health units (Odiit, 2003).

3.4 Research Design

This study was cross-sectional in nature and adopted both qualitative and quantitative methods of data collection. The study was conducted in three phases, with frequent visits to clarify emerging issues from the data already collected and analysed.

The first phase of the study involved identifying HAT villages, households and individuals. On the basis of these, key informant interviews were conducted with elderly people, opinion leaders and staff at KETRI-Alupe Sleeping Sickness Referral Hospital and the Livestock Health Research Institute (LIRI) in Uganda. The purpose of the interviews with the elderly people was to get information on gray areas in the community's understanding of HAT, how the community reacts towards HAT patients, and the changes that have taken place over time (historical perspectives of HAT). During this time, general information about the communities' perceptions, knowledge and local terms for HAT were gathered. This further helped to refine instruments of data collection, especially for the in-depth and focus group discussions (FGDs). In-depth interviews were conducted

with HAT patients and their caretakers. These interviews included in-depth interviews with HAT patients. The aim of this was to collect information on the effects of HAT on the household and their coping strategies.

The second phase involved conducting a household-based survey using a questionnaire to collect quantitative data. During this phase, quantitative data such as respondents' age, household sizes, household economic indicators, and education levels, among others, were collected. The third phase involved conducting focus group discussions (FGDs). Thus, any emerging issues were captured in the FGDs, which were conducted during the final phase of the study. This method was used to also collect information on the cultural effects of HAT on the community.

3.4.1 Population and Unit of Analysis

The study population included all the households of the five districts. The household was the unit of analysis since it is the basic unit of health care. It plays a vital role in health promotion, in the prevention, early diagnosis and treatment of disease (WHO, 1987). In the household, the former HAT patients/their care-takers or the head of the household/spouse were interviewed.

3.4.2 Sample Size and Sampling Strategy

Due to the nature of the study, random or stratified sampling could not be used as these would have needed a longer time to obtain the former HAT patients. Therefore, the study adopted the purposeful sampling strategy where the existing KETRI and LIRI database on HAT patients formed the sampling frame. The

databases are compiled according to districts, locations, sub-locations and villages, and goes as far back as the 1950s. However, for the purposes of this study, only cases from 1990 to 2002 were considered. During this period of study, there were 208 HAT patients in Kenya while in Uganda, the HAT patients were 921. However, due to time and financial limitations and for purposes of comparison we purposively sampled only the HAT patients who were from the bordering districts of both countries that is Teso and Busia and also Bungoma district of Kenya. In Kenya, I had intended to interview all the 203 HAT patients but had problems tracing some of them due to migration and natural attrition thus I ended up tracing and interviewing 152 former HAT patients. On the Uganda side I purposively sampled only 63 HAT patients who were located in the districts bordering Kenya but only managed to trace and interview 51. In addition, non-HAT patients were also included in the study to give it a balanced view. For each HAT household, two neighbouring households, which were not affected by HAT, were identified and included in the study. However, as the study progressed, due to logistics and problems of tracing the HAT patients, including two neighbouring households in the study became time consuming and thus I resorted to including only one non-HAT affected household for each HAT household. In total I conducted 481 interviews (203 HAT and 278 non-HAT respondents).

3.5 Methods of data collection

There are strengths and weaknesses to any single data collection strategy. In using more than one data collection approach, I was able to combine strengths

and correct some of the deficiencies of any one source of data. I therefore made effective use of triangulation. Denzin (1978) has defined data triangulation as the use of a variety of data sources in a study, for example, interviewing people in different status position or with different points of view, data collection methods and handling data.

The research methods that were used in this study included both qualitative and quantitative techniques of data collection. The qualitative techniques constituted a major component of this study largely because of the nature of issues under investigation. The general aim was to use the kind of tools that allowed respondents the opportunity to respond within their most natural environment. Secondly, given the subject matter, there was need to employ the approaches that made it easier for people to “say it all”. Most of these allowed for spontaneity and unstructured procedures during data collection. However, in order to quantify some of the observations and, therefore, discuss their distribution patterns, some quantitative data was also collected. For purposes of verification, triangulation of emerging issues was done.

3.5.1. Documentary Sources

Secondary data was collected through literature search of both published and unpublished materials from various institutions, including KETRI and its sleeping sickness database. A search on the Internet was also carried out to supplement existing information. This secondary data further enhanced the quality of questions to be used in collecting primary data. This method was, however, a continuous process through out the project life span.

3.5.2 Key Informant Interviews

Key informant interviews involved face-to-face interviews with people who were knowledgeable about the situation of HAT and who occupy influential positions within the study area. The interviews involved historical perspectives of the disease and other questions (Appendix One). They were held with medical personnel at Alupe Sleeping Sickness Referral Hospital and LIRI- hospital, former and current medical personnel within the study sites, retired teachers, elderly members of the community and local leaders. The interviews addressed issues such as knowledge of HAT, its historical background and its consequences as well as the coping strategies.

This method allowed me complete freedom and flexibility to explore a broad subject with the respondents who were encouraged to share their views, experiences, values and information. I was also able to further pursue emerging issues. However, this method of data collection has its limitations. It can be time consuming, and the conversation can become unfocused and wander around in circles as the respondent expresses views on many unrelated issues. Second, information gathered from one respondent may not be comparable with that from another.

3.5.3 In-depth Interviews

This method provided richly detailed explorations of individuals' own perceptions and accounts of their experiences for research on the interaction between attitudes and behaviour. This method allowed for the selection of examples that best illustrated the points to be made and were used as a depth-wise elaboration

of the observation and other methods. The main purpose of this method was to illuminate more on the individual experiences of HAT victims. This covered issues on disease symptoms, diagnosis, treatment and total costs incurred in seeking for treatment. The community's attitudes towards them were also established, including the problems they faced in getting treatment.

3.5.4 Structured Interviews

Towards the beginning of the second phase of the project life, the study adopted the survey research method within which the basic tool for data collection was the structured questionnaire. The general aim was to obtain in figures, the distribution patterns of issues already raised in the in-depth and key informant interviews for purposes of statistical analysis and presentation. Once the sample was selected, the respondents were interviewed using a questionnaire to generate information on the socio-demographic characteristics, general knowledge about HAT and control/treatment strategies. Effects of HAT on the community and the coping strategies of affected families were also established.

This method was used to narrow down on topics of interest and special concern and areas to be covered. The questionnaire contained both 'open-ended" and "close-ended" questions to allow appropriate flexibility of the respondents as well as to restrict them to relevant issues (Appendix Three). A total of 481 respondents were interviewed (203 former HAT patients and 278 non-HAT patients). The main advantage of this method was that all the respondents were asked exactly the same questions in the same order, making it possible to compare the responses. This method can thus succeed in achieving a high level of reliability.

Information gathered by this method was triangulated according to emerging issues and used to design the checklists for the FGDs. The survey was based on structured, pre-tested and coded questionnaires. Research assistants under my supervision assisted in administering the questionnaires.

3.5.5 Focus Group Discussions

The FGDs were held to corroborate, elaborate and consolidate findings already gathered from all the other methods. The main purpose was to grant me an opportunity to re-visit emerging issues without necessarily going back to the same respondents. Controversies and debates were taken up in the FGDs, especially as regards the effects of HAT and the coping strategies employed by HAT affected households. Participants were identified on the basis of having suffered from HAT, guardians/care-takers of former HAT patients and those living close to HAT patients but have never had a case of HAT in their households.

In setting up these groups, attention was paid to homogeneity of the participants to give ample room for free discussions. However, in some areas where there were few HAT patients, mixed FGDs were conducted. The groups consist of members of the community. The discussions focused on what these people knew about HAT and its effects and the attitudes and perceptions of the community to HAT patients. A checklist of questions (Appendix Four) was used to guide these discussions.

Table 3.1 summarizes the number of people who were interviewed by sex, method and district while Map 4.1 and Map 4.2 show the distribution of the HAT patients in western Kenya and southeast Uganda, respectively

Table 3.1: Number of people interviewed by method and country

	Kenya			Uganda			Total
	<i>Male</i>	<i>Female</i>	<i>Mixed</i>	<i>Male</i>	<i>Female</i>	<i>Mixed</i>	
KI	9	2	0	2	2	0	15
IDIs	5	7	0	2	2	0	16
FGD (#)*	5 (31)	5 (33)	5 (37)	1(6)	2 (15)	2 (17)	20
SIs	210	168	0	55	48	0	481

*For FGDs, the total number of participants is given in parenthesis

3.6 Data Management and Analysis

Due to the nature of the methodology employed for this study, data analysis was generally undertaken on a continuous basis and in such a way that subsequent phases benefited from what was foregoing. Thus, the triangulation method was also used in the analysis of data. However, at the end of the data collection process, all information gathered were analysed for purposes of answering the main research problem, namely, the socio-economic and cultural impacts of HAT and the coping strategies of households in the Busoga focus. The general approach was to seek for any emerging patterns in the impacts of HAT on communities living in the Busoga focus.

The quantitative data was sorted by district and the questionnaires numbered from the first to the last. The data was also coded and entered into the computer for storage under MS Access 2000 data management. The data analysis was

carried out using two computer programmes, Nudist (N6) for qualitative data and SPSS for quantitative data.

Because of the very nature of the study, qualitative analysis was emphasised for better understanding of the results. Data from key informant interviews, in-depth interviews and focus group discussions were transcribed, coded and analysed according to emerging issues/themes. From the quantitative data, descriptive statistics was relied upon to obtain in figures the distribution and frequencies of issues and themes that emerged from in-depth and key informant interviews.

3.7. Ethical considerations

Before the interviews were conducted, explanations were given to all the respondents concerning confidentiality. The study ensured the privacy and confidentiality by using codes instead of names to refer to the respondents. Confidentiality and privacy were maintained throughout data collection and dissemination stages. Due to the nature of this work respondents were given a brief of the study topic and expectations in the form of an information sheet (Appendix Five) and were expected to sign a consent form (Appendix Six) to show their willingness to participate in the study. To ensure that the respondents gave information voluntarily, the study employed research assistants from the local communities. Since this was a social science study, it did not in anyway pose any danger to the subjects being interviewed. Ethical clearance was received from the Kenya Medical Research Institute (KEMRI).

CHAPTER FOUR

HEALTH SEEKING BEHAVIOUR IN RELATION TO HUMAN AFRICAN TRYPANOSOMIASIS

4.1. Introduction

This chapter presents the results of the assessment of the knowledge, attitudes and practices (KAP) in relation to HAT and the health seeking behaviour (HSB) of households in the study area. However, before presenting these findings, I give a picture of the magnitude of HAT in the study area by presenting its trends within the period covered by this study.

4.2 Trends of HAT in the Busoga Focus

Figures 4.1 and 4.2 present the distribution of the patients in Kenya and Uganda from 1990 to 2002. On both the Kenyan and Ugandan sides of the Busoga foci, the highest number of patients in each country during that period was recorded in 1990. However, the number of patients recorded on the Kenyan side (95) was lower than that from Uganda (248). The trend on the Kenyan side decreased drastically until 1995 when there were no people recorded as having HAT. However, it began to rise again and peaked in 1999 before decreasing again. The trend throughout the period is also similar in Uganda apart from the gradual decrease and the numbers being higher than in Kenya. The differences in numbers between the two countries could be attributed to possible changes in land cover, cattle movements among others while the peaks could be attributed to political instability, changes in government policies among others leading to collapse of vector control programme (Detailed explanation of the differences is given in chapter 7, Section 7.1).

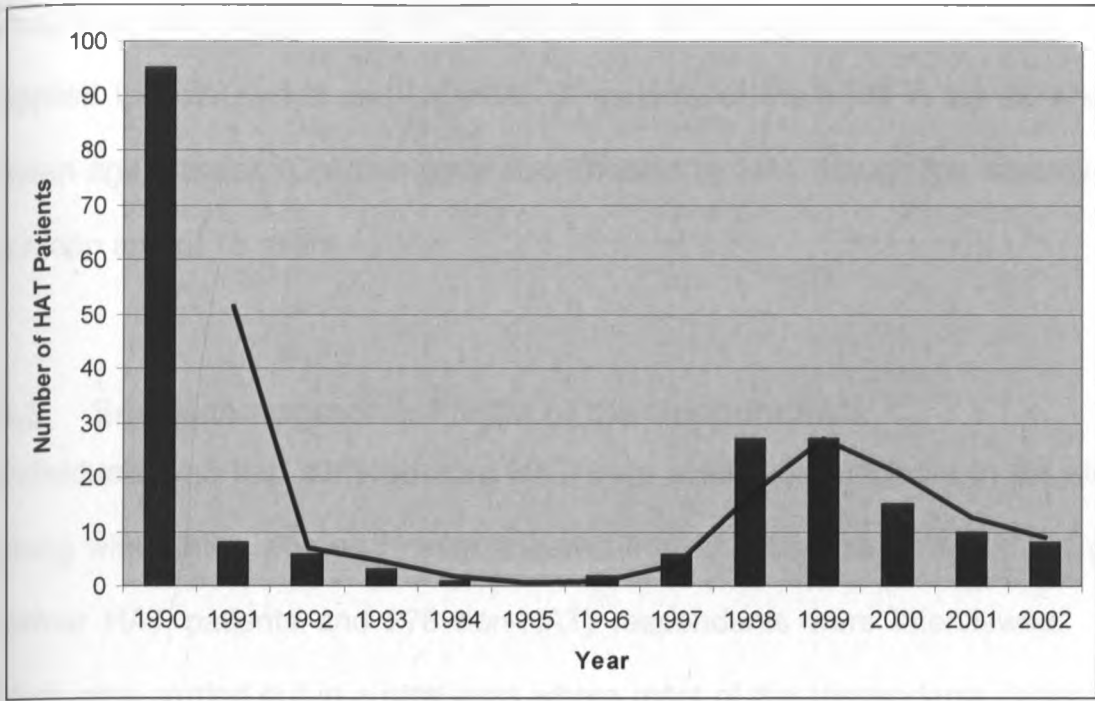


Figure 4.1: Trends of HAT in Kenya, 1990-2002. (Source: HAT database, KETRI)

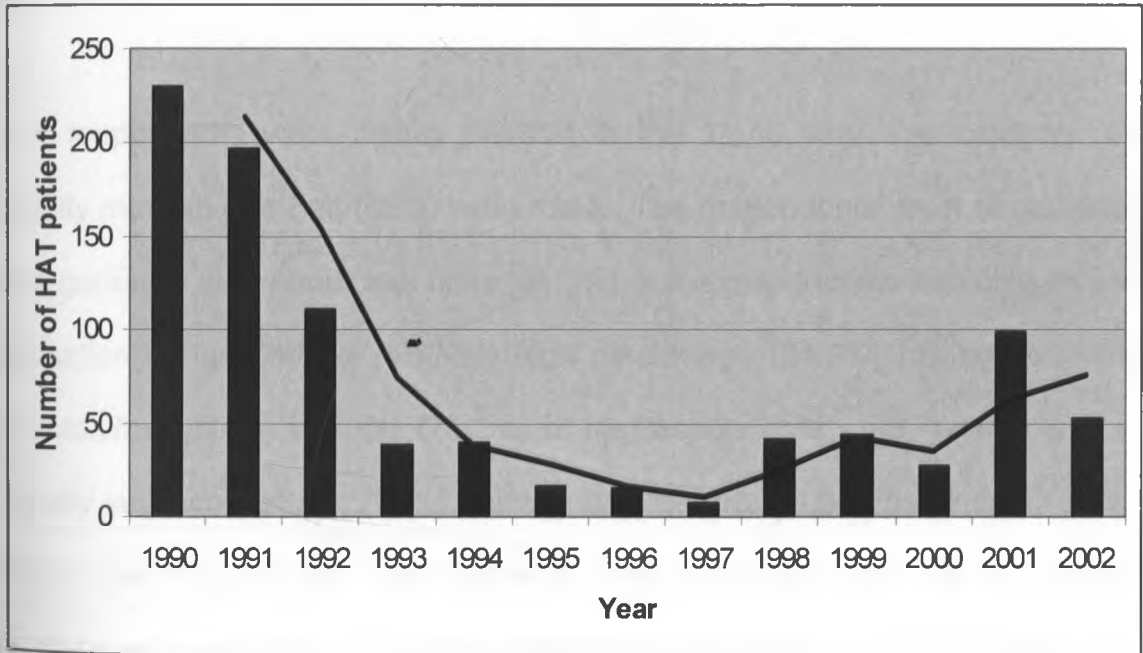


Figure 4.2: Trends of HAT in southeast Uganda, 1990-2002 (Source: Hospital records, LIRI)

Less than half (40%) of the HAT patients in the Busoga foci were female. This applied to both Kenya and Uganda. A majority of them fell in the 25 and 35 mean age bracket. Children were also affected by HAT though the majority had a mean age of 15 years.

4.3 Socio-demographic Profile of the Respondents

Individuals who had suffered from HAT were asked to participate in the study, along with others who had never suffered from the disease. In total, 481 (203 former HAT patients and 278 non-HAT) respondents were interviewed. The study was carried out in a rural area where most of the respondents depend on agriculture as their main source of livelihood. The socio-demographic profile of the respondents is presented in Table 4.1.

The respondents were mainly (46.5%) in the 21-40 year age category and slightly more than a half (55%) were male. The respondents' level of education was generally low. About four fifths (81.3%) of the respondents had only primary education or less with a relatively high percentage (24.3%) having no formal education at all. A majority (78.2%) of the respondents were farmers with an equally large percentage (75%) earning less than Ksh 4,000 per month. About 81% of the respondents were married and only 0.8% and 0.6% were separated or divorced, respectively. The respondents who had been widowed formed 35% of the total respondent population.

Table 4.1: Socio-demographic characteristics of the respondents (N=481)

Variable	Respondents Frequency (%)
Age (Years)	
14-20	39 (8.1)
21-30	105 (21.8)
31-40	119 (24.7)
41-50	83 (17.3)
51-60	66 (13.7)
61-70	51 (10.6)
>71	18 (3.8)
Gender	
Male	265 (55)
Female	216 (45)
Marital status	
Married	389 (80.9)
Single	50 (10.3)
Widowed	35 (7.3)
Separated	4 (0.8)
Divorced	3 (0.6)
Level of Education	
None	117 (24.3)
Primary	274 (57)
Secondary	80 (16.6)
Diploma and higher	10 (2.1)
Occupation	
Farming	376 (78.2)
Business traders	68 (14.1)
Employed	37 (7.7)
Monthly income (Kshs)	
0-3999	360 (75)
4000-7999	75 (15.5)
8000-11,999	29 (6.0)
12,000 and above	17 (3.5)

Source: Survey results

4.3 Knowledge, Perceptions, and Practices in Relation to HAT

The most common disease in the area according to the respondents is malaria (91%). When asked about the most confusing disease in terms of diagnosis and treatment, HIV/AIDS topped the list with 50%, HAT followed with 16%, typhoid (14%) and malaria (12%). HIV/AIDS was termed as the most confusing because it has no known cure and presents symptoms similar to those of many other

diseases. The reason given for HAT being a confusing disease was mainly because it was perceived to be difficult to diagnose since it also presents like many febrile illnesses commonly found in the study areas. Malaria was highly ranked by most (91.8%) respondents as the easiest disease to treat since the drugs to treat it are cheap and easily available while 81% cited HIV/AIDS as the most difficult disease to treat mainly because there is no known cure for it.

Almost all the respondents (97%) had heard about HAT but only about 42% had experienced the disease in their family. Most (94.2%) of them knew that it is caused by the tsetse fly but a few others did not know its cause. Witchcraft, heredity and blood transfusion were also some of the other mentioned causes of the disease. In terms of the local names used to refer to HAT, the Iteso call it *adekanakajo*, the Abasamia refer to it as *ebulwaye bwa ndolo* or *obulwaye wa embuko*, while the Japadhola refer to it as *kudni*, *tuo anindo*, or *tuo ma mongota*. All these names apart from *kudni* and *tuo ma mongota* literally translate to “sleeping sickness” or the “disease that causes one to sleep”. *Kudni* means worms while *tuo ma mongota* means the disease of tsetse flies. *Mongota* is a name used both by the Iteso and Japadhola to refer to the tsetse fly while the Abaluyia refer to it as *embuko* or *mabuko*.

Most of the former HAT patients reported that 30% of the community members thought that their illness was caused by witchcraft, 21.2% of them related it to the tsetse fly, and 34.5% cited HIV/AIDS while 14.3% mentioned other varied causes such as malaria, malnutrition, neglect by spouse and emotional trauma caused by being discontinued from college education.

The main symptoms of the disease as mentioned by the respondents include sleep (69%), fatigue (60%), feeling cold (40%), loss of appetite (28%), body swellings (6%) and miscarriage in pregnant women (1%). However, in the focus group discussions, mental disturbance, weight loss, itching, rashes, joint pains, headache, stiff neck, nausea, partial blindness, stomach-ache and paleness of skin colour were mentioned. Change in texture (soft and straight as opposed to hard and curly) and colour of hair were also mentioned. There was consensus among FGD participants on the similarities of HAT and AIDS. They were thus in agreement with the following statement from one of them whose son suffered from HAT:

Body emaciation just like AIDS. People at first thought the disease was AIDS. We only came to discover it is not AIDS because my son as young as he was had the same signs as those of AIDS. There was no possibility of him being infected since us his parents are not victims at all.

