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Developing gendered One Health understandings of
sleeping sickness across communities and the veterinary,
conservation, and medical sectors in the Luangwa Valley
in Zambia.

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Doctor of Philosophy

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ABSTRACT

This thesis explores how gender roles, institutional processes, environmental and climatic changes interact to shape exposure, risk, vulnerability, and responses to the East and Southern African trypanosomiasis in Mambwe District, Zambia. This thesis examines sleeping sickness within a Game Management Area ecological and socio-political context where conservation and health policies shape the health and livelihoods of people. While global evidence on the health impacts of human African trypanosomiasis, particularly the western African form, is well documented, there is limited research on the systemic factors influencing risk and persistence of the acute form found in East and Southern Africa. Rooted in intersectionality and gender performativity theory, vulnerability theory, and social systems thinking, I employ a qualitative methodology drawing on in-depth interviews, key informant interviews, and observations to examine how macro processes intersect with individual characteristics to shape the experience of risk of contracting sleeping sickness; suffering from associated consequences and the systemic pathways through which vulnerability to the disease is produced and sustained.

The findings reveal three key insights. First, that gender norms and role socialisation of children shapes disease exposure, risk, vulnerability, and utilisation of healthcare. The performance of gendered roles and livelihood activities by women, men, and children increases their exposure to tsetse-infested areas. Second, that limited diagnostic and treatment capacity in rural healthcare facilities, combined with health and conservation policy gaps, inadvertently result in structural violence, producing a cycle of suffering and unaddressed disease burden in the three chiefdoms. The findings also reveal significant gaps in community knowledge of sleeping sickness, contributing to symptom normalisation and late health seeking. Third, that environmental and climatic changes such as prolonged droughts and floods, affect the farmers' mobility and access to already distant healthcare facilities. The findings show that conservation policies and limited investment in infrastructure in GMAs intersect to constrain transport options for the farmers further delaying timely access to diagnosis and treatment.

When considered together, lack of equitable distribution of health resources and infrastructure such as roads and healthcare facilities constrain the participants' ability to access healthcare services, receive diagnosis and treatment of possible cases of sleeping sickness. These findings highlight the urgent need for interdisciplinary One Health responses that incorporate non-biomedical evidence and account for both proximate and structural drivers of vulnerability to sleeping sickness.

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AUTHOR'S DECLARATION

I declare that, except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Ackson Tyson Mwale

DEFINITIONS/ABBREVIATIONS

CSO	Civil Society organisation
DC	District Commissioner
FAO	Food and Agriculture Organization
GMA	Game Management Area
HAC	Human Animal Conflict
HAT	Human African Trypanosomiasis (sleeping sickness)
rHAT	Human African Trypanosomiasis caused by <i>Trypanosoma brucei rhodesiense</i>
gHAT	Human African Trypanosomiasis caused by <i>Trypanosoma brucei gambiense</i>
MDC	Mambwe District Council
MOE	Ministry of Education in Zambia
NTDs	Neglected Tropical Diseases
NZDs	Neglected Zoonotic Diseases
RDTs	Rapid Diagnostic Tests
UNZA	University of Zambia
WHO	World Health Organization

GLOSSARY OF TERMS AND PHRASES

Alimi	Farmers
Agogo	Grandparent/elderly man or woman
Chikusila	Sleeping sickness/ human African trypanosomiasis
Chipatala	Hospital / Clinic
Kamzembe	Tsetse flies
Kudwala mumimba	Diarrhoea/ stomach illness / abdominal pain
Kusanga	Bush/ forest
Manzi	Water
Mankwala	Medicine (modern/traditional)
Mfumu	Chief / traditional leader
Mudzi	Village
Minda	Fields / Farms
Mabvuto	Problems / challenges / suffering
Mwambo	Culture/ traditions
Njobvu/nzovu	Elephant
Njinga	Bicycle(s)
Umfiti	Witchcraft
Nyama	Wild animals / livestock/ pets (context-dependent)

CHAPTER ONE: INTRODUCTION

1.0 Introduction

The emergence and spread of pathogens, including infectious and vector-borne diseases, is shaped by several intersecting social, economic, political, biological, and ecological factors (Kilpatrick & Randolph, 2012). These intersections across human, animal and environmental domains show how disease dynamics are a product of more than one domain. Evidence shows that the populations most at risk are those living in poverty and dependent on natural resource based livelihoods such as subsistence agriculture, timber harvesting, hunting, charcoal burning and livestock keeping (Leach et al., 2017). Structural factors including gender, poverty, and unequal access to economic development and healthcare services further shape who is exposed, infected, diagnosed, and treated (Lindstrand, 2006; Scambler, 2018, 2022). These patterns of vulnerability show the multi-dimensional nature of infectious and vector-borne diseases, especially zoonoses, which require multisectoral collaboration that integrates social, economic, biomedical, and ecological perspectives to address (Kilpatrick & Randolph, 2012).

According to the World Health Organisation (WHO), zoonoses, also known as zoonotic diseases (ZDs), are “any disease or infection that is naturally transmissible from vertebrate animals to humans and often affect the poor and marginalised populations in poor countries” (World Health Organization, 2020b). This means that zoonotic diseases indicate poverty, inequality, and lack of access to basic health services (World Health Organisation, 2017). Due to their ability to affect both humans and animals, zoonotic diseases’ effect on the health, social and economic wellbeing of the rural poor is so adverse (World Health Organisation, 2020). For example, in addition to affecting the physical health of humans which reduces their productivity, some zoonotic diseases such as anthrax also affect livestock, a source of livelihood as well as meat and dairy products for the poor communities living in rural areas (Maudlin, et al., 2009; Rahman et al., 2020). This results in increased and continued poverty as zoonotic diseases rob the communities of their health and sources of livelihood.

Zoonotic diseases highlight the interconnectedness of human, animal, and environmental health. Infectious diseases such as human African trypanosomiasis (HAT), anthrax, rabies and brucellosis are zoonotic (World Health Organisation, 2017), suggesting that their spread between humans and animals is shaped by social and ecological factors such as agriculture, livestock keeping, poverty, weak health systems, and climate change. Most zoonotic diseases are endemic in developing regions such as Africa, and Asia (World Health Organization, 2020b). But due to greater diversity of pathogens and reservoir in wildlife; lack of resources,

political will and investment in medical research; most low-income countries where zoonotic diseases are endemic have neglected these diseases (Maudlin et al., 2009; Rahman et al., 2020). Consequently, due to this neglect, the distribution, prevalence and populations at risk of most zoonotic diseases such as HAT are not clearly understood due to limited information on the true situation in these endemic areas. For example, the World Health Organisations reports (2020) show that cases of HAT have been reducing, however, current evidence show that while it is true of gambiense human African trypanosomiasis (gHAT) found in Western Africa, rhodesiense human African trypanosomiasis (rHAT) found in Eastern and Southern Africa persists and new cases have been recorded in areas where it was said to have been eliminated (Lisulo et al., 2014, 2024; Squarre et al., 2016). This and many other examples show that despite a number of measures being in place, NZDs are still a problem and are a threat to the health of both humans and animals.

While zoonotic diseases remain a global threat, threatening all societies, low and high income, the burden and consequences of these diseases are disproportionately severe for poorer populations living in remote areas of most low-income countries which are characterised by weak healthcare and surveillance systems (World Health Organization, 2020b). Existing evidence shows that victims of zoonotic diseases such as HAT, rabies, anthrax and brucellosis experience loss of self-esteem, exclusion from social and economic activities due to body weakness and pain caused by the disease and its medication (Mwiinde et al., 2017). Although adults and children, men and women, are vulnerable to zoonotic diseases and their consequences, risk factors, help seeking behaviours, treatments and outcomes may vary due to factors such as age and gendered roles and responsibilities (Ochola et al., 2021).

Social and cultural factors, combined with limited access to healthcare and inadequate essential resources resulting from structural inequalities, pose major challenges to the control of zoonotic diseases (Dzingirai et al., 2017b; Franco et al., 2014; Squarre et al., 2016). These challenges have severe consequences on the social and economic wellbeing of affected individuals and their communities (Hotez et al., 2009; Mwiinde et al., 2017). Furthermore, limited government support combined with competing interests among community members, researchers, policy makers, and conservationists hinder the development of capacity to adequately control and manage zoonotic diseases (Grant et al., 2015). As a result, marginalised populations living in rural regions where zoonotic diseases are endemic face increased vulnerability to infection and suffering from the long-term side effects associated with these diseases (Hotez et al., 2009; Mwanakasale, Songolo and Daka, 2013).

The absence of effective interdisciplinary collaboration among researchers, non-governmental organisations (NGOs) and governments interested in zoonotic diseases such as sleeping sickness has constrained progress in its management and control in endemic regions (Burri, 2020; Okwa, 2007). Divergent epistemological understandings of the disease, its management, and the appropriate interventions for its control have contributed to lack of interdisciplinary collaboration (Klein, 2008). Additionally, the absence of a common communication framework has resulted in role duplication among actors such as biomedical disciplines and researchers, NGOs in conservation and government institutions responsible for human and animal health. As a consequence, existing solutions to control and manage sleeping sickness in most endemic regions lack integrated frameworks and multisectoral support and fail to incorporate critical socio-economic dimensions of the disease, such as poverty, social inequality, gender dynamics, and cultural beliefs (Klein, 2008).

Therefore, my study explores how gendered roles influence risk, health seeking, and experiences of suffering related to sleeping sickness in Mambwe District, Eastern Province of Zambia. I also examine how competing narratives from biomedical; veterinary, conservation, and governmental actors shape how affected communities experience and respond to the disease (Lindstrand, 2006). My study contributes new insights to the field of NTDs in Zambia by highlighting the social dimensions of sleeping sickness often overlooked in dominant biomedical approaches and health policy.

After outlining the background to my study, I will introduce the research problem and the structure of my thesis. Throughout, I use the term *sleeping sickness* to refer to human African trypanosomiasis (HAT) found in Eastern and Southern Africa, aligning with the local term *chikusila*, which describes the disease's impact on the sleeping cycle of patients (Brun et al., 2010). I will also use the term *rHAT* to refer specifically to the form of sleeping sickness found in Eastern and Southern Africa, in order to distinguish it from *gHAT*, which occurs primarily in West and Central Africa.

1.1 Sleeping sickness as an illness

Sleeping sickness, also known as human African trypanosomiasis, is a persistent NTD, that continues to pose significant public health challenges in Sub-Saharan Africa. Consequences of sleeping sickness on victims are detrimental. As highlighted by other researchers, such as Malvy and Chappuis (2011), sleeping sickness results in physical suffering, impairments, and death if untreated. Additionally, Mwiinde et al. (2017) argue that victims also experience social and economic suffering due to the impairments caused by the disease. However, despite its severe consequences, rHAT remains one of the most neglected tropical diseases,

and new cases have continued to be recorded in its former foci (Anderson et al., 2015; Squarre et al., 2016). Interventions and solutions for sleeping sickness have overlooked the role of nonbiomedical factors such as social, cultural, and political factors which interact in complex ways, differently affecting various aspects of the lives of populations at risk and contributing uniquely to sleeping sickness' complexity and difficulty to control and eliminate (Burri, 2020; Okwa, 2007). Furthermore, competing interests and narratives among actors interested in sleeping sickness have contributed to the continued lack of consensus on the best approach to manage and control sleeping sickness (Grant et al., 2015).

According to Buyst (1977), human interactions with tsetse flies, the primary vectors of the disease, trace back over 2,000 years, coinciding with the Bantu migrations from Central Cameroon and the Benue Valley of Eastern Nigeria into the wider region. Despite its historical presence, the disease has remained difficult to control due to its complex transmission dynamics, which complicate both prevention and treatment strategies (Brun et al., 2010; Franco et al., 2014). However, this complexity is not merely a result of the pathogen's biology but also due to several nonbiological factors such as socio-economic, cultural and political factors that shape and sometimes hinder effective public health responses.

Sleeping sickness is caused by *Trypanosoma brucei*, a protozoan parasite belonging to the genus *Trypanosoma* that is present in sub-Saharan Africa (Brun et al., 2010). This parasite is transmitted through bites from infected tsetse flies and affects both humans and animals (Stich et al., 2002). Sleeping sickness manifests in two primary forms in humans: West African sleeping sickness (gHAT), caused by *T. brucei gambiense*, and East and Southern African sleeping sickness (rHAT), caused by *T. brucei rhodesiense* (Brun et al., 2010; Franco et al., 2014). These forms of sleeping sickness differ not only in their clinical presentation, but also in their public health implications. For example, West African sleeping sickness typically progresses more slowly leading to a more chronic form of the disease and has been the focus of substantial control efforts compared to East and Southern African sleeping sickness. In contrast, East and Southern African sleeping sickness causes an acute form of the disease, often leading to death within a few months if untreated (Franco et al., 2014; Mwiinde et al., 2017).

However, while *T. brucei gambiense* and *T. brucei rhodesiense* are considered the primary causes of sleeping sickness, emerging evidence suggests that other trypanosome subspecies such as *T. brucei brucei*, *T. congolense*, and *T. evansi* may very rarely infect humans (Deborggraeve et al., 2008; Joshi et al., 2005; Truc et al., 1998). This raises critical questions

about the range of pathogens that may be circulating in endemic areas and the potential underreporting of cases caused by these subspecies of trypanosomes. Although these strains are of questionable significance in epidemiological terms, their presence and limited understanding of their effect suggest gaps in both diagnostic capabilities and disease surveillance.

The transmission of sleeping sickness is heavily reliant on the ecology of the tsetse fly (*Glossina* species), whose habitat is mostly found in tropical environments with abundant wildlife, forest covers and proximity to water bodies (Franco et al., 2014). This ecological dependence limits control efforts especially those that involve destruction of tsetse fly habitats such as clearing of trees over large pieces of land. In most cases, such approaches have resulted in conflicts between conservationists and veterinary experts seeking to control the density of tsetse flies (Anderson et al., 2015). Similarly, the life cycles of tsetse flies are another source of complexity (Brun et al., 2010). For example, unlike other vectors such as mosquitoes whose life cycle begin with laying of eggs, tsetse flies give birth to fully developed larvae, and infection occurs when they feed on a host already carrying the parasite (Brun et al., 2010). However, despite feeding on an infected host, not all tsetse flies carry the mature form of the parasite capable of infecting humans or animals; only a small fraction (0.1%) of tsetse flies are infective (Macleod et al., 2007). This contributes to the ongoing challenges of controlling sleeping sickness in endemic regions, as not all tsetse fly bites result in infection, and the impact of a single infected fly can be unpredictable (Brun et al., 2010).

Additionally, *Trypanosoma brucei* can persist in humans and animals as *silent* reservoirs, meaning that even asymptomatic carriers contribute to the ongoing transmission of the disease (Brun et al., 2010). This poses a particular challenge for control programs, as individuals and livestock in endemic regions may unknowingly harbour the parasite, facilitating its continued circulation (Welburn et al., 2001). The presence of both human and animal trypanosomes in these areas further complicates control efforts, as it creates opportunities for cross-species transmission that can lead to outbreaks in both humans and animals (Brun et al., 2010).

While the geographic distribution of sleeping sickness is well documented, with approximately 360 foci of tsetse flies found across thirty-six sub-Saharan African countries (Maudlin, 2006; World Health Organization, 2020a), the distribution of reported cases remains highly uneven. The Democratic Republic of Congo, for example, accounts for 70% of recent cases, while other countries such as Cameroon, Zambia, and Zimbabwe have

reported fewer than ten new cases in recent years (World Health Organization, 2020a). The reduction in reported cases, particularly of gHAT, is a result of concerted efforts by national governments, international organisations like the World Health Organisation (WHO), and non-governmental organisations (NGOs), which have made strides in disease surveillance, diagnostics, and treatment. These efforts are part of WHO's target to eliminate transmission of HAT by 2030 under its NTDs 2021-2030 roadmap. As a result, significant reduction in the number of gHAT cases, from over sixty million at risk individuals in the past to approximately 50 million between 2016 and 2020 have been recorded (World Health Organization, 2023). However, these gains have not been equally distributed, and the ongoing threat of rHAT remains neglected.

The relative neglect of rHAT compared to gHAT is a significant concern. Cases of rHAT, which are less common but more deadly, have not seen the same decline in prevalence, despite its faster progression and higher fatality rate (Brun et al., 2010; World Health Organization, 2023). This discrepancy is due to, among other factors, insufficient funding, poor healthcare infrastructure, and inadequate diagnostic capabilities in endemic areas (Mwanakasale et al., 2013). Furthermore, while gHAT has been effectively managed through active human surveillance, this approach is far less effective for rHAT due to its broader animal reservoir, which includes both domestic and wild animals (Anderson et al., 2011; Kennedy, 2013). Despite this known complexity, current rHAT control frameworks give limited attention to the multifaceted nature of the disease and its transmission dynamics. For example, from a biological perspective, challenges arise from the distinct pathogenic characteristics of the parasite subspecies that cause sleeping sickness (Malvy & Chappuis, 2011). These parasites exhibit different transmission patterns and clinical courses, which complicates diagnosis, treatment and control protocols (Brun et al., 2010; Kennedy, 2013). Similarly, from an environmental perspective, sleeping sickness transmission is influenced by the habitat of the tsetse fly, which thrives in specific ecological zones, such as forested areas. As noted by Longbottom et al. (2020) and Lord et al. (2018), changes in land use, deforestation, and climate variability have the potential to shift vector habitats and alter disease dynamics.

From a social perspective, various forms of inequality, coupled with inadequate facilities and services, further shape the experience and risk of sleeping sickness by children, men, and women. Limited access to healthcare facilities and diagnostic tools in rural areas of endemic regions often leads to delayed detection and treatment, resulting in severe disease progression and increased morbidity (Mulenga et al., 2015). Additionally, local livelihood

activities such as agriculture, hunting, and charcoal production expose individuals who perform these roles to a higher risk of tsetse fly contact (Nambala et al., 2022). Furthermore, cultural factors such as gender norms, traditional beliefs, and health practices influence response to symptoms and overall health seeking behaviours and adherence to medical protocols (Wharton-Smith et al., 2019). Similarly, social stigma associated with the symptoms of advanced sleeping sickness such as confusion and neurological impairment (Malvy & Chappuis, 2011; Mwiinde et al., 2017; Palmer, 2020), discourages individuals from seeking timely medical care.

Unlike the biological, ecological, and social aspects of the disease, the economic and political aspects determine the availability of necessary resources, skills, and knowledge within healthcare facilities, ultimately influencing the success of control and treatment programs (Odiit et al., 2004). However, as a neglected tropical disease, sleeping sickness often receives inadequate funding, international support, and policy attention, which hinders the development of effective interventions (World Health Organization, 2020a). Consequently, the lack of political will and support for the control and elimination of sleeping sickness, especially rHAT, contributes to weak health infrastructure and insufficient disease surveillance systems, which impedes early detection and control efforts (Mulenga et al., 2015; Mwanakasale et al., 2013; Mwanakasale & Songolo, 2011). Consequently, this oversight has contributed to the slower progress in controlling and eliminating rHAT. Therefore, the lack of active surveillance and screening in regions where rHAT is endemic contributes to poor understanding of the true burden of rHAT as many cases are likely unreported (Brun et al., 2010; Mwanakasale et al., 2013). The underreporting of rHAT cases may suggest that the increasing cases of the disease is a real threat.

Therefore, while progress has been made in reducing the burden of gHAT, the persistent neglect of rHAT highlights significant gaps in global and national health responses. The limited focus on gHAT has led to substantial reductions in reported cases, but the neglected status of rHAT undermines these gains. The lack of diagnostic tools, healthcare infrastructure, and early diagnosis programs for rHAT contributes to underreporting, making it difficult to assess the true scale of the problem and develop interventions to resolve or reduce its impact on victims and their communities (Mwanakasale et al., 2013).

1.1.1 Epidemiology of sleeping sickness (rHAT) in Zambia

Sleeping sickness (rHAT) in Zambia is primarily concentrated in the Luangwa Valley and Kafue National Park in Eastern and Western Province. Transmission occurs in areas characterised by national parks, game management areas (GMAs), and expanding human

settlements, where ecological overlap between wildlife, livestock, and humans facilitates zoonotic spillover. Unlike the Western Africa form (gHAT), rHAT depends on wildlife reservoirs, including domestic animals such as cattle, making difficult to control and eliminate (Anderson et al., 2011). As found by Mulenga et al. (2015), cases of rHAT in Zambia are detected passively through hospital presentation due to delayed health seeking and weak active surveillance in remote communities. Current statistics show that Zambia has recorded below 100 cases of HAT per year (WHO, 2023). For example, a study by Squarre et al. (2016) in Kafue National Park reported a case of rHAT for the first time in 50 years. Furthermore, 7 cases were recorded in 2022 compared to 18 cases in 2024 (WHO, 2023), demonstrating the presence of risk. The WHO (2020) estimates that about 65 million people remain at risk of infection, yet only a fraction of this population is under surveillance.

Case detection of rHAT and gender

Although routine surveillance data in Zambia rarely provide sex disaggregated analyses beyond basic reporting, available evidence suggests gendered patterns in exposure and case detection (Mwiinde et al., 2022). For example, studies by Mwiinde et al. (2022) and Nambala et al. (2022) in Zambia and Malawi respectively, reported higher cases of rHAT among men than among women, a pattern commonly attributed to exposure through gendered livelihood activities such as fishing, hunting, livestock herding, charcoal production, timber harvesting and wildlife related activities that take place in areas with high density of tsetse flies. While this could be attributed to gender roles and norms, variations in reported cases between men, women and children may reflect social and structural inequities which contribute to delayed diagnosis and treatment especially among women and children. In Zambia, studies by Mulenga et al. (2015) and Mwanakasale and Songolo (2011) show that lack of equipment and skills to diagnose rHAT has contributed to misdiagnosis and under reporting of cases by gender.

Human, livestock and wildlife dynamics

Studies examining the relationship between the human-livestock- wildlife interface and transmission of rHAT shows a complex interaction (Anderson et al., 2011; Auty et al., 2016). In Zambia, for example, Anderson et al. (2011) found that wildlife species within protected areas serve as long standing reservoirs of rHAT. Similarly, Auty et al. (2016) argue that increasing human and cattle populations around protected areas alter the transmission and control dynamics of rHAT. This suggests that cattle may increasingly function as a reservoir, indicating a potential shift toward more mixed transmission dynamics and increasing risk of outbreaks in humans and other domestic animals (Auty et al., 2016).

1.1.2 Clinical features and diagnosis of sleeping sickness

Sleeping sickness, regardless of the subspecies of *Trypanosoma brucei* causing it, is characterised by two progression stages: the haemolymphatic and the meningoencephalitic stages (MacLean et al., 2012). The haemolymphatic stage is characterised by the invasion of the blood and lymphatic systems and is typically associated with symptoms such as intermittent fever, headache, pruritus, and lymphadenopathy (Brun et al., 2010). In contrast, the meningoencephalitic stage marks the progression of the infection to the central nervous system, leading to neurological symptoms such as sleep disturbances, neuropsychiatric issues, tremors, motor weakness, and paralysis of limbs (Kennedy, 2006; Malvy & Chappuis, 2011). These symptoms increase in frequency as the disease progresses but are rarely observed during the first stage (Blum et al., 2006).

However, regardless of similarities in progression, the clinical manifestations differ significantly between the two forms of sleeping sickness caused by *T. brucei gambiense* and *T. brucei rhodesiense*. For example, sleeping sickness caused by *T. brucei gambiense* typically progresses more slowly and is chronic, often taking up to three years before reaching the meningoencephalitic stage (Checchi et al., 2008). In contrast, infections caused by *T. brucei rhodesiense* result in a more acute form of sleeping sickness that can lead to death within weeks or months due to rapid progression (Brun et al., 2010; Odiit et al., 1997). This difference in disease progression of the two subspecies of trypanosomes has important implications for the diagnosis, treatment, and control of sleeping sickness.

However, it is important to note that variations in the disease's progression can occur under different social, cultural, economic and environmental conditions resulting in different outcomes. For instance, although *T. brucei rhodesiense* is typically associated with acute forms of sleeping sickness, chronic cases of the disease have been reported in Malawi, highlighting regional variations in disease dynamics (MacLean et al., 2004). Similarly, asymptomatic carriers of *T. brucei gambiense* have been observed in endemic regions, suggesting that chronic forms of the disease may go undetected due to the slow progression of symptoms, which often fail to reach the second stage (Brun et al., 2010). This points to the challenge of assessing the true burden of the disease in endemic areas, where the perceived low prevalence may mask the presence of undiagnosed or asymptomatic cases of both forms of sleeping sickness.

The diagnostic process for sleeping sickness is dependent on the parasite strain responsible for the infection and the stage of disease progression. For *T. brucei gambiense*, diagnosis typically involves a three stage process, screening, diagnostic confirmation, and staging.

This process is necessary due to the nonspecific clinical features that overlap with other febrile diseases (Bisoffi et al., 2005; Jelinek et al., 2002). The Card Agglutination Test for Trypanosomiasis (CATT) has been in use since the 1970s for screening sleeping sickness cases caused by *T. brucei gambiense*, supported by microscopic examination of blood and lymph node aspirates (Brun et al., 2010). While newer techniques such as polymerase chain reaction (PCR), loop mediated isothermal amplification (LAMP) and field designed latex agglutination tests are widely available, they are expensive to use, limiting diagnostic options in many areas such as the rural areas of most developing countries.

In contrast, diagnosing sleeping sickness caused by *T. brucei rhodesiense* does not rely on serological screening tests, but instead on the presentation of clinical symptoms and a history of exposure. A key diagnostic indicator for rHAT is the presence of a chancre, which is often absent in gHAT cases (Brun et al., 2010). Furthermore, because rHAT is associated with higher parasitic loads in the blood, parasitological confirmation can be done through newer techniques such as PCR and LAMP and more standard blood smears, methods which are often sufficient for diagnosis (Brun et al., 2010). This makes diagnosis for rHAT relatively straightforward compared to gHAT, where more complex methods are needed due to the lower parasite density in the blood during the early stages.

The diagnostic complexities associated with sleeping sickness caused by *T. brucei gambiense* and *T. brucei rhodesiense* significantly influence the disease burden, risk of emergence, and the effectiveness of treatment (Brun et al., 2010). The availability and accessibility of diagnostic tools are critical in determining the true prevalence of the disease, especially in remote areas where healthcare infrastructure may be limited. For example, the slow progression of gHAT means that individuals may remain undiagnosed for extended periods, contributing to increased risk of experiencing complications resulting from the untreated disease (Kennedy, 2013). Meanwhile, the rapid onset of rHAT emphasises the need for prompt diagnosis and immediate treatment to reduce mortality rates. This indicates the need for effective screening and surveillance systems for sleeping sickness, regardless of form, in endemic regions.

Therefore, it can be noted that the different forms of sleeping sickness, their varied clinical presentations, and the diagnostic challenges they pose require more than the biomedical and biological understanding of the management of the disease. Improved and better healthcare infrastructure is crucial in ensuring timely detection and treatment, particularly in regions where both gHAT and rHAT co-exist (Kennedy, 2013). However, the omission of various forms of inequalities intersecting with several other factors such as individual characteristics,

culture, religion and gender complicate the understanding of the risk and experience of sleeping sickness' consequences. As highlighted earlier, limited research has been done to understand these dimensions and how they contribute to challenges in health seeking, accurate diagnosis and treatment and overall disease burden in marginalised populations such as rural communities.

1.1.4 Biomedical and non-biomedical responses for humans and animals

Although there is currently no vaccine for sleeping sickness, partly due to the complex nature of the parasite and limited support and funding (Brun et al., 2010), effective treatments for humans and animals do exist. In humans, for example, pentamidine is prescribed in the first stage of the disease, while eflornithine and melarsoprol are used in the second stages of gHAT (Malvy & Chappuis, 2011). Similarly, suramin is used to treat first stage rHAT, while melarsoprol is used for the second stage (Burri, 2010). Furthermore, there is now an oral treatment available as first line treatment for both gHAT and rHAT (World Health Organization, 2024). These treatments, however, present significant challenges and side effects to patients (Brun et al., 2010; Mwiinde et al., 2017). For example, side effects observed in patients on pentamidine and eflornithine medication include hypoglycaemia, diarrhoea, nausea, and vomiting. In addition, more severe reactions such as hypersensitivity, skin reactions, and palsy have been observed in patients on suramin and melarsoprol medication respectively (Brun et al., 2010).

The presence of these side effects raises questions about the balance between the efficacy of these treatments and their safety, particularly in resource poor regions where healthcare access and health education and information are limited. Severe side effects from some drugs such as melarsoprol, poses as serious challenge for healthcare workers and patients, especially when alternative treatments may be unavailable (Burri, 2010; Burri et al., 2000; Seixas et al., 2020). Consequently, this complicates the efforts to manage sleeping sickness effectively. In some instances, these challenges have led to noncompliance to the drug protocols which has contributed to an increase in patients' reliance and preference for alternative treatments such as traditional medicine and religious healing (Ekor, 2014).

While alternative non-medical methods, particularly traditional medicines, have been suggested as complementary treatment to several ailments (Mwangi et al., 2017; Nwodo et al., 2015), research on their efficacy in managing sleeping sickness remains scarce. For example, Syakalima et al. (2018) explored and documented the types of plants used to treat important animal diseases in rural Zambia. The study concluded that ethnoveterinary medicine is widespread among rural farmers. Furthermore, it was observed that some plants

were used across different diseases due to their wide spectrum of action (Syakalima et al., 2018). Similarly, Tolossa et al. (2013) explored plants used for treatment of human and livestock ailments by traditional healers in South Omo, Southern Ethiopia. The study concluded that traditional medicine such as herbs play a significant role in meeting the primary healthcare needs of the participants (Tolossa et al., 2013). Others such as Munsimbwe et al. (2021) explored the trypanocidal activities of the benzophenone glucosides and B- type proanthocyanidin dimers from *Zambian Cassia abbreviate*. The study found that the trypanocidal activities of these compounds could be used to treat trypanosomiasis (Munsimbwe et al., 2022). Similarly, Twumasi et al. (2020) explored the use of traditional medicines in Ghana and found that certain herbs exhibited antitrypanosomal properties.

However, while these studies provide insights into the various plants with medicinal properties and their trypanocidal activities on parasites causing trypanosomiasis in livestock and humans, the focus was principally on general livestock and human diseases. Furthermore, although traditional remedies are a necessary and effective part of the healthcare landscape (Amzat & Razum, 2014; Tolossa et al., 2013), questions on why these alternatives are used in the first place have not been adequately addressed. For example, Ekor (2014) argues that reliance on traditional herbal medicine is influenced by claims of efficacy, high costs and side effects of modern pharmaceuticals, consumer preference for natural therapies, and dissatisfaction with conventional drugs. However, this evidence does not indicate whether reliance on traditional herbal medicine is due to a lack of access to modern treatments, or reflects a deeper mistrust of public healthcare system, exacerbated by historical neglect and ongoing health inequalities and inequities.

Therefore, this evidence suggests that continued reliance on traditional medicine, despite its limited clinical validation, might reflect broader challenges of healthcare availability and accessibility, negative perception of stigma associated with modern medical treatments, and the marginalisation of indigenous knowledge systems in global health policy (Bhakuni & Abimbola, 2021; Nyblade et al., 2019). This evidence also points to the potential of integrating traditional knowledge with modern medicine, especially in contexts where modern healthcare infrastructure is inadequate or inaccessible. However, this has received limited attention from researchers studying trypanosomiasis, especially in humans. Existing research on sleeping sickness and its treatment often overlooks the intersection of poverty, cultural values and practices, and the availability of healthcare in explaining why people turn to these remedies. This gap points to the need for understanding the sociocultural, political,

and economic context shaping perception of illness, access, utilisation and overall health seeking.

In animals, the control of Animal African Trypanosomiasis (AAT), as in the case of human African trypanosomiasis, remains a significant challenge (Pereira et al., 2024). Current treatment strategies for AAT in livestock primarily rely on curative and prophylactic trypanocidal drugs, alongside vector control measures such as insecticide spraying and the use of targets and traps (Giordani et al., 2016; Holmes, 2013). For example, diminazene aceturate provides curative treatment, while homidium chloride and isometamidium offer both curative and prophylactic effects. However, as noted by Holmes et al. (2013), although these drugs are helpful in managing the AAT, like HAT, there is an urgent need to develop safer and more effective alternatives for use in domestic animals. Furthermore, although some cases of resistance to trypanocidal drugs have been reported in 13 Sub-Saharan Africa countries, empirical evidence on the extent of the problem remains limited (Giordani et al., 2016; Holmes, 2013).

Besides medical and traditional treatments, vector control programs were implemented from the 1940s through the early 2000s to curb the spread of sleeping sickness in humans in endemic regions. While these efforts initially succeeded in reducing the density of tsetse flies and the incidence of the disease, decline in international support for vector control programs in the early 2000s contributed to the collapse of these efforts and gains (Anderson et al., 2015; Brun et al., 2010). As a result, many countries, particularly in sub-Saharan Africa, are witnessing a resurgence of sleeping sickness due to reduced support towards vector control programs (Squarre et al., 2016). In addition, while interventions such as clearing tsetse fly habitats initially contributed to reduced vector density, they also influenced changes in ecological conditions, which led to the disappearance of old disease foci and the emergence of new ones in areas with more favourable environmental conditions (Lord et al., 2018; Meyer et al., 2016). Although this evidence indicates the complex nature of sleeping sickness and how difficult it is to combat without considering its multidimensional nature, it also shows that existing interventions are mostly shaped by biomedical and ecological dimensions of the disease. In contrast, the nonbiomedical dimensions of sleeping sickness and their evidence have not been given adequate attention in the development of interventions to control and eliminate the disease.

1.1.6 Population at risk of sleeping sickness and why?

The World Health Organisation (WHO) 2015 and 2020 reports show that 65 million people are at risk of being infected with sleeping sickness in sub-Saharan Africa alone (World

Health Organization, 2015; World Health Organization, 2020). Furthermore, evidence from researchers show that most of the population at risk live in rural areas and engages in outdoor and environment-based livelihood activities such as livestock keeping and farming, hunting, fishing, timber, and charcoal production (Nakamura and Hanazaki, 2017; Rutto et al., 2013). This implies that area of residence and livelihood activities play a significant role in shaping the risk of contracting sleeping sickness. This also suggests that the risk of sleeping sickness reflects how various forms of structural inequality and socio-economic conditions of individuals influence the risk and exposure to the disease (Martin, 2008; Hotez et al., 2009). Therefore, despite decades of efforts to control and eliminate sleeping sickness, it continues to disproportionately affect marginalised populations because of the continued exposure of individuals to risk factors.

Vulnerability to sleeping sickness varies not just by geographic location, but also by gender, age, and social status. Women face unique challenges in accessing care due to their economic position, gendered roles and responsibilities within their households, which influence their health seeking behaviour (Okwa, 2007; Rilkoff et al., 2013). While gender has been acknowledged as a key factor in the spread and management of the disease, current interventions on HAT, especially rHAT, have not adequately addressed the gendered disparities (Vlassoff, 2007). This oversight perpetuates inequities in healthcare access and treatment outcomes between men and women, reinforcing the gap between those who have the resources and ability to access modern healthcare services and those who cannot (Wharton-Smith et al., 2019). As argued by Okwa (2007), women, unlike men, are less likely to have resources and information about diseases and are less familiar with the available medical services. Consequently, women would seek medical health late increasing the impact of diseases and their consequences on their body and social wellbeing due to late diagnosis (Wharton-Smith et al., 2019).

Therefore, the persistence of sleeping sickness in both human and animal populations reflect a deeper challenge which is characterised by the lack of an integrated, holistic approach to managing the disease. As shown, sleeping sickness is shaped not just by biological and environmental factors, but also by several socio-cultural, economic, and political factors. However, the limited inclusion of evidence on nonbiomedical factors of sleeping sickness by most studies inadvertently isolates the disease from its broader context and hinders effective control of the disease. Consequently, addressing the occurrence and persistence of sleeping sickness in new and old foci requires more than just biomedical solutions. It necessitates a critical examination of the socio-political, cultural, and economic factors that

shape both the disease and the response to it. Throughout this thesis, therefore, I emphasise a more holistic, interdisciplinary approach to understanding sleeping sickness, informed by both biomedical and social science evidence to effectively control and eliminate the disease.

1.1.7 Environment, conservation and climate change as drivers of sleeping sickness

Environmental and climatic factors are increasingly recognised as critical drivers in the emergence, transmission, and geographic spread of HAT (Githeko et al., 2000). These factors not only create ecological conditions conducive to vector spread but also intensify human vulnerability to displacement, food insecurity, and continued inability to access healthcare services (Dzingirai et al., 2017a). This shows that climate and environmental changes are central to understanding patterns and risks of sleeping sickness. Although existing evidence suggests that deforestation plays a significant role in the resurgence of vector-borne diseases, more recent studies further show that climate change, particularly rising temperatures and shifting rainfall patterns, contribute significantly to the altering of vector ecologies (Longbottom et al., 2020; Lord et al., 2018; Moore et al., 2011). Research has shown that such changes affect the habitat suitability, density, and distribution of tsetse flies, the primary vector for HAT (Githeko et al., 2000). Longbottom et al. (2020), for example, argues that rising temperatures are facilitating the expansion of tsetse flies into new regions in Zimbabwe and Zambezi valley, thereby exposing previously unaffected populations to the risk of infection. This suggests that conservation supports high tsetse densities whilst also helping to mitigate environmental and ecological change that could promote disease emergence.

In addition to vector dynamics, climate change directly impacts the livelihoods of rural populations who live at the margins of society and depend on the natural environment (Moore et al., 2011). Prolonged dry spells and unpredictable rainfall reduce agricultural productivity and force many into activities such as charcoal burning, hunting, and timber production, livelihoods that increase interaction with tsetse-infested habitats (Dzingirai et al., 2017a; Lord et al., 2018). These shifts not only elevate the risk of contracting sleeping sickness but also reflect a broader pattern where environmental stressors drive risky adaptations (Anderson et al., 2015; Dzingirai et al., 2017a). Meanwhile, increased flooding during the rainy season further complicates access to healthcare services due to impassable roads and damaged infrastructure. Similarly, conservation policies on biodiversity, particularly wildlife and forests, can indirectly sustain the ecological conditions that support or hinder the survival of tsetse flies and trypanosome circulation (Lord et al., 2018). Therefore, although important for biodiversity, under changing climatic and environmental

conditions, conservation policies and efforts can become a critical driver of the transmission of both human African trypanosomiasis and animal African trypanosomiasis (Anderson et al., 2015; Munang'andu et al., 2012).

This shows that conservation efforts and environmental and climatic stressors intersect with socio-economic conditions to intensify disease risk and vulnerability (Longbottom et al., 2020; Lord et al., 2018; Moore et al., 2011). For example, marginalised communities often lack the financial, institutional, and infrastructural capacity to manage the dual burden of climate change and infectious disease risk. Consequently, they experience risk and social suffering, driven not just by the biological realities of sleeping sickness, but also by structural inequalities that limit their adaptive and survival capacity (Lutumba et al., 2007).

Therefore, although biomedical research has acknowledged climate change as a factor in the shifting epidemiology of vector-borne diseases such as sleeping sickness, rabies, anthrax and brucellosis, there remains limited attention to the social determinants that shape how climate impacts are experienced (Githeko et al., 2000). Structural issues such as poverty, weak infrastructure, and unequal access to health services, play a critical role in shaping who is most affected, who can and cannot respond. This reaffirms the need for interdisciplinary responses and the integration of ecological, social, economic, and policy perspectives in understanding the impacts of conservation efforts, environmental and climate change on disease dynamics, risk and transmission of HAT.

1.2 Statement of the problem

As highlighted in the previous section, the persistence of sleeping sickness in most endemic regions reflects several competing interests, which cannot be understood in isolation. While sleeping sickness undoubtedly has a biomedical dimension, it also has a social, cultural, and political dimension that shapes its occurrence and consequences for human communities (Anderson et al., 2015). Lack of deliberate policies and resources to support the control of sleeping sickness, including enhancing the capacity to screen, diagnose, and treat cases, further marginalises rural communities at risk of contracting the disease, excluding them from much needed healthcare resources and worsening their health seeking challenges.

While there is extensive research focusing on the biological and ecological aspects of sleeping sickness in both humans and animals, the socio-cultural, economic, and political dimensions have received limited attention. For example, studies such as those by Anderson et al. (2011) on trypanosomiasis in Zambia have focused on characterising the nature of the reservoir community for the disease, highlighting the importance of understanding the

ecological context in which it thrives. Similarly, Mwanakasale and Songolo (2011) pointed to the limited capacity to diagnose sleeping sickness in rural healthcare facilities as a key factor contributing to the underreporting of cases, creating a false perception that the disease had been eliminated. Anderson et al. (2015) also explored the relationship between sleeping sickness and biodiversity conservation in Zambia's Luangwa Valley, calling for a better understanding of how conservation efforts and disease control can be harmonised and contribute to positive outcomes for all stakeholders. However, despite these valuable insights, existing evidence is largely confined to the biological, and ecological dimensions of sleeping sickness and its vectors. As highlighted earlier in this section, such approaches largely omit the subjective experiences of sleeping sickness and the role of context in shaping the risk of contracting the disease. For example, while Mwiinde et al. (2017) considered the social aspects of sleeping sickness by considering its impact on the economic and social wellbeing of victims, their findings also show the need for in-depth social science studies on the social, cultural and political dimensions of these experiences.

Some researchers, such as Palmer (2020) and Lutumba et al. (2007), have used social science methods to explore the experiences of those affected by sleeping sickness, however, these researchers did not explore the disease's multidimensional nature and how it affects various categories of individuals. Furthermore, existing social science research on sleeping sickness is more focused on gHAT, than rHAT. For example, Palmer's (2020) ethnographic study exploring symptom recognition in Sudan highlights how discourse surrounding symptoms influences health seeking behaviours. However, Palmer's work, while insightful, did not explicitly address power relations, structural violence, or the role of intersecting factors in shaping the risk of contracting the disease. Similarly, research by Lutumba et al. (2007) in the Democratic Republic of Congo focused on the disease burden of sleeping sickness in rural communities but relied on a quantitative approach that did not capture the lived experiences of affected individuals. This suggests that existing evidence on sleeping sickness is limited by its omission of the many ways in which sleeping sickness manifests and affects rural communities. While research on rHAT has captured some underlying social causes of the disease (Mwiinde et al., 2017; Rutto et al., 2013), existing evidence on rHAT show limited understanding of the underlying social, cultural, political, and environmental causes of vulnerability and disease transmission.

Therefore, my thesis provides a detailed understanding of the non-biomedical dimensions of sleeping sickness and their role in shaping risk of contracting the disease. Using an interpretivist approach and a theoretical framework based on intersectionality, vulnerability

and gender theory, I explore the importance of non-biomedical understanding of sleeping sickness in the development of interventions and policies on NTDs. Furthermore, I emphasise the importance of interdisciplinary collaboration to fully address the various dimensions of sleeping sickness. By so doing, my thesis contributes to bridging this knowledge gap by focusing on how different categories of individuals, children, men, and women, are affected by, exposed to, and experience the risk of sleeping sickness in rural settings. In addition to providing a detailed understanding of the challenges faced by these groups, I also explore how broader social, economic, cultural, and political factors influence their experiences.

1.3 Conceptual framework

Drawing on the substantial body of work on sleeping sickness and sociological theory, I explore the gendered One Health understanding of sleeping sickness by situating my study within an intersectionality, social systems, vulnerability and gender framework to address the multidimensional and non-biomedical nature of the disease. This framework shows the opportunities for integrating a social science theoretical approach which considers interdisciplinarity and role of power relations in shaping experiences of vulnerability and suffering by humans, animals and the environment. Throughout this thesis, I show that the risk of contracting sleeping sickness is shaped by an interaction of both social, cultural, institutional and biological factors. I further show that this risk is further exacerbated by healthcare limitations to diagnosis and management of the disease contributing to reliance on alternative methods of treatment and diagnosis. I also argue that while gender is the primary factor shaping the risk to contracting sleeping sickness, it does so by intersecting with other individual characteristics such as ethnicity, age, economic position and marital status. Overall, I argue and show that while more efforts have been invested to understand and control the biological and ecological aspects of sleeping sickness, other equally important aspects of the disease such as social, cultural, political, religious and economic dimensions have been largely omitted. Therefore, I conclude by arguing that controlling sleeping sickness requires a gendered and interdisciplinary approach which considers the multidimensional nature of the disease and the different ways in which it affects varying categories of people.

1.3.1 Research aims

My intention at the outset of this research was, firstly to identify the varying health needs, challenges, impacts and opportunities for women, men, and children in the Luangwa Valley, and how they are mediated by gender; secondly, to examine and understand how

communities, medical, veterinary and conservation services can work together more effectively and develop gendered One Health understandings to reduce the incidences of sleeping sickness; and lastly, to understand how the gendered One Health understandings can inform national policy for controlling NTDs in Zambia through policies, and programme implementation that promotes gender equality and health equity among vulnerable communities. On this basis, three main research questions were formulated which are:

- i) What are the varying health needs, challenges, impacts and opportunities for women, men, and children in the Luangwa Valley, and how are these mediated by gender?
- ii) How do communities, medical, veterinary and conservation actors work together within Zambia's health and conservation policy framework, and how do these interactions shape construction and gendered vulnerability to sleeping sickness?
- iii) How can these gendered One Health understandings inform national policy for controlling NTDs in Zambia through policies, and programme implementation that promotes gender equality and health equity among vulnerable communities?

1.3.2 Analytical framework

I modify my analytic focus and approach to reflect the challenges of the three research questions. For the first research question, in which varying challenges mediated by gender were identified, I draw on intersectionality theory (Crenshaw, 1989; McPhersons and McGibbon, 2011) and vulnerability theory (Zakour, 2010) coupled with concepts of social suffering (Kleinman, 1997) and structural violence (Farmer, 2004/2010). The discussion of vulnerability, risk and the farmers' suffering is informed by structural violence and social suffering. Then for research question two and three focusing on how stakeholders would work together and develop gendered understandings of sleeping sickness and how these understandings can inform national policy respectively, I draw upon Butler's (1992) gender performativity theory and the social systems theory (Parson, 1969; Luhmann, 1982) to explore the relevance of interdisciplinary collaborations among disciplines and the importance of interdependence in addressing several health issues. Overall, underpinning the whole thesis, I rely on extensive literature from medical anthropology, medical sociology, veterinary medicine, One Health and conservation to which I will turn in the next chapter.

1.4 Thesis Outline

The subsequent six chapters will build on the foundation developed in this chapter. The remaining chapters are organised as follows.

In chapter 2, I review previous empirical and theoretical research related to sleeping sickness, providing framings that underpin the empirical chapters of my thesis. I engage with previous research to explore the dimensions of sleeping sickness, the problems it creates and who is affected. I will then introduce the concepts of structural violence, social suffering and risk; situating the notion of risk of contracting sleeping sickness within the intersectionality, and vulnerability theory as means of investigating the role of structural violence in shaping experience of risk and suffering from sleeping sickness and associated challenges. I conclude the chapter by outlining the overall gaps and study objectives.

In chapter 3, I provide an account of my philosophical assumptions and methodological choice and how it informed my research design and methods. In addition, I present and explain how my theoretical framework, grounded in an intersectionality, gender performativity, vulnerability and social systems thinking, informed my participatory approach to understand the multidimensional nature of sleeping sickness and how it affects different aspects of life of people. I will then outline the methods of recruitment; data collection and analysis used in this study. Subsequently, I provide justification for the various methods employed in this research and decisions that I made during fieldwork, and analysis. Finally, I reflect on the ethics and limitations of the study.

In chapter 4, I present the findings about ‘the social construction of sleeping sickness.’ I use two cases of illness to show how illness is constructed and how these constructs affect effective diagnosis and treatment of sleeping sickness. I use these cases to illustrate how the absence of professional diagnosis and treatment of sleeping sickness reinforces belief in the traditional system managing diseases, indirectly contributing to the disease’s invisibility to healthcare workers, communities and policy makers. I also show the relevance and opportunities of interdisciplinary collaborations including non-biomedical evidence in the study of sleeping sickness and other NTDs. Overall, this chapter addresses the second research question: *how do communities, medical, veterinary and conservation actors work together within Zambia’s health and conservation policy framework, and how do these interactions shape construction and gendered vulnerability to sleeping sickness?*

In chapter 5, I draw on the central theme of ‘structural violence’ and ‘social suffering’ to explore the participants’ health, wellbeing and lived experiences within the Lupande Game Management Area. By providing a detailed overview of Zambia’s healthcare system and landscape, I show that participants’ experiences of vulnerability to sleeping sickness, suffering from its consequences and the lack of adequate and accessible basic services reflects structural violence and limited interdisciplinary collaborations in research on

sleeping sickness and other NTDs. This chapter addresses the first research question: *what are the varying health needs, challenges, impacts and opportunities for women, men, and children in the Luangwa valley, and how are these mediated by gender?*

In chapter 6, I build on chapter four and five to establish how gaps in health policies, gender, gendered roles and practices shape experiences of risk of contracting sleeping sickness and challenges such as increased human animal conflicts and poverty, which are associated with living in game management areas. I show how existing policy gaps in health, and the culturally dictated daily chores and activities contribute to exposure and risk of contracting sleeping sickness. Therefore, I draw specific attention to the roles that participants, men and women, performed and how these tasks, intersecting with other social, economic and political factors shape their experience of suffering due to illnesses and human animal conflicts among other challenges. Ultimately, I will address the third research question: *How can these gendered One Health understandings inform national policy for controlling NTDs such as sleeping sickness in Zambia through policies, and programme implementation that promote gender equality and health equity among different categories of people in rural communities?*

Chapter 7, the discussion and conclusion, provides a summary of the main findings of this research and considers the wider theoretical and methodological implications of this study's results within the context of gender, NTDs and One Health. Furthermore, I also provide some policy recommendations that would enhance the understanding of sleeping sickness, its nature and best approaches to controlling and eliminating it in endemic regions such as Zambia's Luangwa Valley.

1.5 Chapter summary and conclusion

In this chapter, I have introduced and explained what sleeping sickness is, its nature, transmission, diagnosis and treatment. I have further showed that although it is a febrile disease, its nature is complex and multi-dimensional with far reaching effects on individuals and communities, particularly in rural areas of endemic regions. To explain this point further, I introduced and explained the biological, political, socioeconomic and environmental dimensions of sleeping sickness and who is affected. While this is important, I have shown that limited research has explored the multi-dimensional nature of sleeping sickness and how illness affects various aspects of individuals. Furthermore, limited research has explored how the multi-dimensional nature of sleeping sickness leads to competing narratives and interests among actors occupying different spaces and positions.

Therefore, using an ethnographically informed participatory approach, my thesis is offering an in-depth analysis of the different narratives and agendas, and areas of conflict and agreement among stakeholders regarding the understanding, control and management of sleeping sickness. I also emphasise the need for a One Health approach incorporating social science approaches and insights to understand the different dimensions of sleeping sickness with an aim of advancing interdisciplinary collaborations in the development of interventions to control and eliminate sleeping sickness.

The subsequent chapters will build on this foundation I have laid here to explore these dimensions in greater detail, aiming to offer a non-biomedical gendered One Health understanding of sleeping sickness by analysing the intersections of gender, environmental vulnerability, and socio-political contexts. Through this approach, my thesis seeks to inform policies and interventions that not only address sleeping sickness' immediate health impacts but also the broader systemic factors that perpetuate its transmission and burden.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

Controlling sleeping sickness is a multi-dimensional challenge as the disease in humans affects people with different characteristics in various ways (Brun et al., 2010; Burri, 2020). Understanding the challenge of this zoonotic and neglected tropical disease requires an understanding of what is known about sleeping sickness and its distribution globally, regional, and at the country level. Advances have been made to control and eliminate sleeping sickness, including the routes to diagnosis, biomedical and social care, its impacts on people (children, men and women), disciplines such as veterinary science and animal health (livestock and wildlife) and the environmental dimensions of sleeping sickness management (Franco et al., 2022, 2024; Odiit et al., 2004; Palmer, 2020). Research suggests that there is a gendered dimension to diseases, including neglected tropical diseases such as sleeping sickness, as gender roles intersect with other factors such as inequality, poverty and lack of policy to shape the experience of risk of contracting these diseases (Wharton-Smith et al., 2019; Mbabazi et al., 2021; Rilkoff et al., 2013). Policy responses to sleeping sickness are shaped by the wider geopolitical environment, which in turn influences interventions and strategic resource distribution aimed at controlling and eradicating sleeping sickness (World Health Organisation, 2017).

I start by first describing the approach to the literature review and then I discuss existing research on sleeping sickness. After a discussion of existing research on sleeping sickness, I go on to consider how approaches to control and management contribute to people's experience of suffering from the disease. Then I consider how these approaches to control and management shape the risk of contracting sleeping sickness and negatively influence the routes to diagnosis, care and management. Drawing on research on the impact of current strategies to manage sleeping sickness on the health of people, livestock and wildlife, I conclude this chapter with a critical review of the existing frameworks and approaches to control and manage sleeping sickness and what is known regarding these interventions within the Zambian context.

Approach to the literature review

While this literature is not a traditional systematic and scoping review in a traditional sense, I relied on an approach that adopts the methods used in the two types of literature review (Arksey & O'malley, 2005; Levac et al. 2010) to map and synthesise existing literature on gender, human African trypanosomiasis (HAT), One Health, the biomedical and social dimensions of diseases within African contexts, with particular attention to Zambia. This

review was guided by two questions namely, i) What is known about gendered vulnerability, methodological and theoretical approaches in the study of HAT, and the extent to which social and cultural dimensions are integrated into One Health approaches in the control and elimination of rHAT in Zambia and other endemic areas in African? What governance, policy, and institutional coordination mechanisms are in place to support rHAT control and elimination, interdisciplinary collaborations, and the existing gaps in integrating gender and social dimensions within these strategies? In addition, I reviewed literature on medical sociology and anthropology to understand explain how micro and macro structures and processes shape experience, construction and perception of diseases such as HAT.