(Male FGD, Teso, Uganda)

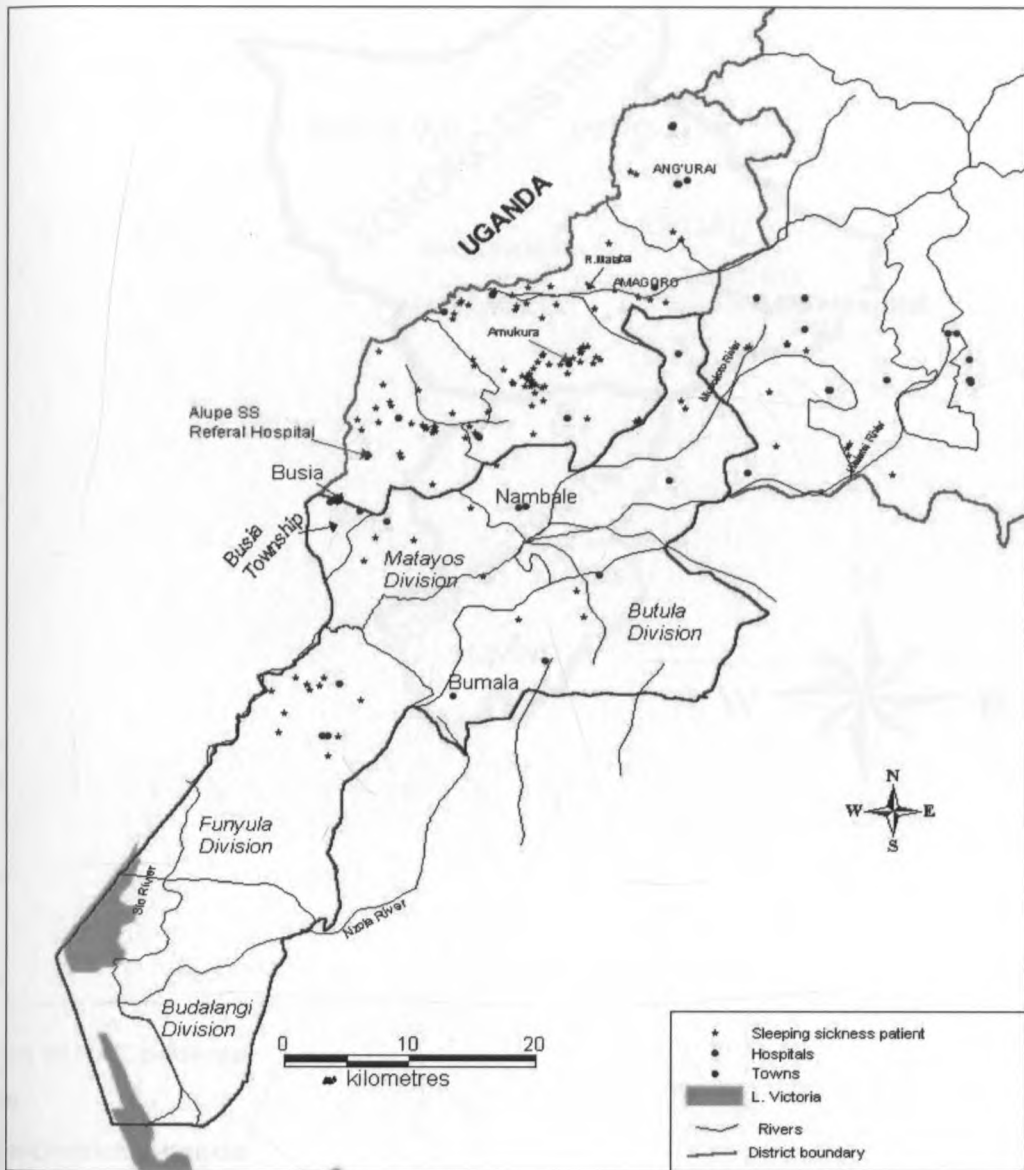
About 68% of the respondents said that all people were at risk of contracting HAT irrespective of age because the tsetse fly can fly anywhere and bites indiscriminately. Both genders were equally at risk of contracting HAT as indicated by 86.7% of the respondents. The activities reported to be exposing a person to HAT were herding (46.8%), bathing in the river, lake or streams (24.1%), fishing (11.9%) and others (17.2%). The "others" category included activities like fetching firewood, grass (for thatching) or water, cultivating the farms and charcoal burning.

Most (99%) of the respondents believe that diagnosis and treatment could only be done in a hospital. Others (0.4%) and another equal percentage of the

respondents reported that it can be done by a herbalist and through prayers, respectively, while 0.2% believed that a diviner can diagnose and treat the disease. Many (95%) of the respondents have to walk between one to ten kilometres to reach their nearest health centre yet only 14% reported that these hospitals are well equipped to handle HAT diagnosis and treatment, meaning that most of the health facilities within a 10 kilometre radius of the respondents were not well equipped to handle HAT. In total 42.2% of the respondents had experienced the disease in their family. The distribution of the HAT patients is shown in Maps 4.1 and 4.2.

Immediate family members (90.6%) were identified as the main care-givers for HAT patients, followed by the community (6.4%) and the extended family (3%). A large proportion of the respondents (70.5%) reported that they do not participate in any form of HAT control.

Eighty-five per cent of the respondents indicated that they had received some information on HAT. About 45% of the respondents cited health personnel as their source of information on HAT, 27.4% cited relatives, 16% *barazas* and 11% cited the radio. The information communicated to the respondents included information on: signs (33.1%), treatment (30.9%), control/prevention (26.2%), and a combination of all the mentioned categories (9.8%).



Map 4.1: Distribution of HAT Patients in Western Kenya, 1990-2002 (Source: Survey Results).



- Homes of HAT patients
- Towns
- ▭ Busia District, Uganda
- ▭ Tororo District, Uganda

Map 4.2: Distribution of HAT Patients in Southeastern Uganda, 1990-2002
 (Source: Survey Results).

4.5 Health-seeking Behaviour

The health seeking behaviour of the former HAT patients and their caretakers is summarized in Table 4.2.

Table 4.2: Health seeking behaviour in relation to HAT (N= 203)

Variable	Respondents Frequency (%)
<i>Type of option first sought</i>	
Over the counter drugs	98 (48.2)
Health facility (Non- HAT)	59 (29.1)
Traditional medicine	23 (11.3)
HAT hospital	16 (7.9)
Diviner	6 (2.9)
Others (Prayer)	1 (0.5)
<i>Duration taken with illness before Correct diagnosis and treatment</i>	
<1 month	47 (23.2)
1 – 2 months	52 (25.6)
2 – 4 months	41 (20.2)
>4 months	63 (31)
<i>No. of trials with different options before correct diagnosis and treatment</i>	
1	19 (9.4)
2	42 (20.7)
3	80 (39.4)
4	47 (23.1)
>4	15 (7.4)
<i>Presentation at HAT hospital was encouraged by:</i>	
Nobody (self-motivated)	6 (3)
Relative	67 (33)
Neighbour	23 (11.3)
Medical personnel	99 (48.7)
Local leader	8 (4)

Source: Survey results

More than a half of the HAT patients had stayed for more than two months before correct diagnosis was done while less than a quarter had stayed for less than one month. Treatment seeking, from the time of onset of disease to correct diagnosis, showed a tendency of almost all the respondents utilizing more than one option for treatment. The health centre was utilized by 29.1% of the people

as a first option, self-treatment using over-the-counter (OTC) drugs was done by 48.2%, traditional medicine was used by 11.3% while 2.9% of the respondents reported having utilized the services of a diviner, and one (0.5%) respondent chose prayer as a first option (see Table 4.2).

On first presentation to the health centres, most (92%) of the HAT patients were diagnosed and treated for malaria. On subsequent visits, the diagnosis and treatment was still for malaria if not typhoid. Many patients tried seeking correct treatment up to four times or more before getting accurate diagnosis and treatment for HAT. Misdiagnosis was therefore very common, forcing most (76.8%) patients to take more than one month before being correctly diagnosed and treated for HAT and thus spending a lot of money. The following case studies exemplify the different treatment options sought before correct diagnosis of the disease was made:

Case study 1

Mother of a three and a half year old HAT patient narrating her story:

It started with malaria-like symptoms and signs then I took him to Dispensary A where he was treated for malaria. The disease worsened and I took him to Hospital B and by this time, his hair had changed its texture. He was again treated for malaria and we returned home. The situation again worsened at home and I took him back to hospital B where he was admitted for one week and three days as he was put on malaria treatment. His condition did not improve so we went back home with the baby in critical condition. At home the family members started relating the disease to witchcraft and called a diviner to come home and treat the boy. He did not recover and again I took him back to hospital B and he was again admitted for one week and treated for malaria. The child could not talk, and had lost appetite. When the situation worsened, I returned home and stayed for about one month trying traditional medicine as the father was trying various ways of getting treatment. When there was no improvement, my husband got annoyed and disappeared from home leaving me with the sick child alone. He now believed what the community members were saying, that the child might be suffering from HIV/AIDS since they were also suspecting that I had HIV/AIDS. One day I locked the child in the house and went to inform my brother about the

problem. The following day he came and found the child in a coma and even started doubting whether he would survive. We took the child to hospital C which specializes in HAT treatment, and the child was diagnosed as having HAT and admitted for one month and two weeks. **(Female, 32yrs, Teso, Kenya)**

Case study 2

A young man who suffered from HAT:

*Initially it started as an ordinary sickness when I began having stomachache. My parents opted to buy me stomachache tablets, which I took for some days but my condition did not improve. They decided to take me to Hospital A where I was diagnosed as being very dehydrated. I was put on a drip but my condition did not improve. My parents then took me to a private clinic B where I was diagnosed as being very dehydrated and anaemic. I was therefore admitted for one week but my condition did not improve. The private clinic B staff gave up on my condition and suggested that maybe I had been bewitched. My parent therefore carried me back home and consulted different diviners who came home to try and save me in vain. Having failed for two days, they went back to their country. A neighbour who had come across a HAT screening team in one of the centres described to them my signs and they offered to accompany her to my home because I was totally unable to even walk. They came and tested me and diagnosed my condition to be HAT. I was therefore referred to the Kenya HAT referral hospital and admitted. **(Male, 30yrs, Bungoma, Kenya)***

Case study 3

Old woman who suffered from HAT in 2002:

When I became sick, the symptoms were just like those of malaria: fever, tiredness, joint pains, coughing and diarrhoea. My family bought me drugs for treating malaria but they did not work. I continued feeling bad and so they took me to the health centre, which also treated me for malaria. Again there was no change so I went to the main hospital where again I was treated for malaria without any improvement. My family decided to take me to a private clinic where I was admitted for one week since I was so weak and dehydrated. There was still no improvement and so my husband brought a musimo (traditional healer) who cut my body and put herbs to cure this strange illness to no avail. He paid a total of Ksh 1,400. After a few days, my condition had not improved so a second musimo was brought but still this did not help me. We tried a third, fourth and fifth musimo to no avail. People started saying that I had contracted HIV. I also wondered where an old woman like me would have got HIV. Finally after about five months, a relative suggested that my family take me to LIRI and that is when they diagnosed me to be suffering from HAT.

(Female, 60yrs, Teso, Uganda)

CHAPTER FIVE
THE SOCIO-CULTURAL IMPACTS OF HUMAN AFRICAN
TRYPANOSOMIASIS ON HOUSEHOLDS

5.1 Introduction

This chapter reports the results of the questionnaire interview, in-depth interviews, focus group discussions, and key informant interviews on the socio-cultural impacts of HAT. An analysis of the respondents' perceptions of the main effects of HAT on the patient and their families showed behaviour change, family/marital conflicts, and emotional burdens to be extensive. Relations with others and overall quality of life were also reported as strongly affected. Stigma (affecting both the family and the person) and diminished self-esteem were widespread.

5.2 Psychosomatic Effects of HAT on the Patients

The disease had varied socio-cultural impacts on the sick person and their families. However, the psychosomatic effects of the disease on a sick person caused most of these impacts. It is therefore necessary to first examine these somatic impacts (Table 5.1) before looking at the consequences.

Table 5.1: Psychosomatic Impacts of HAT (N= 203)

Variable	Respondents Frequency (%)
Loss of weight	92 (45.3)
Body weakness	87 (42.9)
Mental problems	40(19.7)
Reduced libido	25 (12.3)
Death	11 (5.4)

Note:The total sum of responses do not add up to 100 because this was a multiple response question

Source: Survey results

5.2.1 Body Weakness

Body weakness was common to all the respondents, though in the survey, only a few who had suffered from HAT mentioned it. Normally, a disease affects one's physical body and this in turn affects other aspects of the person's daily life. Information obtained from in-depth interviews revealed that the disease made most patients weak to the extent that they could not walk or perform any duties like cultivating of *shambas* or even taking a bath. A 32-year old woman who had suffered from HAT described it as follows:

My body became weak and emaciated. I could not walk and perform basic tasks, so the community could not believe the disease could be treated. Some members in the family especially my husband became worried of my survival since they tried several ways of seeking my treatment but all these efforts were not successful. I could not do basic tasks when I was suffering such as cooking, bathing or even digging.

(Female, 32yrs, Teso, Uganda)

Women who had never suffered from HAT concurred with these effects of HAT and put it as follows, *"Some patients couldn't walk, couldn't eat, couldn't perform basic tasks like bathing and had to be fed like small babies."* **(Non-HAT female FGD, Teso, Kenya)**

5.2.2 Reduced Libido

The disease was also reported to affect the reproductive functions of both men and women. Men were reported to be affected through reduced libido as depicted in the following statement made by a young single respondent of 21-years, *"Sexually I am not aroused. I can't have girlfriends for fear of them finding out that I am sexually dead."* **(Male, 21yrs, Teso, Kenya)**

In another case, a 36-year old married man who has been having a problem with getting an erection since he became ill described his frustration using the following words:

I sleep with my wife in one bed but have no sex because of no erection. Though my mind desires to I just can't. I have been going back for review at the hospital but it still has not improved much. However, I try sometimes and it works but very rarely. (Male, 36yrs, Teso, Kenya)

Among the respondents there were some who did not experience any sexual problems but those who did still bore these effects even at the time of the interview. In a FGD for men who had suffered from HAT, there was consensus that HAT makes some men so weak sexually that they cannot attend to the sexual needs of their wives regularly and some have even failed to impregnate their wives.

5.2.3 Miscarriage

Women also had a share of effects on their reproductive functions and this was mostly related to those who were pregnant at the time of illness. No one mentioned miscarriage or "disappearance" of a pregnancy as an effect on an individual during the questionnaire interview. However, this came up during the in-depth interviews and in the FGDs. The discussants in the FGDs for former HAT patients were all in agreement that miscarriage was common among pregnant women. One 40-year old teacher in one of the villages had the following to say during a key informant interview, when asked about the effects of the disease on an individual.

My sister died. In fact she was pregnant at that time; she miscarried in hospital and was unconscious when all this happened. This illness also affects breast-feeding mothers because milk production goes down. (Female, 34yrs, Teso, Kenya)

Much as miscarriages were said to be common among HAT patients, with one woman claiming that her pregnancy just “disappeared”, another woman who was a spouse to a former HAT patient also claimed that after the husband recovered, she conceived and the pregnancy disappeared. Although probing was done on the reality of the “disappeared” pregnancies, it was not exactly clear what happened. The following was part of a transcription of an interview with a 38-year old spouse to a former HAT patient who claimed that her pregnancy “disappeared”.

SB: *Have you encountered any problem in having children after your husband's treatment?*

Interviewee: *When my husband was sick I was pregnant but I had a still birth.*

SB: *Was it when your husband was in hospital or at home?*

Interviewee: *He had come back from the hospital. The body of the foetus was like fire had burned it. Many parts had blisters full of water. It never cried. We buried it. I later became pregnant again and when the pregnancy was eight months the baby disappeared up to now.*

SB: *Did it come out?*

Interviewee: *No it didn't come out, I don't know where it went. It disappeared at 8 months.*

SB: *The pregnancy was 8 months?*

Interviewee: *Yes after he had come back from Alupe is when I got pregnant. The pregnancy was 8 months then it disappeared.*

SB: *Which year was that?*

Interviewee: *1997*

SB: *1997 is when you got the pregnancy that disappeared?*

Interviewee: *Yes*

SB: *what about the one you gave birth to and had died?*

Interviewee: *The one I gave birth to when my husband was sick?*

SB: *Yes. Which year did you get that one?*

Interviewee: *it was in 1997.*

SB: *1997? Even this other one was also 1997?*

Interviewee: *Which one? The one that disappeared was 1998, around April 1998, after 8 months it disappeared up to now no child.*

SB: *Did you go to the hospital to confirm if there was a baby in the stomach?*

Interviewee: Yes I went and the doctors confirmed there was a baby I used to go to the clinic several times and this time the nurse told me I don't have a baby. I was surprised on what had happened. What could have swallowed my baby in the stomach? I visited the clinic twice during the pregnancy and the baby was there. Even the local midwives

told me the baby was lying well. I even went to the lab, I was tested and the pregnancy was ok.

SB: Later did you ask what happened to the child or what did you do?

Interviewee: I didn't ask, I just told my husband and did nothing about it till now.

SB: Why haven't you even gone back to the hospital to ask?

Interviewee: I did not know what they will say and I feared going because they might not understand. It is very strange for me too.

SB: Since then, have you ever become pregnant again?

Interviewee: No. It even stopped my periods since then.

SB: Do you use any family planning method?

Interviewee: No, I don't.

SB: When the child disappear had you milk in your breast?

Interviewee: Yes.

SB: Have you ever heard about this before else where?

Interviewee: No, it is just me around here.

(Female, 38yrs, Teso, Kenya)

Note: SB refers to the initials of the researcher

Some HAT women patients carried their pregnancies to term but as reported in the FGDs, ended up giving birth to children who they claimed were a bit mentally disturbed.

5.2.4 Mental Problems

Mental illness was only mentioned by about 20% of the respondents as an effect on HAT patients. However, in the FGDs and in-depth interviews, many more patients were reported to have undergone mental disturbance or erratic behaviour during the course of the illness. Others were reported to still exhibit this erratic behaviour even after treatment. During an interview with a village elder, when probed further on how he would tell that one was mentally disturbed, he had the following to say: "These people would smear their faeces on their

bodies if no one is around. They could even eat the faeces.” (Male, 62yrs, Teso, Uganda)

In a FGD with former male HAT patients, mental disturbance was emphasised as one of the adverse effects of the disease. One participant even reported how he was put in charge of a neighbour who had gone mad. The rest of the discussants agreed with him.

This neighbour of mine went mad when we were still in hospital. When set free, he would try to cut the bed wires using his teeth; he used to be tied onto his bed. I was given the duty of looking after him, he at times threw away clothes and walked naked, I would persuade him to put on clothes.
(HAT-Male FGD, Teso, Kenya)

A nurse at the HAT referral hospital was interviewed to shed more light on the mental effect of the disease. She stated that mental disturbance and erratic behaviour were a common characteristic of the HAT patients especially those who were diagnosed as having reached the late stage of the disease. Additionally, she reported that in the initial stages of the disease, the parasites are found circulating in the blood and this is considered the first stage of the disease. The late stage, she added, occurs when the parasites cross the blood brain barrier and enter the central nervous system (CNS). It is at this stage that patients become mentally disturbed or, sometimes, go into a coma. According to her, the drugs used to treat HAT, especially melarsoprol, which is used to treat the late stage of the disease, can also cause erratic behaviour since it is an arsenical-based drug. However, she assured that most of the HAT patients usually fully recover after treatment.

During the course of the research we came across ten former patients who never fully recovered from the mental effects of the disease even after treatment. Surprisingly, all these patients were boys and were affected when they were young yet we also have cases of girls who were affected at a young age without the reported mental problems. The eldest of them was 14-years while the youngest was two and half years old at the time of infection. In-depth discussions with their parents revealed that two of them had since died under circumstances related to their mental state. Two parents reported that sometimes their children roam about and disappear from home even for weeks. The transcription from an in-depth discussion with a mother to one of these children, who was affected in 1999 when he was 12-years old, depicts what the boy goes through and the frustration that she as a parent encounters.

SB: *When you brought him home was he able to walk?*

Interviewee: *No he could not even sit on his own and was still unconscious. We put him on special diet and he regained his body energy and so we took him back to school.*

SB: *In which class was he when he became ill?*

Interviewee: *Class two.*

SB: *Did he repeat class two?*

Interviewee: *Yes and in term one he did well and was number 7 but in term two his performance went down. In term two he developed epilepsy and stopped school. Other children were not comfortable with him and teachers advised me to keep him at home as I try to treat him, but up to now I have not succeeded in treating his epilepsy.*

SB: *Is he still epileptic?*

Interviewee: *Yes, in a day he can fall seven times, he can be disturbed for two weeks and won't walk or eat. In some months he can last two weeks without falling down.*

SB: *Does he feel pain anywhere in his body?*

Interviewee: *He still complains of headaches and stomachaches.*

SB: *It took him how long to at least help you with some minor duties at home?*

Interviewee: *He does not work at all. What he does is just roaming about and at times goes very far where we can't get him. He is a bit*

mentally disturbed also. He only does what his mind drives him to. There is a time he got lost for about a month.

SB: *What problems did you get when he disappeared?*

Interviewee: *It was quite difficult to trace him. We had also thought he might have died. I was worried.*

SB: *When you ask him why he disappeared what does he say?*

Interviewee: *He does not know anything. He said he saw a good road and decided to walk along it all the way to Amukura.*

(Female, 36yrs, Teso, Kenya)

5.3 Socio-cultural Consequences of HAT on the Patient

The socio-cultural consequences as depicted in Table 5.2 resulted from the physical effects of the disease on the patient.

Table 5.2: Socio-cultural Consequences of HAT on the Patient (N= 203)

Variable	Respondents Frequency (%)
Stigma	49 (24.1)
Neglect of homestead	49 (24.1)
Absenteeism in school	37 (18.2)
Emotional burden/trauma	16 (7.9)
Family and marital conflict	10 (4.9)

Note: The total sum of responses do not add up to 100 because this was a multiple response question

Source: survey results

5.3.1 Emotional Burden

Emotional trauma was commonly reported among most of the HAT patients as portrayed in the group discussions and in-depth interviews. The emotional trauma included thinking about one's children and how they would cope with life in the absence of their parents, one's subsistence activities and how these activities would stall, and others thought they were suffering from HIV/AIDS. A former HAT patient stated the following in an in-depth interview: *"I was really worried of my children whom I had left at home for their father was ever drunk and as such my children only depended on my mother in law who was an old woman."* **(Female, 48yrs, Busia, Uganda).** Yet another form of emotional

trauma was loneliness as exemplified in the following statement by a 29-year old former patient: *“One really feels lonely as one lacks company most of the time because the rest of the people are always busy working in different places and as such the patient feels he or she is deserted.”* **(Male, 29yrs, Teso, Uganda)**

Fear of not being able to have children was another form of emotional trauma experienced by the HAT patients as exemplified in the following statement by an old former HAT patient:

I was worried if I would be able to have a baby with my wife because when I was taken ill, my condition was bad and I had also stayed in hospital for a long time. Luckily, we were blessed with a baby girl, one I had desired very much.
(Male, 26yrs, Teso, Kenya)

Other emotional effects as reported in the FGDs with former HAT patients included fear of dying, fear of being injected or done for lumbar puncture and fear of running mad as some of their fellow village mates.