The literature search was conducted in both social science and biomedical databases, reflecting the study's focus on the non-biomedical dimensions of the diseases. Four search engines namely PubMed, One Search, EBSCO and Google scholar were used. Search terms were combined using Boolean operators and included the following gender, structural violence AND intersectionality, [(Human African Trypanosomiasis) OR (Sleeping sickness) OR (HAT) OR (Eastern and southern HAT) OR (rHAT) OR (Western African HAT) OR (gHAT)], (tsetse flies), [(conservation AND HAT) OR (conservation AND sleeping sickness) OR (conservation AND gender)], [(ecology AND HAT) OR (ecology AND sleeping sickness) OR (ecology AND gender)], [(One Health AND HAT) OR (One Health AND sleeping sickness) OR (One Health AND gender)], [(neglected tropical diseases) OR (Sleeping sickness) OR (NTDs AND Zambia)], and geographic identifiers such as [(Africa) OR (sub Saharan Africa) AND (Zambia)]. The search strategy was intentionally broad to ensure inclusion of literature addressing human, animal and environment interactions, and social differentiation in exposure and response to HAT (rHAT and gHAT). Titles and abstracts were screened against my inclusion criteria [i) published in English, ii) on HAT in general or in particular on rHAT or gHAT, iii) in Africa or Zambia, and iv) published on NTDs, gender, vulnerability, One Health, policy, inequality, poverty and elimination], followed by full text review to select relevant studies. I also reviewed published and unpublished government reports related to African trypanosomiasis in Zambia and other endemic African countries.

2.1 Sleeping sickness: a multi-dimensional challenge

The human population has faced numerous diseases that have persisted over time, affecting their health, social and economic wellbeing (Herricks et al., 2017). Diseases such as HIV/AIDS, Ebola, Lyme disease, tuberculosis, dengue fever, and malaria have particularly strained most low income countries especially those with inefficient systems and inadequate healthcare infrastructure (Herricks et al., 2017). The increasing global population has

escalated demand for essential resources, including land for construction and agriculture, water, and forests to fuel industries and growing urban centres (Alirol et al., 2011; Patz et al., 2004). Consequently, the overexploitation of natural environments to meet these demands has altered ecological systems, directly impacting the survival and reproductive cycles of pathogens and vectors, thus heightening outbreak risks (McMichael, 2004). For example, in most African regions, deforestation for settlement, charcoal production, timber, and farming has contributed to climate change and unpredictable weather patterns (Anderson et al., 2015). Similarly, deforestation has been linked to increased malaria incidence in East Africa and the Amazon, while in Eastern Canada and the USA, habitat loss has led to an increase in white-footed mice, reservoirs for Lyme disease (Kilpatrick & Randolph, 2012).

To date, human behaviours and economic practices continue to shape disease emergence and distribution (Kilpatrick & Randolph, 2012). Due to widespread poverty, many rural communities in low income countries depend heavily on the natural environment for survival (Food and Agriculture Organization, 2014). Researchers, such as Anderson et al. (2015), Han et al. (2015) and Mackenzie et al. (2016), argue that resource limitations push rural populations to conduct livelihood activities in vector prone areas, increasing exposure to disease vectors such as tsetse flies. As a result, poverty and inequality at both national and individual levels remain critical determinants of disease risk and transmission, regardless of geographic location (Arcaya et al., 2015). Evidence further suggests that poverty exacerbates both limited access to quality healthcare and increased vulnerability to infections (Richmond et al., 2005; Rutto et al., 2013). To date, high incidences of malaria, cholera, sleeping sickness and tuberculosis are predominantly observed in the world's poorest nations (McMichael, 2004). While some researchers argue that poverty alleviation would mitigate disease susceptibility, economic activities such as agriculture, timber production, and livestock keeping often expose communities to even greater infection risks (Cortes-Ramirez et al., 2021). For example, communities practicing livelihoods in or near protected areas face increased risk of contracting diseases like malaria and sleeping sickness due to constant interaction with mosquitoes and tsetse flies (Nakamura & Hanazaki, 2017; Asaaga et al., 2021).

This interaction between risk factors and rural livelihoods complicates disease control efforts, contributing to the persistence of many infections that continue to cause mortality in humans and livestock and hinder socioeconomic development (Jacobson & Bush, 2018; Mulenga et al., 2015). Previous research shows that disease outbreaks significantly disrupt economic activities, reducing productivity and deepening poverty (Jonas, 2014; Madhav et al., 2017). Furthermore, interventions designed to control disease outbreaks in livestock and

poultry often negatively impact farmers. For example, imposing bans or restrictions on sales and consumption of dairy or meat products further reduce farmers' income which results in financial hardship (Hotez et al., 2009; Nakamura & Hanazaki, 2017).

This cycle of disease and economic instability perpetuates poor health outcomes, social disparities, and vulnerability among marginalised groups (Hotez et al., 2009). The lack of strong political will and government investment in quality healthcare services further exacerbates disease emergence and transmission rates (Anderson et al., 2015; Beyrer et al., 2007). Additionally, inadequate support for poverty alleviation and improved living conditions increases human interaction with disease reservoirs, such as rodents, which carry multiple pathogens (Kilpatrick & Randolph, 2012).

The emergence and spread of infectious diseases such as malaria and sleeping sickness are inherently linked to human livelihoods, social structures, and policy frameworks. To date, evidence shows that individuals most affected by vector-borne and infectious diseases are often the rural poor, engaged in outdoor activities that heighten exposure to vectors (Kilpatrick & Randolph, 2012). These examples show the multidimensional nature of vector borne and infectious diseases which imply that the detection, control and elimination of complex diseases such as sleeping sickness is a nonlinear process which requires and depends on several aspects such as political will, financial support and interdisciplinary collaboration to succeed (Kilpatrick & Randolph, 2012).

2.1.1 Neglected tropical, zoonotic diseases

Neglected tropical diseases refer to a group of communicable diseases prevalent in tropical and subtropical climates across 149 countries (World Health Organisation, 2017). These diseases, caused by protozoa, viruses, and bacteria, have severe physical and mental health consequences on victims (Molyneux, 2013). Neglected tropical diseases include sleeping sickness, also known as, human African trypanosomiasis (HAT), Buruli ulcer, Chagas disease, dengue, chikungunya, Guinea worm disease, leishmaniasis, leprosy, lymphatic filariasis, onchocerciasis, rabies, scabies, and schistosomiasis (World Health Organization, 2017). The World Health Organization (WHO) 20 NTDs, placing over one billion people at risk (World Health Organisation, 2017, 2020; Molyneux, 2013). While NTDs affect diverse populations, they disproportionately impact rural communities in endemic regions, where poverty and lack of basic services is high (World Health Organisation, 2020). Furthermore, the long term effects of some NTDs such as leprosy, coupled with inadequate treatment, contribute to disability, social stigma, and exclusion of patients from economic participation, further entrenching poverty (Weiss, 2008; Fenwick, 2012; Molyneux, 2013). This shows that

NTDs are deeply rooted in social inequality, poverty, and underdevelopment (World Health Organization, 2017). But what are these diseases? According to World Health Organization (2020, p. x),

Neglected tropical diseases are diseases of poverty that impose a devastating human, social, and economic burden on more than one billion people worldwide, predominantly in tropical and subtropical areas among the most vulnerable, marginalised populations.

To date, research shows that most NTDs are zoonotic (Ehrenberg et al., 2020), meaning they are naturally transmitted between animals and humans and vice versa, through various vectors (World Health Organization, 2006). Like NTDs, many zoonotic diseases, such as anthrax, bovine tuberculosis, brucellosis, cysticercosis, and human African trypanosomiasis (HAT), are also classified as neglected (Welburn et al., 2015; Di Bari et al., 2023). Both NTDs and neglected zoonotic diseases (NZDs) disproportionately affect impoverished populations with limited access to healthcare and basic services (Hotez et al., 2020; World Health Organisation, 2006). However, while NTDs and NZDs indicate poverty, inequality, and lack of access to basic services (WHO, 2017), NZDs' ability to affect both humans and animals results in adverse effects on the health, social and economic wellbeing of rural communities (World Health Organization, 2006). For example, apart from affecting the physical health of humans, NZDs also affect livestock, a source of livelihood, income and proteins for the rural communities. Thus, NZDs rob rural communities' health and livelihood through increased poverty and exclusion from benefits of economic development (Welburn et al., 2015; Institute of Medicine, 2011). The World Health Organisation (2015) defines NZD as a subset of the neglected tropical diseases that are naturally transmitted from animals to humans and vice-versa but affect mainly poor and marginalised populations in low-resource settings. According to King (2011, p.13), a neglected zoonotic disease is,

A zoonosis that is commonly associated with poverty and impacts the lives and livelihoods of millions of poor livestock keepers or those living in peri-urban slums primarily in developing countries.

Researchers highlight the adverse social, economic, and physical effects of NTDs and NZDs on humans. For example, Weiss (2008) argues that NTDs such as leprosy cause severe deformities on victims which result in stigma and social exclusion and economic marginalisation. Thus, beyond health consequences, NTDs and NZDs perpetuate poverty and social suffering among victims in rural communities of endemic regions (Fenwick, 2012; Singer & Bulled, 2012). Yet, despite their significant impact on humans and livestock, NTDs

and NZDs receive minimal governmental and international attention especially in developing countries where most of the NTDs are endemic (Welburn et al., 2015; Institute of Medicine, 2011). This neglect, especially in humans, has led to underreporting and underestimation of the true burden, hindering policy responses (Welburn et al., 2015). For example, while WHO data suggest declining sleeping sickness cases in some endemic regions (World Health Organisation, 2020), emerging evidence indicates an increase in reported cases of the East and Southern African sleeping sickness (rHAT) in new and old foci (Squarre et al., 2016). This suggests that official statistics may mask the true risk and prevalence of sleeping sickness, particularly in rHAT endemic regions.

2.1.2 Human African trypanosomiasis (HAT): a neglected tropical, zoonotic disease

As a neglected tropical and zoonotic disease, HAT has long affected human communities, particularly in endemic regions of developing countries (Dzingirai et al., 2017a; World Health Organisation, 2020). The emergence and disappearance of HAT is closely linked to human, animal, and environmental interactions (Maudlin, 2006; Franco et al., 2014). Historically, HAT was successfully controlled through a combination of vector control measures and active screening efforts in the early 20th century across several endemic countries (Stich et al., 2002; Anderson et al., 2015; World Health Organisation, 2020). Some of the adopted and implemented control methods by countries included aerial spraying, use of targets, game culling and deforestation to disrupt the reservoirs and habitats of tsetse flies (Buyst, 1974; Buyst, 1977; Anderson et al., 2015). Despite initial successes, these interventions had severe ecological consequences, threatening biodiversity and leading some wild animal species to the point of extinction (Anderson et al., 2015). However, poor policies, lack of political commitment, and inadequate resources led to the reversal of earlier progress in eradicating tsetse flies and HAT (Anderson et al., 2015; Squarre et al., 2016). At a regional level, Anderson et al. (2015) argue that the failure of regional control programs was partially due to the lack of collaboration among regional and local stakeholders in the affected areas. Consequently, the density of tsetse flies and cases of HAT begun to re-emerge in former endemic foci (Stich et al., 2002; Squarre et al., 2016).

The risk and control of HAT are shaped by an interaction of social, economic, cultural, political, and health determinants, reflecting a need for interdisciplinary collaborations and the involvement of multiple stakeholders (Anderson et al., 2015). Similarly, Franco et al. (2014) and Odiit et al. (1997) contend that the multidimensional nature of HAT makes it impossible to control solely through veterinary or biomedical interventions. However, while Anderson et al. (2015), Franco et al. (2014) and Odiit et al. (1997) recognise the need for collaboration among stakeholders and the role of other socioeconomic, cultural and political

factors, they do not sufficiently emphasise the need to understand HAT's multidimensional nature and its broader effects on communities and sectors beyond biomedicine.

To date, existing research on HAT has not adequately explored its multidimensional nature. Although several researchers have shown the need for an interdisciplinary and collaborative approach, such collaborations have been limited within biomedical disciplines (Cassidy, 2016; Craddock & Hinchliffe, 2015). While there is evidence suggesting that social, cultural, political, and economic dimensions significantly shape people's experiences of HAT and other NTDs and zoonoses, the nonbiomedical aspects remain underexplored (MacGregor & Waldman, 2017). Consequently, social science and biomedical researchers such as Craddock and Hinchliffe (2015) advocate for the inclusion of social science disciplines in research design and practice, evidence in interdisciplinary collaborations addressing health problems, including HAT, emphasising its impact on the physical, social, economic, and cultural wellbeing of affected communities (Anderson et al., 2015; Bardosh, 2014; Craddock & Hinchliffe, 2015; Grant et al., 2015; Woldehanna & Zimicki, 2015; Zinsstag, 2021).

2.1.3 Human African trypanosomiasis in Africa: disease distribution and burden

Despite the global perception that sleeping sickness is no longer a major health concern compared to diseases like malaria and HIV, it remains a significant public health issue in sub-Saharan Africa, causing mortality, suffering, and socioeconomic challenges in 37 African countries (Mwiinde et al., 2017; World Health Organisation, 2023; Hide, 1999). Of these, 24 countries in West and Central Africa are affected by *Trypanosoma brucei gambiense* (gHAT), a chronic form of the disease responsible for 92 percent of reported cases (World Health Organisation, 2023). The remaining 13 countries in East and Southern Africa are endemic to *Trypanosoma brucei rhodesiense* (rHAT), an acute form that accounts for 8% of cases (World Health Organisation, 2024).

The World Health Organisation (2020) and several scholars (Rutto et al., 2013; Wyatt et al., 1985; Zoller et al., 2008), argue that more people in sub-Saharan Africa remain at risk of HAT, with the majority residing in rural areas and engaged in outdoor livelihood activities such as livestock keeping, farming, hunting, fishing, and forestry. Although gHAT and rHAT were largely controlled in the 1960s, changes in government policies, funding, and priorities led to the decline of control programs, reversing earlier gains (Lutumba et al., 2007; Fèvre et al., 2008). Newly independent nations faced competing health and economic priorities and resource limitations, further hampering their efforts to sustain HAT control programs (Anderson et al., 2015). Consequently, cases began to re-emerge in both old and new foci across West, Central, East, and Southern Africa (Kuzoe, 1991; Squarre et al., 2016).

Currently, there is an estimated 360 tsetse fly foci in rural areas of 36 sub-Saharan African countries (Maudlin, 2006; Franco et al., 2014; World Health Organisation, 2020). Of these, 24 have recorded cases of gHAT, while 13 have reported rHAT cases (World Health Organisation, 2020). In the last decade, 70% of reported cases were from the Democratic Republic of Congo, with Angola, Central African Republic, Chad, Congo, Gabon, Guinea, Malawi, and South Sudan recording between 10 and 100 new cases in 2018 (World Health Organisation, 2020). Cameroon, Côte d'Ivoire, Equatorial Guinea, Kenya, Uganda, Tanzania, Zambia, and Zimbabwe reported between 1 and 10 new cases in the same year, whereas some West African nations, such as Ghana and Nigeria, have only recorded sporadic cases over the past decade (World Health Organisation, 2020).

In response, many African governments, in partnership with international organisations such as the Food and Agriculture Organization (FAO) and the European Union (EU), implemented tsetse control programs, including large scale insecticidal spraying, buffer zones, and forest clearing (Anderson et al., 2015). These efforts, active surveillance as well as tsetse control, and investments led to a massive reduction in cases of HAT especially gHAT. For example, in 2017 and 2018, most countries where gHAT is endemic recorded under 2000 and 1000 cases, respectively (World Health Organization, 2023). Furthermore, WHO estimates show a reduction in the population at risk of HAT from 60 million in previous years to 50 million between 2016 and 2020 with only 3 million at moderate high risk (World Health Organisation, 2023). While initiative to control tsetse flies yielded some positive results in reducing cases of HAT, these efforts were undermined by inadequate community engagement, insufficient funding, and failure to integrate local knowledge (Anderson et al., 2015). In some cases, conservation policies inadvertently recreated new habitats for tsetse flies, increasing the risk of rHAT transmission to humans (Munang'andu et al., 2012; Squarre et al., 2016). Furthermore, although the WHO led initiatives and national control programs significantly reduced HAT cases in the 1990s and early 2000s, progress between the two types of HAT has been uneven. For example, while reported gHAT cases had fallen below 1000 by 2022, the true prevalence of rHAT remains unclear due to gaps in disease surveillance, diagnostics, and treatment (Mwanakasale & Songolo, 2011; World Health Organization, 2023). This neglect contributes to limited understanding of the true burden of rHAT and perpetuates the persistence of rHAT on affected communities. In the rest of the chapters, I will focus on rHAT as that is the form of the disease that occurs in Zambia.

2.1.4 The impact of game management areas on sleeping sickness

According to Lindsey et al., (2016), a game management area (GMA) is “a designated area, surrounding National Parks, where wildlife is managed for both conservation and sustainable use through regulated hunting and other economic activities such as agriculture.” Game management areas, in Zambia, are officially designated buffer zones surrounding national parks, established under the Zambia Wildlife Act No. 14 of 2015 and enforced by the Department of National Parks and Wildlife (DNPW) (The Zambia Wildlife Act, 2015). These areas are intended to support both wildlife conservation and community use by allowing regulated human settlement and sustainable resource harvesting while safeguarding core park ecosystems (Lindsey et al., 2016; Simasiku et al., 2008). This policy framework positions GMAs as key instruments for integrating biodiversity protection with rural livelihoods. However, GMAs’ dual role often creates tensions over land use, resource utilisation, and disease vector dynamics (Anderson et al., 2015).

As argued by Munang’andu et al. (2012), conservation programs and changes in land use in GMAs indirectly serve as a thriving environment for the existence of tsetse flies due to lack of human disruption, increasing the risk among local populations including farmers, game rangers, and tourists. However, the increasing population in the country and districts surrounding GMAs has contributed to a growing demand for resources such as water, land for construction and agriculture, as well as grazing (Anderson et al., 2015; Blaney et al., 2009; Terraube et al., 2017). Despite the low agricultural potential of GMAs, they offer significant opportunities to improve the livelihoods of individuals living there through fertile land for farming, hunting and grazing land (Lindsey et al., 2016; Sylvester et al., 2016). Consequently, human settlement in GMAs has increased, exacerbating practices such as shifting agriculture, charcoal and timber production, which are considered contributors to the loss and destruction of habitat (Ghimire, 1994) and the exposure of communities to risks of zoonotic diseases (de Vos et al., 2016; Nakamura and Hanazaki, 2017).

The importance and value of GMAs and other protected areas have been widely highlighted (Fa et al., 2015; Ghimire, 1994; Hackel, 1999). For example, the establishment of community resource boards to co-manage wildlife in GMAs with the government has contributed to access to revenue and income earned from the sale of natural resources. However, scholars such as de Vos et al. (2016), and Nyamwamu (2016) argue that the risks and challenges of living in parts of the GMA characterised by high densities of tsetse flies and wildlife, particularly for households engaged in livelihood activities such as livestock keeping and farming, may outweigh the benefits.

Changes in land use and livelihoods, from agriculture to non-agricultural activities such as hunting, timber harvesting and jobs in the tourism sector, impact the density of tsetse flies and increase the risk of contracting sleeping sickness (Gbetnkom, 2009; McKinnon et al., 2016; Longbottom et al., 2020). Richardson et al. (2012) argue that increasing human habitation of GMAs and the practice of livelihood activities such as subsistence farming and livestock keeping also contribute to human wildlife conflicts (HWCs), ranging from crop raids by elephants, hippos, and monkeys to livestock predation by lions and hyenas. Although human wildlife conflicts contribute to high levels of poverty and food insecurity within communities living in GMAs and near protected areas (Nyamwamu, 2016), constant interactions with wild animals also increases the risk of indirect transmission of NTDs from wildlife, injuries and death (Dzingirai et al., 2017a; Maudlin, 2006). This suggests that although HWCs negatively impact the economic wellbeing of communities, they also contribute to the increased transmission of NTDs such as sleeping sickness.

2.1.5 Summary

Despite decades of interventions on sleeping sickness, the continued disparities in surveillance and diagnostics between gHAT and rHAT have inadvertently contributed to the increase in risk and cases of the disease in endemic regions such as Zambia's Kafue National Park (Squarre et al., 2016). Increasing cases suggest that while control measures have reduced tsetse fly density in some areas, conservation programs and changing land use patterns in game reserves have inadvertently created conditions favourable for tsetse fly survival (Simarro et al., 2010; Squarre et al., 2016).

2.2 Impacts and consequences of sleeping sickness on people and communities

In the One Health model, the research emphasis on the dimensions of health, animals and environmental dimensions of disease transmission, vector behaviour and ecology needs to be balanced by a deeper, more nuanced exploration of the social, cultural, economic, and political dimensions that shape disease risk, healthcare seeking behaviours, and treatment experiences (Brun et al., 2010; Franco et al., 2014). Although some studies have highlighted the social determinants of HAT (Mwiinde et al., 2017; Odiit et al., 2004; Zoller et al., 2008), this evidence does not always address subjective experiences, power relations, and structural inequalities. Similarly, while some social science research has explored the role of cultural practices (Palmer et al., 2014; Lee and Palmer, 2018; Palmer, 2020), it has not sufficiently examined how socio-cultural factors intersecting with institutional barriers and political dynamics shape disease risk, response, and management.

Understanding the different dimensions (biomedical and non-biomedical) through which sleeping sickness manifests itself and affect rural communities is important in controlling and developing interventions. For example, while case detection and treatment are a role of the biomedical dimensions, risk of contracting sleeping sickness is shaped by social, cultural, and environmental dimensions (Bardosh, 2014). In addition, economic and political dimensions also affect the availability of resources, skills and knowledge among the healthcare facilities which are necessary for successful control and treatment of sleeping sickness (Odiit et al., 2004). Addressing sleeping sickness requires an integrated, interdisciplinary approach that goes beyond biomedical interventions to understand the complex realities shaping disease risk, experience, and management (Conrad, Meek and Dumit, 2013). By acknowledging the multidimensional nature of sleeping sickness, research and policy interventions will be better positioned to develop comprehensive strategies that address not only the biological factors, but also the socioeconomic, cultural, and political conditions sustaining the disease.

To date, the impacts of sleeping sickness, gHAT and rHAT, on the health of victims and their livelihood are well documented (Bukachi et al., 2009, 2017; Leach et al., 2017). In addition to causing physical weakness, the disease leads to low self-esteem, exclusion from social activities, and reduced participation in economic endeavours (Mwiinde et al., 2017). The animal form of the disease also severely impacts communities' livelihoods, particularly in areas where agriculture and livestock farming are central to survival. Furthermore, it affects men, women and children differently due to the nature of the roles that they perform in their households (Nambala et al. 2021). In the following section, I further consider the impacts of sleeping sickness on various dimensions of the lives of the people and the existing gaps in the literature.

2.2.1 Socioeconomic impacts of sleeping sickness

To date, research on sleeping sickness has primarily focused on its effects on the physical wellbeing of victims (Brun et al., 2010; Franco et al., 2014). However, as indicated in the previous section, the disease's impact appears to extend far beyond physical pain and suffering, affecting the social and economic aspects of communities. In their study estimating the economic and social consequences for patients diagnosed with rHAT in Muchinga, Lusaka, and Eastern provinces of Zambia, Mwiinde et al. (2017) found that, in addition to physical weakness, sleeping sickness resulted in low self-esteem and exclusion from social and economic activities. Consequently, most households where patients or former patients lived were characterised by poverty due to reduced involvement in livelihood

and economic activities due to physical weakness caused by the disease and the side effects of its medication (Mpanya et al., 2012).

Beyond its direct impact on human health, trypanosomiasis also affects livelihood activities, particularly livestock keeping which directly impacts the farmers' economic wellbeing (Mwiinde et al., 2017). Bukachi et al. (2017), in their study on the socioeconomic burden of rHAT and household coping strategies in southwestern Kenya, observed that the disease disrupted daily activities, led to food insecurity, low dairy and meat production, poor academic performance and death. Consequently, rHAT deprived families of essential protein sources and contributed to diminished household income and labour availability for cultivation. In addition, Bukachi et al. (2017) and Kuzoe (2001) argue that the biological damage caused by the disease and its treatment impairs former patients' ability to engage in economic and social activities. When rHAT remains undiagnosed, and the primary caregiver is also the household's breadwinner, both productivity and income decline as families exhaust their already limited resources and time in a protracted search for treatment (Bukachi et al., 2017). Consequently, affected families remain trapped in a cycle of economic hardship and poverty, burdened by healthcare costs and the inability to maintain stable livelihoods (Bukachi et al., 2017; Kuzoe 2001).

Similarly, the social consequences of rHAT are equally serious, particularly in relation to stigma, self-esteem, and community relationships. Mwiinde et al. (2017), in their study estimating the economic and social consequences for patients diagnosed with human African trypanosomiasis in Muchinga, Lusaka and Eastern Provinces of Zambia, found that sleeping sickness patients in Zambia were frequently stigmatised because they were suspected of being HIV positive. This association discouraged many individuals from seeking HAT testing out of fear that a positive diagnosis would lead to assumptions about their HIV status (Mwiinde et al., 2017). Additionally, Mwiinde et al. (2017) noted that physical weakness caused by the disease and its treatment led to diminished self-esteem among former patients, particularly women, who feared they would be perceived as unattractive by potential partners. There is a notable lack of studies examining the role of gender in shaping the experiences of those affected by sleeping sickness. Women, who often play central roles in household care and economic activities, may experience different socioeconomic and health challenges compared to men (Mwiinde et al., 2017; Bukachi et al., 2017). Findings by Mwiinde et al. (2017) highlight the broad social implications of sleeping sickness, extending beyond immediate medical concerns to affect personal identity, social interactions, and marital prospects (Mwiinde et al., 2017).

Beyond individual experiences, sleeping sickness disrupts household functioning, contributing to poverty, food insecurity, and the disruption of children's education. In Ethiopia and Uganda, Abro et al. (2023) and Bukachi et al. (2017) observed that illness within a household often forced children to assume additional domestic and economic responsibilities when a breadwinner was either ill or occupied with caregiving duties. Additionally, the slow onset and neurological effects of sleeping sickness frequently led to suspicions of witchcraft, exacerbating tensions within affected communities (Palmer, 2020). In Zambia, for example, a lack of early diagnosis has contributed to widespread misattributions of the disease to supernatural causes, further isolating patients and delaying appropriate medical intervention (Mwanakasale and Songolo, 2011; Mwiinde et al., 2017).

Despite well documented evidence on the socioeconomic impact of rHAT, much of the existing research has focused on its effects on specific aspects such as agriculture and livestock production (Reid, 1997; Swallow, 2000). While this focus is important, these studies primarily estimate economic losses without adequately examining how structural factors such as healthcare access, land use policies, and economic inequalities intersect with livelihood activities such as livestock keeping in shaping individuals' vulnerability and experiences of the risk of contracting sleeping sickness.

2.2.2 Impacts on livestock keeping and agricultural production

Beyond the health and social consequences, sleeping sickness significantly affects rural communities' agricultural activities. Evidence shows that livestock farming in endemic areas is particularly vulnerable to animal African trypanosomiasis (AAT), also known as *nagana*, leading to reduced milk and meat production and increased animal mortality as well as impairing livestock fertility, reducing calving and kidding rates (Swallow, 2000). For example, Swallow (2000) argues that AAT led to a 30% and 50% reduction in the total cattle population in Zimbabwe and Ethiopia, respectively. Similarly, there was approximately 50% reduction in milk and meat production. The resulting constraints hindered the development of the dairy and meat industries, which could serve as economic lifelines for rural communities. Another study by Muhanguzi et al. (2017) on AAT as a constraint to livestock health and production in Karamoja region in Uganda emphasises that the animal form of trypanosomiasis reduces livestock productivity, including milk, meat, and fertility. The loss of income from livestock and the subsequent reduction in household resources increase poverty and vulnerability to other diseases as farmers lack income to enhance their access to health resources and drugs, further exacerbating rural suffering (Abro et al., 2023).

The above evidence shows that the two forms of trypanosomiasis, human and animal, contribute to poverty and suffering as they prevent the successful establishment of integrated livestock-crop farming systems (Swallow, 2000). While trypanocidal drugs can manage the disease in livestock, limited access to veterinary services, insufficient resources, and lack of knowledge among rural farmers hinder effective treatment (Aksoy et al., 2014; Bouyer et al., 2013). This creates a vicious cycle of poverty, where farmers are unable to protect their livestock from the AAT, which in turn further limits their income and worsens their vulnerability to HAT. In Ethiopia, studies reveal that trypanosomiasis significantly reduces oxen's work efficiency, leading to an estimated 40% decline in agricultural productivity for farmers who rely on cattle for cultivation (Abro et al., 2023). A study by Gilbert et al. (2002) on the relationship between tsetse presence and the intensity of land cultivated found that there is a relationship between the intensity of cultivation and density of tsetse flies. Gilbert et al. (2002) found that areas with more tsetse flies had low animal traction and agricultural activities compared to those areas with low density or no tsetse flies. Consequently, affected farmers are unable to cultivate large plots of land, which reduces yields, diminishes income, exacerbates poverty, directly heightens food insecurity, and increases the risk of malnutrition among affected populations (Gilbert et al., 2002). Thus, the threat of sleeping sickness not only reduces the availability of healthy livestock but also constrains farmers' agricultural potential and economic wellbeing.

Furthermore, existing evidence also suggests that trypanosomiasis directly affects agricultural labour (Bukachi et al., 2017; Swallow, 2000). Sleeping sickness disproportionately impact adults, who either endure prolonged illness or devote time to caring for sick relatives (Swallow, 2000). This labour displacement shifts agricultural and livestock responsibilities to children, reducing the quality of farming practices and overall household productivity (Bukachi et al., 2017). The implications extend beyond individual households, as diminished agricultural output translates into broader economic instability, reduced agricultural and livestock productivity, and poverty (Bukachi et al., 2017). Previous research also shows that the consequences are particularly severe for female headed households, where the loss of agricultural income further amplifies vulnerability to poverty and social suffering (Farnworth et al., 2016). Thus, sleeping sickness not only diminishes economic opportunities but also strips affected communities of their ability to secure medical care and sustain livelihoods (Food Agriculture Organization, 2014). By undermining agricultural productivity and livestock viability, trypanosomiasis, regardless of its form, erodes farmers' agency, deepening cycles of vulnerability and deprivation (Bukachi et al., 2017; Swallow, 2000).

2.2.3 Community knowledge and perception of sleeping sickness

While the availability and accessibility of healthcare are critical in controlling and managing diseases, community knowledge and awareness of illnesses and available healthcare contribute significantly to the success of these efforts (Palmer et al., 2020; Palmer, 2020). Knowledge not only makes communities aware of the existence of diseases but also of their nature, transmission, and prevention, thereby increasing the likelihood of early diagnosis and treatment (WHO-FAO-OIE, 2004). For example, a study by Palmer (2020) on sensing sleeping sickness in South Sudan found that people sensed sleeping sickness using both biomedical and ethno-psychological concepts, which prompted them to seek healthcare and indirectly enhanced early diagnosis and management of the disease. Palmer's (2020) observation highlights the importance of community knowledge and awareness in the diagnosis, and treatment of sleeping sickness and the overall success of health interventions.

However, existing research presents mixed findings regarding levels of knowledge about sleeping sickness. Some studies in different parts of Africa suggest widespread awareness of the two forms of the disease, while others highlight significant knowledge gaps. For example, Bukachi et al. (2018) examined knowledge, attitudes, and practices related to sleeping sickness in Yei County, South Sudan, and found that while communities had general knowledge of the disease, misconceptions and stigma persisted. Their study also identified reliance on both traditional healers and biomedical healthcare, with several structural barriers limiting access to medical services (Bukachi et al., 2018). However, Bukachi et al. (2018) did not explore the underlying factors driving the use of traditional medicine, nor did they examine whether these choices were gendered. Furthermore, the study occasionally mixed gender with biological sex, leaving gaps in understanding how gender roles influence disease risk and health seeking behaviours.

Similarly, Kovacic et al. (2016) investigated community memories of past sleeping sickness interventions to assess whether historical trauma affected present day disease control efforts. Their findings revealed both positive and negative recollections, particularly concerning diagnostic and treatment procedures. Communities expressed scepticism toward biomedical interventions, often preferring traditional healing methods due to deeply rooted beliefs about disease causation. However, while Kovacic et al. (2016) acknowledged these perceptions, their study did not examine how broader social structures and institutional inequalities shaped these experiences, and the process of diagnosing and treating sleeping sickness.

Odiit et al. (2004) studied health seeking behaviours and awareness of sleeping sickness in eastern Uganda, revealing that despite general knowledge of the disease, healthcare was

often sought late. Unlike Palmer's (2020) findings, which linked awareness to proactive health seeking, Odiit et al. (2004) observed delays due to factors such as reliance on traditional medicine. However, while Odiit et al. (2004) highlights reliance on traditional medicine as one of the hindrances contributing to delayed diagnosis, their study did not examine the structural conditions that perpetuate dependence on nonbiomedical treatment options. For example, it is not clear how healthcare access disparities, cultural factors and gender roles influence illness interpretation and healthcare decisions.

Mpanya et al. (2012) adopted a qualitative approach to document the economic and socio-cultural factors which may influence community participation in active sleeping sickness screening and treatment activities in the Kasai Oriental province in the Democratic Republic of Congo. Despite widespread knowledge of the disease's risks, barriers such as lack of confidentiality in screening, fears about drug toxicity, poverty, and limited awareness of available services hindered healthcare access (Mpanya et al., 2012). Similar to Ochola et al. (2021), their study also found that women were more knowledgeable about symptoms than men, likely due to their caregiving roles (Ochola et al., 2021). This contrasts with Okwa's (2007) conclusion that men are more informed about NTDs. However, Mpanya et al. (2012) did not explore how gender and the associated gender roles, such as firewood collection, herding, and cultivation, shape differential exposure to tsetse flies and, consequently, variations in disease risk. Furthermore, while the study identified key barriers to healthcare access, it did not address the role of structural and institutionalised inequalities in shaping communities' experiences with the healthcare system.

Overall, while existing literature acknowledges community awareness of sleeping sickness, its transmission, and symptoms, findings remain inconsistent, particularly in Zambia, where evidence suggests varying levels of awareness among both communities and healthcare providers (Mulenga et al., 2015; Mwanakasale et al., 2013; Mwiinde et al., 2022). To contribute to the existing body of knowledge, my study adopts a different methodological and philosophical approach to explore sleeping sickness through communities' experiences, environmental interactions, and social contexts. Ultimately, my study aims to provide a more detailed and context specific understanding of the sociocultural and structural factors shaping awareness and healthcare seeking behaviours related to sleeping sickness.

2.2.4 Summary

Taken together, the evidence above gives insight into the multidimensional effects and nature of sleeping sickness, with socioeconomic repercussions extending beyond the individual patient to affect their entire household and community (Bukachi et al., 2017). While social

science research has contributed to understanding the disease's broader impact (Palmer, 2020), current studies often neglect its nonbiomedical dimensions especially those rooted in interdisciplinary analyses of gender and power.

2.3 Gendered dimensions of sleeping sickness

Although human animal interactions play a significant role in the transmission of zoonotic diseases, the role of gendered roles and responsibilities, structural, and institutional factors remains under researched. While some studies have examined economic effects, disease, and ecological resilience in GMAs (de Vos et al., 2016; Terraube et al., 2017), the role of gender intersecting with micro and macro factors, such as individual characteristics and institutional factors, has not been clearly established, particularly with regard to the risk of contracting sleeping sickness. Researchers such as Mbabazi et al. (2021) and de Vos et al. (2016) have highlighted the risks associated with gendered roles men and women play, but limited attention was given to understanding how institutional inequalities, reflected through the unequal distribution of economic and health resources, shape gendered inequalities, which may affect the risks of exposure to sleeping sickness for men and women.

Like other social, economic, and cultural factors such as poverty, gender is a crucial yet often misunderstood determinant of health (Lindstrand, 2006). In some cases, gender has been narrowly associated with women (Allotey & Gyapong, 2005), an approach that has influenced gender equality policies and campaigns in ways that may overlook broader gender dynamics. However, Allotey and Gyapong (2005, p. 3) define gender as “the culturally and socially constructed aspects of being ‘male’ or ‘female’, reflecting both the relations between individuals at a personal level and the values and norms permeating the broader social structure.” Although sex and gender are conceptually distinct, they are often conflated. Clarke (1983, p. 66) illustrates this by noting how a “biological male” is assumed to be a “social male,” just as a “biological female” is presumed to be a “social female.” This understanding of gender is problematic because it overlooks the sociological nature of gender, which extends beyond biological differences (Rathgeber & Vlassoff, 1993). While sex and its associated roles provide a connection between individuals and the social structure in shaping self-concept and personality, societal norms ultimately define the expectations, behaviours, and roles assigned to different genders (Vlassoff, 2007). These norms, in turn, influence how individuals experience illness, seek medical care, and bear the consequences of disease (Vlassoff, 2007).

Thus, despite efforts to integrate gender into health interventions, programs, and policies, outcomes have often fallen short of expectations due to persistent misconceptions of gender.

This suggests that a correct understanding of gender and its role in shaping disease dynamics provides a basis to understand the broader social, cultural, political, and economic realities that shape the daily lives of men and women, including their health and how they utilise health resources. Recognising how gender intersects with cultural beliefs and traditional practices to shape behaviours provides critical insights into how men and women experience, respond to, and are exposed to the risk of contracting sleeping sickness within their communities (Allotey & Gyapong, 2005; Dias, 1996).

2.3.1 Gender responsibilities and sleeping sickness

Gender shapes social experiences for both men and women, yet it is often primarily associated with women due to their disproportionate exposure to social challenges. As noted by Azad et al. (2020) and Ojanuga and Gilbert, (1992), women face increased negative impacts from various social, economic, and cultural factors compared to men. For example, gender inequalities in education, income, and health disadvantage both men and women in rural communities; however, more women are particularly less likely to have access to health information, disease prevention strategies, and medical services (Azad et al., 2020; Dahal et al., 2022; Okwa, 2007). This suggests that while gender influences disparities in access to resources, intersecting inequalities in education and income exacerbate the differential experiences of suffering and vulnerability to NTDs such as sleeping sickness by men and women (Ochola et al., 2021; Wharton-Smith et al., 2019). It also shows that gender and its influence on division of labour and roles significantly influence health by shaping access to healthcare, food, water, and exposure of different demographic groups to disease vectors such (Garnier et al., 2022; Mbabazi, et al., 2021; Ochola et al., 2021; Vlassoff & Moreno, 2002).

Despite recognition of these dynamics, gendered understandings of disease risk have yet to be effectively integrated into policies and interventions targeting NTDs (Okwa, 2007). Current research on gender and NTDs largely operates outside interdisciplinary and sociological frameworks that incorporate intersectionality, structural violence, and social suffering. For example, Wharton-Smith et al. (2019) examined gender related barriers to health seeking behaviour in Ethiopia and found that social norms restricted community awareness programs for schistosomiasis, lymphatic filariasis and other NTDs leading to delays in healthcare access, especially for women, who often resorted to traditional remedies. Similarly, Ochola et al. (2021) studied the impact of HAT, schistosomiasis and leishmaniasis on women's health in Kenya and found that, despite affecting entire communities, these NTDs disproportionately harmed women and children due to gendered roles and responsibilities. These studies highlight the social consequences of NTDs, including poverty,

stigma, and exclusion, which in turn reduce healthcare seeking behaviour. Another study by Rilkoff et al. (2013) examined gender dimensions in NTD treatment programs in Uganda and found that structural and socio-behavioural barriers hindered both men and women from accessing care, with men experiencing specific obstacles not adequately addressed by existing interventions.

Although these studies provide valuable insights, they remain limited in scope. Many focus primarily on the impact of NTDs on women, neglecting how gender differentially influences risks and experiences for men. For example, Ochola et al. (2021) broadly examined NTD impacts on women and children but did not analyse how gender functions as a determinant of risk and healthcare access for men. Similarly, Rilkoff et al. (2013) concentrated on treatment barriers for pregnant women but did not consider gendered risks of disease exposure. Furthermore, while women and men were Rilkoff et al. (2013) study's focus, limited focus was given to understanding the risk of contracting schistosomiasis in men. For example, while women and children perform most household tasks such as fetching water, and collecting firewood in risky conditions (Ochola et al., 2021), men also experience prolonged exposure to disease vectors through activities like herding, charcoal burning, hunting, and timber harvesting. Nambala et al. (2021) analysed the demographic attributes of rHAT cases in Malawi from 2012 to 2020 and found that men comprised 70.2% of cases, with all fatalities occurring in the second stage of the disease. Their findings suggest gendered disparities in exposure but did not explore the underlying sociocultural and structural factors contributing to these differences. Furthermore, while Nambala et al. (2021) revealed associations between clinical symptoms and disease outcomes, they did not explore the biological and non-biological mechanisms driving the observed patterns. This omission highlights broader limitations in existing research, which often neglects how structural inequalities exacerbates suffering in rural communities affected by sleeping sickness.

At a macro level, studies have examined gender, equity, and human rights in NTD programs. However, most studies have treated gender in broad terms, overlooking its intersections with individual and environmental characteristics such as ethnicity, age, economic resources, and geography in shaping vulnerability to specific NTDs. For example, Mbabazi et al. (2021) identified gender gaps in NTD programs and emphasised the importance of addressing social and structural factors that influence disease risk and exposure. However, they did not examine how different NTDs affect populations in distinct contexts. Similarly, a study by Garnier et al. (2020) on how women can be agents of change in their communities, in the political domain or in the private sectors, found that inclusion of a gender perspective, indigenous people and knowledge into interventions and collaborative approaches, would

enhance the management and conserving of natural resources. In another study, Garnier et al. (2022) found that equal representation of women at decision making and policy making level is a fundamental aspect to building resilience and preparedness for future pandemics. Although Garnier et al. (2020) and Garnier et al. (2022) argued for integrating gender perspectives and indigenous knowledge into resource management and disease interventions; they focused on macro level empowerment rather than the micro level gender dynamics that shape exposure and health outcomes in endemic communities. While their work (Garnier et al., 2020, 2022) highlights power and decision making as factors shaping health, it does not address how gender and structural inequalities embedded in the daily lives of communities influence the risk of contracting sleeping sickness and utilisation of healthcare services in rural settings.

By prioritising macro level analyses and biomedical dimensions, previous studies overlook the role of non-biomedical dimensions and culturally determined gender roles in shaping vulnerability to sleeping sickness. While Garnier et al. (2022) advocate for the inclusion of women as agents of change, their research does not consider the different ways in which gender norms at the community and household level shape the risk of contracting sleeping sickness and health seeking. Similarly, Allotey and Gyapong (2005) examined gender's impact on NTD exposure and management but did not analyse how intersecting social and cultural factors influence perception, risk, and healthcare access for men and women. These limitations highlight the need for evidence that integrates micro level gender analysis with broader structural and institutional perspectives in order to understand intersecting micro and macro factors shaping risk of contracting NTDs. Ultimately, current evidence fails to address how institutional structures, acting upon identities shaped by gender and other individual characteristics, contribute to social suffering and structural violence in rural contexts.

2.3.2 Gendered impacts of sleeping sickness

Sleeping sickness affects men, women, and children in different ways based on their roles, livelihood activities and vulnerabilities within society (Bukachi et al., 2017; Mwiinde et al., 2017). The impacts of sleeping sickness extend across various sectors and spheres of society including health consequences, social, agriculture, livestock, and the environment and affects rural communities of endemic countries whose livelihoods depend on the natural environment for survival (Mwiinde et al., 2017; Swallow, 2000). High levels of poverty and food insecurity within communities increase the exposure of men and women to environments with a high density of tsetse flies and other disease vectors. For example, as observed by Dzingirai et al. (2017a), men hunt in deep forests where they are more likely to

encounter vectors such as tsetse flies that transmit diseases between humans and animals, leaving them at risk of infection with NTDs (Maudlin, 2006; Wyatt et al., 1985). Similarly, women and children visit the bush in search of firewood, fruits, mushrooms, and other wild foods, which puts them at risk of encountering vectors transmitting NTDs (Ochola et al., 2021; Okwa, 2007). Additionally, conservationists and policymakers face the challenge of balancing control of sleeping sickness and its vectors with the need to protect and conserve the environment (Anderson et al., 2015). Overall, the socioeconomic wellbeing of communities in endemic regions, as well as the national economy, suffers due to reduced productivity in agriculture and livestock, as the human and animal forms of trypanosomiasis undermine human labour and depletes livestock, both essential sources of income in rural settings (Bukachi et al., 2017).

While a number of elements such as the economic effects on surrounding land use, the role of protected areas in supporting human health, and social-ecological resilience have been researched extensively (de Vos et al., 2016; Terraube, et al., 2017), the risk of contracting sleeping sickness has not been studied within the contexts of intersectionality, structural violence, and social suffering. As I will further elaborate in the next chapter, intersectionality refers to the idea that social identities and experiences are shaped by multiple overlapping factors, such as gender, race, and class, which interact to create unique forms of marginalisation (Crenshaw, 1991). Similarly, structural violence highlights how systemic inequalities and institutional failures, rather than individual choices, produce and sustain vulnerabilities within certain groups (Galtung, 1969). Lastly, social suffering expands the understanding of harm beyond physical pain, emphasising how social, economic, and political conditions contribute to both psychological and emotional distress (Kleinman, 1997).

2.3.3 Gender, conservation, and health risks

Human interaction with the environment and other animals dates back centuries, forming a reciprocal system of interdependence (Rock et al., 2009). Research indicates that this balance is fragile, and any disruptions can have cascading effects on ecosystems (Nakamura & Hanazaki, 2017). However, with increasing human populations, the demand for resources is high and contributes to encroachment into wildlife habitats and ecosystems, disrupting ecological functions and biodiversity (Anderson et al., 2015; Gandiwa et al., 2011). The increased human presence in these areas has altered the socioecological balance, affecting ecosystem services essential to human and animal survival (Faude et al., 2010). One significant consequence is the displacement of wildlife, which disturbs the natural relationships between vectors and reservoirs (Franco et al., 2014). As humans and their

domestic animals settle in former wildlife habitats, they become new hosts for vectors such as tsetse flies, increasing vulnerability to diseases such as sleeping sickness (Maudlin, 2006; Franco et al., 2014; Dzingirai et al., 2017a).

Despite these challenges, studies show that protected areas provide crucial livelihoods for rural communities (Blaney et al., 2009; Terraube et al., 2017). For example, Sylvester et al. (2016) found that despite the challenges associated with living near protected areas, perceived benefits such as access to nutrition, farmland, grazing land and the cultural value of these livelihoods continue to attract populations (Ghimire, 1994; Hackel, 1999). While these cultural value livelihoods are central to their identity and culture, they remain in tension with conservation policies, ecological risks, exposure to tsetse flies and wildlife hazards (Anderson et al., 2015; Nyamwamu, 2016; de Vos et al., 2016). Researchers such as Anderson et al. (2015) have highlighted how land use changes influence vector density, while others like Nakamura and Hanazaki (2017) have argued that land use regulations can alter local livelihoods. Therefore, policies that encourage conservation through alternative income activities, such as tourism, may benefit ecosystems but can also lead to economic food insecurity, and increased vulnerability to zoonotic diseases due to thriving habitats for vectors such as tsetse flies (Gbetnkom, 2009; McKinnon et al., 2016).

To date, extensive research has established the dependence of rural communities on natural resources and the health risks associated with their proximity to protected areas (Anderson et al., 2015; Dzingirai et al., 2017a). However, existing studies on the environmental determinants of risk of contracting sleeping sickness have largely focused on individual aspects such as nutrition, deforestation, and livelihood strategies (Faude et al., 2010; Anderson et al., 2015; Nakamura & Hanazaki, 2017). Few studies have examined how these factors intersect with gender, socioeconomic inequality, and cultural practices in shaping disease vulnerability. For example, a study by Rojas (2000) explored community based conservation through a gender lens but did not examine how gender roles influence disease risks. Similarly, Wekesah et al. (2019) assessed gender disparities in conservation agriculture but did not analyse how these disparities impact exposure to zoonotic diseases. While their study emphasised that women face greater health risks than men, the study did not specify the nature of these risks and how they shape disease transmission and health seeking behaviours. Other studies on gender and conservation focused on the inclusion of women and men in resource management (González & Martin, 2007; Ochola et al., 2021). However, limited attention has been given to how daily socioeconomic activities such as farming, herding, water collection, charcoal burning, and timber cutting differently expose men and women to NTDs like trypanosomiasis.

Studies such as Farnworth et al. (2016) have highlighted how gender dynamics influence conservation agriculture adoption, yet they have not examined its implications for disease vulnerability and health seeking. Similarly, Lau (2020) highlights how simplistic conceptualisations of gender in biodiversity conservation can lead to inequitable outcomes. However, despite acknowledging the misconception of gender and power imbalances in conservation, Lau's study does not consider how these inequalities contribute to differential exposure to NTDs, especially sleeping sickness. Furthermore, by framing conservation primarily within a biological context, Lau (2020) overlooks the socioeconomic, political and cultural dimensions of disease vulnerability, including the role of poverty, institutional inequalities, and gendered labour patterns.

A study by González and Martin (2007) on gender in the conservation of protected areas highlights the importance and need for including gender in conservation. González and Martin (2007) advocate for integrating gender perspectives in conservation beyond recognising inequalities to fostering equitable resource management. However, their study does not address how gendered roles and responsibilities shape disease exposure in conservation areas. Furthermore, they do not explore how protected areas serve as risk zones for both men and women, increasing their exposure to vectors and zoonotic diseases, thereby worsening socioeconomic hardships. On the other hand, Leach et al. (2017) examine the complex relationships between zoonotic diseases, ecosystems, and livelihoods in Zambia, Zimbabwe, Sierra Leone, and Ghana. They highlight the role of socioeconomic factors in shaping disease risks but offer limited discussion on how cultural practices, gender norms, and social hierarchies affect exposure to HAT. Additionally, Leach et al., (2017) do not address how gendered access to healthcare services influences treatment outcomes.

While existing research indicates the importance of biodiversity conservation in shaping disease dynamics, it often neglects the nonbiomedical dimensions such as gender disparities, poverty, and systemic inequalities that influence disease risk, healthcare access, and overall wellbeing of individuals. Thus, my study aims to bridge these gaps by exploring the gendered dimensions of sleeping sickness, demonstrating that beyond biological factors, structural factors such as power imbalances, institutional inequalities, and economic deprivation, shape disease risk, healthcare access, and health outcomes.

2.3.4 Summary

The continued neglect of NTDs, as further explained in the following section, leaves endemic communities particularly vulnerable, in part, due to insufficient commitment from policymakers and healthcare stakeholders (Whitehead, 1992). While both men and women

face risks of contracting NTDs such as sleeping sickness, schistosomiasis and leishmaniasis, gendered roles and responsibilities, alongside institutional factors such as healthcare access, shape their vulnerability. Health disparities between men and women in NTDs are deeply rooted in systemic resource distribution, which influences access to services (Arcaya et al., 2015). Therefore, my analysis emphasises the need for an integrated, intersectional approach that moves beyond broad gender categorisations to critically examine the structural and cultural dimensions of risk of contracting sleeping sickness and healthcare access.

2.4 The problem of sleeping sickness and One Health perspectives

The multidimensional nature of sleeping sickness has created a complex challenge in its understanding and management. This complexity is further compounded by the conflicts that arise among stakeholders, each holding different interests and solutions (Grant et al., 2015). The dimensions of sleeping sickness, the populations at risk, and its widespread effects across various sectors requires a critical examination of why sleeping sickness remains problematic to human, animal and environmental health and why its control has resulted in conflicts among stakeholders. After summarising these conflicts, I go on to consider why a One Health perspective offers a useful framework for understand the multiple dimensions of sleeping sickness.

2.4.1 Sleeping sickness and conflicts between active and non-active actors

Drawing on the research literature, active actors in sleeping sickness interventions and research can be broadly summarised as shown in Table 1 below, those involved in wildlife conservation and management; biomedical and healthcare professionals developing and providing treatment and care for those actors at high risk of contracting rHAT. As shown in Table 1 below, actors interested in conservation argue that measures like clearing bushes disrupt ecological balance and accelerate climate change (Longbottom et al., 2020; Lord et al., 2018), while veterinarians and local communities contend that vegetation retention increases exposure to tsetse flies, heightening the risk of disease transmission to both humans and livestock.

To date, evidence in the study of sleeping sickness shows that critical aspects such as gender, culture, and socioeconomic factors have received insufficient attention (Mbabazi et al., 2021; Rathgeber and Vlassoff, 1993; Friedson-Ridenour et al., 2019). Disease transmission is influenced by cultural and gender dynamics within communities yet sleeping sickness interventions have had limited impact because gender mainstreaming policies remain at a macro and institutional level, without narrowing down policies to the community level (Allotey & Gyapong, 2005; Rilkoff, Tukahebwa, Fiona M. Fleming, et al., 2013). Critics of

the prevailing biomedical focus in managing sleeping sickness claim that this approach marginalises nonbiomedical knowledge and perspectives, limiting its overall efficacy (Bardosh et al., 2020; Craddock & Hinchliffe, 2015). This tension highlights the multidimensional nature of sleeping sickness and the different approaches to its management, rooted in both biomedical and nonbiomedical understandings.

Table 1: Active actors and their competing interests in sleeping sickness

Actor(s)	Interests	Competing interests
Government: Ministry of Health, district health offices, surveillance units	Disease control, case detection, public health outcomes, funding, donor alignment	Prioritise diseases with higher case numbers or donor visibility; less focus on systemic drivers such as gender
Government: Veterinary & Livestock Services Ministry of Fisheries and Livestock, Department of Veterinary Services	Control of animal reservoirs, livestock productivity and health, disease surveillance	Conflicts with conservation and environmental actors; lower integration with the human health sector
Government: Environmental & Wildlife Ministry of Green Economy, Department of National Parks & Wildlife (DNPW),	Protect biodiversity, manage wildlife areas (GMAs), eco-tourism revenue	Conflicts on human settlement in GMAs and introduction of livelihoods such as farming and livestock keeping
Researchers & Academics Universities, One Health researchers, social scientists	Knowledge production, policy influence, collaboration	Face resistance from government ministries to collaborate
Local communities: Farmers, fisher farmers, pastoralists, women's cooperatives	Access to natural resources, livestock, health services, livelihoods	Marginalised in decision-making; resist conservation restrictions, relocate to unsafe areas due to land scarcity
Traditional leadership: Village Headmen, local chiefs, customary land allocators	Maintain authority over land, social cohesion	Resist state or NGO interventions
Private Sector Livestock traders, safari/lodge operators	Economic gain (livestock productivity, eco-tourism)	Private incentives which do not align with public health goals

As established, sleeping sickness is transmitted by tsetse flies, which thrive in savanna vegetation and water bodies (Franco et al., 2014). Control measures to mitigate these vectors include aerial spraying, use of fixed and moving targets, and habitat destruction through clearing bushes (Anderson et al., 2015). While these methods have proven effective in reducing both human and animal incidences of trypanosomiasis and tsetse fly density between the 1940s and early 2000s (Anderson et al., 2015), their environmental costs cannot

be overlooked. Interventions such as bush clearing contribute to increased environmental degradation, including accelerated climate change, which exacerbates weather patterns and ecological instability (Longbottom et al., 2020; Lord et al., 2018). The environmental consequences of clearing vegetation to control tsetse fly density accelerate climate change, leading to challenges such as droughts, floods, and rising temperatures, all of which directly impact disease dynamics (Longbottom et al., 2020; Lord et al., 2018).