5.3.2 Stigma

The former HAT patients also reported that they experienced a lot of stigma, some from within the family, while others from the community. The stigma as reported by an Assistant chief of Kaliwa sub-location in Teso district revealed that stigma was rampant in the initial years when the disease had just emerged in the village in the early nineties. He further explained that since many people did not know about it, the rest of the community would claim that a HAT patient had HIV/AIDS and this was also perpetuated by similarity in the symptoms of the two diseases. Others thought the patients were bewitched and thus feared getting into contact with them. The erratic behaviour and mental disturbance displayed

by some of the patients was also a factor in perpetuating stigma as reported by the chief. All the discussants in the FGDs involving former HAT patients and their guardians were in agreement that most HAT patients were stigmatized to the extent that some community members would even refuse to greet them or visit their homes. Some respondents reported that sometimes when their friends were passing by their homes and saw them sitting outside, they would even opt to change the route they were using so as not to have to pass near the patient's home. The extent of the stigma can be seen in this statement by a former HAT patient:

My extended family deserted me and would call me a mad man. Even the rest of the community deserted me and stayed away saying that I was bewitched and had evil spirits. They even kept away and stopped passing through our home. When they passed by the gate, they would pass quickly while looking the other way, fearing that they would also get the evil spirits from me and they used to call me a mad man.

(Male, 19yrs, Busia, Uganda)

Stigmatization did not only come from outside the family but also from within as one 45-year old HAT patient from Busia district in Kenya explained: *"My husband couldn't even share a meal with me. It was only my children who used to take care of me."* The HAT patients were stigmatized both as individuals and as a group as reported by one of the key informants who was an assistant chief of Kaliwa sub-location in Teso district which was affected by a HAT epidemic. He said the situation was so bad that people from other villages did not want to visit anyone in Apatit, greet them or transact any business with them, especially sale of livestock. They believed that the disease was "the Apatit disease" and thus did not want to be associated with anyone from Apatit. The stigma as reported by the key informants was even present in church where people would shun

anyone from Apatit sub-location and not even shake hands with them. Another kind of stigma was self-created as a result of some embarrassing symptoms of the disease as reported in the following statement: *“This disease made me isolate myself from others as my stomach was swollen with a lot of gas and would rumble frequently; this really scared me from associating with my friends as I thought they would laugh at me.”* (Male, 33yrs, Teso, Kenya)

5.3.3 Absenteeism from School

About 18% of the respondents reported that absenteeism from school was common among children who were affected by HAT. This was because they were either too weak to go to school or had to spend a lot of time seeking treatment and thus had to miss going to school as reflected in the following transcription from an in-depth discussion with a boy who was affected when he was 11 years old:

SB: *How did the disease affect your schooling?*

Interviewee: *I went back to school but then after treatment, which forced me to stay in hospital for about six weeks, my academic performance went down. I used to be among the top five but I dropped to among the last in class.*

SB: *What about during the illness?*

Interviewee: *During the illness I stopped going to school for some time because I wasn't feeling well and had to go to hospital frequently.*

(Male, 23yrs, Teso, Kenya)

One of the symptoms of the disease, sleep, also caused one 14-year old patient, to stop going to school because his classmates would laugh at him whenever he slept in class, while the teachers would beat him claiming that he had spent the night in a disco. This affected him and as a result, he decided to stop going to school for fear of being laughed at or beaten by the teachers. A parent to one of the boys who was also affected by HAT revealed the same during an in-depth

interview when he reported that his son would run away from school for fear of being teased by other children, or being punished by the teachers for sleeping during class time.

5.3.4 Death

Death, an irreversible effect of HAT, was reported by about 6% of the respondents in the structured interview. Further probing with a key informant from the HAT hospital reported that during the period under review by this study, that is 1990 to 2002, about 42 people died in the Busoga focus while undergoing treatment. She further claimed that many others may have died in the villages before being diagnosed with the disease. This transcription from an in-depth discussion with one of the village elders further demonstrates this:

SB: *Did many people die before tsetse was discovered?*

Interviewee: *Yes many of them died.*

SB: *About how many people died?*

Interviewee: *In our group who were taken to Alupe four people died in hospital. One old man here died at home due to people's carelessness. He had every symptom of tsetse but people thought he had been bewitched. Even the assistant chief's wife also died; in fact she was pregnant at that time.*

SB: *What happened to the baby?*

Interviewee: *The doctors tried to save the baby but it also died.*

(Male, 68yrs, Teso, Kenya)

The results presented reveal that the disease had various impacts on individuals. However, since individuals do not live in a vacuum but in families, the study also reviewed the impacts of the disease on affected families and the findings are presented in the following sub-section.

5.4 Consequences of HAT on the Family

Household members of HAT patients were equally affected by the incidence of HAT as shown in Table 5.3.

Table 5.3: Effects of HAT on the Household (N= 203)

Variable	Respondents Frequency (%)
Work problems	166 (81.8)
Emotional burden	114 (56.2)
Food insecurity	63 (31)
Stigma	50 (24.6)
Missed school	43 (21.2)
Reversal of roles	23 (11.3)
Marital and family conflict	15 (7.4)
Death	3 (1.5)

Note: The total sum of responses do not add up to 100 because this was a multiple response question

Source: Survey results

5.4.1 Work Problems

Work problems in the form of disruption of subsistence activities were reported by many (82%) respondents. This was elaborated in the FGDs when the participants agreed that diseases, especially those like HAT that take long to diagnose, disrupt the normal work activities of other family members. They explained this by reporting that when a family member is sick, the rest of the family members have to slow down on their normal daily activities as they spend time looking after the patient, taking the patient to hospital to seek treatment or simply worrying about the health and fate of the patient. Women who had never been affected by HAT made the following observation on how HAT disrupted the normal duties of the family members:

Even after returning home from hospital, family members had a difficult time because they had to help them walk, eat, bathe and look for food for both the patient and themselves. Thus they couldn't concentrate on their normal work.

(Non-HAT females FGD, Teso, Uganda)

A 34-year old woman who suffered from HAT sympathized with her husband whose normal work schedule was disrupted as captured in her following statement during an in-depth discussion:

When I was taken ill, my husband couldn't concentrate on his job since he had to travel quite a long distance every morning to come and see me in hospital, and at the same time see to the welfare of the children despite the fact that he would have to travel far.

(Female, 34yrs, Teso, Kenya)

5.4.2 Emotional Trauma

Slightly more than a half (56%) of the respondents reported emotional trauma as a problem faced by family members. Children missed parental love as reported in the FGDs. The following quotations from in-depth discussions express how the family members of HAT patients were emotionally affected:

My parents and siblings were quite saddened by my illness. Teachers of school were grieving for the loss of a bright student because I dropped out of school.

(Male, 12 yrs, Teso, Kenya)

Most family members such as my husband became worried of my survival hence they became desperate and they could not perform their activities.

(Female, 25yrs, Busia, Kenya)

I also became worried of my children who were motherless. They went hungry due to lack of food as they had nobody to provide for them. This really annoyed me very much and almost made me curse God for having caused the illness.

(Female, 32yrs, Teso, Uganda)

My body became weak and emaciated. I could not walk and perform basic tasks, so the community could not believe the disease could be treated. Some members in the family especially my husband became worried of my survival since they tried several ways of seeking my treatment but all these efforts were not successful.

(Female, 42yrs, Teso, Kenya)

Children in school lost concentration as they got worried of the parent's recovery..

(Male, 68yrs, Teso, Kenya)

Worry and fear also arose when family members would accuse others for having bewitched the sick person as described by a 21-year old HAT patient:

My mother and her co-wife clashed over the issue of witchcraft because my real mother believed that my step-mother had bewitched me. Therefore, by the time I came back home from hospital, I found that they were at loggerheads. This was very disturbing and eventually my step-mother ran away from my father, cursing our family. We became very worried thinking she would do something harmful to our family.

(Male, 21yrs, Teso, Kenya)

The community members also experienced emotional trauma. This was especially experienced in those communities where many people were affected.

A key informant when probed further on how the community was affected by the HAT outbreak had the following to say:

A cloud of sadness hung over the entire village. People became sad, people couldn't work because every body in the village was in a state of desperation, most children left schooling as they worried over their parents' recovery. People got worried but they couldn't do anything. In this village many people had fallen sick so people wondered what had gone wrong. Here alone in Kateleny'ang we were 60 sick people!

(Male, 38yrs, Teso, Kenya)

Death resulting from HAT also caused emotional trauma as family members of the departed were reported to be full of grief and sorrow. Many family members were emotionally affected as demonstrated in the above excerpts. Other emotional burdens arose as a result of marital conflict as described in the following sub-section.

5.4.3 Conflicts

Marital/family conflict: Seven per cent of the respondents reported experiencing marital and family conflict as a result of HAT. Some conflicts arose as a result of erratic behaviour in the HAT patient as reported by respondents in

the in-depth interviews and as narrated by a mother of one of the former HAT patients.

One can easily run out of one's mind as you may find at times one becomes very wild ever crying thinking that one is deserted so you may find that the patient is normally in disagreements with the rest of the family and always involved in quarrels.

(Female, 58yrs, Busia, Kenya)

Other conflicts as elaborated in the FGDs arose due to mistaken symptoms or misdiagnosis of the disease by family and community members. The disease led to conflicts when a spouse of a HAT patient suspected that the patient had HIV/AIDS. Some wives were deserted by their spouses who thought that they were suffering from HIV/AIDS, an untreatable disease as demonstrated in the following statements from in-depth interviews:

By the time I was sick, I really became very weak sexually as I couldn't attend to my wife. We used to quarrel about this and she almost abandoned me but she came to understand that it was due to illness but even after treatment, I haven't regained fully as I can only do it once or twice in a week.

(Male, 41yrs, male, Teso, Kenya)

There developed hatred between me and my co-wife because she talked evil things about me saying that I had brought AIDS in the family with an intention of destroying her life- so this made us enemies until I was declared free from AIDS is when she came and apologized to me.

(Female, 32yrs, Teso, Uganda)

We used to quarrel a lot in the house because my wife used to complain that I had brought "slim" or AIDS to the house and therefore wanted to leave me. I told her that even if she left, she was already infected. I therefore convinced her to stay until she buried me then she could leave. However, when I came back from hospital, we just got along well.

(28yrs, male, Teso, Uganda)

My husband became very angry with me because I couldn't stand and walk therefore even going to toilet was a problem and was wetting myself on the bed, which my husband could not stand and so he used to quarrel me.

(32-yrs, female, Busia, Kenya)

Conflicts with community members: Most of the patients reported that some members of the community thought that they were suffering from funny diseases like AIDS and would thus tease the HAT patients by calling them funny names. This teasing brought conflicts between the patients and members of the community. Some of these conflicts arose due to suspicions and accusations that some particular people in the community had bewitched their family members as attested to by the Assistant chief of Apatit: *“Some people started conflicting in the village claiming their wives were bewitched by some characters within the community.”*

The following narration from an interview with the chairperson of the *Iteso* cultural committee further explains how the disease brought conflict among members of the community:

The disease started killing people without the people knowing what it was. The community thought it was witchcraft. For example, just before the sleeping sickness outbreak, one farmer whose tobacco was stolen consulted an emuron who told him that the people who stole his tobacco would all die. So when people started dying of the disease the community thought that these are the people who stole the tobacco while in reality it was the tsetse fly. This brought a lot of misunderstanding between the tobacco owner and the community who were accusing him of having brought death to the village. **(Male, 68yrs, Teso, Kenya)**

There was, however, some disagreement among a group of former male HAT patients when they were asked how the community was affected by HAT, as demonstrated in the following transcription:

SB: *How does the disease affect the community?*

Participant 4: *There is no effect to the community because in most of our communities, there is a lot of individualism so you find that when you get a problem it is upon you and your nuclear family which is affected but you can't find somebody from outside coming to share it with you.*

For instance by the time nagana destroyed our cattle, most of the people became very happy as they now has access to free meat?

SB: *Do you all agree with him?*

Participant 2: *No, for my case, the community was very much worried of losing its members and also of the disease that had attacked the community.*

Participant 5: *My family members together with some community members paid me frequent visits at least to say sorry to me and some offered to help with the payment of debts.*

(Former HAT patients, mixed FGD, Bungoma, Kenya)

5.4.4 Reversal of Roles

Reversal of roles was cited by about 11% of the respondents. This was reported to occur when a spouse of the HAT patient or his/her children had to step in to perform the HAT patient's normal duties with some even having to clean, bathe, dress and feed the HAT patients. The discussants revealed that when a man was sick, the wife was often required by circumstances to take over the husband's activities such as farming or look for part-time jobs tilling other people's land to get some income or food to support the family. This was besides performing her daily reproductive roles and taking care of the husband as exemplified in the following statement from a female FGD, *"We also had to perform the role of the husband and our burden increased."*

On the other hand, when a woman was sick, it was her co-wives (if she had any), her children or her sisters who would come in to take care of her and perform her domestic chores. However, one man revealed that he had to step in and performs the wife's roles as portrayed in the following statement: *I had to start cooking for my family yet cooking is a female chore."* Some children, especially the elder children, were said to be forced by circumstances to undertake the domestic chores in the home, such as cooking, fetching water and firewood,

looking after the sick parent and younger siblings, besides their school work. This was reported to occur especially among girls, and was common when the HAT patient was a mother. Participants in an FGD involving women who had never suffered from HAT were all in consensus with the following statement: *"Some children stopped schooling to take care of their younger siblings."*

5.4.5 Death

About 2% of the respondents interviewed reported death in the family as an effect of HAT. This was reported to occur when either the sick person died or when a member of the family died due to a non-HAT disease, though the informants would claim it resulted from neglect. Some participants in an FGD for non-HAT females noted the following: *"The sons became sorrowful as a result of death caused by sleeping sickness to their father."* In addition, the communities were also affected by the death of HAT patients. This was more severe for those villages that were experiencing the disease for the first time as reported by a key informant from the HAT hospital. This transcription taken from a discussion with former male HAT patients, demonstrates the extent of the deaths and their effects on the community:

SB: *Were there many deaths from HAT?*

Participant 2: *Even the Assistant chief who has just passed lost a father and a wife because of sleeping sickness. His wife died at Alupe.*

Participant 1: *Even the father of the other Assistant chief died of sleeping sickness. His had worsened and he was mentally disturbed. Even his brother was sick. He was treated but his had greatly worsened and he died. Many people died in this village around that time.*

SB: *Because of such many deaths how was the village affected?*

Participant 10: *Most of us were taken to Alupe for treatment but those whose illness had worsened died, but for us whose illness was at an early stage, we survived. In fact development in the village goes down because everywhere there are deaths.*

Participant 2: *The whole village was saddened by the whole situation at that time. Everywhere people grieved and mourned, people even didn't have the morale to work.*

(Former male HAT patients, FGD, Teso, Kenya)

A village elder in Apokor village of Teso district in Kenya also reported that the community lost some highly educated and resourceful people in the community as a result of death from HAT.

5.4.6 Absenteeism from School

Twenty-one per cent of the respondents reported that absenteeism from school was common among school going children. This was reported to be either due to lack of school fees because one of the parents was ill and thus the family income was all directed towards seeking treatment or because the breadwinner was sick and thus there was no income during that time. A mother reported that her children were forced to be absent from school so that they could perform the domestic chores and this was said to be common in most families with a HAT patient. The following quotation from an in-depth interview with a wife to one of the HAT patients demonstrates how lack of fees caused school absenteeism:

My children suffered a lot for they dropped out of school due to lack of school fees. I was not able to pay the fees since it was my husband who used to undertake casual jobs and use the money he got to pay fees. One of the children was sent home and stayed for four months at home. My husband requested me to go to the hospital and get some 600/- which he had saved, and use it to pay the fee balance so that our children could go back to school.

(Female, 38yrs, Teso, Kenya)

5.5 Effects of HAT on Social Relationships

Many of the effects explained above also had an impact on the social relationships between the sick person and the immediate family, extended family and the community. About 18% of the responses indicated that the HAT patients

faced rejection from their immediate family members while 42% reported that the patients faced stigmatization from the extended family. The relationship of the HAT patients and the community was the most stigmatized as cited by about 40% of the respondents.

Social relationships were affected in that some spouses of the patients opted to remarry while the spouse was sick and in hospital undergoing treatment as revealed in the in-depth interviews. When asked whether she experienced any problems in her relationships, a young woman of 22 years was annoyed about how her husband had married another wife and neglected their children as expressed in the following statement:

I was also affected in the sense that my husband reached the extent of marrying another wife following people's advice that I would die. This decision of marrying really annoyed me because he left my children suffering and opted to marry another wife so by the time I came from hospital I found him concentrating on my co-wife and never even bothered to come and see me.
(Female, 22yrs, Teso, Kenya)

Men too were not spared as illustrated by the following statement from a key informant interview with a 44-year old male teacher from Katelenyang village in Teso-Kenya, when probed on how HAT affected family relationships, "A man who was also sick was deserted by the wife and kids and up to date, they have never returned."

Misdiagnosis of the disease was also a contributory factor to the break-up in social relationships as some people thought the HAT patients were bewitched while others thought that the patients had HIV/AIDS. One of the village elders had the following to say when asked whether the disease brought conflict:

The disease brought conflict within the families because some people believed they had been bewitched while some spouses separated and stopped sharing houses because some thought the other one had got AIDS. After treatment they realized it was not AIDS but HAT and so the situation changed.
(Male, 62yrs, Teso, Kenya)

A former Laboratory technician at the HAT hospital further elaborated how witchcraft interfered with social relationships, when he narrated how his aunt who had HAT was thought to be bewitched by her husband and co-wife:

For my aunt's case where it is believed that it was witchcraft that killed her, you find that there is no freedom of association because for my case I am not allowed to go and visit my uncle who is alleged to have colluded with his younger wife to kill his elder wife (my aunty). Therefore he is a man who is considered dangerous and to be avoided.

(Male, 32yrs, Busia, Kenya)

Men whose wives were sick opted to marry other wives thinking that their sick wives would die. This was brought out in the words of a 30-year old woman and seconded by a group of women, who had never suffered from HAT, in an FGD, as stated below, respectively:

The main reason he married another wife was because he thought I was going to die and my mother-in-law supported her son's idea of marrying another wife because it looked definite I was going to die. When one is sick, one can easily lose a marriage partner for fear of death.

(Female, 32yrs, Teso, Kenya)

Misunderstandings were also common especially among co-wives who wrangled over their husband's property as portrayed in the words of one of the wives to a former HAT patient during an in-depth discussion:

There was misunderstanding between me and my co-wives during my husband's illness as my co-wives grabbed everything Stephen had and left me with nothing. When he died he left me in great poverty.

(Female, 39yrs, Busia, Kenya)

Mental disturbance caused by HAT was also reported to affect family relationships, as the sick person did not want any association with any member

of his or her family. This was agreed on in an FGD involving women guardians of HAT patients as shown in the following statement by a wife to one of the former HAT patients:

The man was very harsh and wild as he didn't require any association-be it with his children or wives- because he always complained of severe headache that needed no noise at all. He would always quarrel when people made noise and this caused the rest of the family to stop associating with him because they feared him.

(Female FGD, Teso, Kenya)

Discussions with the HAT patients who were affected when they were young and still in school exposed the fact that their socialization with others was curtailed as reflected in the following statement from an FGD held in Teso District, Kenya: *“To us who were youths we could not visit our friends and relatives hence we could not socialize with them. So our rate of socialization with other people decreased.”*

Apart from the youth missing out on socialization, married individuals also reported that they missed socializing with friends. One HAT patient reported that while sick, he missed drinking *ajonon* (a local brew common among the Iteso) with his friends, while a wife to one of the HAT patients missed her socializing with her fellow women as reflected in the following statement: *“When he was sick my social life was interrupted since I couldn't go out to meet other women. I had to stay close to him.”*

As a result of the effects of HAT, some children of the affected families decided to change their social status as reported in an in-depth-discussion with a wife to one of the HAT patients who died, and a widow who suffered from HAT, respectively:

Since my husband was sick, I had problems of getting money even to pay fees for my children. This annoyed my younger daughter of 13 years and she decided to run away from home and get married.

(Female, 39yrs, Busia, Kenya)

For me when I was admitted in the hospital, I left the children alone at home. My son was forced to leave schooling and marry in order to rescue the situation.

(Female, 42yrs, Teso, Kenya)

Households affected by HAT used different ways to cope with the situations that arose due to HAT.

5.6 Practice of Traditional Rituals

The disease made some communities return to some long forgotten cultural beliefs and traditions as a way of dealing with the situation as illustrated in the following words of a key informant:

Always when there is an outbreak of a given disease people tend to try various ways of rescuing the situation, so people went and revived some of the culture they abandoned in the past. **(Male, 38yrs, Teso, Kenya)**

However, some people tried seeking treatment in hospitals first, but when this did not work, it was reported that they resorted to consulting diviners. Among the Babukusu, the community thought that the problem was brought by the ancestors and therefore one former HAT patient's son reported that they had to slaughter two cows, prepare local brew and other types of food then invite the community members to their place to perform some ritual. However, this did not help the situation and his father died. This caused everybody to ignore the ritual and term it very useless.

Among the Iteso also, it was reported that during the HAT outbreak especially in some villages, many people practised an expensive ritual of exhuming the dead and thatching houses to appease the dead who were said to be tormenting the

living. The following transcription which was extracted from a discussion involving former HAT patients, further illustrates this and also brings out the dilemmas the community faced:

SB: *Did SS affect the Iteso culture in anyway?*

Participant 2: *Yes, some people consulted diviners while others did the "egwasit" ritual which is performed when, for example, a married woman develops rashes, grows thin, is sent back to her parents where a cow is slaughtered and the woman has to carry a big chunk of meat on her head up to her home which is believed to heal the patient. On the way she is not to look behind where she is coming from otherwise she won't recover.*

SB: *Was the practice there before?*

Participant 1: *Yes the signs of the disease in which "egwasit" was performed just resemble those of SS.*

SB: *Why was "egwasit" performed?*

Participant 6: *It was done to heal people who complained of bodyache, fever, painful swollen legs and emaciation or just like SS?*

SB: *Did the ritual heal during those times?*

Chorus: *Yes some of them, not all.*

Participant 1: *It reached a time when men also suffered and people didn't know what to do since the ritual is performed to heal only women and children, so people stopped performing "egwasit". Nowadays people will sit down and see for how long someone has been sick and then take them to hospital.*

Participant 2: *Some people performed another ritual called "emisebee"*

SB: *What is "emisebee" and when and how was it performed?*

Participant 2: *It is a ritual performed to heal somebody with mental problems. An expert is invited to perform it whereby one is given small gourds to shake and some people dance around him chanting. People who suffered from this disease also complain of body ache, fever and dullness just like SS.*

SB: *Did people get healed?*

Participant 3: *Yes and it is still being performed to date.*

Participant 4: *Those who were not healed stopped performing the ritual and got saved.*

SB: *Is there any other ritual that was performed to heal SS?*

Participant 2: *Yes, "ecom". It is mostly performed when children are sick, that is, are dull, have fever and painful body. They are made to bathe in water mixed with herbs at their mother's parents home. A hen is slaughtered and some meat tied around the child's neck.*

Participant 2: *All these rituals were meant to treat the same illness which resembles SS because they are all alike.*

SB: *Have the people stopped performing these rituals or they are still practising them?*

Participant 6: *The people have changed their attitudes.*

Participant 3: *The Teso traditions are still being performed since people usually perform them as one way or one alternative of seeking treatment.*

Participant 6: *People usually perform some traditional rituals to try if a person can recover. But after failing to recover that's when they take an action of going to hospital.*

(HAT patients mixed FGD, Teso Kenya)

However, some participants denied that HAT affected their traditions. They reported that they were saved and thus did not believe in the traditional cultural practices. These participants further said that no cultural practice could cure HAT patients. They also added that people initially thought that HAT was as a result of witchcraft but once it was discovered to be HAT, sick people were advised to go for check-up and treatment in hospital.

5.7 Breakdown in Social Relationships

Relationships among community members were also affected when people would be suspicious of each other as narrated by a village elder:

The relationship in the community deteriorated. This was because in most of the cases when there is an outbreak of a certain disease in the area most people at first relate it to witchcraft. People will start suspecting each other as bewitching them.

(Male, 62yrs, Teso, Kenya)

Breakdown in relationships was also reported to occur when the community would stigmatize the HAT patients either because they suspected them to be suffering from HIV/AIDS or from having been bewitched. The socio-cultural impacts of HAT were quite immense and some of these impacts could have had negative implications for controlling the disease. The impacts were more adverse in areas such as Teso and Bungoma, which had never experienced cases of HAT before. However, as a result of the outbreak, the communities in the affected areas were more enlightened about the disease.

CHAPTER SIX

THE SOCIO-ECONOMIC IMPACT OF HUMAN AFRICAN TRYPANOSOMIASIS ON THE COMMUNITY

6.1 Introduction

Issues related to financial problems encountered by former HAT patients and their families as well as the community are presented in this chapter. However, besides financial issues, other effects related to the socio-economic problems that the communities faced are also exposed in this chapter.

6.2 Effects of HAT on the Individual/Household

The majority (91.1%) of the sick people could not continue with their normal work routines as a result of the illness. The Psychosomatic effects of HAT weakened the sick persons so much that eventually they could not work at their normal maximum capacity. Some had to stop working altogether and depend on their families for support. Financial problems set in for a majority (81.3%) of the individuals as a result of constantly trying out different treatment options in a bid to cure the disease. As depicted in Table 6.1, it was not only the sick people that faced socio-economic problems, but their families too. The nature of these effects is explained in the following sub-sections:

Table 6.1: Socio-economic Effects of HAT on Individuals/Households (N= 203)

Variable	Frequency (%)
Effects on sick person	
Financial constraints	165 (81.3)
Neglect of homestead	49 (24.1)
Death	11 (5.4)
Loss of property	5 (2.5)
Dropped out of school	4 (2.0)
Effects on households (N=203)	
Financial constraints	185 (91.1)
Food insecurity	63 (31.0)
Loss of property	8 (4.0)
Dropped out of school	7 (3.4)
Death	3 (1.5)

Note: The total sum of responses do not add up to 100 because this was a multiple response question

Source: Survey results

6.2.1 Financial Constraints

Financial constraints were experienced by both the individuals and their households due to increased expenditure on seeking treatment before they finally got diagnosed for HAT as the following statement from a 58 year-old female key informant from Teso district, Uganda, reveals: *“The sickness increased the expenditure in the family since at first a lot of money was spent when seeking treatment before sleeping sickness was discovered.”*

Almost half (48%) of the respondents spent money on buying over-the-counter (OTC) drugs to try and manage the HAT problem in its initial stages. However, when the HAT patient's condition did not improve, the health care facility was the next stop. Due to the fact that HAT presents itself as other febrile diseases, a number of the patients kept shifting from one health facility to the next with the hope of getting an improvement in the HAT patient's condition. All these health-seeking options put a strain on most of the respondents' finances in the form of drugs, transport, laboratory tests and other hospital charges such as the hospital card. This notwithstanding, a number of the respondents reported that they had to resort to alternative sources for health seeking such as use of diviners and traditional medicine. These also further put a strain on the patients' and their families' finances. This is because most diviners performed rituals that involved some expensive practices such as slaughtering animals as depicted in the following transcriptions:

At first we believed it was malaria so we had to move from one health centre to another but in vain. We tried as a family to contribute money to take him to Bungoma District hospital where he (the patient) was diagnosed but was found to have typhoid associated with acute malaria so they switched to treating malaria and typhoid but the patient's condition

did not improve. Having failed medically, we now came to believe it was witchcraft so we tried different diviners but there was no change. We were almost losing hope knowing that it was witchcraft until the patient was finally taken to Alupe where he was diagnosed and found to be suffering from sleeping sickness.

(25-year old son to a 52-year old HAT patient, Bungoma, Kenya)

For my brother's case we really believed it was witchcraft due to the different and complicated symptoms so it consumed a lot of our money. For instance, the first diviner consumed 10,000 Kenya shillings since he really convinced us that somebody had bewitched my brother. He therefore tried his "things" but they didn't do my brother any good. We switched our minds to another diviner from Kakamega who also tried in vain. Soon we realized that on the diviners alone, we had used almost 25,000 Kenya shillings without any improvement on my brother's condition. It was not until he was taken to Alupe that he was diagnosed and found positive for sleeping sickness.

(32-year old brother to an 18-year old HAT patient, Bungoma, Kenya)

In addition, an Assistant Chief whose father died of HAT had the following to say about how the disease affects a person economically:

Sleeping sickness affects one in a way that you find somebody spending a lot of money and trying to save the patient but in vain. At long last you find that someone has used all his/her resources to cater for medication which eventually results in great poverty.

(Male, 38yrs, Teso, Kenya)

Apart from the cases cited above, a very large number (93%) of the HAT patients were reported to have incurred expenses while seeking treatment. More than a half (57.6%) of those who incurred expenses, spent up to about 4,000 Kenya shillings, 22.6% spent between Ksh 4, 000 and Ksh 8,000 while 6.4% spent between Ksh 8,000 and Ksh 12,000. A small percentage (6.4) also spent over 12,000 Kenya shillings. Out of the 189 respondents who reported having incurred costs, about 80% experienced difficulties in getting the money and had to resort to various methods to raise the required money. Sixty-four per cent of the respondents sold their agricultural produce, 54% got assistance from family

and friends, 26% took loans, and 22% sold family assets while 17% used their own savings.

To cope with the increased expenditure on seeking treatment for the HAT patients, a number of the affected families had to sell some of their property or farm produce. Goats, cattle, sheep, chicken, maize, millet, groundnuts and beans were among some of the farm produce sold or given away to help in seeking treatment. Household property such as bicycles, mattresses and blankets were among the household property sold while land was either sold or leased out to get money to cope with the financial constraints encountered while seeking treatment for HAT. Others incurred debts, which became difficult to pay as shown in the following two transcriptions from in-depth interviews with wives to two former HAT patients:

We used a lot of money, for instance, I alone before counting what his brother gave I sold one sack and three gorogoros (6kgs) of finger millet and two sacks of maize. We also borrowed 3000/- from a friend. To date I am still paying by doing manual jobs on her farm.

(Female, 32 yrs, Teso, Kenya)

The repayment of debts incurred during his hospitalization was hard as the disease had rendered the family poor.

(Female, 39yrs, Busia, Kenya)

Financial problems also set in, as many HAT patients could not continue with their routine daily activities and moreso, economic activities. This mostly applied if the HAT patient was the breadwinner of the home as was agreed upon by a group of participants, in an FGD, involving women who had never experienced a case of HAT in their homes. While discussing the topic on socio-economic

impact of HAT on an individual, they concurred with the following statement, which was made by one of them:

One is affected in a way that one may be a widow or widower and as such depends on oneself for provision of basic necessities. So you find that when one is sick, everything remains at a stand still, for instance, going to the "shamba", which might result in famine in one's home.

(Non-HAT patients, female FGD, Teso, Uganda)

On the other hand, the widow or widower may have a sick child and thus face difficulties in terms of continuing with the normal economic activities, as shown in the following transcription from an in-depth interview with an 19-year old former HAT patient, who had the following to say about his widowed mother:

In the process of raising money for my treatment, my mother's business collapsed since she used the business money for my treatment. She couldn't continue with the normal farming activities. My siblings had to stay with my grandmother since my mother was busy looking for money and caring for me.

(Male, 19yrs, Busia, Kenya)

When one's economic activities stalled, it became difficult for one's family to cope without the financial contribution that one used to make. Coupled with the increase in expenses on health seeking, the problem was compounded and in some cases, people were forced to go into debt or sell their property to keep up with the demanding expenditures as explained in this excerpt from an interview with a wife to one of the former HAT patients:

For my husband's case it was initially mistaken for witchcraft because he was having a land dispute with his brother. We therefore took him to a diviner who required a lot of money, which we couldn't raise so we had to come back home. We then decided to borrow money and take him to Nangina Mission hospital where he was diagnosed and found that it was sleeping sickness. We had to go back home and borrow money for transport to Alupe. At Alupe he was treated for two months before he was discharged. When he came back home he was so weak that he couldn't even hold a cup of water.

(Female, 39yrs, Busia, Kenya)

The above excerpt also reveals the approximate duration that a HAT patient stayed in hospital. This had adverse implications on the economic activities of the patient and his/her family because, having to spend two months in hospital implies that if you were the breadwinner then your family suffers for two or more months. In addition to this, the family members are also tied down to visiting the patient in hospital for that duration, thus their productivity is reduced. Further to this, even after treatment, the patients were still weak and thus needed more time to recuperate, implying that they were still unable to perform their economic activities for some time after being discharged from hospital.

However, it was not only the breadwinner's economic activities that stalled but also those of other family members who had to abandon most of their activities to spend time taking the patient to hospital and giving the care needed. When the patient was admitted in hospital, the problem worsened as family members spent a lot of time and money, going to visit the patient daily. This impacted negatively on their economic activities and is clearly depicted in the following excerpt from a transcription of an in-depth interview with a 25-year old lady whose husband deserted her when she fell ill:

My mother who took care of me could not go to the shamba to work. Hers was to look for money and look after me and visit me daily in hospital. At that time, she had planted some vegetables like "sukuma wiki" and had invested some of her money in terms of buying seeds, and insecticides for spraying. Therefore the vegetables dried up as there was nobody to take care of them and this was a big loss for her.

(Female, 32yrs, Teso, Kenya)

Apart from the family members being unable to perform their economic activities due to time and money spent in taking care of the HAT patient, psychological

aspects, in the form of worry, also contributed to this inability to perform those activities. A 42-year old husband to a former HAT patient succinctly brought this out in the following statement:

Now that my wife was sick, I really became very worried as I thought my wife would die so you find that I couldn't even attend to my "shamba" work due to too much thought, something that brought hunger in my family.

(Male, 42yrs, Teso, Kenya)

The extended family was also not left out in experiencing these financial constraints as some of them had to step in to assist their overburdened sons and daughters. A young wife to a 30-year old HAT patient narrated her experience as follows:

I was really affected in that the task of looking after our three children was left entirely on me. Unfortunately I was unable to cope so I had to involve my parents to help take care of the children and yet the season was very dry so my parents really faced it rough in terms of acquiring food for my children. It also gave my parents a hard time to provide me with bus fare to and from Alupe to check on my husband. The disease brought famine in my home as my husband who usually attended to the "shamba" work was now sick and for my case I was not used to digging or doing heavy work.

(Female, 25yrs, Teso, Kenya)

The above excerpt shows that HAT's effects went beyond the individual to affect even other members of the extended family. Family members were forced to step in to assist each other depicting the kind of social fabric and network that still exists in the community.

Financial constraints were also experienced when families spent a lot of money seeking treatment from various sources before the disease was properly diagnosed. In addition to this, many people practised rituals such as exhuming the dead and thatching houses to appease the dead who were believed to be tormenting the living. These rituals were costly and took a lot of valuable time of

the community as a group of men who had suffered from HAT revealed in a FGD and concurred with this statement: *"It was expensive to exhume the dead and one had to pay 500 Kenyan shillings, provide a goat or a cow, a hen, and food."* This ritual was practised by a number of people and this was costly to the community in terms of money and time.

Some community members spent a lot of time and money on transport going to the HAT hospital frequently to visit their sick neighbours. The HAT patients who were frequently visited by fellow community members were mostly opinion leaders within the community, as exemplified by the statement of a village elder in Lugala location of Busia district who had fallen sick: *"My community was very worried because they thought they were losing a very resourceful man in the society. Therefore people had to gather from time to time praying for my quick recovery."* However, one former HAT patient who was in the same FGD disagreed with this statement by saying: *"My community never bothered in any way with me as everything was left to my immediate family. They would say, "Every man for himself and God for us all". I therefore didn't feel any community concern and my family had to bear all the financial expenses themselves."* This implies that the community members would incur financial and time costs to visit people who they knew were "important" in the community and not any ordinary member of the community.

In another aspect, financial constraints were encountered indirectly when people started to drink to forget their problems. Women who were not affected by HAT revealed that as a result of the "strange" disease that did not seem to have any

cure, some men whose family members suffered from HAT were frustrated to the extent of resorting to drinking, as a way of forgetting their problems.

6.2.2 Neglect of Homestead

Twenty-four per cent of the respondents mentioned neglect of the homestead as one of the economic factors they faced as a result of HAT in the family. This was experienced when most of the adult population in the home was frequently away from home, either seeking treatment in hospitals or spending a lot of their time visiting and taking care of the sick in hospital. This problem was more severe for families who had a sick parent and more so if the patients were also the breadwinners. Some families had to delegate the running of their homes to relatives. A female teacher who was interviewed as a key informant described this effect in the following statement:

Houses collapsed due to lack of maintenance as responsible members had gone to hospital to take care of the sick. Children also left the running of the homes to their relatives since there was no one in control of the family.
(Female, 34yrs, Teso, Kenya)

When the responsible people in the home were ill or busy taking care of other sick family members, the running of the home was affected and things were frequently not well managed by those left in charge especially if they were young children, or even relatives who also had their homes to manage. The homestead management was thus thrown into disarray and many things tended to get spoilt or vandalized. One 18-year old former HAT patient reported that when he was admitted in hospital, his mother had to stay with him for almost a month and leave the home unattended and this led to problems back at home as explained in the following statement:

Since my mother stayed with me in LIRI (hospital) for almost a month, there was no one to look after the home. When she went back home, the place was bushy, our chicken had been stolen and there was no food.

(Male, 18yrs, Busia, Kenya)

The children left in the homestead were also affected by the lack of a responsible person in the home to take care of them. Some children slept hungry and their security was also compromised. A FGD with a group of women who never experienced a case of HAT in their families concurred with the following observation made by one of them:

There was no one to take care of the children when the parents were sick. They become hopeless in life. Children slept on empty stomachs (hungry) and they were not secure staying alone in the homes.

(Non-HAT female FGD, Teso, Kenya)

This shows that even the people who did not experience a case of HAT in their families observed the effects of HAT among their neighbours and realized that it was a disease with many adverse effects on both the affected and the infected.

6.2.3 Food Insecurity

Food insecurity was mentioned by 31% of the respondents. A variety of reasons led to the shortage of food. The fact that the productive members of the family spent a lot of their time and many days trying to seek for treatment meant that they either spent little time or none at all on their farms. The disease struck at various times of the planting season, for some, it was during the time for preparing the land for planting, for others, it was during weeding time while for some others it was during harvest time. The effect was more severe on the women whose husbands had contracted the disease. This was also reiterated in a FGD involving former HAT male patients who concurred with the following

statement when they were discussing the socio-economic effects of HAT on the family: *"The family was affected in that the wives lacked somebody to slash for them during the cultivating period to prepare the land for planting."*

The above statement implies that since the land was not prepared for cultivation, probably the family did not plant during that season and hence did not have any crops to harvest leading to food shortage. This was also exemplified by a 45 year old HAT patient who reported the reason why his family lacked food as follows: *"My family lacked food because there was no one to farm because both my wife and I were in hospital. When I was admitted, she had to stay with me to take care of me."* The fact that the disease weakens people also contributed to the lack of the farms being cultivated as emphasized in the following transcription from a FGD involving former male HAT:

The biggest problem was that people were greatly weakened and could not work. As a result famine set in. The wife who may work on the farm has to take care of you and as such also cannot work on the farm. She can only go to a neighbour to borrow something or do some odd jobs in people's homes to get some money. If all the people in the house were okay, such a problem wouldn't have arisen. (Male, FGD, Busia, Kenya)

Food insecurity also set in because much as the households had already ploughed, planted and weeded, problems set in when there was lack of labour to harvest the crops. Some respondents reported that since the family members were giving most of their attention to the sick person, they did not have much time or sufficient labour to do the harvesting. As such, some of the crops were either stolen or got spoilt in the farm especially when the rains came before the farmers had completed harvesting their crops.

The selling of agricultural produce to meet the financial expenses incurred while seeking treatment, also contributed to food insecurity in the homes. The following transcriptions from in-depth interviews elaborate further on this:

Hunger came in as the available food was sold in order to seek medical help.
(Male, 51yrs, Bungoma, Kenya)

My father had to borrow money from his association which really gave him a hard time to re-pay. My parents also had to part with their three cows in order to raise funds. I had also harvested some 20 goris (40kgs) of maize, which had to be sold for the acquisition of money for treatment.
(Male, 30yrs, Bungoma, Kenya)

I sold all my food to meet hospital and drug expenses, and also to pay the diviner.
(42-year old widow who suffered from HAT, Teso, Kenya)

The farm remained untilled because people didn't have the energy to work as most of those who had bullocks or oxen lost them to nagana (animal trypanosomosis) or sold them to meet financial expenses. We even sold four of our cattle to get finance to help us in seeking treatment. We even gave some to emurwon (diviner) who we sought for treatment.
(48-year old father to a former HAT patient, Teso, Kenya)

Lack of oxen to plough meant that the size of land put under cultivation during that season was relatively small in comparison to other seasons. This implied that the harvest for that season was also minimal and hence the hunger experienced by most of the HAT-affected households.

At the community level, food insecurity increased since most of the community members were not able to concentrate on their farming activities. The HAT outbreak affected many people, to the extent that in almost every home in Apatit village, there was a HAT patient. At the beginning of the outbreak, people were confused and very worried because they did not understand what they were suffering from and this caused panic in the community as people who were not

sick were wondering who and what next. The Assistant Chief of Kaliwa sub-location reiterated this in the following statement:

There was no food because the disease affected many people causing a problem in carrying out farming activities because people were talking about the disease. The community was worried wondering who would be next as they thought they had been attacked by a strange disease.

(Male, 38yrs, Teso, Kenya)

This reduced the time they spent in the farms and thus productivity for that season was low. In addition, the community members spent a lot of valuable time visiting their sick relatives and neighbours as they pondered over their own fate. In Katelenyang village alone of Teso district, there were 60 sick people; thus their family members' valuable time was spent in taking care of the sick and seeking treatment. This meant that they could not fully concentrate on and participate in the farming activities leading to less land under cultivation.

At the same time of the HAT outbreak, the disease also affected livestock and many of them died. This affected the hectarage under cultivation leading to low food production and hence contributing to food insecurity. This can be further elaborated in the following transcription from an interview with a community health worker when he was asked about the socio-economic effects of HAT on the community:

Looking at the economic activities of people living around they are mostly farmers and the type of farming mostly depends on ox-ploughs and not tractors. Therefore as a result of trypanosomosis wiping out the cattle the farmers were not in a position to till their land. Hence a lot of land was left fallow simply because tractors are expensive and at the same time they are a few in the area hence it was not easy to get a tractor to till the land. Most people had no personal tractors hence it was difficult for them to plan their farming activities on time and also, they did not have the energy to till the land since many were sick.

(Male, 52 yrs, Busia, Kenya)

Valuable time that should have been spent in working on the farms was spent in community gatherings for funerals and burial ceremonies, and this would take a number of days depending on the number of people that died in that village. An in-depth interview with a former KETRI technician revealed the following about the socio-economic effects of the disease on the community:

The community is affected in that when a patient happens to die then the community feels that gap of their beloved member and at times it costs the community time to gather for funeral contributions which they would have used on some other things, such as working on their farms.

(Male, 32yrs, Busia, Kenya)

A lot of time was also spent on undertaking control activities for prevention against HAT as described in the following statement from a 41-year old former HAT patient: *“After realizing that it was the tsetse fly that causes sleeping sickness the community members had to abandon some of their activities like working in their shambas and concentrate on bush clearing.”* Other members of the community were forced to sell their land to raise money for seeking treatment. This implies that their total farm land reduced and hence decreased hectareage under cultivation leading to a decrease in food production.

6.2.4 Loss of Property

Loss of property was also an effect experienced by some HAT patients and their families. This was experienced in many forms and one of them was through theft. Some respondents reported that since they, meaning the adults, were in hospital, there was no responsible person left at home and people took advantage of that and stole their property. Former male HAT patients confirmed this in a FGD and concurred with this statement made by one of them. *“Since we*

were all in hospital, people stole our property like bananas in the shamba, chicken and utensils.” Other respondents reported that loss of property occurred when they had to give away some of their household goods to cater for services offered by the diviner. Much as this was some sort of payment for services rendered, some respondents did not view it as such and still considered it as loss of property as depicted in this statement made by a 33-year old woman who suffered from HAT and had to undergo some rituals under different *emurons*:

The emurons took away my household items like pans, bed-sheets, blankets and our clothes. My family even had to slaughter a cow under the direction of one emuron and I was made to eat the meat raw yet I did not recover. The emurons just became rich at the expenses of my sickness.
(Female, 33yrs, Teso, Kenya)

The above statement reflects the bitterness the lady had and she did not view the taking away of her property as being rendered for services offered since the *emurons* did not manage to treat her condition successfully. As a result of this she regarded it as loss of property. Her views represent the views of many other HAT patients and their families who had to undergo the same. A 19-year old former HAT patient also expressed a similar view in an in-depth discussion as transcribed below:

I even got annoyed with my mother for giving away my new mattress to one of the traditional healers because she did not have money. To date I have never been able to get another good mattress like the one she gave away and I still blame her for giving it away. When this particular traditional healer came, my mother did not have enough money so she gave him a cock, ten thousand and my mattress. All this traditional treatment did not work.