The lack of comprehensive nonbiomedical knowledge about sleeping sickness, particularly regarding its social, economic, and political dimensions, further fuels ongoing disagreements about effective management strategies (Grant et al., 2015). Nonbiomedical disciplines, such as social sciences, have highlighted how factors like social norms, economic conditions, and political policies influence health outcomes (Harris & White, 2019). Despite the overwhelming biomedical understanding of the disease, social sciences have an essential role in addressing the gaps in our knowledge about how human behaviour, livelihood activities, and cultural practices influence disease transmission, thereby informing more inclusive and holistic interventions (Lapinski et al., 2015). For instance, while sleeping sickness is caused by biological pathogens, the interaction between human livelihoods, cultural practices, and exposure to disease vectors is also crucial in determining the risks (Maudlin, 2006; Franco et al., 2014). This shows the need for interdisciplinary approaches that incorporate social sciences alongside biomedical research to better understand the dynamics of sleeping sickness and improve control strategies (Bardosh, 2014b; Craddock and Hinchliffe, 2015; Plowright et al., 2008).

Despite the significance of these insights, social science evidence on the social determinants of health has not been given the same prominence as biomedical research in shaping interventions and policies aimed at tackling sleeping sickness (Lapinski et al., 2015; Rock et al., 2009a). Although numerous studies have contributed valuable insights into the dynamics of human-animal interactions and the ecology of sleeping sickness, many still fail to incorporate a broader, interdisciplinary perspective. For example, while Nyimba et al. (2015) and Mbewe et al. (2015) focused on the prevalence of animal African trypanosomiasis (AAT), their studies primarily emphasised veterinary aspects without addressing the implications of these findings for human populations. Nyimba et al. (2015) found that most goats studied tested positive for AAT, indicating increasing cases of AAT in the areas studied. Similarly, Mbewe et al. (2015) reported and concluded that anaemic cattle were positive for pathogenic trypanosomes in addition to other causes of anaemic cattle. Similarly, Holt et al. (2016) analysed community vulnerability to AAT but largely overlooked human suffering and disease transmission risks to nearby communities.

This narrow focus on biomedical factors, while informative, fails to address the full spectrum of human and environmental health concerns. Although Holt et al. (2016) identify the different levels of community of vulnerability, this suffering is only limited to the livestock and household income while other aspects of human suffering and vulnerability to the disease are not highlighted. The need for a more integrated approach becomes evident when considering studies like that of Munangandu et al. (2012), which highlights ecological risks related to tsetse fly and wildlife interactions but did not explore the role of policy or social factors in exacerbating human vulnerability to sleeping sickness and other environmental challenges. This further indicates a gap in the existing literature, one that does not fully capture how nonbiomedical factors such as cultural, socioeconomic and structural factors shape disease dynamics and human suffering in endemic areas.

Overemphasising biomedical and ecological aspects, while ignoring the social and political dimensions, hinders the development of effective, comprehensive interventions for disease control. This does not imply the complete absence of social science research and evidence in the study of trypanosomiasis. However, to date, studies that have used social science evidence have done so to provide information regarding cultural beliefs and practices shaping risk of diseases (Bardosh, 2014; Craddock & Hinchliffe, 2015). Yet, relating social sciences to only understanding factors that influence ‘risk’ has the potential of missing the role of social, cultural and religious practices in mitigating or escalating the risk of diseases such as sleeping sickness (Michalon, 2020; Wilkinson & Leach, 2015). For example, culture beliefs and norms have been mostly perceived by biomedical experts and other public and veterinary experts in negative light as a hinderance and barriers to behavioural change (Manderson & Aaby, 1992; Martin, 2008; Tanner et al., 1986). Therefore, social science evidence provides an opportunity to understand the role of different contexts, social, cultural economic, and political factors on knowledge about trypanosomiasis, diagnosis, and health seeking.

2.4.2 Taking a One Health perspective to research sleeping sickness

Taking a One Health approach offers the opportunity to resolve some of these tensions by providing a useful framework to consider the implications for human, animal, and environmental health on the management of sleeping sickness. This framework recognises that the complexity of sleeping sickness cannot be understood through biomedical lenses alone and that interventions must be inclusive of social, cultural, and economic factors to effectively reduce disease transmission and improve health outcomes for affected communities. The One Health framework, rooted in intersectionality and social systems theory, serves as a basis for understanding the disease and developing efficient interventions

to control it. This approach and framework acknowledge the role of different disciplines and stakeholders in informing and understanding sleeping sickness. Although One Health is predominantly associated with biomedical disciplines, a sociological approach by incorporating sociological theories has the potential to explore the multidimensional nature of sleeping sickness, how it affects different aspects of people's lives, and how its management and control lead to competing interests among actors in various spaces.

One Health is often perceived as new, though it has existed in various forms for a long time (Lerner & Berg, 2015; Riley et al., 2021; Zinsstag, 2021b). This perception arises from the evolving nature of the concept, shaped by health challenges, scientific advancements, and the shifting political, social, economic, and environmental landscape (Bresalier et al., 2020). Initially, One Health was preceded by the term 'One Medicine,' a term first used by Osler and later developed by Schwabe to highlight the commonality between human and veterinary medicine (Bresalier et al., 2020). However, since Schwabe's introduction of 'One Medicine,' the One Health concept has become more focused on research primarily related to natural and health sciences (Bresalier et al., 2020), reinforcing arguments by Killewo et al. (2016) that the One Health approach is an extension of traditional public health theories and methods.

The One Health concept is used to refer to different things. According to the One Health Global Network (2015), One Health involves a coordinated, collaborative, multidisciplinary, and cross sectoral approach to address risks originating at the animal-human ecosystem interface. King et al. (2008, p.260) offers another perspective, calling One Health an "integrative effort of multiple disciplines working locally, nationally, and globally to attain optimal health for people, animals, and the environment." In contrast, Falzon et al. 2018, p.210) view it as an approach based on the idea that "human, animal, and environmental health are intimately connected and mutually dependent." Baum et al. (2017) extend this definition to include food security, poverty, gender equity, and health systems strengthening. Despite these varied definitions, they share a common emphasis on collaboration across sectors and disciplines, particularly focusing on the human animal environmental interface. However, while these definitions emphasise interdisciplinary collaboration, they often overlook the importance of nonbiomedical factors, which are crucial for a holistic understanding of health (Craddock & Hinchliffe, 2015).

To date, One Health research has been primarily rooted in veterinary science and medicine, which has limited its scope in addressing broader issues that extend beyond these disciplines (Bresalier et al., 2020; Woods et al., 2018). Although research in ecology and human

behaviour has been incorporated into the approach, critics argue that One Health has neglected evidence from nonbiomedical fields, particularly the social sciences (Craddock & Hinchliffe, 2015; Lapinski et al., 2015). Craddock and Hinchliffe (2015) contend that social sciences have not been prioritised in the One Health agenda, contributing to the sidelining of important insights from these fields. The literature reveals a clear bias toward veterinary and comparative medicine, disciplines derived from the 'One Medicine' and 'One World, One Health' frameworks (Mackenzie & Jeggo, 2019).

Considering these critiques, it is essential to consider a broader definition of One Health, one that embraces the contributions of all relevant disciplines. Evans and Leighton (2014, p. 414) defined One Health as “a paradigm in which health is determined by a broad, inclusive and interdependent continuum of cause and effect across ecosystems and human and animal populations that fully embraces food security, biodiversity, economic prosperity, emotional and mental wellbeing.” Similarly, the One Health High-Level Expert Panel (OHHLEP) et al. (2022, p. 2) defines One health as “an integrated, unifying approach that aims to sustainably balance and optimize the health of people, animals, and ecosystems. It recognizes the health of humans, domestic and wild animals, plants, and the wider environment (including ecosystems) are closely linked and interdependent.” While different, these definitions advocate for a more inclusive approach, one that extends beyond infectious and zoonotic diseases to include critical issues like food security, economic wellbeing, and emotional health. Evans and Leighton's (2014) definition offers a platform for interdisciplinary collaboration that recognises the social, political, cultural, and economic factors influencing health outcomes, including the risk of contracting sleeping sickness.

2.4.4 Interdisciplinary One Health collaboration, which way to go?

Collaboration among disciplines, institutions, and organisations is critical in addressing complex issues that span multiple interfaces. Scholars argue that such collaboration is essential as it brings together diverse perspectives and expertise to tackle complex problems (Julkowska et al., 2017; Katz & Martin, 1997). The One Health approach, by its nature, requires collaboration among various stakeholders to address issues at the human, animal and environment interface (Berger-González et al., 2021). However, despite the acknowledged importance of collaboration, low levels of interdisciplinary engagement have hindered One Health's ability to effectively address the full scope of relevant issues (Kimball et al., 2008).

Research suggests that successful interdisciplinary collaboration hinges on several factors, including the strengthening of institutional structures (Henderson et al., 2012; Kolaczinski

& Webster, 2003), the willingness of disciplines to engage (Allen et al., 2014; Landford & Nunn, 2012), and the sharing of resources such as methods, tools, language, and concepts (Kolaczinski & Webster, 2003; Sopirala et al., 2014). Despite these insights, disciplinary silos (Ramadier, 2004) and intradisciplinary collaboration remain obstacles (Errecaborde et al., 2019; Lapinski et al., 2015). Furthermore, incompatibilities in research methods, tools, and terminologies, alongside a lack of political will and support, continue to undermine the integration of knowledge across disciplines (Petts et al., 2008; Stock & Burton, 2011).

Research on collaboration distinguishes between three main approaches: multidisciplinary, interdisciplinary, and transdisciplinary (Dalton et al., 2021; Ramadier, 2004). Although each approach encourages collaboration, they vary in how they manage the contributions of different disciplines. Multidisciplinary and interdisciplinary approaches tend to maintain the core principles of each discipline while seeking common ground to address a specific issue (Hall et al., 2012). Both approaches aim to simplify complex problems by adopting models, theories, and conclusions that are compatible across disciplines (Rosenfield, 1992). In contrast, transdisciplinary collaboration integrates the methods, skills, and knowledge of all involved disciplines, fostering the development of new frameworks, models, and theories that transcend disciplinary boundaries (Berger-González et al., 2021; Ramadier, 2004).

While transdisciplinary collaboration appears to be an ideal model for One Health, its emphasis on creating new frameworks contradicts the foundational principles of One Health and the unique strengths of each discipline. Therefore, I propose an interdisciplinary One Health approach that integrates the strengths of all disciplines and stakeholders, leveraging their expertise to address the complex issues at the heart of the approach (Berger-Gonzalez et al., 2021; Ramadier, 2004). Drawing on systems thinking, which emphasises the interdependence of components within a system, this approach is particularly relevant for studying sleeping sickness, a multidimensional disease, which requires interdisciplinary collaboration for effective understanding, control, and management of the disease.

2.4.4 Summary

Thus far, I have argued that the cumulative effect of sleeping sickness in humans and animals disrupts livelihoods, reinforcing economic instability in rural communities where the disease is endemic. I have also revealed that existing research has not sufficiently examined how these impacts are mediated by gender, nor has it explored how an interdisciplinary approach could provide more holistic solutions. My study addresses this gap by integrating these perspectives within a One Health, interdisciplinary approach, offering a more comprehensive analysis of how the risk of contracting sleeping sickness is perpetuated by

structural inequalities in endemic communities. Consequently, my study contributes to the understanding of the nonbiomedical dimensions of sleeping sickness and the structural forces that perpetuate its risk and consequences among children, men and women in rural communities.

2.5 Researching sleeping sickness (rHAT) using One Health perspectives

The complex, multidimensional nature of sleeping sickness, involving biomedical, ecological, agricultural, and socioeconomic dimensions requires a collaborative approach that incorporates diverse perspectives from multiple disciplines. As shown in studies like Hamill et al. (2017) and Schelling et al. (2007), collaborative efforts between communities, professional experts, and stakeholders can significantly reduce costs and improve service delivery in remote areas, demonstrating the value of interdisciplinary cooperation. However, despite these positive examples, interdisciplinary collaboration in the management of sleeping sickness remains limited, mainly due to competing interests and differing perceptions of the disease. This lack of collaboration hinders progress, especially in addressing neglected variants of the disease, such as the east and southern Africa variant of sleeping sickness (rHAT).

2.5.1 The challenge of Human African Trypanosomiasis in Zambia

Zambia's rich wildlife and biodiversity, which include twenty (20) national parks and thirty-six (36) game management areas (GMAs), in addition to other protected areas, cover an estimated 40% of the total land mass of the country (Government of Zambia, 2010). Like other East and Southern African nations, Zambia has a long history of endemic sleeping sickness (Munangandu et al., 2012). While the Zambian government has been actively involved in rHAT control efforts since before the country's independence (Buyst, 1977; Grant et al., 2015), the success of previous programs targeting tsetse fly populations were undermined by poor policies, inadequate support and high implementation costs (Anderson et al., 2015; Steverding, 2008). Zambia has been using non-persistent insecticide impregnated odour-baited screens, livestock treatment with insecticides, and nighttime aerial spraying covering over 5,000 km² in Shangombo and 6,300 km² in Mulobezi (GRZ, 2015; Steverding, 2008). While these approaches are highly selective for tsetse flies, they faced limitations regarding long term effectiveness and coverage (GRZ, 2015). The failure to maintain control efforts, coupled with inadequate game management policies, has facilitated the increase in cases of rHAT in old foci such as the Kafue National Park (Squarre et al., 2016).

Between 2013 and 2023, Zambia reported only 75 cases, a decrease from the 82 cases recorded between 2000 and 2009 (World Health Organization, 2023). However, challenges in diagnosing rHAT contribute to underreporting and an underestimation of the true burden of the disease (Mwanakasale and Songolo 2013). The World Health Organization (2023) estimate that approximately 65 million people are still at risk of infection, with only a fraction of the population under surveillance in Africa. This is supported by recent studies that point to an increase in animal African trypanosomiasis (AAT), which could signal the presence of rHAT (Mbewe et al., 2015; Nyimba et al., 2015). A study by Squarre et al. (2016) documented a new case of sleeping sickness in Zambia's Kafue National Park after more than fifty (50) years. Studies by Franco et al. (2017) and Simarro et al. (2008) identified cases in previously unaffected areas like Kafue National Park and in regions where control measures were once effective, such as Luangwa Valley. Furthermore, research by Lisulo et al. (2022) highlights the presence of animal sleeping sickness in domestic animals, such as dogs, which are known reservoirs for rHAT parasites (Brun et al., 2010). Areas like Mambwe District, once considered low risk (Mwiinde et al., 2022), may be experiencing higher prevalence of sleeping sickness than previously estimated. Factors such as low awareness of sleeping sickness in rural areas, a shortage of trained medical staff, and inadequate diagnostic tools hinder the identification of rHAT cases (Mulenga et al., 2015; Mwanakasale & Songolo, 2011). Additionally, the high prevalence of malaria and other febrile diseases in these areas may also lead to misdiagnosis and mismanagement of possible cases of sleeping sickness (Mubemba et al., 2022). This indicates that the current decline in sleeping sickness cases in Mambwe district and Zambia at large may not reflect the true burden of the disease, especially for rHAT which receives limited diagnosis efforts compared to gHAT (Brun et al., 2010).

Despite significant research into the biological and ecological aspects of sleeping sickness, the understanding of its social, economic, and political dimensions of rHAT in Zambia is limited. While studies highlight the role of environmental factors in disease transmission (Anderson et al., 2015) and vector control and clinical management (Brun et al., 2010; Kennedy 2013), there remains a lack of research exploring the sociocultural and economic impacts of sleeping sickness on affected populations. Existing research using social science methods have mostly focused on gHAT in contexts with established screening and diagnostic systems (Palmer, 2020; Odiit et al., 2004) and offers limited insight into the understanding of the nonbiomedical nature of rHAT.

2.5.2 Healthcare delivery and accessibility in Zambia's game management areas

The health challenges of game management areas (GMAs) in Zambia, to some extent, reflect the country's healthcare delivery system. Despite the increased risk of contracting NTDs and other diseases, rural areas and communities living in GMAs and near protected areas still suffer from inadequate healthcare infrastructure and services (Mulenga et al., 2015). The healthcare system in Zambia offers universal healthcare, but economic challenges and policy inconsistencies have hindered its ability to offer adequate and comprehensive services beyond basic care (Mubemba et al., 2022). Despite government efforts to improve service delivery in the health sector, shortages of essential infrastructure and equipment, low levels of qualified health workers, and shortages of essential drugs and medical supplies characterise the Zambian healthcare system (Ministry of Health-Zambia, 2022). Increasing poverty and inequalities in income distribution have caused health programs to stall, leaving the country with shortages of essential drugs, facilities, and equipment that contribute to a healthcare system unresponsive to the needs of its citizens (Amzat & Razum, 2014).

As of 2021, Zambia had 3,320 health facilities, of which 2,834 were government owned, 101 were faith-based healthcare facilities, and 385 were private owned. Of the government owned facilities, seven were fourth level hospitals, seven were third level hospitals, 36 were second level hospitals, 100 were first level hospitals, 62 were mini hospitals, 1,720 were health centres, and 1,388 were health posts (Ministry of Health, 2021). According to the World Health Organization, Zambia had a doctor patient ratio of 1:12,000, more than double the recommended ratio of 1:5,000. The 2020 WHO report further showed that the nurse-to-patient ratio was 1:14,960 compared to the recommended ratio of 1:700 (Ministry of Health (MOH) Zambia, 2022; World Health Organisation, 2020).

In terms of diagnostic services, the Zambia National Health Strategic Plan (2022) indicates that only 398 out of 2,834 government owned health facilities have laboratories. Due to limited skilled staff and infrastructure, only five laboratories out of the 398 provide histopathology services (National Health Strategic Plan, 2022). Similarly, less than two thirds of health facilities were able to perform basic urine dipstick and malaria diagnostics, and only 35 percent offered rapid diagnostic tests for STIs such as syphilis, while 94 percent offered HIV diagnosis, 14 percent offered general microscopy, six percent offered full blood count services, and four percent provided TB testing (Ministry of Health, 2021; National Health Strategic Plan, 2022).

These structural challenges within the health sector constrain Zambia's healthcare system's ability to monitor, control, and manage the healthcare needs of its citizens, especially in rural

areas (Mubemba et al., 2022; Mwanakasale et al., 2014; Mwanakasale et al., 2011). For example, as noted by Mulenga et al. (2020) and Mwanakasale et al. (2011), the lack of equipment and skilled personnel to detect NTDs such as sleeping sickness has resulted in misdiagnosis and mistreatment among rural communities. Therefore, although Zambia's healthcare system challenges affect the entire country, the poor communities in rural areas suffer the most from drug shortages, inadequate healthcare facilities, and understaffing. As argued by Zyaambo (2012), such system failures inadvertently limit rural populations' access to healthcare services, contributing to an increased rate of misdiagnosis of potential cases of sleeping sickness and reliance on self-treatment using herbs and other alternatives.

Research elsewhere has highlighted the importance of early diagnosis of sleeping sickness in the early referral of potential cases and healthcare seeking behaviours among communities due to awareness of the signs and symptoms (Palmer et al., 2014; Palmer, 2020). While Zambia lacks a clear policy and plan for the diagnosis of sleeping sickness, other countries such as the DRC, Uganda, Tanzania, and Sudan have embedded active diagnosis of sleeping sickness into their healthcare systems. For example, Uganda has a national sleeping sickness surveillance system, which involves community-based health workers collecting blood samples within their communities (Lee & Palmer, 2018).

Therefore, limitations of the healthcare delivery system suggests that prioritisation and investment in control and screening programs for sleeping sickness is dependent on political will and support. While major Zambian healthcare facilities may have the diagnostic equipment, most rural healthcare facilities lack the diagnostic tools and skills to adequately diagnose and treat sleeping sickness (Mubemba et al., 2022; Mulenga et al., 2020; Mwiinde et al., 2022). These limitations in the healthcare system leave the rural population at risk of under reporting, misdiagnosis, and mismanagement of possible cases of sleeping sickness resulting in Wedeath (Mwiinde et al., 2017).

In Zambia, research on sleeping sickness awareness presents two conflicting narratives. Some studies suggest that communities in endemic regions possess substantial knowledge about the disease, while others highlight low awareness levels, even among healthcare workers. For example, Mwiinde et al. (2022) assessed healthcare management of sleeping sickness in the Eastern, Muchinga, and Lusaka provinces of Zambia, finding that patients in all four districts (Mpika, Mambwe, Chama, and Rufunsa districts) were aware of the disease and its vector. Similar to Palmer's (2020) findings in Sudan, Mwiinde et al. (2022) noted that common symptoms among male and female patients included fever, body pain, sleep disturbances, and headaches. However, it remains unclear whether individuals recognised

these symptoms as indicators of sleeping sickness or whether their knowledge directly influenced healthcare seeking behaviours. In contrast, other studies still observe low levels of knowledge and awareness of sleeping sickness. For example, Mwanakasale, et al. (2013) in their study, clinical presentation of human African trypanosomiasis in Zambia, found low awareness of sleeping sickness and diagnostic skills among medical practitioners in Eastern and Northern provinces of Zambia. Mwanakasale & Songolo (2011) further argued that inadequate equipment, low awareness of sleeping sickness, and limited expertise among healthcare workers contributed to diagnostic challenges and possible under reporting of cases.

Although the social, economic, and health challenges faced by rural communities are widely recognised (Simasiku et al., 2008), interventions and policies rarely address their lived experiences. Instead, as Douglas and Wildavsky (1982) argue, policies are often imposed on these populations, failing to address their real problems, and instead blaming them for their own suffering and its consequences. Although official statistics in Zambia (Zambia Statistics Agency and ICF, 2019) document various forms of health, social, and economic suffering, rural areas bear the heaviest burden due to the inequitable distribution of infrastructure and services.

Whereas existing research on sleeping sickness has made important contributions towards the understanding of the disease, it remains limited by its focus on biomedical models and neglect of the complex social dynamics that influence disease transmission and health outcomes. Although efforts to include nonbiomedical aspects have been made, these studies adopted methodological and theoretical frameworks which omitted the lived and subjective experiences of communities. Furthermore, existing evidence does not consider a more integrated, interdisciplinary approach as adopted by my study which considers the intersecting roles of gender, power, ethnicity, and socioeconomic status in shaping the risk of contracting sleeping sickness. As indicated, bridging the gap between biomedical and social science perspectives offers opportunities to researchers to better understand the multidimensional nature of sleeping sickness and contribute to more effective, contextually appropriate public health interventions.

2.6 Chapter summary and conclusion

In this chapter, I have provided a broad overview of the literature surrounding sleeping sickness, gender, and One Health. I have considered how approaches to control and management contribute to people's experience of suffering from the disease. Then I also considered how these approaches to control and management shape the risk of contracting

sleeping sickness and negatively influence the routes to diagnosis, care and management. Furthermore, I reviewed the existing frameworks and approaches to control and manage sleeping sickness and what is known regarding these interventions within the Zambian context. In the next chapter, I will introduce my theoretical framework, research questions, and the methods used to answer my research questions. I will also address the ethical considerations and explain how the data were collected, analysed, and managed.

CHAPTER THREE: METHODOLOGY

3.0 Introduction

In the previous chapter, I established what is known about sleeping sickness, the human form of trypanosomiasis, why it is a significant problem, how it affects people and their livelihoods and why it remains difficult to control. I also considered the importance of gender as a critical dimension in understanding sleeping sickness and other illnesses. Additionally, I examined the ways in which sleeping sickness, gendered roles, livelihoods, and interactions between people, livestock, and the environment are interconnected. I argued that the complexity and multidimensional nature of sleeping sickness requires an interdisciplinary approach to effectively address its occurrence and impacts. My study uses a One Health approach to provide an interdisciplinary, intersectional understanding of sleeping sickness using social science methods to capture the multiple dimensions of sleeping sickness.

The first section of this chapter presents my study's ontological and epistemological assumptions, which form the foundation of my theoretical framework, approach, and methods. I explore how an interpretivist approach can enhance understandings of sleeping sickness and present the theories and perspectives that guide my understanding of the problems associated with the disease presented in the previous chapter. The second section presents my research questions and then details the methodological approach, demonstrating how my philosophical assumptions and theoretical framework shaped my choice of research methods to respond to my research questions. I explain why I adopted a participatory approach relying on ethnographic methods and techniques developed for rapid ethnographies as my primary study approach. Finally, the last section discusses the research process, including participant recruitment, the implementation of interviews and observations, and the management and analysis of data. Given my reliance on a feminist theoretical position and methodological approach, I will write in the first person to place my own positionality and reflexivity within the interpretation of the research and to indicate that for a study as mine, it is not possible to completely remove myself from the research and the subsequent accounts of people I spoke to. Thereafter, I will present a summary to conclude the chapter.

3.1 Philosophical assumptions and theoretical approaches

This section forms the foundation of my approach to studying sleeping sickness. I discuss my theoretical position and explain why an interpretivist approach is a crucial aspect in the study of sleeping sickness and other neglected tropical diseases (NTDs). I also highlight the

limitations of relying solely on biomedical approaches in understanding the multidimensional nature of sleeping sickness.

3.1.1 Philosophical assumptions and position

Before explaining the philosophical position and theoretical framework which guided my study, I will first address key concepts namely paradigms, ontology, epistemology, interpretivism, and positivism. Guba and Lincoln (1994, p.107) define a paradigm as “a set of basic beliefs (or metaphysics) that deals with ‘ultimates’ or first principles. It represents a worldview that defines, for its holder, the nature of the world, the individual’s place in it, and the range of possible relationships to that world and its parts.” Ontology concerns the nature of reality, questioning whether reality is singular and measurable or if multiple realities exist, subjectively constructed and interpreted by researchers and participants (Guba & Lincoln, 1994). Epistemology, on the other hand, refers to “beliefs regarding the nature, sources, possibilities, and limitations of knowledge” (Crotty, 1998, p.3). It focuses on understanding whether knowledge can exist independently of experience, whether it is universal or relative, and what its limitations are (Creswell, 2013). These two philosophical assumptions underpin the foundation of research approaches, giving rise to interpretivism and positivism.

Interpretivism is based on a subjectivist ontology, suggesting that social reality is constructed, interpreted, and experienced through human interaction (Braun and Clarke, 2013; Creswell, 2013). As Denzin and Lincoln (2011) and Mertens (2012), notes, this theoretical perspective assumes that this reality is also subjective, and diverse (Denzin & Lincoln, 2011; Mertens, 2012). This implies that individuals’ experiences of social reality vary across contexts and must be understood within their specific lived experiences (Haraway, 1988). In contrast, positivism is based on an objective ontology and posits that knowledge of social reality can be objectively developed using statistical methods (Bryman, 2004; Creswell, 2013). This approach is rooted in the belief that social phenomenon exists independent of actors (Denzin & Lincoln, 2000).

Guba and Lincoln’s (1994) definitions situate paradigms as belief systems based on ontological, epistemological, and methodological assumptions. This suggests that a researcher’s approach to answering research questions is shaped by this basic belief system. Consequently, paradigms determine how researchers view reality, the world, and their relationships with research participants (Guba & Lincoln, 1994). However, differences in these foundational beliefs between natural and social sciences have led to diverging

perspectives on reality, knowledge production, and the researcher- participant relationship (Guba & Lincoln, 1994).