(Male, 19yrs, Busia, Kenya)

Loss of property was also experienced when the patients and their families had to sell some of their property to cater for the medical expenses incurred as

depicted in the following statements from an in-depth and key informant interview, respectively:

My mother was very worried about me and she sold part of our land to raise money for my treatment.

(Female, 21 yrs, Busia, Kenya)

People were forced to part with their wealth, for instance, goats and cattle, in order to raise funds for treatment, which was very costly.

(Male, 52 yrs, Busia, Kenya)

Much as the respondents reported incurring a lot of expenses for treatment of HAT to the extent that they had to sell their property, interviews with two key informants who work as nurses in the HAT hospitals in Kenya and Uganda clarified that most of these medical expenses incurred by the respondents, were incurred before proper diagnosis was done. Once proper diagnosis had been done and HAT discovered, treatment for the disease was carried out free of charge in both hospitals.

6.2.5 Poor Academic Performance/School Drop-outs

The school performance of some children were affected either directly because they were HAT patients or indirectly because they had a HAT patient in the family. The children who suffered from HAT had to miss school several times due to ill-health. For some children, sudden sleep during the day, which is one of the effects of HAT, would affect them when they were in class and this would make them the laughing stock in class. Teachers would punish them not knowing that they were sick. This made some children lack concentration in class or miss going to school altogether, and this had a negative effect on their performance as explained by a 19-year old boy who fell ill when he was in standard five:

In school, the teachers would often beat me because I was always sleeping in class. The teacher would say that I must have gone to a disco and danced the whole night and that is how they would explain my frequent dozing in class. The other children in class would often laugh at me. My performance went down terribly. I used to be between number 19 and 20 but after I got sick, I dropped to 100.

(Male, 19yrs, Busia, Uganda)

Some (18.2%) of the school going children were forced by circumstances of ill health to miss school several times while 2% eventually dropped out of school.

One 19-year old boy, during an in-depth interview, echoed this by saying:

Sleeping sickness has interrupted my studies. My performance deteriorated and I had to stop schooling. I am quite sad because by now I should have been through with my secondary education.

(Male, 19yrs, Teso, Kenya)

Due to the duration taken in treating the disease, some children went back to school after treatment, but because some had been away for some two or three months, their academic performance was affected and some had to repeat the same class several times while some ended up dropping out of school. The following transcriptions from in-depth interviews further demonstrate the extent of the problem:

I went back to school but then after treatment, my academic performance went down. I used to be among the top five but I dropped to among the last in class. My uncle stopped paying school fees because he considered it a waste of money since my performance had deteriorated.

(23-year old boy from a polygynous family and mother is a widow)

In term one he did well and was number 7 but in term two his performance went down. In the course of that term, he developed epilepsy and stopped school. Other children were not comfortable with him around and teachers advised me to keep him at home as I try to treat him, but up to now I have not succeeded in treating his epilepsy.

(36-year old mother to a 15 year old former HAT patient)

I appeal to you that if there is a way these people can be restored back to normal, it would really help. My son has schooled for 11 years and is still in standard 2. He also likes playing but at times he doesn't know what he is doing especially to other children and as a result others beat him. He also sometimes roams and disappears from home.

(40-year old father to a 16-year old former HAT patient)

The above transcriptions echo the agony that the children and their parents went through, and are still experiencing as a result of poor academic performance resulting in school drop-outs.

Children whose parents or family members suffered from HAT also experienced schooling problems. Some of these problems were as a result of the families trying to cope with the financial constraints experienced as a result of seeking treatment. This led to problems of school fees and thus some children had to stop schooling for some time while others dropped out completely.

A 38-year old former HAT patient was saddened by the whole situation when her daughter dropped out of school due to lack of fees and ended up getting married. She had the following to say when interviewed about the effect of HAT on her children:

All of the money in my family was geared towards my treatment and therefore there was no money for fees for my children. This even forced my younger daughter of 13 years to drop out of school and get married as she thought that was the only resort.

(Female, 38yrs, Busia, Kenya)

Apart from lack of school fees, lack of food also led to school absenteeism. This came up in a FGD with women who had suffered from HAT and they all assented to the following statement, made by one of them: *"Children couldn't go to school on an empty stomach (hungry) since all the food that was there was sold to try to*

make the patient recover.” Some of the children had to cover long distances to school and this may explain why when one was hungry, chances of one missing school were high and also one may lack concentration in class. Some of the children thus opted to try and look for food and this meant time away from school.

Yet other children had to stop schooling for some time due to increased responsibilities to take care of either their sick parents, their younger siblings or to take care of the home. A FGD with men who had to take care of their sick wives concurred with the following statement: *“Some children stopped schooling to take care of either their sick mother or father or other children in the home.”* The same observation was also made by a group of women who had never suffered from HAT as depicted in the following statement: *“Some children stopped schooling to take care of the younger children.”* The increased responsibility on the school going children negatively affected their school attendance and by extrapolation, probably their performance too.

At the community level, school performance was affected, as most children could not go to school due to lack of school fees, which arose due to increased medical expenses. Others were forced to drop out of school temporarily to take care of their siblings while some were HAT patients and thus could not attend school due to ill-health. A FGD with young people who had suffered from HAT confirmed that school performance was negatively affected as captured in the following statement: *“Averagely, the school performance dropped from areas which were affected by sleeping sickness.”* Some children were worried about their sick

parents and could not concentrate in school and this ended up affecting their performance. The communities which had a big number of HAT patients were the ones most affected as some of the teachers also fell victim to the disease and thus missed going to school for some time.

6.2.6 Death

Death of HAT patients occurred in some homes and left a feeling of helplessness among the surviving family members. The helplessness of the relatives of those who died can be exposed in the following statement of a husband to one of the former HAT patients who ended up dying:

We tried many hospitals for treatment but never succeeded. I even tried traditional healers, spiritual healers up to Kitale. When I came back from Kitale, my relatives advised me to try Alupe for check up and treatment. She was found positive and in the late stage of the disease and it could not be treated. She became mad and her hands became numb. Had I known earlier that it was sleeping sickness she wouldn't have died.

(Male, 40yrs, Teso, Kenya)

A number of deaths within a span of one year were recorded in a village known as Apatit in Teso district of Kenya, where a HAT epidemic was experienced. The Assistant Chief stated that when the disease first affected the community, many people thought it was witchcraft and thus sought treatment from diviners. However, when the main diviner in the village also succumbed to the disease, many people stopped believing in the diviners and decided to try those from other villages. Due to this process of trying to seek treatment from different sources, the disease in most patients progressed to the late stage and by the time they were diagnosed for HAT, some did not recover and ended up dying.

Death also contributed to a myriad of other problems especially if the dead person was the breadwinner in the home. A 41-year old widow narrated her ordeal, *“I was widowed after my husband had died of sleeping sickness therefore life became very hard for me in terms of acquiring food for the family, paying school fees for the children and so I have to lead a poor life of begging.”* Death also indirectly led to loss of income through expenses used for the organization of the burial ceremony. It also meant the loss of valuable time of the family members as they spent their productive time organizing for the burial ceremony instead of engaging in their daily work.

Impact of Death on the community: The death of HAT patients was a big blow to the community. In Mourkeyan Sub-location of Teso district in Kenya, a key informant reported that about eight people died before the disease was discovered, while in Apatit, Teso district, Kenya, about 30 people died. Death meant that funerals had to be organized and burials conducted, causing profound grief and a lull in many economic activities. Death robs a community of valuable, productive members, apart from increasing the financial burden of the community in meeting funeral and burial expenses especially since the funeral ceremonies can last for more than two days.

The socio-economic effects of HAT on the individuals and households were varied and immense and can be summed up in the following statement by a husband of one of the former HAT patients:

People can't work as they have to take care of the sick and as a result hunger creeps in. It also becomes difficult to meet medical expenses and at the same time pay school fees. Some children dropped out of school due to lack of fees. Poverty also set in as the family sold property in order to seek medical treatment.
(Male, 40yrs, Teso, Kenya)

CHAPTER SEVEN

DISCUSSION

7.1 Introduction

This chapter presents the discussion of the findings of the study. The main themes of the discussion are trends of HAT in the study area, health seeking behaviour, as well as the socio-economic and cultural impacts of HAT.

7.2 Trends of HAT in the Busoga Focus

HAT was adequately controlled in Africa in the 1960s. However, in the last 30 years it has been increasing in some countries. The increase has been attributed to social and political changes, failure of national health authorities to give due attention to HAT control, lack of adequate resources, and competing national health priorities (Kuzoe, 1993). These have resulted in epidemics and resurgence of the disease in old foci, and its appearance in new areas.

The outbreak of a HAT epidemic in 1990 in Uganda was linked to political instability and civil war during and after the rule of Idi Amin (Berrang-Ford *et al.*, 2006). Moore and Ritcher (2001) and Smith *et al.* (1998) attributed the re-emergence of HAT epidemics in Sudan, Democratic Republic of Congo and Angola to civil conflict and instability. Civil war, as in the Uganda case, is reported to influence the transmission potential of HAT in a number of ways, including: breakdown of veterinary and public health services; collapse of vector control; regrowth of bushy tsetse habitat in abandoned agricultural fields and increasing displacement of human and animal populations into marginal or

swampy areas where they are more likely to be bitten by flies (Abaru, 1985; Smith *et al.*, 1998).

As much as the outbreak in Kenya in 1990 could be traced back to Uganda due to livestock movement from there to Kenya, other factors such as changes in government policies may have also played a contributory role. A policy change through Sessional Paper No.1 of 1986, on Economic Management for Renewed Growth, marked the advent of cost-sharing and private sector involvement in the delivery of services, among them tsetse control. Before then, tsetse and trypanosomiasis control had been fully a government responsibility. The shift in government policies made it difficult for farmers to adjust to the changes (Olet, 2003; Bukachi *et al.*, 2007, unpublished) hence possibly contributing to a lapse in the tsetse fly control activities. Laveissere (1990) and Hide (1999) indicate that a breakdown of tsetse fly control measures leads to the spread of tsetse flies even to new foci. In Uganda, the spread of *G. fuscipes fuscipes* resulted in a HAT outbreak in a new area (Okoth & Kapaata, 1986). A ban on the use of DDT and deltrin, which were initially in use for ground spraying (Angus, 1996; Olet, 2003), land use and environmental factors may have also played a contributory role to the outbreak in Kenya (Hide, 1999).

The epidemic in Uganda declined in the 1990s in conjunction with increased stabilization of Uganda's economic and political situation (Rodriguez, 2005). This also paved the way for vector control activities (Lancien, 1991; Okoth *et al.*, 1991), which were successful in reducing the tsetse fly numbers, and hence reduced incidences of HAT. The drastic decline in Kenya could be attributed to

the intensive control strategies that were put in place by the National HAT Control Programme by systematic tsetse fly trapping using traps and community involvement in tsetse control, thereby dramatically reducing the tsetse population by up to 99% (Angus, 1996; Mwangi, 1996).

The trends of HAT in Kenya and Uganda from 1990 to 2002 seem to follow a similar pattern. However, the magnitude in Uganda is much higher (Fig 7.1) and instead of taking a continuous downward trend from 1999 as in the Kenyan situation, it peaks up again from the year 2000 onwards and the country still experiences cases of HAT to date while Kenya has not experienced any cases since 2003. A WHO report (2003) also confirms that the districts in southeastern Uganda bordering Kenya have continually reported over 200 HAT cases annually and have thus been categorised as part of the countries considered to be 'highly endemic' while Kenya is among the countries with sporadic or low endemic levels (WHO, 2001b) reporting less than 50 cases annually (WHO, 2006).

Geographically, the two areas seem to be similar but the reasons why Uganda still experiences incidences of HAT while Kenya does not are yet to be unfolded. Berrang-Ford *et al.* (2006) attribute the differences to possible changes in land cover, cattle movements, population distributions and densities, and socio-economic conditions. However, little information and research has been conducted to assess such changes, and little evidence exists to suggest differential change that would make one area particularly vulnerable. A study by Rutto (2007) on assessing the impact of land use and land cover on the epidemiology of HAT in the Busoga focus may shed some light on this.

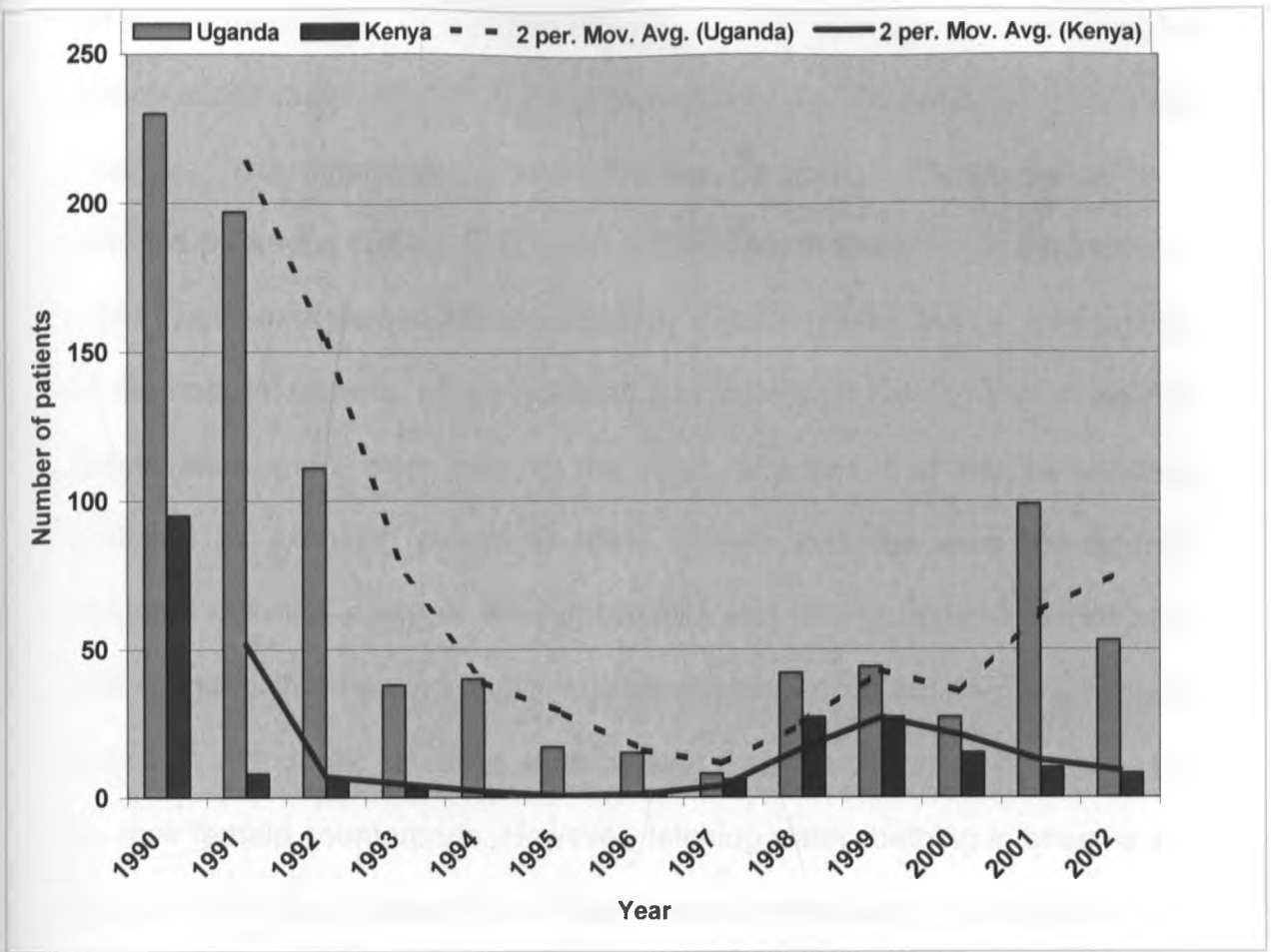


Figure 7.1: Trends of HAT in the Busoga Focus, 1990-2002 {Source: Hospital records (LIRI & KETRI)}

However, much as Kenya has not experienced occurrences of HAT in the recent past, the ongoing incidence of disease across the border in south-eastern Uganda should warrant continued control measures to prevent the spread of HAT and subsequently its impacts on the communities living in the endemic areas. Furthermore, trade of cattle is common among the two bordering communities and emergence of HAT in eastern Uganda has been attributed to importation of cattle infected with *T.b. rhodesiense* to the market from the endemic HAT focus (Fevre *et al.*, 2005).

There were more men than women affected by HAT in both countries during the duration under study. However, the differences in Uganda are higher than those in Kenya. The difference between the two genders in Kenya are small as confirmed by Angus (1996), who found no significant difference in the incidence of HAT between male and female patients. This, however, was in contradiction with the hospital records, which indicated that more than half (57.7%) of the HAT patients were men, and also to the main activities that the respondents mentioned as exposing people to HAT. These activities were mainly male dominated activities such as herding (46.8%) and fishing (11.9%). Smith *et al.* (1998) confirm that herding cattle, a predominantly male activity, is a high-risk occupation in endemic countries, thus causing males to be more exposed to HAT than their female counterparts. However, fetching water, bathing in streams and rivers and fetching firewood are also factors contributing to exposure and therefore expose both genders to the risk of HAT.

Nevertheless, studies on other tropical parasitic diseases (Brabin, 1990; Brabin & Brabin, 1992; Michael *et al.*, 1996; Hammad *et al.*, 1997; El-Khoby *et al.*, 2000), have also found results similar to those of this study. They observed that the incidences are generally higher in males than in females because, there are substantial variations between men and women in the type and duration of their daily activities within the local biotopes where parasitic disease may be transmitted, possibly resulting in profound differences in exposure between the two sexes. This could also be the explanation why more males than females

suffer from HAT since the men may be participating in more activities within the tsetse habitat and also during the peak hours of tsetse fly activities.

The trends throughout the years for Uganda (Fig 7.2) in terms of gender are consistent with the results that there were more men than women.

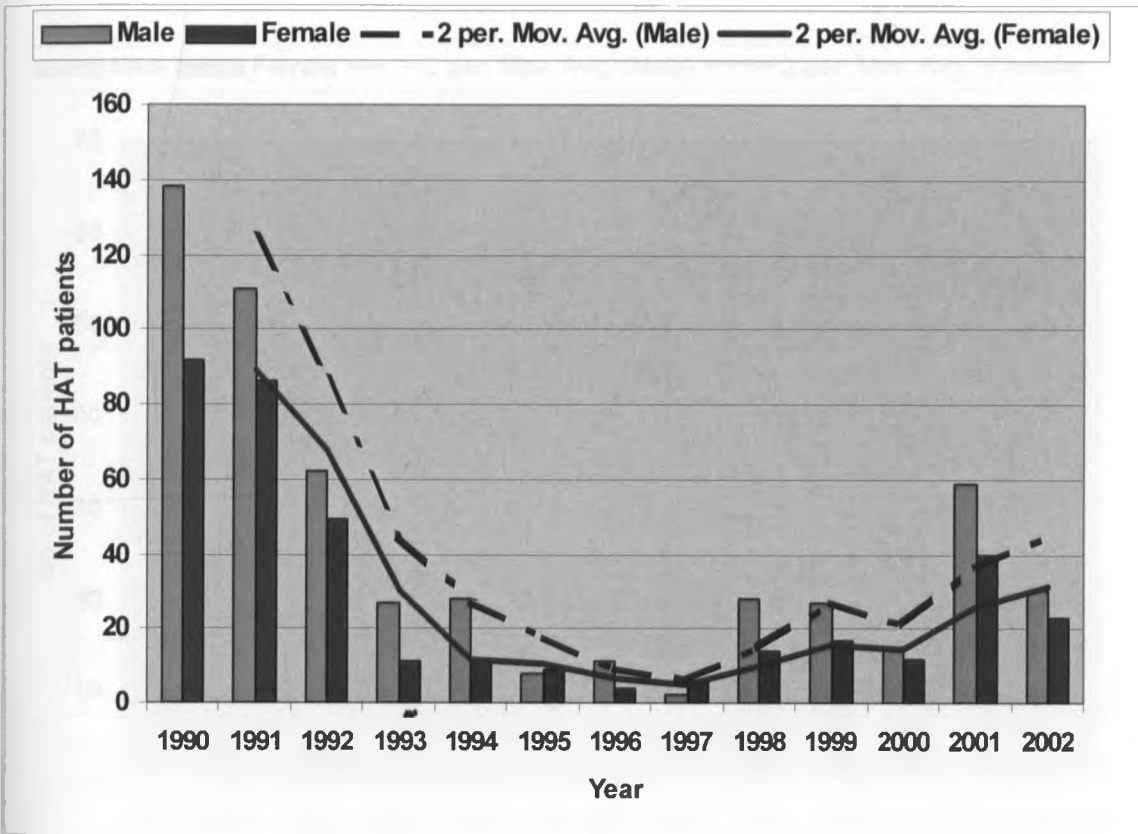


Fig 7.2: HAT Numbers by Gender in Uganda, 1990-2002 {Source: Hospital records (LIRI)}

However, the trends in Kenya (Fig 7.3) follow a different pattern where, in some years there were more female than male patients much as the overall figures indicate that the male patients were slightly more than the females. This study postulates that the males may have either migrated to towns to look for

employment or are more involved in non-agricultural activities like the famous *boda-boda* (bicycle taxi) business common in the area, leaving women to work on the farms and thus were increasingly exposed to risk of HAT. Lay *et al.* (2007) lend their argument to this notion in a study on non-agricultural activities in western Kenya. They observe that lack of sufficient agricultural assets to sustain subsistence has led more males to take on non-agricultural activities, leaving the females to handle the agricultural activities.