Therefore, ontologically, I approached my study with the recognition that social realities, including gender dynamics and health disparities, exist independently of individuals but are socially constructed, partial, and context specific (Haraway, 1988). As argued by Simmel (1910) in “How is Society Possible?”, while nature can be perceived as consciousness, it goes beyond what we capture through our senses to include how our minds, based on our experiences and contexts, shape and assemble our senses of perception. This suggests that knowledge about reality is situated and that both my participants and I hold different, partial views of the world due to our varied backgrounds and experiences (Haraway, 1988). Consequently, epistemologically, I approached my study recognising that knowledge about experience of risk of sleeping sickness is not universal but relative, contextual, situated and co-produced in the field by the researcher and participants. Consequently, I was constantly part of the construction of reality about the participants’ experiences of structural violence and risk of contracting sleeping sickness. At the same time, I engaged in reflexive practices that acknowledged my own biases and how they shaped my interaction with the participants and interpretation of their accounts (Shai, 2020).

Based on my ontological and epistemological position, my perspective aligns with Bourdieu’s constructivist structuralism, which asserts that objective structures cannot be separated from mental structures that internalise these objective structures (Ritzer, 2003). I acknowledge the role of both micro and macro processes in shaping human behaviour and actions. In this case, micro processes involve individual level meaning making and interaction, while macro processes encompass broader structural influences such as social norms, economic conditions, and institutional policies (Collins, 1988; Knorr-Cetina, 1981). This perspective emphasises how individual agency is shaped by structural constraints, as seen in farmers’ decision making processes. For example, while farmers may wish to avoid tsetse fly infested areas, structural factors such as poverty and economic problems influence their settlement in high risk areas to earn a living (Anderson et al., 2015). This suggests that decisions and opportunities to act in ways individuals desire are shaped by the existing social structures which unconsciously shape individuals’ actions (Guba and Lincoln, 1994). This belief, therefore, entails that to understand how the farmers’ lives and interaction with the environment are shaped by social, political and cultural factors, I needed a methodological approach which revealed the influence of social structures on human behaviour and experience of suffering due to institutionalised inequalities in distribution of resources.

However, despite the interdisciplinary nature of sleeping sickness, research on NTDs has largely been dominated by positivist approaches. Even studies incorporating participatory methods often operate within positivist epistemological assumptions. Research conducted in sub-Saharan Africa predominantly employs positivist methodologies to examine trypanosomiasis in humans and animals (Nowbuth et al., 2023; Mulenga et al., 2021, 2020, 2015; Namangala et al., 2013). While Mwiinde et al. (2017) utilised a mixed methods approach to explore the socioeconomic impacts of sleeping sickness, their study remained grounded in positivist assumptions. These methodological limitations restrict understanding of the sociocultural and political dimensions of the disease, as well as the power structures influencing disease risk and access to healthcare. Although the extent of health inequality can be measured quantitatively, the role of experiences and their meanings, social structures, and power can only be understood through an interpretivist approach which, according to Denzin (1999, p. 510), “seeks to understand how people enact and construct meanings in their daily lives.”

Therefore, while positivist approaches are useful for explaining causal relationships and disease epidemiology (Morgan, 2022), their emphasis on fixed laws of causation and focus on reductionism limits their ability to capture micro level processes, such as power dynamics and gendered inequalities, that shape disease risk. Positivism’s assertion that reality is singular and measurable further disregards the multiple, subjective experiences that define social reality (Atkinson & Housley, 2003). Consequently, the structural factors influencing the participants’ risk of contracting sleeping sickness such as poverty, gender roles, and social inequality remain inadequately explored. Thus, the positivist approach to the study of sleeping sickness inadvertently contributes to omission and masking of the underlying social, cultural and economic conditions shaping how farmers with varying characteristics subjectively experience risk and consequences of sleeping sickness.

To understand the intersection of macro and micro processes shaping gendered risk of contracting sleeping sickness, health seeking behaviours, and healthcare service utilisation, I needed a theoretical framework and methodological approach that accounted for both structural influences and individual agency (Hedström, 2005). This implies that to analyse the dimensions and complexities of sleeping sickness, I needed an approach that asserts the existence of social reality that is inseparable from its actors and context; an approach which would help me to examine the interactions between human, animal, and environmental relationships and how they contribute to broader issues such as disease, food insecurity, and poverty (Denzin, 1999). Consequently, my ontological and epistemological commitments led me to adopt a participatory interpretivist approach informed by ethnographic methods

and techniques developed for rapid ethnographies which I will further explain below. Furthermore, I used this approach because it aligns with feminist methodologies which emphasis the inclusion of one's discomforts and experiences in the process of research by highlighting power imbalances and inequalities which is embedded in society's structures and process (Chadwick, 2021).

Throughout this thesis, therefore, I positioned risk, vulnerability and experience of suffering to sleeping sickness as being embedded in the social structures, systems of power and access to resources (Farmer, 2004; Kleinman, 1997; McPherson and McGibbon, 2011). Further, I positioned the risk of contracting sleeping sickness as socially constructed by those that have the power to create and shape the narratives around certain diseases (Douglas & Wildavsky, 1982; Foucault, 1982). These positions also highlight that the risks of contracting diseases among farmers are contextual and socially constructed, and that these constructs and meanings of their daily experiences are subjective and not objective facts (Denzin, 1999). Therefore, while it is possible to estimate the possible effects of poverty on the participants' risk and exposure to sleeping sickness, existence of these predictors is rooted in the underlying internalised social conditions and processes, which shape how meanings and reality is created and cannot be separated from the actors (Bourdieu, 2003).

Having established my philosophical position and view of the sleeping sickness problem, I draw on four sociological theories, intersectionality and theory of gender performativity, vulnerability theory, and social systems theory, to guide my analyses of how disease risk is shaped by micro and macro processes. I also use these theories to emphasis and support the need for interdisciplinary One Health collaborations in the study of sleeping sickness, its multidimensional nature and associated challenges. In the next section, I provide a detailed discussion of these theories within the context of my philosophical position.

3.1.2 Using intersectionality, gender performativity, vulnerability and social systems theory to understand risk of sleeping sickness

Intersectionality emerged as a critical response to the homogenisation of women's experiences within feminism, particularly through the work of critical race feminist Kimberlé Crenshaw. Crenshaw (1991) argued that feminist approaches often failed to consider differences in experience between Black and White women, effectively merging Black women's experiences with those of men and resulting in a lack of *voice* for Black women. Bowleg (2012, p. 178) further contends intersectionality is primarily concerned with “reflect[ing] the social realities of inequality and power in society, yet at the same time does

not lose sight of the individual experiences that reflect, shape and construct those social structures.”

Intersectionality theory is based on four main tenets. The first tenet states that individuals’ social identities are shaped by multiple intersecting factors such as age, gender, and ethnicity, which cannot be considered separately (Mattis et al., 2008); these categories are socially constructed processes influenced by broader representations of identity (Crenshaw, 1991). Secondly, intersectionality theory recognises that these intersections create social identities that are not merely the sum of their parts but produce unique experiences (Hankivsky et al., 2014). Third, intersectionality considers both the micro experiences of individuals and the macro contexts in which these experiences are constructed (Hankivsky, 2014; McPherson & McGibbon, 2011). As Durkheim’s analysis of suicide indicates, macro level events influence individuals’ health decisions and outcomes (Mills, 1959). Similarly, Mills’ (1959) sociological imagination highlights how personal misfortunes, including poverty and unequal access to healthcare, are linked to broader social processes beyond individual control, which like Durkheim’s analysis, shape how individuals experience social suffering and vulnerability. The fourth tenet states that due to intersectionality of micro and macro factors, individuals within a particular social context can occupy varying identities and overlapping positions (Crenshaw, 1991).

Applying these tenets to my study, intersectionality theory is particularly relevant in studying gender and sleeping sickness in rural communities, as it highlights how overlapping identities and systemic inequalities shape risk of contracting the disease, access to healthcare, disease awareness, and exposure to other health risks (Crenshaw, 1991). While risk of sleeping sickness and other NTDs may be linked to individual choices, such as settling in tsetse fly infested areas, intersectionality theory suggests that these experiences are influenced by broader structural processes such as lack of education, employment, and economic opportunities, which increase dependence on the natural environment (McPherson & McGibbon, 2011). Addressing sleeping sickness, thus, requires not only medical interventions but also a shift in approaches used to identify underlying causes of risk among different social groups. Therefore, drawing on this theory, it can be argued that intersecting individual, and structural factors contribute to health inequalities and experience of risk, showing how micro and macro forces combine to create vulnerability and suffering in rural communities.

However, some scholars, including Hancock (2007) and Roth (2004), critique intersectionality theory, arguing that its origins in amplifying the voices of minority women

of colour in the United States of America obscure broader power relations in rural contexts, particularly regarding health (Choo & Ferree, 2010). While it is true that the theory originated in a context with a culture, power relations, gender and race perceptions that are different from my field site where all participants belong to the same race but different tribes, the theory's tenets remain valuable for identifying interconnected factors reinforcing health inequalities among rural communities such as the field site. Therefore, the intersectionality theory helps to highlight how participants' experiences are shaped not by a single factor but by the intersection of multiple social, economic, and political forces. This theory thus provides insights into the underlying processes that produce and maintain vulnerability and suffering from diseases within rural communities.

To understand the gender roles of participants and their role in shaping experience of risk of contracting sleeping sickness, I draw on Butler's theory of gender performativity (Butler, 1988). According to Butler (1988), gender is not a fixed identity but rather an ongoing process enacted through repeated social performances that are regulated by social norms, expectations and power relations. These performances such as behaviours, roles, and bodily acts contribute to the socially recognised attributes associated with women and men, which appear as a stable gender identity (Butler, 1988; Moreau, 2019). Therefore, the theory of gender performativity is instrumental in understanding how men and women come to be positioned differently in relation to risk of contracting sleeping sickness, exposure to tsetse flies, and health seeking behaviour (Kankya et al., 2025; Odiit et al., 2004). For example, women's caregiving roles, daily chores such as fetching water or collecting firewood, and men's roles in livestock herding and timber production are not merely cultural functions but gendered performances that expose them differently to tsetse infested environments (Moreau, 2019). These performative acts are shaped by and reproduce broader systems of inequality, and their repetition reinforces structural vulnerabilities to various challenges including poverty, and diseases such as sleeping sickness.

Therefore, Butler's conceptualisation helps to highlight how risk to sleeping sickness is embodied through internalised gendered practices and institutionalised norms (Butler, 1988; Goffman, 1956; Moreau, 2019). It also reveals how health interventions and responses including those informed by One Health principles, which largely do not focus on these everyday performances, may fail to capture the context based ways gender operates across the human, animal and environment interface (Cataldo et al., 2023). Thus, the gender performativity theory helped me to explore not only who is at risk, but also why and how those risks are maintained among these categories of people through gendered social practices.

I also used vulnerability theory by Zakour and Gillespie, (2013) to explain the risks and impacts of living within a GMA. According to Zakour and Gillespie (2013) and Bonanno and Gupta (2009), vulnerability is primarily linked to both protective and risk factors of a society's social systems. This theory is based on twelve assumptions that outline the nature and determinants of vulnerability. Like intersectionality theory, vulnerability theory highlights the role of social, economic, and political environments in shaping vulnerability and its extent within communities (Collins, 2008; McEntire, 2004). The stratification of communities based on these factors leads to varying degrees of vulnerability (Bottero, 2007). Most relevant to this study, Zakour and Gillespie (2013) argue that unequal distribution of resources, power, and dysfunctional institutional systems influence vulnerability and its consequences (Wisner & Wisner, 2004). This suggests that vulnerability arises from an intersection of individual, environmental, and institutional factors that cannot be fully understood through a single disciplinary lens (Zakour, 2010). Consequently, both social and biomedical perspectives are necessary to comprehensively analyse vulnerability to sleeping sickness.

Although vulnerability theory is often applied to disasters, its broad scope encompasses various social conditions contributing to suffering. As noted by Zakour (2010), social environments, including cultural, political, and economic contexts, shape human animal interactions with physical environments (natural, built, and technological) and influence decisions about how to manage these environments (Gillespie, 2008; Zakour, 2010). This perspective suggests that vulnerability is shaped by the way social systems govern physical environments through policies and decisions that have varying impacts on individuals. Unequal distribution of resources, including power and income, further exacerbates vulnerability and exposure to risks. Therefore, vulnerability theory informs my understanding of the problem of sleeping sickness by demonstrating that vulnerability occurs across human, animal, and environmental domains. The occurrence of diseases such as sleeping sickness is not solely due to tsetse fly exposure but results from a complex interplay of political, socioeconomic, cultural, and environmental factors, demonstrating the need for a collaborative, interdisciplinary approach to developing effective solutions to manage and control sleeping sickness.

Overall, this theory helps to explain why certain groups are more vulnerable to sleeping sickness and face greater barriers to prevention and treatment than others. Through this framework, I argue that complex inequalities shaping sleeping sickness risk and healthcare access among participants result from intersecting factors such as ethnicity, gender, and class (McCall, 2005). These factors are embedded within broader social structures and unequal

power relations extending into household dynamics (Choo & Ferree, 2010). Consequently, studying the nonbiomedical dimensions of sleeping sickness within an endemic rural setting provides critical insights into the processes producing and reproducing gendered advantages and disadvantages in disease risk and healthcare access (Choo & Ferree, 2010).

I also drew on the social systems theory by Parsons and Luhman to guide my study. The social systems theory is rooted in the functionalist perspective, which uses the organic analogy to analyse society (Calhoun et al., 2012). Social systems theory conceptualises society as consisting of interconnected units, each interacting to form a cohesive whole (Dossa, 1990). Proponents of social systems theory argue that these elements are interdependent and mutually influential. While systems thinking has been widely applied across disciplines, I focus specifically on social systems namely, organisational and interaction systems, as defined by Parsons (1966) and Luhmann (1981).

Parsons' theory argues that social systems consist of multiple actors and subsystems, each interacting within an environment structured by shared symbols and relationships (Calhoun et al., 2012). For Parsons (1966), systems undergo reorganisation through structural differentiation, a process where relationships between systems evolve as new subsystems emerge. In applying this theory to the One Health approach, structural change can be seen in how different disciplines interact and reorganise their roles to facilitate collaboration. While such changes are crucial at a structural level, they primarily serve to enhance collaboration between stakeholders including communities, biomedical, and nonbiomedical disciplines (Bardosh, 2020). The reorganisation of these subsystems allows for clearer roles, responsibilities, and boundaries within the One Health framework, fostering more effective interdisciplinary collaboration in addressing complex health issues, such as sleeping sickness (Parsons, 1966).

Luhmann's (1982) theory offers a contrasting yet complementary perspective. Unlike Parsons, who emphasises the structural organisation of systems, Luhmann (1982) argues that communication is the fundamental unit of social systems, providing the foundation for understanding and observing these systems. While Durkheim believed that solidarity held society together and its systems (Calhoun et al., 2012), Luhmann contends that communication enables the creation of systems, which are characterised by ongoing interaction and exchange (Mathies, 2012). According to Luhmann (1982), systems are autopoietic, suggesting that systems self-produce communication within themselves and their subsystems. However, unlike Parsons' view, Luhmann argues that these systems are not static; they can evolve and adapt through interactions with other systems in their external

environment. This adaptability allows systems to respond to environmental changes, suggesting that interdisciplinary collaborations within the One Health approach are dynamic and subject to change based on ongoing interactions between disciplines (Conrad, 2013).

Furthermore, Luhmann's (1982) view contrasts with Parsons' emphasis on hierarchical ordering, as Luhmann argues that modern systems function through their distinct roles rather than their rank within a hierarchy. This approach allows systems to form intersystemic relationships, facilitating cooperation across boundaries while maintaining their independence (Mattheis, 2012). Through these functional relationships, systems can develop stronger connections and coordinated structural development, even as they preserve their autonomy (Luhmann, 1982; Mattheis, 2012). This idea of *functional coupling* is crucial for the One Health approach, which relies on the interaction of diverse disciplines with distinct epistemologies and ontologies.

While Parsons and Luhmann differ in their conceptualisations of social systems, both offer valuable insights into how the One Health approach can help to achieve effective interdisciplinary collaboration in the control and management of sleeping sickness. For instance, the interdependence and constant interaction of disciplines and stakeholders, as advocated for by both theorists, can lead to mutual learning and the development of shared values, goals, and expectations that would lead to effective interventions (Bardosh et al., 2020; Bardosh, 2014; Conrad, 2013). Thus, the One Health approach can overcome the challenge of maintaining the epistemological and ontological integrity of each discipline while fostering collaborative solutions to health challenges like sleeping sickness (Bardosh, 2014; Luhmann, 1982). A critical implication of these theories is that, although the disciplines and stakeholders interested in sleeping sickness within One Health may differ in their backgrounds, resources, and priorities, a well-structured interdisciplinary approach can integrate these actors (Conrad et al., 2013b). Therefore, informed by my research questions and theoretical framework, I adopted a participatory qualitative approach, drawing on ethnographic methods and techniques developed for rapid ethnographies which I turn to in the following section to answer my study's research questions which are:

- i) What are the varying health needs, challenges, impacts and opportunities for women, men, and children in the Luangwa Valley, and how are these mediated by gender?
- ii) How do communities, medical, veterinary and conservation actors work together within Zambia's health and conservation policy framework, and how do these interactions shape construction and gendered vulnerability to sleeping sickness?

- iii) How can these gendered One Health understandings inform national policy for controlling neglected tropical diseases such as sleeping sickness in Zambia through policies, and programme implementation that promote gender equality and health equity among different categories of people in rural communities?

3.2 Methodological Approach

Having established my philosophical position and theoretical assumptions, which provided the foundation for exploring and understanding sleeping sickness and its associated problems, I now turn to the methodological approach adopted to answer my research questions stated earlier. As previously indicated, my methodological approach is rooted in interpretivism, aligning with both my theoretical framework and my view of social reality. Drawing on Haraway's (1988) concept of situated knowledge, my approach acknowledges the existence of multiple realities that shape individuals' experiences of risk in contracting sleeping sickness and its social, economic, and health-related consequences (Denzin, 1999; Longino & Lennon, 1997). By integrating intersectionality theory and feminist ideas, I examined how power inequalities, gender, and other intersecting factors influence individuals' experiences of the risk of sleeping sickness, its consequences, and its broader impact on the wellbeing of victims. My methodological approach allowed for the incorporation of diverse methods and perspectives, emphasising the value of understanding the 'emic' viewpoint, in contrast to the 'etic' viewpoint of what participants do, where they do it from and how it exposes them to the risk of contracting sleeping sickness (Henwood, 2008).

While gendered understandings of sleeping sickness could be examined through various qualitative approaches, such as phenomenology, narrative inquiry or case study research, I adopted a participatory approach informed by ethnographic methods and techniques developed for rapid ethnographies (Atkinson & Hammersley, 2019; Vindrola-Padros & Vindrola-Padros, 2018). This choice was guided by my research questions stated above and theoretical framework which recognises that multiple intersecting realities that are contextual and situated, shape risk of contracting sleeping sickness, health seeking and experience of structural violence (McPherson and McGibbon, 2011). Ethnographic methods allowed me to explore the multiple dimensions of sleeping sickness while immersing myself in the lived realities that shape individuals' risk of sleeping sickness, health seeking behaviours, and healthcare utilisation in rural communities (Goffman, 1956). While ethnography is often associated with long term fieldwork, I adapted its flexibility and situated approach to suit my methodological framework by employing intensive short term field visits and in-depth interviews to collect ethnographic data efficiently. In the following

section, I provide a detailed account of the methodological approach and specific methods adopted in this research. I will start the section with a discussion of why a qualitative interpretivist approach was adopted.

3.2.1 Rationale for a qualitative interpretivist perspective

For a study using a One Health approach to understand the nonbiomedical nature and impacts of sleeping sickness through interdisciplinary collaborations, it is expected that a mixed methods pragmatic approach would be adopted. It can be argued that, relying solely on an interpretivist approach in such a study may appear to be “solving one problem by creating another.” However, the following reasons explain why I adopted an interpretivist rather than a pragmatic mixed methods approach.

Firstly, most studies on sleeping sickness have been informed by positivist approaches and methods (Craddock & Hinchliffe, 2015; Woldehanna & Zimicki, 2015). While this approach is valuable in explaining the cause and effect relationships between social processes and disease occurrence, it has limited capacity to account for the underlying social, cultural, and political factors that shape disparities in exposure and consequences of sleeping sickness between women and men (Morgan et al., 2016). Sole reliance on positivist methods to examine the gendered nature of sleeping sickness contributes to masking differences in experiences, exposure, and vulnerability between genders. Consequently, policies and interventions based on such evidence may fail to adequately address the structural factors that sustain and reinforce the gendered risk and effects of sleeping sickness (Morgan et al., 2016; Johnson et al., 2009). The interpretivist approach and participatory methods, by contrast, provides an essential foundation for understanding social phenomena and their implications within a One Health framework (Arcaya et al., 2015; McCartney et al., 2021). Moreover, evidence generated using an interpretivist approach informed by a feminist epistemological position complement the vast existing evidence on sleeping sickness generated using methods rooted in positivism.

Secondly, the interpretivist approach provides a framework for exploring participants’ characteristics, lived experiences, and how these shape their perceptions of risk, exposure, and management of sleeping sickness (Schwandt, 1994). This suggests that people’s experiences and their meanings can only be understood through an approach that considers individuals’ subjective experiences of social reality and acknowledges that views of the social world are partial, situated, and contextual (Haraway, 1988). Through this approach, I explored how risk and exposure to sleeping sickness are embedded within systems of power and social institutions (Armstrong, 2022; Atkinson Paul, 2007; Foucault, 2014).

Additionally, key informant interviews enabled a detailed analysis of points of agreement and disagreement among stakeholders, shedding light on the reasons for differing narratives on the control of sleeping sickness and how these could be harmonised through an interdisciplinary One Health approach. The interpretivist approach was thus adopted because it allowed for a critical engagement with the subjective experiences, perspectives, and narratives of affected communities and key stakeholders in the management and control of sleeping sickness (Longino, 1997).

To date, the methodological gap in current research on sleeping sickness has contributed to a limited understanding of its nonbiomedical dimensions and the challenges associated with its effective control. Furthermore, this gap constrains the understanding of how cultural and social factors influence disease risk, health seeking behaviour, and health outcomes across different social groups, including children, men, and women. As a result, my construction and interpretation of sleeping sickness necessarily differ from that of other scholars in the field, given our differing ontological and epistemological orientations (Denzin & Lincoln, 2011). While I acknowledge the contributions of positivist and objectivist perspectives, my approach which is rooted in feminist epistemology advocates for a One Health interdisciplinary lens that accounts for what Allen, (2011,p. 25) describes as “the experiential, the private, and the personal” aspects of participants’ lives, particularly those in marginalised or disadvantaged positions (Wharton-Smith et al., 2019). This theoretical and methodological stance provided a robust foundation for examining issues of power, social inequality, and gender in relation to the risk of contracting sleeping sickness, health seeking behaviours, and health outcomes in rural communities. In the following section, I will further elaborate on how I employed an ethnographically informed participatory approach, drawing on methods developed for rapid ethnographies (Vindrola-Padros & Johnson, 2020), to investigate participants’ characteristics, their contexts of interaction, and the ways in which these interactions shape their risk, exposure, and management of sleeping sickness.

3.2.2 Ethnographic and rapid ethnographic methods

The origins of ethnography can be traced to the works of Franz Boas, Alfred Redcliffe-Brown, and Bronislaw Malinowski, who conducted anthropological studies in small communities in the early twentieth century (Atkinson & Hammersley, 1994). Ethnography is an established methodology in disciplines such as anthropology and sociology, where researchers aim to understand the everyday lives of communities through observations within local settings (Denzin, 1999). Conceptually, ethnography serves both as a method for explaining and describing the culture and experiences of participants in detail (Atkinson,

2007) and as a broader epistemological orientation that guides researchers in studying specific social phenomena (Gobo, 2008). Achieving this requires collecting detailed data to ensure an accurate representation of participants' experiences, culture, and interactions (Braun & Clarke, 2013; Degeling and Rock, 2020).

As an approach, ethnography “privileges the cognitive mode of observation as its primary source of information” (Gobo, 2008, p. 4.5). A key feature of ethnography is to explain and describe the culture and experiences of participants in detail and accurately through the collection of detailed data from participants by being there (Atkinson, 2007; Degeling & Rock, 2020; Geertz, 1988). While different types of ethnographies exist, they are always situated within specific times, places, and researcher participant interactions (Geertz, 1988). Similarly, the scale and duration of ethnographic studies depend on multiple factors, including disciplinary focus and research objectives. Some ethnographies have studied entire communities (Geertz, 1988), while others have focused on lived experiences of specific events, such as the 1995 Chicago heatwave (Klinenberg, 2002).

However, in recent years, researchers have increasingly adopted shorter ethnographic approaches, including rapid ethnographies and patch work ethnographies (Günel & Watanabe, 2024; Vindrola-Padros, 2021). Vindrola-Padros (2021, p. 6) defines rapid ethnographies as studies conducted over “a short, compressed, or intensive period of time,” ensuring that research captures key social, cultural, and behavioural dynamics, engages with relevant theories, promotes reflexivity, and triangulates data from multiple sources, often involving multiple field researchers to enhance validity and efficiency. Patchwork ethnography, on the other hand, is “ethnographic processes and protocols designed around short-term field visits, using fragmentary yet rigorous data, and other innovations that resist the fixity, holism, and certainty demanded in the publication process” (Günel & Watanabe, 2024). Similar to patchwork ethnographies, the primary goal of rapid ethnographies is to produce high-quality insights using the same theoretical and methodological rigour as traditional ethnography but within a shorter timeframe, often to inform policy decisions (Vindrola-Padros, 2021). Although prolonged fieldwork is traditionally considered crucial (Manderson & Aaby, 1992), its duration can be shortened when researchers are already familiar with the field site (Vindrola-Padros, 2021).

Unlike traditional ethnographies, rapid and patch ethnographies condense fieldwork into shorter periods while maintaining the core principles of ethnographic inquiry. They focus on capturing “relevant social, cultural, and behavioural information on human experiences and practices while engaging with anthropological and social science theories and promoting

reflexivity” (Vindrola-Padros, 2021, p. 6). While extensive fieldwork remains an important aspect of ethnography (Reeves et al., 2013; Atkinson & Hammersley, 1994), scholars (Günel & Watanabe, 2020; Vindrola-Padros, 2021) argue that high quality data can still be collected within a shorter timeframe using rapid and patch ethnographies.

Given my familiarity with the field site, its local structures, and operational systems, minimal time was required for orientation and gaining access (Shai, 2018). Therefore, while my study is not ethnographic in the traditional sense, it relies extensively on ethnographic methods, particularly observations and in-depth interviews. Additionally, I employed a combination of group interviews, walking interviews, and key informant interviews to engage with herders, timber producers, and professionals from government and nongovernmental organisations and institutions. This approach facilitated meaningful interactions with participants, allowing for the collection of rich and detailed data within a limited timeframe (Vindrola-Padros, 2021).

3.2.3 Finding the methodology

Since my aim was to go beyond superficial appearances of risk and understand the underlying factors shaping participants’ experiences of vulnerability to sleeping sickness, I adopted a participatory qualitative approach grounded in ethnographic methods and techniques developed for rapid ethnographies. While my study is not an ethnography in the traditional sense, it relied entirely on ethnographic methods, specifically, observations and in-depth interviews with farmers. Additionally, as I will elaborate later in this chapter, I conducted group, walking, and key informant interviews to engage with herders, timber producers, and professionals from Civil Society Organisations (CSOs) and government institutions respectively.