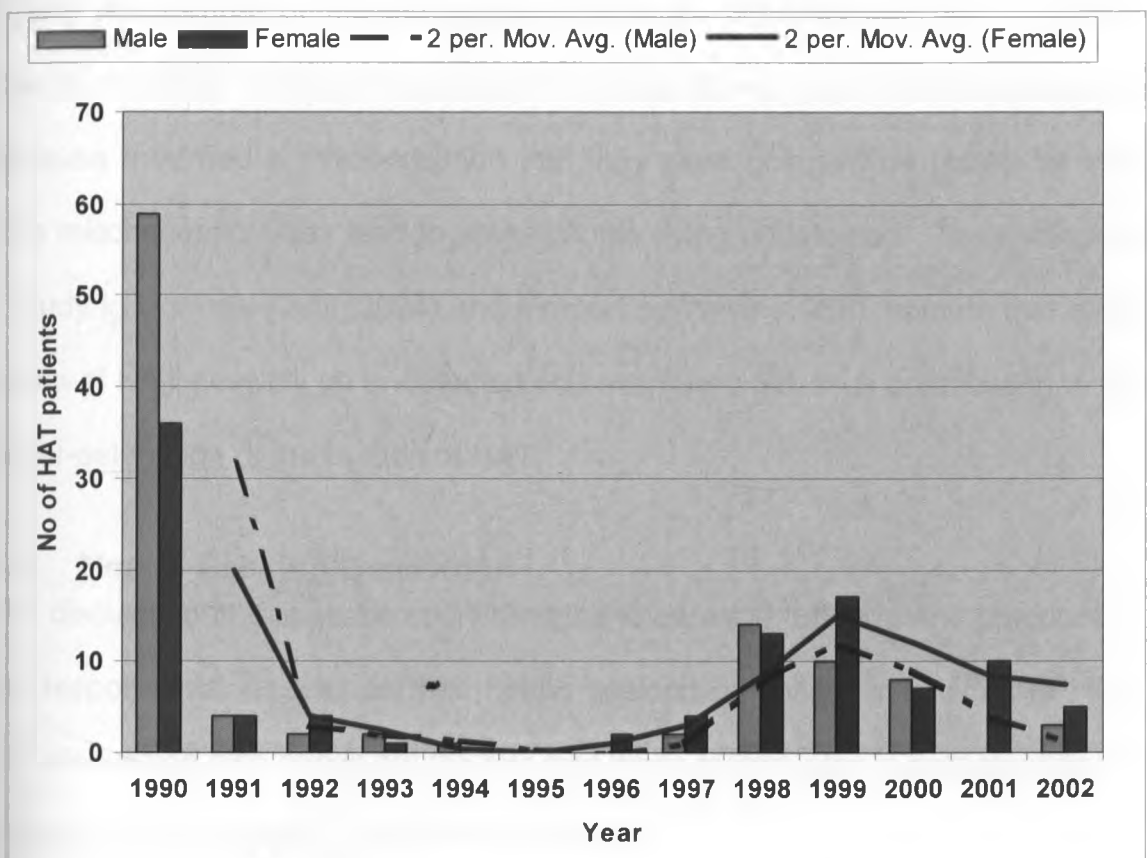


Fig 7.3: HAT Numbers by Gender in Kenya, 1990-2002 {Source: HAT database, KETRI}

On the other hand, may be the females were more responsive to the sensitization campaigns (Mwangi, 1996) carried out in the area and were therefore participating more in going for screening as opposed to the males. A

study on HAT in Cameroon (Asonganyi & Ade, 1994) found that generally, women tended to participate more keenly in case-finding sessions whose marginal goal was to detect cases among the asymptomatic population and hence concluded that women might have a better health-seeking behaviour than men. KETRI reports indicate that during HAT screening campaigns, more females than males present themselves at the screening centres and this may have contributed to more case finding among the females. Additionally, Mwangi (1996) reports that during the active surveillance activities for HAT in western Kenya, a number of people especially the males did not go for the free screening because they had a misconception that they were going to be tested for HIV. This misconception may lead to many people dying undetected. The findings of a study in Uganda (Odiit, 2004) and a report by WHO (1998), confirm that many cases of HAT possibly go undetected and eventually die, thus contributing to the under-estimation of the burden of HAT.

7.3 Health Seeking Behaviour

The discussion in this section concerns the knowledge, attitude and practices of the respondents, as well as their health seeking behaviour in relation to HAT.

The discussion also brings out the role that these factors play in perpetuating the impacts of HAT on individuals and households.

Perceived causes of HAT: When HAT initially emerged in the study area in the late eighties, a majority of the people neither knew about it nor its cause (Mwangi, 1996). The HAT patients reported that initially when they felt sick, the community members attributed their sickness mainly to HIV and witchcraft.

However, at the time of conducting this study (2003), the knowledge levels concerning its cause and symptoms were high (94%). This could be attributed to past experience with the disease and the education and awareness campaigns, which were carried out after previous disease outbreaks by Mwangi *et al.* (1998) and Okoth (1998) in Kenya and Uganda, respectively. Nonetheless, a few (6%) respondents still attributed HAT to witchcraft, blood transfusion and heredity.

Much as this percentage computed from the results of the formal survey may seem low, more respondents opened up during the in-depth interviews and reported that when conventional treatment from the health facilities initially failed, they ended up linking HAT to witchcraft and thus sought treatment from diviners. Mwangi (1996) also noted that in spite of the community members in Western Kenya correctly linking the disease to tsetse flies, the belief in witchcraft as the cause of the disease was still rampant. This is in line with a report on HAT in Lambwe valley (Welde *et al.*, 1989). A study on HAT in Niger (Touko *et al.*, 1997) and mental illness in Zimbabwe (Nyati and Sebit, 2002) also established parallel views. Linking the disease to wrong causes may have either led to inappropriate treatment or delay in seeking treatment. Kyomuhendo (1998) reported that linking HAT to sexually transmitted diseases especially HIV/AIDs, which some people believed are perpetrated by women, led some women to avoid seeking treatment lest STDs and/or AIDS were diagnosed.

Information received on HAT: This study shows that a high number of respondents had received information from health care personnel. This could be as a result of information that was given to the HAT patients while undergoing

treatment in the HAT hospitals. This study postulates this because the percentage of respondents (45%) who cited health personnel as their source of information on HAT almost corresponds to the percentage of respondents (42.2%) who had experienced the disease in their families. The health personnel (48.7%) and relatives (33 %) seem to have played a major role in not only disseminating HAT information but also in encouraging the sick to go to the HAT hospitals. The timely sensitization of health personnel and communities affected by or at risk of outbreaks of HAT may therefore improve HAT surveillance as also stated by Odiit (2004) in a study of health seeking by HAT patients in eastern Uganda. Subsequently, this may help reduce the adverse impacts of HAT by reducing its incidence and delayed diagnosis.

Lay terms used to refer to HAT: Among all the communities in the study area, the local name for the disease is a derivative of the word sleep, which is one of the main symptoms of the disease. For example, the *Iteso* refer to sleep as *kajo*, the *Abasamia* refer to it as *ndolo* while the *Japadhola* call it *nindo*. A report by Buguet *et al.* (2001) confirms that the disease (sleeping sickness) gets its name from the distorted sleeping patterns, which occur as the disease progresses. However, this can be misleading because people who are seen to be sleepy all the time are referred to as having HAT. This can have a negative impact in terms of seeking treatment because one may wait to start sleeping before seeking HAT treatment yet reports indicate that sleep is normally one of the symptoms of the late stage of the disease. At this stage, the trypanosomes cross the blood-brain barrier causing neural damage and host reaction, leading to the

classical symptoms of HAT, among them, irregular sleep patterns (Buguet *et al.*, 2001; Hide, 1999; Jordan, 1986; Molyneux and Ashford, 1983).

Perceived age at risk: In terms of persons at risk, the respondents reported that everyone irrespective of age were at risk of contracting HAT because the tsetse fly has no boundaries and bites indiscriminately. Abaru (1985) confirms this in his observation in Uganda that the young and energetic persons first became infected, but as the epidemic unfolded the older age-groups bore the brunt. He also indicate that all other age-groups were affected and attributed it to the closeness of contact between the fly and the local population. Conversely, further analysis of the ages of the recorded HAT patients indicated that the disease mainly affected people in the productive age group (21-50). This is confirmed by previous reports (Kuzoe, 1983; KETRI, 2004; Odiit, 2004) on HAT. When an active age-group in a population is affected, chances of socio-economic problems arising are very high and this impacts negatively, not only on the individual, but also on the household, community and country as a whole.

Perceived symptoms of HAT: The main symptoms of the disease as mentioned by the respondents correspond to recorded information about the symptoms of HAT (Molyneux and Ashford, 1983; Jordan, 1986; WHO 1996; Hide, 1999). Additionally the symptoms of the early stage of the disease are largely non-specific and are frequently associated with diseases like malaria, typhoid and HIV/AIDS commonly found in the area. Similar observations have been made by Jordan (1986), Hide (1999), Kuzoe (1993) and WHO (2001a), when they report that the symptoms of the early phase (nausea, fever, and lethargy) are

nonspecific and easily confused with those of other diseases such as influenza and malaria. This non-specific nature of HAT symptoms may present difficulties in early diagnosis of the disease leading to misdiagnosis, and to many patients presenting in the late stage of the disease or dying before proper diagnosis is done.

According to hospital records in the study area, a majority of the HAT patients presented in the late stage of the disease. Odiit (2004) also made similar observations in his study in southeastern Uganda. WHO (1998) and KETRI (2004) report that late-stage presentation of HAT is associated with increased risks of death and of transmission of the infected trypanosomes from the sick person to other individuals. This further perpetuates the socio-economic and cultural impacts of HAT on the individual and the household by causing problems related to long duration spent in hospital by the patient and care-givers during treatment and negative consequences related to death of the patient. Since late-stage HAT cases are expensive and difficult to treat, active surveillance, early treatment, and outbreak prevention can considerably reduce the HAT incidences and consequently its impacts.

Perceived capacity of health facilities to manage HAT: While most (99%) respondents believed that HAT could only be diagnosed and treated in a hospital, only a few of these health facilities within a 10 kilometre radius were well equipped according to the patients, to handle HAT diagnosis and treatment and this fear is not unfounded. A study in Western Kenya to assess the capacity

of health centres to diagnose and manage HAT confirmed that most health centres did not have the equipment or the personnel to handle HAT and thus the suspicion index of HAT was low, leading to frequent misdiagnosis (Sulo & Karuga, 2003).

Odiit *et al.* (2004) also state that delay in diagnosis was not only attributable to the patient, but also to the frequent failure of the local health personnel to diagnose HAT, among symptomatic patients, at first presentation. This could have been as a result of low suspicion index for HAT, or lack of adequate training on the part of the health providers. Due to the costs of staffing and equipping HAT treatment facilities, there are few health units equipped for diagnosing and treating the disease (Odiit, 2003). The inability of health care personnel to diagnose HAT may have led patients to resort to alternative health care, which the study postulates may have led to the greatly increased financial expenses that were spent on health seeking, besides spreading the infection to other household members, thus contributing to the socio-economic and cultural consequences of HAT on the households.

Health seeking behaviour: Almost all the HAT respondents went through a process of multiple and varied health seeking for diagnosis and treatment. About 70% of the HAT patients had tried three different options and more before correct diagnosis and treatment. The popular sector (Kleinman, 1980) was the first option utilised by almost half (48%) of the HAT respondents as they administered self-treatment using over-the-counter drugs. This is similar to findings in malaria

studies among some communities in the Philippines and Kenya (Miguel *et al.*, 1998; Nyamongo, 1998).

Use of health facilities featured next among the options first sought. Among the health facilities utilized, mission hospitals and private clinics featured prominently besides the government health facilities. Records from the HAT hospitals indicate that a reasonable number of patients were referred from the mission hospitals. The private and mission hospitals may have been utilized much due to their close proximity to the communities, availability of drugs and less waiting time. However, as Nair *et al.* (1997) indicate concerning tuberculosis, the poor patients may end up in public health services, mainly because they cannot afford to pay for prolonged care in the private sector.

Slightly more than half (51.2%) of the patients reported that they sought diagnosis and treatment using more than three different options before being correctly diagnosed and treated for HAT. This contributes further to delayed diagnosis, which has negative implications on HAT control, in addition to the HAT affected households. Furthermore, Kyombadde *et al.* (2000) indicate that the difficulties in detecting the trypanosomes in a patient may constitute an important problem for trypanosomiasis control programmes since the patients may remain untreated and serve as reservoirs of infection.

Delayed diagnosis: More than half the patients had symptoms for at least three months before they were correctly diagnosed for HAT. The median time lag from symptom onset to starting HAT treatment was between three and four months.

Treatment delays in this study are almost similar to those of previous studies carried out in Uganda (Odiit, 2004) and Kenya (Sulo & Karuga, 2003), which found that slightly more than half of the patients had a delay of at least 60 days before being correctly diagnosed. The delay from first awareness of symptoms to beginning treatment is a matter of considerable public health concern because delayed treatment had implications not only on disease outcome but also on the economic and social aspects of the patient and his or her household. In addition, because of delayed diagnosis, many patients were presenting in the late stage of the disease and thus had to be treated using melarsoprol (Freidheim, 1951), also known as Mel B, which is the first line drug for this stage. Melarsoprol has serious adverse effects and relapses and the duration of hospitalisation while undergoing treatment can last up to 40 days (Pepin & Milord, 1994). This causes a serious drawback for patients and their families.

Knowledge, attitude and beliefs play a significant role in the decisions that people make in solving their health problems and thus can help determine the impact of disease on them. These findings show that the health seeking behaviour of the HAT patients has a negative impact on the disease outcome and on both the patients and their households.

7.4. Socio-cultural and Psychological Impacts

The effects of HAT were not just experienced at the physical level, but also at the psychological and social level as discussed in the following sub-section.

7.4.1 Psychological impact

Psychological impact was common especially due to the Psychosomatic effects of the disease and the long-term hospitalization that made the HAT patients incapable of undertaking their daily chores. In addition, the fear they faced that they would be a burden to others or that in their absence their children/dependants would not be able to undertake their daily chores or fend for themselves worsened the equation. Fear of the unknown was common to most of the patients. The ultimate of the fears was death. As much as death is an inescapable, universal, and natural fact of life in our societies, the fear of death brings an ongoing anxiety into daily living. The HAT patients reported fearing the inability to predict what the future would bring and the process of dying. Studies on terminal illness such as cancer and AIDS (Smith *et al.*, 1984; Catania *et al.*, 1992; Hines, 2004) have elicited similar findings and as reported by Penson *et al.* (2005) fearing death is a rational response, which for too long, has been ignored by medicine and medical staff. The role of the health care provider in comforting and counseling patients and their caregivers would be important in helping the patients cope well with the disease and treatment.

7.4.2 Socio-cultural Impact

The Psychosomatic effects disrupted not only the HAT patient's daily life, but also that of the other household members. The inability of the HAT patients to perform normal daily tasks put pressure not only on them but also on their households. Other members of the family were forced to take up the patient's responsibilities, thus disrupting the normal functioning in the household.

Kyomuhendo (1995) observed the same in a study on HAT in south-eastern Uganda. Furthermore, reversal of roles occurred as some husbands were forced to cook and take care of the children when their wives were sick, women were forced to take on the role of the bread winner while children took on adult roles, robbing them of their childhood.

Effect on men: Men's role as bread winners were compromised by the illness creating difficulties in providing financial assistance to the household thus undermining their social roles and social values. The social and ideological role in Africa views men as breadwinners (Silberschmidt, 2005). Consequently, men who are affected by HAT cannot fulfill their breadwinning role and thus their status as heads of household is seriously challenged. These findings authenticate those from similar studies on HIV/AIDS (Barnett & Blaike, 1991 ; Barnett, 1994) which concluded that the changes in the social system as households adapt may involve the break-up of families leading to a growing number of female-headed households.

Effect on women: Kleinman (1989) states that the family is the main domain of health care in the popular sector, with women commonly providing the health care. This statement is confirmed by findings from this study which indicate that the immediate family and more so the women were the main care-givers for HAT patients. This also corresponds with other studies on mental health (Nyati, 2002), epilepsy (Nkwi & Ndonko, 1989), Tuberculosis (Geetharamani, 2001), Malaria (Kimbi *et al.*, 2005) and HIV/AIDs (Barnett *et al.*, 1995). In line with this, in households where the men were sick, women's burdens and responsibilities

were increased as women were forced to take on double roles as care-givers and breadwinners. This is in line with a report by Boserup (1980), which asserts that socio-economic change and breakdown of traditional social institutions in Sub-Saharan Africa have left women in a disadvantaged and vulnerable situation with increasing burdens and responsibilities. Furthermore, in situations where the breadwinner died, women were forced to take on the role and responsibility of the breadwinner. This has led to the emergence of female-headed households and is posing challenges to orthodoxy, male hegemony and patriarchy (IFAD, 1999).

Traditionally, in many cultural set-ups there were activities and roles that a male member of the household had to play for the smooth running of the family. Therefore women in female-headed households may encounter daunting problems as they try to represent their households in domains that are culturally defined as male. In addition, a woman on assumption of the headship of the household finds herself in a new world of challenges where she has to confront social, economic, psychological, child related and other problems. She has to face stiff opposition from other quarters and she is at a disadvantageous position compared to her counterparts in male-headed households (Vardhan, 1999). Nonetheless, many of these women have taken control over their own lives and are working hard to try and surpass boundaries and limitations as also confirmed in a report on female-headed households in Iran (Kristiansen, 2003).

Effect on children: The illness or death of parents or guardians from HAT robs children of the emotional and physical support that defines and sustains childhood. It left a void where parents and guardians once provided love, protection, care and support. The children were frequently left in the care of their grandparents who, mostly, due to harsh social or economic conditions were unable to assume the additional responsibilities of these families and children affected by HAT. Some children therefore spent their childhood providing care and assistance and taking responsibility of the running of the home. Similarly, Ngwira *et al.* (2001) and Nyambedha (2006) observed that children whose parents were sick or died of HIV/AIDS become decision-makers, responsible for the social and economic future of the family, and filled these roles without the physical and emotional protection, guidance and support that they deserved. The foregoing implies that children were not allowed to be children and thus missed out on their childhood, which in turn affects their future as adults. Furthermore, the care that older siblings can provide for younger children is likely to be inadequate because of the increased poverty of the household and the lack of maturity and experience of the caretaker, leading to poor health, hygiene and nutrition; absence from school, and developmental delays. This is comparable to findings from other studies on the impact of HIV/AIDS in Africa (Barnett & Blaike, 1991; Monasch & Boerma, 2004; Corrigan *et al.*, 2005). Noteworthy, girl children were more affected when they had to take on responsibility of the sick or dead parents and thus miss out on school or drop out all together and some opting to get married at a young age. In the absence of alternatives, more and younger

girls marry early as reported by Ngwira *et al.* (2001) and UNICEF/UNAIDS (1999) in studies on HIV/AIDs in Malawi and Eastern and Southern Africa, respectively.

Impact on reproductive health: Sexual virility is a central feature of the “masculine mystique” that is part of male programming in many cultures and many traditional norms and values defining men and masculinity are still deeply embedded in most men. Thus, the men who experienced reduced libido as a result of HAT found themselves in an awkward and embarrassing situation. This is because notions of masculinity are closely associated with male honour, which is equivalent to virility, sexuality and sexual performance as, also noted in studies done in other parts of the world (Cornwall & Lindisfarne, 1994; Connell, 1995; Silberschmidt, 2001). Men who have lost their libido may experience loss of self-esteem and may live in fear of divorce by their spouses or may actually undergo a marriage break-up. Reduced libido may therefore have a negative impact on the family relations. However, the cause of the reduced libido in men is not quite clear and more studies need to be done to find out the relationship between HAT and reduced libido or sterility.

On the other hand, miscarriage was common in women who suffered from HAT when they were pregnant. The miscarriage from HAT could be attributed to the effects of both the HAT parasites and the toxicity of the drugs used in its treatment. Molyneux and Ashford (1983) report that the drugs used especially in the late stage of the disease are toxic and often lead to fatal complications.

Miscarriage may have had psychological consequences on the women who experienced this as exemplified by Patton & Wood (1999), that miscarriage may

trigger many personal issues about a woman's fertility, her identity as a parent or her relationship with her partner, and her own attitude to life and death. Gender socialisation dictates that having-children is essential for women to be seen as complete. Therefore, the clash between social pressure to reproduce and the experience of miscarriage amongst other reproductive difficulties may lead to a variety of psychological phenomena. Similar observations have been made by other studies on reproductive difficulties faced by women in other parts of the world (Zucker, 1991; Watson, 2006). Moreover, throughout Africa, failure to bear a child has long been a major cause of divorce or of men marrying additional wives (Chojnacka, 1980; Gage-Brandon, 1992)

Mental problems: A number of the HAT patients experienced some form of erratic behaviour during illness though some continued to experience the same even after treatment. Moreover, Robays *et al.* (2007) also identified personality changes and behaviour problems arising from HAT and further reports that former HAT patients are not taken seriously even after successful treatment and cure because of the loss of decorum they suffered during the disease. The disease, like malaria, affects the central nervous system especially when the parasites have crossed the blood brain barrier and this may cause the erratic behaviour observed before treatment. However, the erratic behaviour observed during and after treatment may be as a result of the drugs used to treat the disease. The arsenical drugs used in the treatment of the second/late stage of disease should ideally lengthen the productive life of infected individuals if effective, allowing them to continue with their daily activities. However, this study indicated adverse drug reactions, which may be long-term and even permanent.

These include drug related encephalopathy and even death. Mental problems were mostly noted in children even long after treatment. In line with these findings, studies on HAT in children in Cameroon (Cramet 1982; Aroke *et al.*, 1998) reported that children treated with melarsoprol had slow psychomotor development, psychoneurotic disorders and reduced physical growth and sexual maturity. The mental effects were more common in male than female children. It is not clear, however, whether this difference is attributable to gender related exposure, sex hormones or genetics. This warrants a more detailed study.

The children who still exhibited signs of mental problems were reported to have been discharged when the HAT treatment was completed though the mental problem was still persistent. This implies that the children may have been discharged after the parasites cleared in their system, but still had an additional problem-mental that was not tackled at the hospital. In accordance with the WHO definition of health, these children were probably discharged from hospital when they were still not healthy and this may have led to the problems they and their families faced thereafter making their reintegration back to the community difficult. This therefore exacerbated the negative impacts of HAT on the affected households.

Caring for a mentally affected patient is demanding on the caregivers and households, altering family and social structures and individuals who assume the caring role, and power dynamics within the household (Isiugo-Abanihe, 1994).

The multiple roles assumed by women who were the main caregivers of the affected children created an excessive burden making it difficult for them to

maximally engage in their daily chores and other economic activities. They and their families had to deal with the stress of coping with disturbed behaviour, disruption of household activities, restriction of social activities and even bear the negative impact of stigma and discrimination. The fact that up to 90% of the care due to illness is provided in the home by women and girls (UNAIDS, 2007) aggravates the situation for the female gender, as girls are taken out of school to provide care and women's workload increases, making them more dependent on others.

Stigma: Some members of the community, who by then attributed HAT to witchcraft or HIV/AIDS, stigmatized HAT patients who exhibited mental problems. This stigmatization may have caused some families to hide their patients from the public eye thus compounding its severity and its effects on the household. Stigmatization and its effects have also been documented for several other diseases (Vlassoff & Bonnilla, 1994; Vlassoff *et al.*, 1996; Vlassoff *et al.*, 2000) and found to affect the sick in terms of access to health services, basic rights within their communities and ultimately the severity of their condition. Self-enacted stigma was also common as patients isolated themselves from others for fear of being a social embarrassment. AIDS stigma has been found to affect preventive behaviours and perception of treatment of people living with HIV/AIDS by communities, families and partners (Gerbert *et al.*, 1991).

Conflicts: Conflicts both within marriages, families and the community arose due to various reasons. Erratic behaviour in some patients led to disagreements and marital conflicts among spouses who could not stand the behaviour of their sick

partners. The sick children who experienced mental problems also had problems fitting back into school and were frequently engaged in fights with other children. This may have made some of the HAT affected children drop out of or be withdrawn from school because they could not cope.

Marital conflict also arose when the HAT patients could not perform their conjugal obligations. This almost caused a rift in some marriages as also described by Robays *et al.* (2007) in the DRC. A study on dementia patients and quality of their marital relationships (de Nugt *et al.*, 2003) also identified that deterioration of marital relationship quality was specifically associated with the presence of behaviour problems in the patient. Such conflicts may contribute to break-up of families and subsequently lead to disruption of social set-ups and functioning of households.

Conflicts also arose due to misunderstanding of the cause of HAT. Marital conflicts arose when spouses would accuse their sick partners of having brought AIDS and hence death to the home. This is in line with a report (TDR, 1997) that indicated that some members of the HAT endemic communities believe that HAT is closely linked to sexually transmitted diseases (STDs), especially HIV/AIDS and believe that women perpetrate STDs. However, the present study revealed that it is not only the women who are blamed for bringing AIDS, but men as well.

Conflicts between the HAT affected individual, households and the non-affected also arose as accusations of who bewitched who were traded. Families that did not have a HAT patient were accused of having bewitched the whole village and

were thus not in good books with the rest of the community members leading to interpersonal tensions. Witchcraft often linked to supernatural forces, has been used to explain virtually any illness which is sudden, whose cause is mysterious or cannot be cured by modern medical science and technology (Tembo, 1993; Bever, 2000). Tembo (1993) further reports that accusations related to witchcraft are believed to be responsible for conflicts among close social acquaintances and relatives, leading to mindless death and extreme social discord through persecution of innocent people. The findings of the present study, indicating that bewitching accusations elicited strife amongst co-wives and close relatives is in accord with other reports (LeVine, 1962; Galt, 1982) suggesting that suspicions of witchcraft is common among co-wives. The conflicts that arose due to suspicion of witchcraft caused disruptions in interpersonal relationships leading to bitterness and hatred. These social tensions as a result of accusations of sorcery caused by HAT were also described by Gouteux and Malonga (1985) and Robays *et al.* (2007) in DRC.

Lack of resources also caused conflicts in the households as the meager resources were diverted towards health seeking and care. Some female children, annoyed with their parents for not providing their school fees, opted to get married as a solution to their economic problems. In so doing, they were perpetuating traditional beliefs that view early marriage as a strategy for economic survival. UNICEF (2001) reports that according to some traditional sets of values, early marriage of girls lingers on as a culturally and socially sanctioned practice, used as a strategy to pass the economic burden for their

care to others. Nonetheless, these girls involved in early marriages may have to contend with profound physical, intellectual, psychological and emotional impacts, besides cutting off educational opportunity and chances of personal growth. In addition, Barton & Mutiti (1998) contend that early marriage for girls implies premature pregnancy and childbearing, and is likely to lead to a life-time of domestic and sexual subservience over which they have no control.

Conflicts at whichever level had a negative impact on the family, household and the community. Family relationships were strained endangering marriage stability that could have led to divorce. The social costs to the family in terms of disrupted organizations and family life, social avoidance because of HAT and mental manifestations were quite rife in the affected communities.

Death: Though reported deaths were few, this does not negate the fact that there may be underreporting. A study by Odiit (2003) established that for every one reported death of HAT, in southeast Uganda, twelve deaths went undetected. Additionally, a report by WHO (1998) indicates that the number of cases reported annually is over 40,000 while the actual number of cases is estimated at about 300,000 cases annually, implying high level of under-detection. The implications of this are that many deaths could have occurred in the study area, disrupting the normal functioning of households and communities by robbing them of key personalities, important in undertaking significant social roles.

From the foregoing, the disease carries with it vast social and emotional effects which impact negatively on both the family and the community, disrupting their social functioning.

7.5 Socio-economic Impacts

The impact of disease epidemics on patients and their households are incremental and worst hit are those communities that are already poor with inadequate infrastructure and limited access to basic services. HAT had a negative impact on households by affecting their socio-economic base as discussed in this section.

7.5.1 Financial Burden

The research findings indicate that the occurrence of HAT in a household had diverse socio-economic implications on the patients, their households and the community as a whole. Since it is problematic to discuss the socio-economic impacts on the individual without drawing from the household, this discussion focuses on both as a unit. In doing so, I follow Berman *et al.* (1994) and Sauerborn *et al.* (1995) who report that the household is preferred as a unit of analysis for assessing the economic costs and consequences of illness, because decisions about treatment are based on negotiations within the household (but not necessarily from an equal bargaining position). They further assert that the costs of illness do not only fall on the sick but on other household members who care for the sick and accompany them to get treatment. This cost also affected the household budget, which had implications on the resources available to other members.

A majority (91%) of the households faced financial constraints while trying to deal with the HAT problem. These constraints were brought about when households sought treatment from many different sources before being properly diagnosed for HAT and, as a result, incurred a lot of direct costs. Diagnosis of HAT is difficult (de Atouguia & Kennedy, 2000; Hide 1999), especially in its initial stages since its symptoms are similar to many febrile illnesses that are common in the study area. Furthermore, many hospitals within the foci are not well equipped with the necessary equipment and human resources to diagnose the disease. In Kenya there is only one hospital, Kenya Sleeping Sickness Referral Hospital-Alupe that is well equipped to diagnose and treat HAT. In southeastern Uganda, two hospitals, LIRI and Busolwe, can treat while five additional health facilities are equipped to diagnose the disease. However, delayed diagnosis was still common, contributing to many patients presenting to the HAT hospitals in the late stages of the disease. This delay in diagnosis caused patients and their households to try out many alternatives of health care leading to increased expenses on treatment seeking.

The costs of HAT drugs are currently met by the World Health Organization and hence the free treatment for HAT in the hospitals (Odiit, 2004). Nevertheless, the results of this study indicate that patients often sought treatment from a range of private providers before attending the HAT hospitals and health centres for proper diagnosis. In addition, even when they visited the HAT hospitals where treatment was meant to be free, often, there were “hidden” non-medical treatment costs mainly for transport and special foods such as fruits and high

protein foods. Therefore, the direct costs incurred by patients and their households included all expenses that were linked to seeking and obtaining treatment, including medical and non-medical expenses such as transport or special foods such as fruits. Molyneux and Ashford (1983) report that people suffering from HAT have increased nutritional requirements of up to 50% greater for protein and 15% for energy. The pressure on the households to purchase these special foods was great and this forced many households to look for ways of coping with the increased expenses.

Almost all (93%) the HAT patients incurred direct costs in terms of expenses for seeking treatment. The results indicate that many respondents spent up to 8,000 Kenya shillings. These are very high expenses considering that about 80% of people living in the foci live below the poverty level and earn less than a dollar per day (GOK, 1999). The ramification of this is that HAT continues to ravage people who are already living in abject poverty.

Additionally, HAT in some cases affected more than one parent or household member. This is due to the nature of transmission that is associated with socio-economic activities within a tsetse fly infested foci (Okia *et al.*, 1994; Meda & Pepin, 2001)). There is frequently a familial clustering of illness and death that pushes the household into a downward spiral of impoverishment. Karuga *et al.* (2005) reported that out of the past HAT patients treated at the HAT hospital in Kenya, about 29% were related and most were from one of the villages, Apatit, where part of this study was conducted. About 25% of the related patients had more than one sick relative. Having more than one patient in the household

further compounded the socio-economic impact of the disease, increasing the financial expenses on seeking treatment, buying nutritious foods, and thereby further burdening the household members in terms of time taken in providing care.

Indirect costs: Both the direct and the indirect costs of HAT were important in assessing its socio-economic impact on the households. Other socio-economic studies carried out on other diseases have also included the direct and indirect costs in their assessment (World Bank, 1994). However, according to Chima *et al.* (2003), the scope of indirect costs included in studies varies and can include the time spent seeking treatment by the patient and caregiver and the morbidity time during which the patient or caregiver stops or reduces his/her productive activities.

In this study, financial constraints were also experienced when the patients and, by extension, their households could not continue with their normal economic activities and this led to the indirect costs of illness. These included the loss of productive time due to illness for both patients and caregivers. Care for the sick was primarily a household and family responsibility as reported in this study, with the burden falling heaviest on women who lost a lot of productive time on giving care. Similar findings were observed by Barnett *et al.* (1995) who reported that according to the gender systems, women, who are the traditional caregivers, spent a considerable amount of time taking care of the AIDS patients.

Women lost more days in foregone labour and income because in general they work longer hours than men, performing both productive and reproductive activities, and were the main caregivers within the household. Invariably, when women were ill other productive members of the community, particularly female relatives, were drawn out to provide caretaker services. This is especially so due to the overstretched facilities in treatment centres.

Due to the prolonged hospitalization while undergoing HAT treatment, people suffering from HAT had reduced capacity to participate in productive activities including income generation and gainful employment. This is potentiated by functional incapacities and increased dependency that also drains household resources (Kuzoe, 2001; WHO, 1998). Some patients lost their jobs as a result of being away for a long duration while for others, their businesses stalled thus causing them to lose their sources of income. The quantity and quality of labour was further affected as members of the affected households spent time looking after the sick and less time in agricultural pursuits. This implied that households had to find a way of coping with the new situation of decreased income and increased expenditure on health.

Death: Death was the ultimate outcome of HAT as a number of households lost family members. In addition, the death of a family member put a strain on the already impoverished households as they were faced with the impending task of giving their relatives a decent burial. Financial expenses increased as funerals demand preparation of meals, entertainment and expensive burial ceremonies.

The effects were more severe on households that lost a breadwinner and by extension, foregone income earning opportunities. HAT mainly affects the productive age group and therefore death robs the family of the main support pillar leading to the threat of families and education of children (Shaw *et al.*, 2001). Forsythe and Rau (1996) opine that the death of one or both parents triggers a host of sociological, economic and psychological effects on the children.

The communities were also affected by the death of HAT patients. This is because the death of a community member usually calls on community members to show solidarity with one another in terms of contribution of money and other items, and spending time with the bereaved family. Considering that most funerals in the study area could be prolonged for up to seven days, there was loss of quantity and quality labour for agricultural and economic activities. Russell (2005) reports that in the case of AIDS morbidity and mortality, other members of the society are also affected, for the 'time spent visiting the sick or at funerals is in a way a subscription to society and thus enables the family to claim benefits in return, during times of hardship.

7.5.2 Coping Strategies

Coping strategies can be defined as a set of actions that aim to manage the costs of an event (shock) or process that threatens the welfare of some or all of the household members. Ultimately coping strategies are seeking to sustain the economic viability and sustainability of the household (Sauerborn *et al.*, 1996). In this case it describes how individuals and households mobilised to cope with

illness costs. It has become a frequently used term in development literature, initially highlighted by work investigating household responses to famine and then to structural adjustment programmes (Moser, 1998). The coping strategies led to the following impacts on households.

Loss of productive labour time: The socio-economic impacts of HAT as revealed in this study are similar to those of other debilitating illnesses described elsewhere in eastern and southern Africa (World Bank, 1994). The loss of adult labour leads to a suite of changes in affected households' use of land and other resources. Agricultural activities were often delayed, with negative effects on production, and land was often left fallow. Corey and Muula (2004), in a study on HIV in sub-Saharan Africa, report that surviving household members may be under increased pressure to seek agricultural labour, paid in cash or kind or may pursue non-agricultural income generating activities that yield a quick return. In the Busoga foci, the HAT epidemic contributed to this problem, because adults who were absent from home for long periods to nurse sick relatives in hospital could not properly care for and guard their own fields and animals. Similar studies (Kimbi *et al.*, 2005; Fox *et al.*, 2004; Getaw, 2001) also reported increased socio-economic impact due to loss of productive labour time.

Loss of household assets: Loss of labour was not the only immediate effect of morbidity and mortality caused by HAT. A host of expenses were incurred during the illness, at a time when income was also reduced. The various customs surrounding adherence to expensive cultural alternatives to treatment, for example, *egwasit*, *emisebee* or *adingo* or funerals, further created demands on

the affected household's savings and assets. This left few resources or none at all that could be devoted to agriculture. The low level of public health care system also led people to seek health services in parallel systems and especially from traditional healers/diviners, whose fees were generally exorbitant. At the time of death, there were expectations to spend lavishly to appease the spirits so that death could be cleansed from the village. This further played a role in increasing the financial strain already caused in the households.

The study revealed that a substantial number of households that were affected by HAT and that had disposable assets including reserve food stocks (80%) were forced to sell them, 64% reduced extent of cultivations, 54% borrowed/begged from family members, 26% took loans, 22% sold alternative family assets and 17% depleted savings. Selling in distress meant that the returns were meager and also contributed to increased indebtedness. This is in line with the findings from a global study on the economic and social burden of malaria (Sachs & Malaney, 2002).

The sequence of responses to illness and death, reduced production, shift to less demanding and remunerative enterprises, sale of assets, and indebtedness resulted in deepening impoverishment for many afflicted households.

Intra-household labour substitution: The families who were forced by the nature of treatment of HAT to leave their children in charge of the home while they were in hospital, lost important assets like land, livestock or household goods. The vulnerability of children left to become decision makers, responsible

for the day to day running of the home, exposes them to being taken advantage of by other adults. Forsythe and Rau (1996) in a study on HIV/AIDs in Kenya, reported cases of children being taken advantage of by adults who either grabbed or swindled them out of their property. Critical agricultural resources were thus lost by the affected households, further deepening impoverishment. Reduced production, consumption and income as a result of prolonged illness put household members other than the person with HAT at risk of malnourishment since reserve food stocks were the first to be disposed of in order to meet both the direct and indirect costs of treatment. Women in particular were left with few means to secure their own and their family's living than to burden their own extended families or seek alternative means of survival such as providing labour in other people's farms for a fee.

With limited or no welfare safety nets as attested to by some respondents, HAT imposed high costs on individuals and households over time due to regular treatment seeking and incapacitation of the sick. The high costs of illness associated with HAT, often went beyond most households' monthly budget. The strategies adopted to meet these costs were relatively risky coping strategies to mobilise substantial additional sums of money. From this study, the overwhelming impression is that the cost burdens of HAT can be extremely high for poor households, forcing risky coping strategies that reduce their asset portfolios, increase vulnerability to future shocks and posing questions about the sustainability of 'coping' strategies.

7.5.3 Food Insecurity

HAT is a health problem with profound socio-economic implications, including its effect on the ability of households to acquire enough nutritious foods for household members. HAT resulted in or contributed to exorbitant health care costs, labour shortages, a decline in household asset base, breakdown of social bonds and loss of livestock. All these effects contributed to food insecurity.

The main economic activity of communities in the Busoga foci is farming as attested to by 78% of the respondents. Furthermore, the farming system in this foci is labour intensive and draws its labour from the households (Mbulamberi *et al.*, 1989). Problems therefore set in when the labour force required to work on the farms was either lacking due to weakness caused by illness, or was diverted to caring for the HAT patient. This implies that there was a shortfall in the labour required to work on the farms thus leading to poor harvests or none at all. Okorosobo (2000) and Gelaw *et al.* (2001) report that HIV and Tuberculosis, respectively, lead to shortages of able-bodied adults, particularly in the peak seasons of planting and harvesting, resulting in low agricultural yields.

Households are said to be food-secure when the following four elements are in balance with each other: food availability, equal access to food, stability of food supplies, and quality of food. For rural households, the equitable availability of stable quantities of nutritious food depends on food production (often using family labour, land, and other resources), food purchase (using household income), assets that can be quickly turned into food or cash as necessary, and social claims on extended families through custom and societal structures such as

community social networks (FAO, 1990).

HAT morbidity and mortality therefore affect food security by reducing the household's ability to produce and buy food, depleting assets, and by reducing the insurance value of social networks as the household consistently calls in favours (Kyomuhendo, 1995). HAT morbidity affects agricultural productivity by affecting labour availability, and forcing households to reallocate labour from agriculture to patient care, while mortality permanently removes adult labour from the household leading to foregone opportunities. This combination of adult morbidity and mortality and the associated reallocation and withdrawal of labour led to a number of adverse changes, which led to food insecurity:

Loss of livestock: This study found that livestock was sold to generate cash for patient care, and in some cases the livestock was slaughtered for consumption during funerals yet some animals either died or were lost because of poor management. When households lose livestock, they also lose fertilizing manure, milk for the family, and "ambulatory" savings in addition to oxen for ploughing. Most farmers in the Busoga fōci depend upon draught power to prepare their land for cultivation. In the absence of the oxen which were either sold, slaughtered or died, the size of land put under cultivation was grossly reduced, leading to relatively low production and hence food insecurity (PAAT, 2000; Connor, 1994).

Loss of farm management resources and skills: Subsistence agriculture requires the interaction of human, financial, and physical resources, and all adult

household members contribute to this interaction in some way (FAO, 1990). Nevertheless, HAT contributed to a breakdown of the chain when both adults were away, one sick and the other as caregiver. As a result, the children who were still immature were compelled to embrace adult responsibilities such as farm management while yet lacking in skills and knowledge on managing family enterprises. This situation was further compounded by their lack of an ability to draw from social networks, experience, and physical strength, often remaining hungry. This possibly led to them getting malnourished. A similar situation has been observed for HIV/AIDS patients in Senegal (Niang and Van Ufford, 2002).

Inability to earn income: By affecting adults, the key earners of non-farm income, HAT dramatically reduced households' earning power and, therefore, their ability to buy food and related goods and services. Illness and funerals forced households to spend most of their cash savings on care, treatment, and other expenses, with adverse consequences for food availability. Furthermore, the available food stocks held in reserve were also sold to meet the cost of seeking treatment. The results of the study also showed that family members of HAT patients were not only consuming fewer meals but would sometimes sleep hungry since there was no food available and they were often too young to work for an income. This was especially true of young children whose parents were either both sick or were away in hospital.

Loss of assets: Food security hinges on the presence of household assets, which create a buffer between poor years of crop production, on the one hand, and consumption and exchange for needs, on the other. In times of need, assets

such as livestock, land, trees, and even furniture can be readily converted into cash to buy food. Households often accumulate assets as an insurance strategy, but HAT forces them to dispose of their assets. Livestock, agricultural produce and household assets were sold, while land was leased out to help meet the increased medical expenses. These “robbed” households of their security and buffer for use during tough times like when crops fail and there is little food. Impoverishment of households and their long-term vulnerability are also reported in Chand *et al.* (2004) in respect to tuberculosis in India.

Increasing dependency: HAT results in a heightened level of dependency for external sources of support. Some married women had to turn to their parents to assist in terms of taking care of their small children, while they were away in hospital as caregivers to sick husbands for prolonged periods. Similarly, some men were forced to depend on their extended families for food since they did not have time to work on their farms, let alone prepare food. All the above in turn put a strain on the social networks and extended families. This study found that households headed by survivors, notably widows and orphans, were more highly dependent on outside sources of support, further compromising their access to food. A report by Forsythe and Rau (1996), in harmony with this, argues that orphans and widows are denied the right to inherit land and hence left with no property, thereby forcing them to depend on others for their survival.

7.6 Socio-economic Impact of HAT on Children

Impact on education: HAT affected the academic performance of both children who got infected and those who did not. Those who were infected were absent

from school many times while seeking treatment, and for an additional period of about two to three months while undergoing treatment. This meant that they were absent from school for prolonged periods, thus adversely affecting their academic performance. Studies by Kimbi *et al.* (2005), Barnett and Haslwimmer (1994) on malaria in Cameroon and HIV/AIDS in eastern Africa, respectively, reported similar findings. Classical symptoms of HAT, according to Hide (1999), include: disruptions of biological rhythms, inappropriate and irregular sleep patterns, and loss of concentration and coordination. This explains why some HAT affected children had problems with excessive sleep and loss of concentration during class. The "sleep" symptom of HAT affected their attendance and performance in class due to the teasing, embarrassment and punishment they faced from teachers and students. This causes heightened emotional trauma and stigma that in turn impacts on their aptitude, affects concentration and hence deteriorates academic performance. Gwen *et al.* (2005), Swartz and Gorman, (2003) and Sharp (1995) also made similar observations in their study on bullying and its effects on academic achievements of victims.

On the other hand, non-infected children were also affected by virtue of having a HAT patient in the home and the impacts were more adverse when the HAT patient was also the breadwinner. This is because, many times the breadwinner happened to be the father and once incapacitated by illness, then household income was also affected. The implication of this was that children were either withdrawn from school or sent home for lack of school fees and thus being forced to be absent from school for many days. Absenteeism as we know affects school

performance as was also revealed in this study. Other children stopped schooling temporarily when they were forced to take on adult roles and take care of the home and their siblings and this adversely affected their school performance. A review of data from studies in Kenya on the impact of malaria on performance and learning also revealed similar observations (Holding and Snow, 2001).

A number of the children who were both affected and infected eventually dropped out of school either because of lack of school fees or poor performance. Many others had to repeat the same class and thus lagged behind as their classmates moved on to the next class. Similar findings have also been reported in studies on socio-economic impacts of other diseases, for example, HIV/AIDs (Edmonson *et al.*, 1994) and tuberculosis (Geetharamani *et al.*, 2001). Female children are particularly more affected when they resort to or are forced to drop out of school and get married in order to supplement family income as a way of coping with the great financial strain experienced by their families while trying to deal with HAT.

In this way, the father's disease results in an increase of stress for young girls and was found to be a serious impediment to their studies, and a possible cause of school dropout. Again, when the mother herself is sick, the situation worsens because her daughters will have to take care of her (Barnett & Blaike, 1992). Finally, in situations where the mother cares for an ill child, the burden of her domestic chores is borne by her daughters or by other girls who live in the same compound (Niang & Van Ufford, 2002).