Given that I employed an interpretivist approach rooted in a feminist epistemology (Anderson, 2000; Collins, 2003; Smith, 1990), adopting a participatory design provided access to insights into the complex interactions between humans, animals, and the environment. This perspective enabled me to examine how community risk and exposure to sleeping sickness are linked to livelihood activities, environmental interactions, and engagements with livestock and wild animals. Additionally, my research approach facilitated an exploration of the cultural norms, beliefs, and practices that shape various social roles, their spatial dimensions, and their modes of performance (Atkinson, 2007; Hammersley and Atkinson, 2007; Denzin, 1999). Consequently, adopting ethnographic methods and techniques for rapid ethnographies allowed me to identify the structural barriers to healthcare

and the intersecting social, ecological, and biological factors that hinder the development of a gendered understanding of sleeping sickness (Binot et al., 2015).

Additionally, the integration of feminist epistemology was crucial, as it immersed me in participants' lived experiences, traditional beliefs, and socioeconomic inequalities. This immersion not only enhanced my understanding of their realities but also compelled me to confront my biases while gaining a more comprehensive understanding of the communities and ecosystems in which participants live and how these factors shape their risk and exposure to sleeping sickness (Mauthner & Doucet, 2003; Shai, 2020). Thus, my study aligns with postmodernist, feminist, and critical approaches that emphasise reflexivity in fieldwork and data analysis because researcher's worldviews and experiences influence how they form objects of their study (Mccabe et al., 2009).

3.2.4 The field site and the study focus

Traditionally, anthropologists have suggested that ethnographies are to be done in unfamiliar places to the researchers to uncover unique cultural practices and social structures and reduce biases from preconceived notions (Geertz, 1988). While this is true for most anthropologists, sociologists such as Hammersley and Atkinson (1983) suggest that ethnographies can be done on micro geographies including familiar places to researchers. This implies that while researching unfamiliar places has its own advantages, researchers can carry out ethnographies in places they consider their *at home*. Although conducting ethnographies in one's *at home* is perceived not advantageous because of the researcher's insider role, conducting them in familiar places to researchers still allows for deeper emic perspectives which allow the research to understand the community from an insider's viewpoint providing more context based understanding of cultural practices and social behaviour (Geertz, 1973). As I will explain in the next sections, I sought a setting that was characterised by high density of tsetse flies, practicing of agriculture and livestock production activities, existence of governmental institutional and nongovernmental organisation on conservation and generally, easily accessible. This led me to Mambwe District within the Lupande Game Management Area. While other areas such as Mpika and Chama districts had similar characteristics, Mambwe district offered a better choice given my limited resources and time.

Thus, of the six chiefdoms in Mambwe district, I chose three chiefdoms namely Malama, Mnkhanya and Nsefu. Malama Chiefdom is located on the eastern side of South Luangwa National Park (SLNP) in an area densely populated with wildlife and heavily infested with tsetse flies. Mnkhanya Chiefdom is located southeast of the SLNP with mild wildlife and presence of tsetse flies. Nsefu chiefdom is located northeast of the park within a moderate

wildlife-populated zone, with moderate tsetse densities (Lisulo et al., 2024). The three chiefdoms provided an ideal site because in addition to the indigenous Kunda speaking people, most immigrants such as the Chewa farmers settled in these chiefdoms where they practiced farming, livestock keeping and charcoal production. Furthermore, these areas had higher density of tsetse flies, bushes and wild animals compared to the farmers around Kakumbi area. Therefore, although I would consider the field site as my at home based on my language, ethnicity and citizenship, it remained an unfamiliar place to me because of my urban upbringing, lack of lived experience of tsetse flies and variation in environmental and cultural processes in which I was brought up, making it an ideal field site for my study.

3.2.5 Mambwe district as a study setting

Mambwe district is a rural district in the Eastern Province of Zambia located in the Lupande Game Management Area northwest of Chipata, the provincial headquarters of the Eastern Province (Mambwe District Council, 2019). Although the district is considered a tourist and agriculture district, current official statistics show that like many other rural districts in Zambia, Mambwe district is still experiencing high levels of illiteracy and lacks adequate services such as health, clean water, education and road networks (CSO, 2022; CSO, 2012; Mambwe District Council, 2019). In addition to the social and economic challenges, Mambwe district is characterised by high density of tsetse flies, high temperatures and seasonal droughts and flooding which occasionally affect agriculture and livestock keeping (Anderson et al., 2015; Banda et al., 2013).

Although the tourism business in Mambwe district is growing, the general population's wellbeing is still characterised by poverty due to lack of trickle down effects of tourism benefits (Mambwe District Council, 2019; Udelhoven, 2006). While the tourism sector in Mambwe district plays a role in defining the economic wellbeing of the people through parttime and seasonal jobs in lodges, walking safaris and supply of local vegetables, its benefit to the community is not significant as most of the population within the district have continued to rely on subsistence farming, fishing, producing charcoal and hunting as their main livelihood activities (Mambwe District Council, 2019). Consequently, the social economic outlook of Mambwe district and the three chiefdoms where this study was conducted is that characterised by poverty, low levels of education, and limited access to both health and economic resources. Among the farmers I spoke to and the general population in Mambwe district, formal employment was very rare due to low levels of opportunities and generally low education levels.

The 2010 national population and housing census shows that Mambwe district's population has significantly changed from 47,376 people in 2000 (CSO, 2002) to 68,918 people in 2010 (CSO, 2012) and is further projected to increase to above 131,000 habitants by 2030 (Mambwe District Council, 2019). Although several factors such as high fertility rate, poverty, illiteracy and low use of contraceptives shaped the change in population size, several researchers have suggested that increased migrations into Mambwe district from the surrounding districts such as Katete in the south, Petauke and Sinda in the west, Lundazi and Mpika in the east and north respectively, have contributed to this increase (Banda et al., 2013). Although factors such as tribal and family conflicts were identified as push factors, researchers such as Anderson et al. (2015) have argued that migrations into Mambwe district are partly due to the increasing population and demand for fertile land for settlers from neighbouring districts such as Katete, Lundazi and Chadiza.

Whilst Mambwe district is predominantly Kunda, more non-Kunda speaking ethnic groupings such as Chewas, Nsenga and Tumbuka among others have settled in the district. As I will go on to discuss in later chapters, most villages in Nsefu, Mnkhanya and Malama chiefdoms were composed of a mix of native Kunda population and small population of migrants from Chewa, Nsenga, and Tumbuka backgrounds. As a result, interethnic interactions within villages in the above three chiefdoms contributed to a hybrid ethnic and cultural outlook of the study site which indirectly shaped the livelihood and activities practiced by Kunda and Chewa farmers in Mambwe district.

3.2.6 Entry, access and acceptance in the field site

I arrived in Mfuwe of Mambwe district on 4th June 2023. The first and second week in Mfuwe were characterised by efforts to gain trust and acceptance by the community. I had initially planned to enter the field through the healthcare centres so that I could follow patients who were screened for sleeping sickness. However, after I learnt that the local rural healthcare facilities were not actively screening for sleeping sickness due to lack of capacity, I decided to enter the field through the participants' villages. Many other researchers looking at sleeping sickness have used the healthcare centre as a point of entry which they used to identify respondents (Mwiinde et al., 2022) and participants (Palmer, 2020). While I agree with this approach, I decided to observe and interview the farmers within their homes due to limited information on confirmed cases of sleeping sickness from rural healthcare facilities. Furthermore, this approach allowed me to explore and observe practices, and livelihood activities that shape the participants' risk of contracting sleeping sickness. However, my approach does not imply that I did not carry out observations and interviews at healthcare facilities. It simply implies that unlike in previous studies which used the healthcare facility

as point of recruitment, I focused on the village where farmers at risk of contracting sleeping sickness live.

Therefore, to achieve my research goals, I started by applying for permission from the National Health Research Authority and the University of Zambia School of Humanities and Social Sciences Research Ethics Committee (HSSREC) to undertake my research in Mambwe district. By March 2023, I had received clearance from the two institutions and only remained with permission from government ministries. While permission from the Ministry of Tourism and Ministry of Fisheries and Livestock was given by second week of May 2023, permission from the Ministry of Health came in the first week of June, 2023. After receiving clearance from the ministries, I started my research by having a key informant interview at the Ministry of Fisheries and Livestock in the second week of May 2023 in Lusaka. This interview was important because it laid down the foundation to understand the current policy framework on sleeping sickness and the existing challenges affecting interdisciplinary collaborations in Zambia.

While access from gatekeepers was easily offered due to the supporting documents from Lusaka, it was not easy to access community members. Firstly, my fieldwork was conducted between May and July when most farmers were harvesting their crops making it difficult to schedule interviews. However, through the village headpersons, I managed to get hold of some farmers and learnt of their work schedule which allowed me to plan my visits to the villages. Despite having this contact, I still needed to gain their trust especially that I was visiting from Lusaka which contributed to the possibility of some participants misunderstanding my identity. For example, because of their familiarity with the research assistants and the nature of the vehicle I used during field work, most participants and community members, including some gatekeepers, thought I worked for the government or a nongovernmental organisation (NGO). This was evident in the way I was treated and received by some gatekeepers at the provincial and district offices, where some officers opened up on what was happening to a point of sharing information that I termed sensitive. Similarly, some community members thought I was collecting challenges communities were experiencing on behalf of the government. Despite clarifying my identity as a student, a citizen of Zambia, and a native of the Eastern Province, as well as my fluency in Kunda and Chewa, aspects of my identity remained unclear to participants. However, my ethnicity and language skills significantly accelerated the process of gaining their trust and acceptance among Kunda and Chewa farmers.

For example, after participants and gatekeepers learnt that I was a Nsenga from Petauke, a district on the southwest of Mambwe district, one of the gatekeepers used the phrase *ah, kansi niwemwana wasu* ‘, which means ‘you are our child’. This acceptance that I am *their child* helped me to gain access and acceptance among the farmers than I had initially expected (Shai, 2020). This was seen through the farmers and key informants’ openness during interviews especially on issues such as charcoal burning, hunting and timber production which are considered *sensitive* due to fear of legal consequences, as admitting involvement could lead to arrest, fines, or imprisonment. Similarly, some farmers especially women, allowed me to help in activities such as fetching water and cutting wood (Figure 1 below) as well as being available to listen to the various discussions by men which were outside the confines of my research focus as shown in Figure one below. After gaining access among the farmers, working with Miss P and Miss R who had previously done research work within the chiefdoms, I scheduled in-depth interviews in advance and asked for details of upcoming community meetings so that I could conduct group interviews which, as suggested by Palmer (2020), was important to understand communal knowledge about sleeping sickness and cultural norms and practices that shaped risk and vulnerability among Kunda and Chewa farmers.



Figure 1: Gaining acceptance: cutting wood while a woman looks on

The varying identities assigned to me by participants, despite the clarification about my identity, confirms Hammersley and Atkinson’s (2001) argument that participants tend to think that ethnographers assumed and presented identities which they are not. To some participants, especially farmers, the wrong identities assigned to me implied that I would help record their challenges, while to some key informants, I was there to monitor or observe how they were carrying out their duties. This was mostly reflected in how participants responded to questions during interviews especially on topics relating to challenges and recommendations. The responses were always ‘*go and tell the government,*’ or ‘*please as you plan, include us as you can see the challenges we have here.*’ However, I decided to engage in self-conscious presentation of *self* by constantly making it clear to the participants that I was not any of those things they thought I was but a mere PhD student (Coffey, 1999). I repeatedly indicated that although I lived in Lusaka and worked at the University of

Zambia, I had no influence of power to make changes to the problems the participants experienced. However, I clarified that the only indirect benefit of this study was the recommendations which would be made based on the findings, although these did not guarantee any change. Furthermore, I emphasised that as a PhD student and researcher, I was there to learn from them about their experiences and understanding of sleeping sickness, including the broader challenges associated with the disease within the context of gender. This meant that, despite my academic position, background, and experience, I had no first-hand experience of *kamuzembe* or *chikusila*. Thus, regardless of my perceived status, I approached the study as a learner, seeking to understand their lived experiences with tsetse flies, sleeping sickness, gender, and the ways cultural practices shaped their health.

However, while I was granted entry and acceptance, most Kunda and Chewa farmers, along with some key informants, still regarded me as an outsider despite my status as a native of the Eastern Province and a citizen of Zambia. This suggests that although my culture, language, and ethnicity positioned me as an insider, placing me in my *at home* in a national and cultural sense (Hammersley & Atkinson, 1983), I remained an outsider due to my urban upbringing, residence, and limited familiarity with the participants' lived experiences in the game management area (Shai, 2020). This dual perspective highlights the complexities of insider-outsider dynamics in ethnographic research. While the farmers and key informants recognised my ethnic and linguistic ties to the region, my urban upbringing and background made me an *outsider* and *stranger* to their daily realities, including their livelihoods, practices, and experiences of risk related to sleeping sickness and human animal conflict. This implies that although ethnographers can be in their *at home*, it is possible that they can still be considered outsiders based on their own characteristics and experiences. This reinforces the argument by Hammersley & Atkinson, (1983) that while ethnographies are traditionally to be conducted in areas unfamiliar to researchers, it is still possible for ethnographers to conduct research in their *at home* because of their outsider roles.

Therefore, recognising this dual positionality allowed me to integrate my local insights with a critical external analysis of subtle yet significant social patterns and contradictions that a complete outsider might overlook (Shai, 2020). Throughout my fieldwork, I maintained and remained reflexively aware of my status as both an insider and an outsider based on my ethnicity and urban upbringing.

3.2.7 Positionality and reflexivity

Drawing from Goffman's concept of the backstage (Calhoun et al., 2012), issues of positionality and reflexivity are an important ongoing self-awareness process. Therefore,

researchers need to recognise their role as active agents, shaping and being shaped by the social context. According to Shai (2020, p. 3), “the researchers’ self-reflection on their positionality relative to research participants is a significant first step in conducting credible qualitative research and advancing knowledge production on different phenomena.” My characteristics as a Nsenga married man, with tertiary education, working and living in Lusaka, and a Christian shaped my understanding of the social, cultural and historical context influencing gender dynamics and health disparities in Mambwe district. Although my education and other characteristics provided my analytical tools and thinking during my field work, it also positioned me within a certain social economic status which potentially shaped my perception and interpretation of the farmers’ experiences in rural setting. However, my reliance on the farmers’ understanding of their environment, experiences with tsetse flies and wild animals to understand how cultural and religious beliefs shaped gendered experience of risk of contracting sleeping sickness among Kunda and Chewa farmers helped to address the power differences.

Therefore, throughout my field work, I was aware of the privileges and limitations that come with my identity and did not take any views by participants for granted. I constantly reflected on my own biases based on my experiences, political, religious, and cultural views and how they would shape my interpretations of the farmers’ experiences of risk and vulnerability and suffering (Denzin & Lincoln, 2011; Shai, 2020). Therefore, I strived to maintain reflexivity not merely as a methodological consideration, but as a key analytical tool, which was used to critically examine how my own opinions, views, and beliefs influenced the research process and outcomes. Consequently, reflexivity in this study does not only reflect my experiences but also reflects how power is located and accessed within the field site (Skeggs, 2002).

Therefore, I acknowledge that the knowledge that was generated is specific to the three chiefdoms of Mambwe district and is not absolute because my interpretation of participants’ narratives and experiences of risks to contracting sleeping sickness is embedded in my positionality and personal backgrounds (Denzin & Lincoln, 2011; Rose, 1997). Although awareness of my interests and motivation in this research may appear as a bias, I argue that presenting my motivations, beliefs and interest is important because it helps to validate, situate, and make plain my positionality and its role in my interpretation of the data (Olmos-Vega et al., 2023; Shai, 2020). Therefore, my experiences and relations with participants during field work allowed me to identify and account for the study’s limitations and that my interpretation of the data collected from participants reflect and represent the voices of the participants (Reeves et al., 2013).

3.2.8 Issues of consent and confidentiality

Consent and other ethical considerations are a cornerstone for any research. Although important, I was aware that in ethnographically informed studies, written consent is not adequate in expressing ethnographic engagement within the field site (Barrett & Parker, 2003). For this reason, consent was embedded in the whole data collection process. Further, this research conformed to all ethical requirements for social science research such as voluntary participation of research participants, confidentiality, and informed individual consent. Ethical approvals from relevant ethical review boards from the University of Glasgow and the University of Zambia were obtained. Further, permission and authorisation from the National Health Research Authority, Ministry of Health, Ministry of Livestock and Fisheries as well as the Ministry of Tourism via the Department of National Parks and Wildlife was obtained to carry out the study in Mambwe district. Further, all participants granted written and oral consent and permission to participate, and audio record the interviews, except for participants involved in walking interviews where the conditions made it impossible for the interview to be audio recorded. In such cases, detailed notes were taken.

However, I also experienced some dilemmas. For example, one participant gave an example of her lived experience of the health challenges in the community. She narrated how her son failed to receive any help from the rural clinic. Her son was referred to Kamoto hospital for further treatment, but she has not yet gone to the hospital due to lack of money. Meanwhile, due to lack of drugs and diagnosis, her son was not given any drugs to manage the condition. I saw tears in her eyes as she narrated this story to me. As a researcher using a feminist epistemology, I was found in a difficult situation, whether to help the woman with money or to stick to the ethical principles (Smit & Onwuegbuzie, 2018). Although I gave participants a snack and a drink as token of appreciation for their time, I wished I could help this woman beyond the biscuit and drink. This remained on my mind for a long time.

3.3 Methods and data collection

This section sets out how I undertook the research. Firstly, I describe how study participants were recruited for each group and how data were gathered. I then go on to describe how the qualitative data were analysed.

3.3.1 Selection of participants

Unlike in quantitative studies where sampling is used to randomly select a representative sample (Bryman, 2016), sampling in qualitative studies aims to select ‘information rich’ participants within the community and those participants with knowledge on issues such as conservation, veterinary and human medicine. For this reason, it is important to note that

sampling in qualitative research, as stated by Atkinson (2007) and Reeves et al. (2013), serves the purpose of identifying participants who can give detailed accounts regarding specific events, experiences, or issues. In this case, I selected participants who gave varying accounts regarding their experience and understanding of sleeping sickness, how it can be managed and controlled in the Luangwa Valley. Put together, these participants and key informants provided a detailed and rich account regarding practices, ways of life and experiences of people within this specific social context (Atkinson, 2007; Braun & Clarke, 2013; Creswell, 2013). For example, the experiences of men who produce charcoal and timber were different from the experiences of men and women that are involved in farming. Similarly, the experiences of women were different from the experiences of men in accessing and utilising available health services. Further, varying views, perspectives, and possible interventions from professionals with varying backgrounds and ministerial affiliations were also uncovered.

Based on the above account, purposive sampling was used to select community participants who were interviewed using in-depth, group and walking interviews (Reeves et al., 2013). These included women, men and children who were involved in farming, herding, charcoal burning, timber production, collecting firewood, fetching water and other household chores. The researcher had hoped to use snowball sampling to select participants that were involved in hunting; however, due to law enforcement, no one admitted knowing a hunter. For this reason, only purposive sampling was used to select community members and key informants or professionals who took part in the study (Reeves et al., 2013; Atkinson and Pugsley, 2005). Therefore, using this method of selecting participants, the researcher had access to all possible participants with varying characteristics and backgrounds, which resulted in the collection of detailed data on the community's experiences (Atkinson and Pugsley, 2005), a key aspect in an ethnographically informed study. Therefore, study participants were recruited using the sampling method stated above as follows.

Community members (women, men, and children)

Community participants included women, men and children who live in the three chiefdoms namely Nsefu, Malama and Mnkanya. These were recruited purposively as long as they met the inclusion criteria which in this case was, living within one of the chiefdoms, male or female, aged 13 years and above. The study excluded all adult members who could not express their own opinion. Although the study did not initially intend to include children below the age of ten, I realised that during the walking interviews and group interviews that the children did not know their ages, but they looked to be between ten (10) and fifteen (15) years old (Table 3). I interviewed community members with different characteristics and

who belonged to different categories, which included caregivers (women), herders (boys and men), timber and charcoal producers (men) and agriculturists (women, men, and children), and those who performed house chores such as fetching water (women and children), washing (women and girls), collecting firewood (women and children) and cleaning (women and girls).

Table 2: Background information for community participants

SN	Sex	Age	Marital status	Education	Ethnicity	Religion
1	Male	66	Married	Standard 5	Chewa	Christian
2	Male	63	Married	Grade 8	Chewa	Christian
3	Female	35	Married	Grade 3	Chewa	Christian
4	Female	32	Married	Grade 7	Kunda	Christian
5	Female	48	Widowed	Grade 7	Kunda	Christian
6	Female	45	Married	Grade 7	Kunda	Christian
7	Female	39	Widowed	Grade 8	Chewa	Christian
8	Female	42	Married	Grade 7	Chewa	Christian
9	Female	56	Married	Grade 2	Chewa	Christian
10	Male	37	Married	None	Chewa	Christian
11	Male	62	Married	Standard 5	Kunda	Christian
12	Male	45	Married	None	Chewa	Christian
13	Male	83	Married	Standard 2	Kunda	Christian
14	Male	58	Married	Grade 2	Chewa	Christian
15	Female	59	Widowed	Grade 7	Kunda	Christian
16	Female	59	Married	Grade 7	Kunda	Christian
17	Female	31	Single	Grade 7	Kunda	Christian
18	Male	73	Married	Form 3	Chewa	Christian
19	Female	unknown	Married	None	Chewa	Christian
20	Female	42	Married	Grade 9	Chewa	Christian
21	Female	53	Married	Grade 8	Chewa	Christian
22	Male	60	Married	Grade 6	Chewa	Christian
23	Male	unknown	Married	Grade 6	Chewa	Christian
24	Male	48	Married	Grade 7	Chewa	Christian
25	Male	39	Married	Grade 12	Kunda	Christian
26	Male	34	Married	Grade 4	Kunda	Christian
27	Female	23	Married	Grade 5	Kunda	Christian
28	Male	53	Married	Grade 8	Chewa	Christian
29	Female	39	Married	Grade 9	Chewa	Christian
30	Female	42	Married	Grade 6	Kunda	Christian
31	Female	49	Married	None	Kunda	Christian
32	Female	26	Divorced	Grade 4	Ngoni	Christian
33	Female	40	Married	None	Mambwe	Christian
34	Female	42	Married	None	Kunda	Christian
35	Female	61	Widowed	None	Chewa	Christian
36	Male	68	Married	Grade 7	Chewa	Christian

Table 3: Background information for children

SN	Sex	Age	Grade
1	Male	13	6
2	Male	11	5
3	Girl	10	5
4	Male	Does not know	3

Key informants

Key informants interviewed in this study had varying backgrounds ranging from those that have experience in ecology and conservations to those that are professional experts in human and animal health (Table 4). In terms of gender, four were men while one was female. These are members of the community and are in position of power or influence. Identification and recruitment of key informants was straight forward because the letters of permission and clearance from respective ministries directed me to respective key informants of interest to the study in the field site (Reeves et al., 2013). Since all key informants were expecting me, scheduling of interviews was much easier. With the help of the local contact person, I contacted the key informants to discuss their availability to participate in the study and to agree on a day, time, and location of the interview (Braun & Clarke, 2013).

Table 4: Background information for key informants

SN	Sex	Age	Marital status	Education	Ethnicity	Religion
1	Male	57	Married	Tertiary	Ngoni	Christian
2	Female	32	Married	Tertiary	Tonga	Christian
3	Male	38	Married	Tertiary	Bemba	Christian
4	Male	55	Married	Tertiary	Bemba	Christian
5	Male	58	Married	Tertiary	Bemba	Christian

To improve transparency and clarity during the recruitment of community participants and key informants, I provided all participants with an information sheet outlining the study's aims. In addition, I explained to them how they were selected, how the data collected will be handled and stored, their rights, and contact details in case of any challenges or need for further details. As a requirement, all participants were asked to read and sign/ thumb print on consent forms and participant information sheet to show consent. Further, those participants who could not read or write, the forms were read to them in their local language (Nyanja). After that, I gave all the participants an opportunity to ask questions before I started the interviews to make sure they understood. All ethical considerations were taken into consideration to protect the participants' identity and opinions by using pseudo names during the interview and in the transcripts.

Therefore, based on the above account, I interviewed forty five community participants and key informants. Community members were categorised as men (19), women (22), and children (4), boys (3) and girls (1) (Table 2 and 3). Further, these groups were further categorised based on the tasks that they do and other roles that are assigned to them based on their gender and age as explained above. Although most roles and tasks are specific for specific genders and age group, I found that some of the roles such as fetching water, farming

and collecting firewood were done by all genders although women and children are the ones that mostly do these roles (Okwa, 2007). Tasks such as cooking, cleaning, caregiving and looking for relish was mostly a task that women and girls did. Men and boys on the other hand did herding and tending of livestock, cutting trees to expand fields, building and thatching houses among other things. For this reason, I also conducted walking interviews (3) to interview herders and those doing chores because these categories do not sit in one place. This approach did not disturb them in any way because they carried on with their work without any destruction.

Although my presence was noted, the participants were comfortable to talk to me whilst doing their task in their natural environment (O'Neill and Roberts 2019). Group interviews (3) were used to interview groups of community members in order to get their understanding, perception, and experiences with tsetse flies, sleeping sickness and health (Coreil et al., 1989). In addition to the above interviews, I also sought professional knowledge by interviewing five key informants who worked as civil servants (Table 4). Like community members, key informants were selected using purposive sampling (Creswell, 2013). I interviewed participants who are professionals in the fields of wildlife management, conservation, human and animal health.

3.3.2 Data collection process and methods

Data collection in ethnographic studies is shaped by the data available to provide understanding of the focus of the ethnography. While most ethnographies, as suggested by O'Reilly, (2004), involve active participation in the local context over long period of time, as earlier explained, I relied on a methodological approach that combined ethnographic methods and techniques developed for rapid ethnography. Therefore, while my ontological and epistemological position aligned with ethnographic approach, my study was not an ethnography in a traditional sense. Similar to Palmer (2020), I used in-depth interviews alongside observations and photography to understand who does what, where, with whom and the non-verbal actions and interactions which shaped individual's behaviours and their exposure to risk of contracting sleeping sickness. As suggested by Whyte (1984) that observations do not help researchers to know 'why' individuals do what has been observed; combining in-depth interviews and observations complimented each method. Furthermore, drawing on Bourdieu's concept of field (Calhoun et al., 2012), in-depth interviews and walking interviews allowed me to get into the social landscapes where power dynamics are negotiated, while group and key informant interviews illuminated the collective narratives and how individuals position themselves within the various social landscapes with respect to healthcare and vulnerability to sleeping sickness. Table 5 below illustrates how each data

collection method was used to collect data for each question, the type of data collected and sources.

Table 5: Data collection methods

Research Questions	Data Collection Method	Data Collected	Data Sources	Empirical Chapter	Focus
1. What are the varying health needs, challenges, impacts and opportunities for women, men, and children in the Luangwa Valley, and how are these mediated by gender?	Interviews (In-depth, walking, group, and key informant interviews) Observations (photography)	Interview transcripts, field notes from walking and group interviews, observation notes, photos	Community members, key informants, observations	Chapter 5	Chapter 5 examines the lived experiences, gendered exposure to rHAT, and everyday vulnerability due to healthcare system challenges
2. How do communities, medical, veterinary, and conservation actors work together within Zambia's health and conservation policy framework, and how do these interactions shape the construction of gendered vulnerability to sleeping sickness?	Interviews (In-depth, walking, group, and Key informant interviews) Policy review	Interview transcripts, field notes from walking and group interviews, policy discourse	Community members, key informants, observations, and policy documents	Chapters 4 and 6	Chapter 4 analyses how sleeping sickness is constructed and how this construction shapes responses, health seeking and collaborations among actors
3. How can these gendered One Health understandings inform national policy for controlling NZDs in Zambia through policies and programme implementation that promote gender equality and health equity?	Interviews (In-depth, walking, group, and Key informant interviews) Policy review	Interview transcripts Policy discourse	Community members, all key informants, policy documents	Chapter 6	Chapter 6 integrates community and institutional perspectives to examine how governance processes and policy shape gendered vulnerability and interdisciplinary collaborations. to generate gender responsive One Health policy recommendations.