CHAPTER EIGHT SUMMARY AND CONCLUSION

8.1 Introduction

The main objective of this study was to establish the socio-economic and cultural impacts of HAT and the coping strategies of households in the Busoga focus. The study set out to assess the effects of HSB on HAT affected individuals/households, to determine the socio-cultural impacts of HAT on affected households and to establish its socio-economic impacts on such households. A summary of the main findings is presented in the next section.

8.2 Summary

The framework in Fig 8.1 summarizes the findings of this study. It is a modified version of an amalgamation of two frameworks (Hausmann-Muela *et al.*, 2003 and Russell, 2004). However, it mainly draws from the conceptual framework for analyzing the economic burden of illness for households (Russell, 2004). The original conceptual framework by Russell was derived from studies that investigated the household cost of illness, coping strategies and their economic consequences at the household level. Russell's framework is applicable to this study save for the fact that it does not include the socio-cultural impacts of disease, which go hand in hand with the economic impacts to influence the health seeking behaviour of HAT patients. The present study therefore built upon Russell's framework to encompass the socio-economic, cultural and psychosomatic impacts of HAT on households. It also borrowed from the vulnerability spiral of Hausamann-Muela *et al.*, (2003) to show a connection between socio-economic impacts of HAT and a favourable environment for tsetse flies infestation.

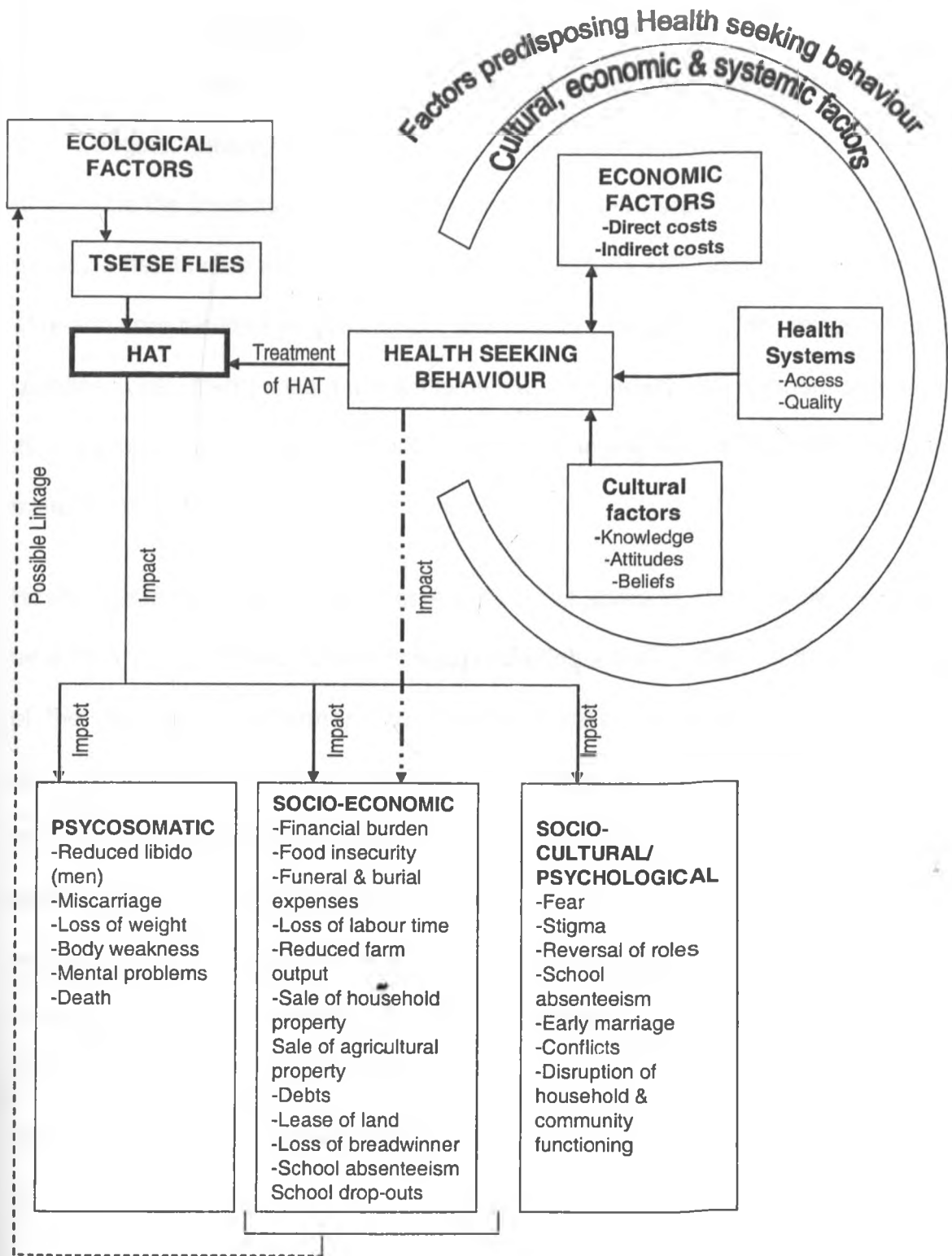


Fig 8.1: Socio-economic and Cultural Impacts of HAT

The incidence of HAT begins from a favourable ecological environment for infected tsetse flies to thrive. Once a person is bitten by an infected tsetse fly, illness begins, leading to Psychosomatic impacts at the individual level. In order to alleviate the impacts of HAT, patients have to seek treatment from the available health care sources. These sources include self-treatment, treatment at health care facilities in government and private clinics/hospitals, mission health facilities, local pharmacies and traditional healers. Health or treatment seeking is itself a product of convergence of several predisposing factors, including health systems as well as economic and cultural factors.

Health systems: The quality of care in terms of ability to correctly diagnose and treat HAT was identified as an obstacle to finding a HAT patient at an early stage of the disease. Furthermore, the quality of care and access to health care services influenced where people sought treatment. Most patients sought treatment in health facilities near them and reported that most of these health facilities were not well equipped to diagnose or treat HAT. When treatment from one facility was perceived to have failed, households sought alternative facilities or sources for treatment hence applying a trial and error search for treatment. The median time lag for starting HAT treatment was between three and four months and much of this lag is attributable to the health service provider's failure to diagnose HAT. Moving from one provider to another delayed the diagnosis and the start of treatment. This also increases the severity of the psychosomatic impacts on patients as well as health seeking costs to their households.

Economic: The high cost of seeking treatment contributes to high costs of HAT. Direct costs (directly related to seeking treatment) and non-medical costs (such as transport or special foods) burdens were exacerbated by the widespread use of multiple health care options. These costs are among the most commonly mentioned obstacles to adequate HSB of the poor for obtaining prompt and adequate treatment and access to preventive measures. On the other hand, the health seeking behaviour of the patients and their households such as seeking treatment from multiple sources and moving from one provider to the next, affected the economic base of the households by increasing their financial expenses on health, causing them to resort to coping strategies.

Cultural: The disease was also sometimes erroneously attributed to HIV/AIDS or witchcraft, causing patients to be stigmatized. This leads to adverse social and economic effects on HAT affected households. This wrongful association of the cause of HAT to HIV/AIDS or witchcraft leads to delay in seeking treatment thus perpetuating the negative effects of HAT on the individual. The HAT infected individuals, being a source of new infections, further affects the health of other household members.

HAT itself, if not treated early, has serious implications on the patient and his/her household. The most direct impacts result at three levels: Psychosomatic, socio-economic and socio-cultural/psychological.

Psychosomatic impacts: The Psychosomatic effects affected the HAT patients as individuals. The current study has identified a number of these effects. They

include reduced libido for men; miscarriage in women; loss of weight; body weakness and mental problems/erratic behaviour and death. The HAT patients who were mentally affected even long after treatment, were mostly male children and they experienced problems reintegrating back into the community. These Psychosomatic effects contributed to socio-economic and cultural impacts on households and the community.

Socio-economic impacts: The socio-economic impacts of HAT affected both the HAT patients and their households. They incurred increased financial costs as they sought treatment and care from one health provider to another. These costs are broken down into direct and indirect costs. Direct costs refer to household expenditure linked with seeking treatment, including non-medical expenses such as transport or special foods. Indirect costs refer to the loss of household productive labour time for patients and caregivers. The financial expenditure on seeking HAT treatment ranged from 4,000 to 12,000 Kenya shillings. This caused a financial burden to the households already considered to be living on less than a dollar per day. Coping strategies were employed by the affected households to deal with the increased financial expenditure. These included: sale of household property; lease of land; sale of agricultural produce and livestock; assistance from family and friends; use of personal savings and borrowing of money from social networks. All these impacted negatively on the affected households. Subsequently, this led to: food insecurity; impoverishment of households and communities already living below the poverty line.

From available data, the disease mainly affects people within the productive age group (21-50 years) hence causing adverse socio-economic and cultural impacts on the affected households and communities. Loss of valuable time taking care of the sick also led to loss of household productive labour time. This meant that people were not able to cultivate or harvest their farm produce in good time thereby contributing to poor harvests and food insecurity. Lost labour time due to illness often means household capacity to earn income is reduced at a time when it needs additional money to pay for treatment. Other socio-economic impacts included: school drop-outs, school absenteeism; decline in businesses; loss of jobs; early marriages especially for girls; loss of breadwinner and increased funeral and burial expenses.

Socio-cultural/psychological impacts: The socio-cultural impacts experienced included: fear of the unknown; fear of death; psychological trauma; stigma; reversal of roles, which greatly increased the burden and responsibilities of women and children. The normal household functioning was disrupted by reversal of roles as women took the main task of care giving while children took over the responsibility of running the homes. Early marriages especially for girls were reported among HAT affected households. Marital conflicts were also widespread as the HAT affected spouses were accused of having brought AIDS into the home. Other conflicts were between family members as accusations about who bewitched who were traded. This caused social tension among extended families and the community. Death as a final outcome of HAT led to

disruption of household and community functioning through the loss of people with key social roles.

Borrowing from the spiral of vulnerability expounding on health-seeking process (Hausmann-Muela *et al.*, 2003), this study hypothesizes that the socio-economic impacts of HAT have the potential of pushing the already impoverished households into a position of vulnerability and risk of new HAT infections through reduced participation in HAT control activities. This implies that the process of illness due to HAT and its ensuing impacts on households can be a vicious cycle with adverse outcome on poor households, if not put in check. The possible link between socio-economic impacts and ecological factors is depicted by the dotted line in figure 8.1.

8.3 Conclusion

In the preceding chapters, the socio-economic and cultural impacts of HAT on individuals as well as households have been examined. It was found that HAT has socio-economic and cultural consequences on affected households, notably that it furthers the process of impoverishment. Linked to this is HSB of affected households, which has profound effects on their socio-economic base. The extent to which HSB impacts on households depends on these predisposing factors: economic, cultural and health systems. They influence HSB, which in turn affects HAT outcome and subsequently its impact on individuals and households. Attitudes and beliefs about HAT causation lead to delay in seeking appropriate treatment. This causes socio-economic and cultural impacts in that the patient may not be able to work due to illness, causing the household to re-

organise themselves to take on the responsibilities of the ill person. Health system's failure to diagnose HAT also contributes to households seeking treatment from multiple facilities or sources of treatment. This increased the financial expenses of most households, forcing them to adopt coping strategies to meet the increased expenses on health. Economic factors in terms of cost also affected the HSB of the affected households.

The diffuse and ambiguous symptoms of HAT perpetuate its impacts on individuals and households. The symptoms of HAT mimic those of other diseases common in the study area leading to misdiagnosis and inappropriate treatment. This contributes to the delay in starting HAT treatment and consequently impacts negatively on the socio-economic and cultural aspects of the households.

HAT disrupts the socio-cultural set-up of household and increases the burden and responsibilities of women and children. The daily activities of household members were disrupted by the incidence of HAT, leading to increased responsibilities for some and reversal of roles. This disrupted the normal functioning of households.

HAT impoverishes households already living below the poverty line. HAT negatively affected the economic base of affected households by causing them to direct most of their income and time to treatment seeking and care. The coping strategies employed to cope with the sudden increased expenditure led to additional impacts on households.

HAT is not only a health issue but also a socio-developmental issue. It affects health, income levels, relationships and roles, educational performance and attainment as well as productivity and the development of affected individuals, households and communities.

8.4 Recommendations

The major contributions of this study can be seen in the context of the following three areas. First, the study is rich in policy and programmes for alleviating impacts of endemic diseases in the study countries. The study clearly shows that ill-equipped health care facilities whether modern or traditional are a great liability to the society because their poor diagnosis of diseases and delays in diagnosis send bad signals to patients and this reinforces the need for patients to seek alternative treatments which often come late with deadly consequences or very costly results. Such situations perpetuate the cycle of poverty in a country. Secondly, the study reveals diseases such as HAT are an important chain in the cycle of poverty. Third, health education is a vital process in any strategy to eliminate disease epidemics.

From the foregone findings, discussion and conclusion, the study makes two types of recommendations, namely programmatic recommendation and future areas of research.

Programmatic recommendations:

- As much as Kenya has not reported any HAT cases since 2003, it is necessary to continue implementing control measures so as to guard against any outbreaks.. the potential for outbreaks still exist, due to the

porous border with Uganda. Uganda still records 100 cases every year and due to livestock movement across to Kenya, among other factors the war against HAT in Kenya is not yet won. A continuous, concerted inter-border control measures should be put in place so as to reduce the incidences of HAT. This should entail among others, the involvement of communities in HAT surveillance and control to ensure sustainability.

- The psychosomatic effects of HAT on sick people are sometimes irreversible. A case in point is the mental effects which this study observed to have lingered on well beyond completion of treatment. Since health is not just the absence of infirmity but a state of physical mental and spiritual well being, the policy on HAT treatment should include among others, linking the affected HAT patients to other agencies or institutions that can rehabilitate and reintegrate them back into the community. This will help improve the quality of life of the affected HAT patients
- Effective control of HAT requires case finding at an early stage of illness, both for the welfare of the patient and to minimise spread of the disease and development of drug resistance. Also, the case finding process should entail no more than minimal financial costs for the patient. Moving from one provider to another often delays the diagnosis and the start of treatment, and thus increases the likelihood of developing psychosomatic effects and also becoming a health treat to other family members, and it often involves considerable costs to patients. The delay from first awareness of symptoms to beginning treatment is a matter of considerable public health interest. Therefore effective strategies for case

finding of HAT at an early stage of illness must be established and put in place. In addition, training and involving other public and private health facilities that are located in the endemic areas in HAT diagnosis and referral of HAT patients will help reduce the time lag in starting HAT treatment.

Recommendation for future research

- A study on quality of life of HAT patients after recovery and their households is a must considering that this study has articulated the effects of HAT and how they sometimes persist even beyond recovery from the disease.
- A detailed study on the quantification of the economic impacts of HAT including the time allocation caring for the sick or seeking treatment, and lost opportunity ought to be carried out to further contribute extensive and quantifiable information on the topic of study.
- Since this study was cross sectional and retrospective in nature, a longitudinal study incorporating current HAT patients should be carried out to get the current and exact situation of the HAT impacts.

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APPENDICES

APPENDIX ONE: Key Informant Interview Guide

1. Knowledge about Sleeping Sickness

- Local names for Sleeping sickness?
- What causes it?
- Who do you consider to be most vulnerable to the disease?
- How do you recognise sleeping sickness?
- Give a background of the disease over the years.
- What is the current status of sleeping sickness?
- Is it increasing or decreasing?

2. Attitude towards sleeping sickness patients

- Do you know of any victims of sleeping sickness?
- How does the community treat them?
- Do they recover after treatment?

3. Consequences of the disease on the individual, household and community.

- How does the disease affect a person?
- What are the implications of sleeping sickness on the family?
- What are the effects of the disease on the community?
- What can be done by the community to help sleeping sickness patients?

4. Coping strategies employed by individuals, households and community.

- How do victims of sleeping sickness cope with the disease?
- How is the disease treated?
- Is it expensive to treat?
- What is being done to control the disease?

APPENDIX TWO: In-depth Interview Guide

Case study number _____

1. Biographical data

- Age of respondent _____
- Sex _____
- Marital status _____
- Religious affiliation _____
- Level of education _____
- Relationship to household head _____

2. Knowledge about sleeping sickness

- What causes sleeping sickness?
- How does one get sleeping sickness?
- Where did you get information about sleeping sickness?
- Did you know about the disease before or after being infected by it?

3. Narrative

- Story about how the patient got sleeping sickness and experience he/she went through.

4. Treatment sought/coping mechanisms developed

- Where did you seek treatment?
- How long did it take before the patient was correctly diagnosed with HAT?
- Was the treatment successful?
- What problems did you encounter when seeking treatment?
- What problems did you face after treatment?

5. Effects of the disease on the patient and family

- How did the disease affect you?
- How did the disease affect your family?
- How many hours were spent looking after the patient?
- How much money did you spend on treating the disease?

6. Advice to the community about sleeping sickness

- What have you learnt from your experience with the disease?
- What advice would you give a sleeping sickness patient?
- What advice would you give the community?

APPENDIX THREE: Survey Questionnaire

I am Salome Bukachi and I work at the Kenya Trypanosomiasis Research Institute. I am doing some research on the disease sleeping sickness, which as you know is a common disease in this area. We would therefore like to find out what you know about the disease, how it affects the family income in terms of time and money, how it affects the family set-up, and community's reaction to a sleeping sickness patient. We would also like to understand how the people of this community respond when they are ill, especially when they have Sleeping sickness. Could you please give us information? Thank you in advance for your co-operation.

All information given in this study will be kept in strictest confidence.

Please answer frankly where choices are given. Circle the option, which matches your answer. Otherwise, write out the information asked for in the blank space after the question.

Name of interviewer _____

Date _____

Questionnaire number _____

SOCIO-DEMOGRAPHIC CHARACTERISTICS

- 1 Enumeration Village _____
- 2 S/Location _____
- 3 Location _____
- 4 Division _____
- 5 Sex 1.Male 2.Female
6. Age _____
7. Religion 1. Catholic 2. Protestant 3. African Traditional Religion
4. Muslim 5. Others (Specify) _____
8. Marital Status 1. Single 2. Married 3. Divorced 4. Widowed
5 Separated 6. Other (Specify) _____
9. Level of Education 1.None 2. Primary 3. Secondary 4. College
5. University and above
10. Occupation 1.Govt employed 2.Private Sector 3Private business
4.Unemployed 5.Other (Specify) _____
11. Income per month 1. 0 – 3000 2. 4000 – 6000 3. 7000-9000
4. 10000 and above

12 Other sources of earnings _____

KNOWLEDGE ABOUT SLEEPING SICKNESS

13. What are the 5 most serious health problems/diseases in this area in order of importance?

14 Have you heard about the disease sleeping Sickness (SS)? 1. Yes 2. No

15 What is the local name for sleeping sickness? _____

16 What are the major signs for sleeping sickness? _____

17 What causes sleeping sickness? 1. _____ 2. _____
3. _____ 4. _____

18. How does one get it? 1. Bite of tsetse fly 2. Blood transfusion
3. Inherited 4. Others (specify) _____

19. Who is likely to get SS? 1. Children 2. Adults 3. Males
4. Females 5. Others (Specify) _____

20 If a person gets SS can he/she pass it on to someone else? 1. Yes 2. No

21. Have you got any information on SS? 1. Yes 2. No

22. From what source did you get your information about SS? 1. _____ 2. _____

23. Who do you think should take care of a person with SS? 1. His/her family 2. Hospital staff
3. Community 4. Don't know 5. Others (Specify) _____

PRACTICES WITH RESPECT TO SLEEPING SICKNESS

24. Have you or any of your family members ever suffered from SS? 1. Yes 2. No

25. Which year was this? _____

26. How did you know that it was SS? 1. _____ 2. _____ 3. _____

27. What was the occupation of the patient at that time? _____

28. Where did the patient contract SS?

29. What was done as the first thing to cure the illness? 1. Used herbs 2. Used patent medicine
3. Visited traditional healer 4. Went to hospital
5. Other (Specify) _____

30 Why did you choose this course of action? 1. Nearest source 2. Cheapest source
3. Most effective 4. Others (Specify) _____

31 For how long had the patient stayed without treatment /medicine?

1. Less than a week 2. One week 3. 2 - 3 weeks 4. 4-5 weeks

5. 6 Weeks & above

32. Did the person feel better after the first treatment? 1. Yes 2. No
33. What else was done? List all the modes of treatment adopted chronologically and total costs involved _____

34. Which method finally worked? _____
35. What is the estimated total cost of money you used to treat the disease? _____

- 35b Has the patient recovered? 1. Yes 2. No
36. Did you know about KETRI-ALUPE SS referral hospital? 1. Yes 2.No
37. Who told you about it? 1. _____ 2. _____ 3. _____

IMPACTS OF THE DISEASE

38. How did the disease affect you/your family? (Probe for any losses incurred)

39. What was the attitude/reaction of your family/friends/neighbours towards you/the patient?

40. What are the constraints in being/living with a sleeping sickness patient?

- What are the social consequences of being a sleeping sickness patient /relative?

KNOWELDGE ON CONTROL

41. Do you know of any form of **Prevention** against SS? 1.Yes 2.No
42. Which prevention methods do you know? (List them) _____

43. Which methods of SS **Control** do you know? _____

44. Who told you about them? _____
45. Do you think they are effective? 1.Yes 2.No
46. What do you think should be done to control the disease? _____

THANK YOU

APPENDIX FOUR: Focus Group Discussion Guide

1. **Definition of Sleeping Sickness**
 - Local names for sleeping sickness
 - Knowledge about the causes of the disease
2. **Symptoms of HAT**
 - Identification of sleeping sickness.
3. **Vulnerability**
 - Who is affected by sleeping sickness?
 - Why are they vulnerable to the disease?
 - How often do people get sleeping sickness?
4. **Treatment/Prevention/Control**
 - How is it treated?
 - How can it be prevented?
 - What are you doing to prevent the disease?
 - What is the community doing to prevent/control the disease?
 - What can be done to improve on the control measures?
5. **Community reactions to sleeping sickness patients**
 - What are your reactions to sleeping sickness patients?
 - What are the community reactions to sleeping sickness patients
6. Community practices as concerns sleeping sickness.
7. **Social consequences of Sleeping sickness.**
 - What are the effects of sleeping sickness on the individual, family, community

THANK YOU