Observation

Participant observation involves observing what participants do, with whom, when and where. It also focuses on interaction and gestures used, both verbal and non-verbal. As argued by McKechnie and Given (2008, p. 573), observation is “one’s senses, especially looking and listening in a systematic and meaningful way”. This suggests that participant observation involves a researcher actively participating in the daily activities of a community being studied (Cohen, 2000), but at the same time observing and taking notes of what is happening to “establish patterns of interaction and activities that others can check and build upon” (Whyte 1984, p. 19).

Therefore, I lived within Mfuwe from first week of June to second week of July 2023 to experience the everyday life of the Kunda and Chewa farmers and understand their behaviours within the context of their culture, livelihoods and health (Fetterman, 1989). During my stay, my observations of the Kunda and Chewa farmers focused on what the farmers do, who does what, when and where this is done. I used to arrive in the respective chiefdoms early in the morning around 8.30am and leave around 3.30pm to observe categories of farmers responsible for the various chores, where they are done and by whom. This time was also ideal to observe livestock and how farmers, especially men and young boys interacted with their livestock and how this interaction shaped their risk of contracting sleeping sickness. Similarly, arriving in the villages in the morning allowed me to observe what women and girls do, where and when. For example, as I will discuss later in this thesis, during one of my visits to Chilembo of Nsefu Chiefdom on 23rd June 2023, I noticed that most men were seated along the road, either under a tree playing a traditional game called *nsolo* or were at a small shop sharing a smoke or drink, while others sat near each other on a small bench chatting. In contrast, women were ever busy multitasking. Around mid-afternoon, more women and children carrying containers were flocking around the only borehole and source of clean water for more than twenty-five villages to fetch water. I saw one woman, who appeared to decide who fetches next. I tried to help but she explained that owners of containers were the ones who were supposed to pump the water. I explained that I would like to help anyone willing and if it were ok. She agreed, with a straight face. A few metres from the borehole, was a household where I noticed a woman cooking. She was also shelling peanuts and chasing goats off her vegetables on a mat.

During these visits, I made short observation and reflexive notes of each day I spent in the field which were recorded in my notebook (Figure 2) and sometimes on the notepad application on my phone as this was seen to be less disruptive in open places (Hesse-Biber, 2017). These notes included phrases, and expressions which were jotted down in a way that only me could understand (Emerson et al., 2011). These short notes were later expanded every evening after field visits to contextualise and make complete sense of the notes. I noted down any relevant observations including those that did not relate to the topics to add context to my notes and gain more insights into the livelihoods and life of the farmers. For example, one Friday morning, I heard of a strange death of a young man that had occurred in one of the nearby villages. To add more context, I asked further questions to explore and understand what happened, who died, what a normal death is and why this death was considered strange. So, my observations were not limited to tsetse flies or livestock, or women and men, but extend to everything that shaped the lives of the farmers, reflecting the intersecting factors

that shape experience of suffering and experience of vulnerability and risk of contracting neglected tropical diseases such as sleeping sickness.

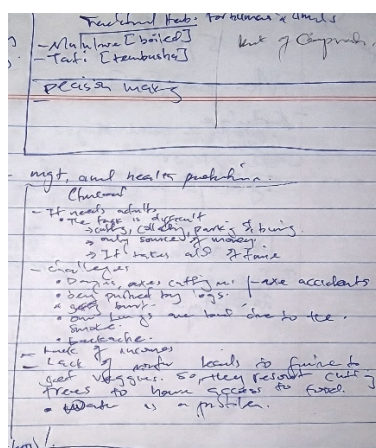


Figure 2: Observation notes

After developing the notes, I saved them on a word document where I would see patterns as the research progressed making it possible to see issues that were being referred to constantly and omitted. For example, while farmers in all chiefdoms complained of availability of tsetse flies, underfunded healthcare facilities, lack of water and road facilities, they did not complain about the risks of tsetse flies on their health. While they discussed that poor water sources caused diarrhoea and tsetse flies affected their livestock, mostly, Kunda and Chewa farmers omitted the health risks associated with the environmental and infrastructure challenges on their lives.

My observation notes were complemented with photos of livestock, wild animals and the natural environment which I took. I also took photos of items such as charcoal, firewood as well as water sources. Although most photos did not include participants, permission was obtained to take photos of the surroundings near participants' homes, their water points, containers, and domestic animals. In cases where photos of people were taken, permission and consent from participants was obtained. All photos were de-identified according to ethical guidelines regarding handling of photos of participants (Hammersley and Atkinson, 2007).

Throughout the process, I constantly reflected and analysed the information I was collecting, though by reflecting on the observation notes, and while listening to recorded interviews. Although I did not rely on a fixed topic guide and several other data were discussed and observed, I focused on data that was related to my research questions. For this reason, I did not record and note everything that was observed during my field work. Living in Mfuwe and travelling to different Kunda and Chewa villages in the three chiefdoms gave me an opportunity to experience how socially constructed understanding of illness and diseases

such as sleeping sickness are interpreted and understood within the local cultural and religious context and how gender roles and responsibilities assigned to different gender shape exposure and risk of contracting sleeping sickness.

In-depth interviews

As Hutchinson states, “observing, by itself, is never enough because it begs misinterpretation” (Hutchinson, 1988, p. 125). This suggests that while important, as argued by Whyte (1984), observation as a method does not offer a complete explanation of social life. Thus, I used in-depth interviews to gain further understanding of the observed behaviour, habits, and practices of the Kunda and Chewa farmers. By gathering the farmers’ reflection of their experiences of suffering and vulnerability to risk of sleeping sickness, in-depth interviews allowed me to bridge the gap between what I observed and what the farmers said, lending “meaning to their observed experiences” (Hutchinson et al., 1994, p. 125). Therefore, as suggested by (Galletta & Cross, 2013), interviews provide information to explain and understand experiences of all categories of participants through formal or informal conversations that elicit meanings of observed phenomena that the researcher may have misunderstood or misinterpreted.

I started my in-depth interviews by asking the farmers questions on general issues about the community. Informal conversation with the farmers helped them relax and become comfortable. The informal conversations later evolved into a more focused conversation focusing on their background, daily routines, and then on gendered division of roles, their livelihood activities and associated risks, community health, challenges, and opportunities. During the interviews, I probed for specific incidents, experiences, and reflections, including reasons why participants answered or viewed issues the way they did. Although I had a topic guide, I rarely looked at it, and this made the in-depth interviews more personal and helped the farmers to be free as we explored how they experience the risk of contracting sleeping sickness through their day-to-day livelihood activities. It is worth noting that while I obtained valuable information from informal conversations, formal interviews provided more details and information. For example, informal conversations were easily disrupted, and questions on hunting and charcoal production were not easily discussed in public for fear of being reported to the authorities.

Walking interviews

As mentioned earlier, it was not possible to interview some farmers using in-depth interviews. As a result, I used walking interviews to speak to farmers and children who could

not be interviewed using in-depth interviews due to circumstances such as working or unavailability. According to O'Neill and Roberts (2019, p. 17), a walking interview is where a researcher "follows a participant ethnographically- a walk on their daily round or activities." During walking interviews, the researcher acts as a companion to the participants, gaining more insights into their daily lives and experience with the natural environment (O'Neill & Roberts, 2019). I conducted four walking interviews with herders, a herbalist and timber producers and women doing their daily chores in Malama and Nsefu Chiefdoms respectively. During the walking interviews, all ethical obligations were taken into consideration. Similarly, I took into consideration all local norms that guided interaction of men and women, and environmental factors that could affect the walking interviews. For this reason, I carried out the walking interviews in such a way that I did not put my life or that of the farmers, man or woman, in danger or disrupt the existing social relationships of the farmers (O'Neill and Roberts 2019). Like in-depth interviews, I started the walking interviews with a general question about who the farmers are and what they do. Follow up questions and probes came up as the conversation progressed during the walk. In some cases, I helped the farmers with the respective chores they were performing as our conversation progressed. However, due to some environment conditions, audio recording became a challenge. Thus, I relied on detailed notes jotted down in my notebook and sometimes using the notepad application on my phone (Kinney, 2017).

However, due to local norms guiding the interaction between married women and men, walking interviews with women participants doing chores were done in the presence of the female field assistants. I noted that during our walking interview, the women were more comfortable talking to the female research assistants than me. Partly, her behaviour was shaped by the culture that controls interaction of married women with other men. We walked together to the water source (lagoon and well) and areas where firewood was collected, I made observations of the area and what participants were doing. I asked her to explain what was happening and why, as explained in later chapters, she explained how *mwambo* 'traditions' in the rural areas guide the works that women do and that is why we found them there.

In contrast, my walking interview with the timber producers and herbalist was more open and comfortable. It involved a walk from his home to his workshop and then into the bush, where we went to collect some herbs. As I helped him dig and clear the bushes, he explained how most species of trees used for timber and herbal medicine have been depleted by charcoal producers who cut down '*anything*'. As a result, he had to go further in the forest

or back to Katete where he came from in search for these species, a process which he considered dangerous and risky.

Interviews with *achibeta* (herders) focused on their experiences in the areas where they take their livestock for grazing. We walked from *malo odyetseramo ng'ombe* (grazing land for cattle) to the lagoon where women were fetching water earlier. After that, the herders proceeded to their village to milk the cows before returning to the grazing land. In terms of walking pace, interviews with women and the herbalist/timber producer were easier because the participants set the pace. However, for the herders, it was different. The cattle set the pace of our walk as illustrated in Figure 3 below.



Figure 3: A boy with cattle during a walking interview with herders

Group interviews

According to Coreil (1994, p. 194), group interviews refer to “different types of interviews which include consensus panels, focus group discussions, natural groups, and community groups.” I used natural group interviews to interview groups within their natural context of the field without following controlled formats (Coreil, 1994). With permission from headmen and community members, I attended four village meetings, two in Katemo of Mnkhanya Chiefdom and two in Nsefu area of Nsefu Chiefdom. However, one meeting in Katemo did not make it possible to carry out a group discussion as community members had other responsibilities. As a result, I relied on three of the meetings, one in Katemo and two in Nsefu. Because I was now a familiar face within the villages, it was easy for me to ask for permission from head person and the community members in attendance if they were interested in taking part in a group interview. I made it clear to them that they did not have to take part if they were busy or not interested. In all group interviews, I sought permission and consent from the participants to audio record the conversation, which was given. However, because of the informal and natural nature of the natural group interviews, I did not provide consent forms. Thus, only verbal consent was audio recorded to show consent to participate and to audio record the group interview (Braun and Clarke, 2013). For this reason, participants were advised not to give personal information.

Based on the above, three group interviews were conducted with men and women to explore the community narratives around gendered nature of community roles, health, risk to diseases and health seeking behaviour (Coreil, 1994). All group interviews were held under a *msoro* tree without the presence of the headperson. The group interview allowed me to understand the overall community knowledge of sleeping sickness, how their cultural and religious beliefs shape their perception of illness and health seeking. While these issues were discussed, most participants, especially men, focused on discussing the challenges of the community and need for help. For this reason, group interviews for men and women started with general discussion of the community's health and infrastructure challenges, then we moved on to topics of interest.

Key informant interviews

Key informant interviews, like in-depth interviews, supplement observations. I carried out interviews with men and women who are professional experts in the fields of conservation, wildlife management and human and animal health. I interviewed Key informants in advance so that I could use reflections of these interviews to inform the in-depth interviews with the farmers. Interviews with key informants focused on their daily work, experiences and interaction with the environment, wildlife, and the communities they served. I asked them on the micro and macro aspects of sleeping sickness with focus on the existing policy framework and collaboration strategies on the management of neglected tropical diseases such as sleeping sickness; and whether the existing policy framework and strategic mechanism considered the gendered nature of the risk of contracting sleeping sickness. Most importantly, despite being a native of the region, I asked the key informants in Mambwe district about the cultural practices and norms to inform my observation and interaction with the farmers. All the key informant interviews were conducted in the key informants' offices except for one key informant in Lusaka who I interviewed from one of the offices at the University of Zambia, where he worked as a part-time lecturer.

Review of existing policy

To have a detailed understanding of the current policy framework on health, control, and management of sleeping sickness in Zambia, nine different policy documents, acts and strategic plans were reviewed to identify the goals and gaps on gender and access to health, interdisciplinary collaborations, and management of neglected tropical/ zoonotic diseases. As argued by Bacchi and Eveline, (2015), my approach to policy review attempted to highlight Foucault (1978) and Douglas' (1992) arguments that those in power shape discourse on health and what would be considered risk. Therefore, my review treated policy

as a discourse, a reflection of structural violence which inadvertently reinforce and perpetuate social suffering through unequal distribution of economic and health resources. Therefore, I obtained relevant policy documents that address issues relating to gender and health from the Ministry of Health (National health policy, National Health Strategic Plan, Zambian Strategic Plan 2013-2016 Non-Communicable diseases, and their risk factors, National One Health Strategic Plan), Ministry of Gender and Child Development (The gender equity and equality act, National gender policy), Zambia wild life act, and the Ministry of Fisheries and Livestock Strategic Plan 2020-2021. This approach to policy review was appropriate for this research because it allowed me to understand the policies within their historical context and to identify gaps in the existing policy framework on gender and access to health, interdisciplinary collaborations, and management of neglected tropical diseases.

3.3.3 Overview of the data collected

In the first and second week of field work, I had informal conversations with the local people who I met in a local barbershop, butchery, and restaurant. These interactions gave me a lot of information about how the field site is structured and how to approach the data collection. I spent the proceeding weeks conducting key informant interviews and a series of in-depth, walking and group interviews in addition to making observations and taking photos explaining the social life of people in Mfuwe. Table 6 below summarises the data collection methods used and their outputs.

Table 6: Overview of data collection methods and outputs

Method	Output	Number of participants
In-depth interviews (number completed)	31 IDIs	31
Group interviews (number completed)	3 GIs	-
Walking interviews (number completed)	4 WIs	9 (boys=3; girl=1; women=2; men=3)
Key informant interviews (number completed)	5 KIIs	5
Observations (weeks)	9	-
Photos (number taken)	188	-
Policy documents reviewed	9	(2 policies; 5 acts of parliament; 2 strategic plans)

3.4 Analysis and interpretation

3.4.1 Data preparation and management

In-depth interviews (including group and walking interviews) with community participants were conducted in *chiNsenga/chiKunda* and *chiChewa* while key informant interviews were all conducted in English. At the end of fieldwork, all interview audios in local languages

were transcribed and translated into English. Further, to avoid misrepresentation of the farmers' responses, all interviews were transcribed verbatim including all words said by participants to contextualise the discussion. To protect the identity of the community participants and key informants I spoke to, all transcripts and photos were anonymised by removing any markers or pointers that may lead to the identification of participants. Thereafter, all anonymised transcripts, field notes and photos were organised and uploaded to the secure cloud offered by the University of Glasgow. The organised and anonymised data was then uploaded into NVivo which was used to store, and manage the data (Braun and Clarke, 2006).

3.4.2 Analysis, interpretation and representation

While much of the data analysis was done after fieldwork, this process began during the fieldwork (Atkinson, 2007). While ethnographers are expected to draw their own conclusions about the meanings of their observations, Whyte (1984, p. 95) suggests that "even in our own society, we should interpret what we observe with caution." Whyte (1984) suggests that regardless of whether ethnographers study familiar or unfamiliar locations, their background experiences and culture introduce certain biases in the research process which shape their interpretations. Therefore, although this thesis has tried to let the Kunda and Chewa farmers' accounts speak for themselves, I have made my own interpretations of their actions, behaviours and experiences of suffering and vulnerability to sleeping sickness and attacks from wild animals. Therefore, while this thesis presents and reflect accounts and experiences of the Kunda and Chewa farmers, the interpretations of the information collected are mine.

Ultimately, the whole process of data analysis and interpretation was informed by the theoretical lens of the study and the farmers' accounts of their experiences. Therefore, to interrogate regularities, and variations among participants' accounts, I compared the accounts between women and men who played different roles and were involved in different tasks. In the analysis of group interview data, focus was towards uncovering participants' points of agreement, differing views and experiences regarding their understanding of sleeping sickness and how risks, and exposure is shaped by gendered roles and responsibilities. All photos were analysed based on the context and were used to complement the observations and emerging themes from the data collected (Reeves et al., 2013). This approach to analysis reveals the various ways in which societal structures and power dynamics are inscribed in the health narratives of community participants providing insights of how various forms of inequality and gender shape health experiences, access, and utilisation.

My analysis was informed by Charmaz's (2014) grounded theory coding approach, which involved reading transcripts repeatedly to understand the data and to identify core ideas. I then proceeded with open coding to code each transcript by assigning labels to parts of the transcripts portraying ideas about the study focus (Thornberg & Charmaz, 2014). Reading transcripts, deciding on codes and then coding to more specific codes was an important component that helped to further understand the data (Charmaz, 2014). This was then followed by focused coding, which was done inductively and thematically to create analytical and thematically linked codes (Silverman, 1993). All field notes were incorporated at this stage to refine the emerging codes and to place them into broader accounts to ensure that the analysis reflected the experiences, accounts, and events of participants of Malama, Mnkhanya and Nsefu chiefdoms (Emerson et al., 2011). Thereafter, I proceeded to build the codes into categories of important themes (Charmaz, 2014), which also informed the structure of this thesis's empirical chapters with prominent and key findings being provided more space in the chapters.

While several scholars note that the process of coding results in fragmentation of data and loss of the narrative of what was said, throughout this thesis (Atkinson Paul, 2007), I included personal accounts of the Kunda and Chewa farmers' experience of barriers to healthcare, suffering and illness in their everyday lives. While I did not use vignettes, quoting accounts of the farmers' personal experiences allowed me to capture the intersecting factors that constrained their access to healthcare services and shaped their experience of risk to sleeping sickness. Furthermore, as argued by Farmer (2005, p. 31) that structural violence is best described through 'details of biography,' the excerpts and accounts from the farmers further provided insights into structural violence that shaped the farmers' risk of contracting sleeping sickness and experience of suffering during the process of seeking healthcare services to manage illness and vulnerability to human animal conflicts.

3.5 Chapter summary and conclusion

In this chapter, I discussed my methodological approach and its underlying philosophical foundations. Throughout the chapter, I drew on Haraway's (1988) idea of situated knowledge, which highlights the partial and contextual nature of understanding social reality. Additionally, I elaborated on how a feminist epistemology shaped my approach towards issues relating to inequality, power, and reflexivity in the processes of data collection, analysis, and interpretation (Collins, 1988; Smith, 1990). I finished this chapter by providing a comprehensive discussion of the field site, and the methods employed to capture and understand the intersecting social, economic and institutional factors that shape gendered risks of contracting sleeping sickness and health experiences and outcomes in Mambwe

district. Building on this chapter, the subsequent chapter will explore the social construction of sleeping sickness in Mambwe district contextualising the study of sleeping sickness within sociological theory and setting the background for the proceeding chapters which will explore Community health in a human wildlife livestock interface and gender realities and risk of sleeping sickness in Mambwe district.

CHAPTER FOUR

SOCIAL CONSTRUCTION OF THE REALITY OF SLEEPING SICKNESS IN MFUWE

4.1 Introduction

This chapter situates the social construction of sleeping sickness within sociological and anthropological theories. I explore how Kunda and Chewa farmers' experience of risk is socially constructed and embedded in broader systems of inequality and power within Nsefu, Malama, and Mnkhanya Chiefdoms. I argue that the participants' individual characteristics intersect with their community's social, cultural, and institutional processes to shape their experience of risk of contracting sleeping sickness and suffering from its consequences and challenges associated with living in a game management area (GMA). Overall, this chapter will address the second research question: *How do communities, medical, veterinary, and conservation actors work together within Zambia's health and conservation policy framework, and how do these interactions shape construction and gendered vulnerability to sleeping sickness?*

Using various sociological and anthropological research, I argue that the participants' perception of risk of contracting sleeping sickness reflects an intersection of their cultural beliefs on illness and existing institutional processes that shape health narratives and responses. I also reveal that narratives suggesting low risk of contracting sleeping sickness in Mambwe district reflect how power, as discourse, shapes and reinforce gendered inequalities, vulnerability, and responses to the risk of sleeping sickness in rural communities such as those of the Chewa and Kunda. By this statement, my findings contribute to broader literature that while exposure to vectors is a basis for contracting sleeping sickness, several social and cultural factors intersect with structural factors and individual characteristics such as gender, ethnicity, economic position, and age to shape individuals' experience and perception of risk of contracting the disease.

Overall, my analysis in this chapter shows that the risk of contracting sleeping sickness among the participants' in the three chiefdoms is shaped by both biological and sociocultural factors. This implies that while biomedical interventions are critical to addressing sleeping sickness in Mambwe district, this approach is incomplete without considering the role of nonbiomedical factors, such as social, cultural, and structural factors that shape material and non-material deprivations contributing to health inequalities and vulnerability to neglected tropical diseases (NTDs). Therefore, the analysis developed in this chapter provides the

context for interdisciplinary collaborations and within which the proceeding chapters of the thesis are developed.

4.1.1 Literature and approaches

Throughout this chapter and thesis, I will refer to literature on risk (Douglas, 1992; Douglas & Wildavsky, 1982), symbolic power (Bourdieu, 1989), structural violence (Farmer, 2004) and power (Foucault, 1978, 1982), to show that the participants' perception and experience of vulnerability, risk, suffering and agency are shaped by structural constraints which contribute to health inequalities and risk to NTDs within their communities. I will also draw on Goffman (1956) and Berger and Luckmann (1966) theories on impression management and social construction respectively to show how risk and illness, like any social condition, are a products of interaction between individuals whose construction of risk and illness is shaped by their existing religious and cultural beliefs and practices which unconsciously and independently shape their beliefs and actions. I also draw on feminist (Smith, 1990) and intersectionality literature (Crenshaw, 1991; McGibbon & McPherson, 2011) to show that although Kunda and Chewa farmers in Nsefu, Malama and Mnkhanya Chiefdoms are vulnerable and at risk of contracting sleeping sickness because of environmental conditions, their exposure to risk of sleeping sickness is shaped by an intersection of gender, ethnicity, economic resources and age among other factors (Vlassoff, 2007; Wharton-Smith et al., 2019). Furthermore, individual characteristics, intersecting with structural and institutional factors, ultimately shape the farmers' experience of risk of contracting sleeping sickness and its consequences.

4.2 Community participants: *aKunda* ndi *aChewa* (Kundas and Chewas)

Given the social and cultural dimensions of sleeping sickness, I ensured representation from different ethnic and community backgrounds. Participants were drawn from Kunda, Chewa, Bemba and Ngoni (KIIs) ethnic groupings, allowing for a comparative understanding of how socio-cultural contexts influence experiences and perceptions related to sleeping sickness. However, it is worth mentioning at this stage that although some participants identified as belonging to other ethnic groupings such as Chewa, most of the participants belonging to smaller ethnic groups considered themselves as Kunda. This was because these participants have lived in Mambwe district all their life. For this reason, I considered such groups as Kunda except for those who specifically identified as a non-Kunda. Therefore, my participants mostly identified themselves as Chewa (n=20) and Kunda (n=14) while others identified themselves as Mambwe (n=1), Bemba (n=3), Tonga (n=1) or Ngoni (n=2).

The varying characteristics and backgrounds of the participants formed a strong basis to understand how gendered understanding of sleeping sickness is constructed within the three chiefdoms by situating the findings within their broader socio-economic and cultural contexts. The diversity within the sample enriched the qualitative insights, ensuring that the analysis captured a wide range of lived experiences of sleeping sickness further providing details on how structural violence contributes to perception of risk of sleeping sickness, health seeking and overall social suffering from consequences of the disease. In the following section, I build on these background characteristics to explore how participants' varying background characteristics shape the risk of contracting sleeping sickness, perception of the disease, health seeking and experience of the disease's consequences.

Having presented the ethnic groupings of my participants, I will proceed to present other characteristics of the individuals I spoke to in order to provide context for the study findings. I present data on the demographic and background characteristics coming from forty five (45) participants, men (n=19), women (n=22) and children (n=4). I considered these individuals with varying background characteristics to capture their varied experiences and perspectives on the non-biomedical nature of sleeping sickness and its impacts on their wellbeing and communities. As explained earlier in chapter three, my study's participants lived in various chiefdoms of Mambwe district. For example, community participants lived in villages in Nsefu (Chulu 2, Chilemba, Kadewe), Malama (Malama) and Mnkanya (Katemo, Chikusu). On the other hand, some key informants lived in Lusaka while others within Mambwe Boma and the Cropping area which are within Mnkanya and Kakumbi chiefdoms respectively.

It can be noted that in terms of gender and age, I selected a sample which included men (n=19) and women (n=22), including girls (n=1) and boys (n=3) ensuring gender diversity in the study. These participants were aged between 20 years and 85 years, with the majority (n=20) aged between 20 years and 45 years followed by those aged between 46 years and 70 years (n=16). Three (n=3) participants were aged above 70 years while the other two (n=2) did not know how old they were. Of the boys and girls (n=4) interviewed in walking interviews, their ages ranged between 10 years and 14 years as most of them did not know their exact age. The participants' gender and age distribution are particularly important in understanding different social experiences and perspectives related to sleeping sickness across different age groups and gender categories.

Therefore, the above characteristics and information about participants provide a foundation for understanding how their individual and community characteristics influence their health

seeking behaviour, exposure to risk of diseases and the severity of the consequences of the diseases. Furthermore, this information provides insights into the different narratives, perception of sleeping sickness and approaches to detection, management and control among professional experts working in different fields. This is important to my study because it provides insights into how gendered One Health approaches can be achieved by exploring possible points of agreement to deal with sleeping sickness in the Luangwa valley.

In the following section, I present a detailed discussion of the Kunda and Chewa participants within the context of this study. I further discuss their religious and tradition beliefs on health and illness. This understanding is very important as it shapes and influence construction of undiagnosed diseases, health seeking behaviour and overall impact of disease on the health and wellbeing of the community.

4.2.1 Mfuwe, Kunda and Chewa participants outline

The term Mfuwe is believed to be a mispronunciation of the name *Fulwe* by a settler from the Western province of Zambia. Because of differences in languages spoken between the Western and Eastern provinces of Zambia, the visitor's pronunciation of *Fulwe* sounded as *Mfuwe*, and over time, the name Mfuwe has been formalised and recognised as the official name for the area. Mfuwe is located within Mambwe district and Malambo constituency of the Eastern province of Zambia (Mambwe District Council, 2019, 2020). This district occupies the central part of the Luangwa valley, an extension of the East Africa rift valley (Banda et al., 2013). Mambwe district is situated within the Lupande Game Management Area (GMA) of the South Luangwa National Park (SLNP) located across the Luangwa River on the western side of Mambwe district (Lisulo et al., 2014). Several water bodies such as the Mwangazi and Musandile rivers in the north and the Lusangazi River in the south, and the Luangwa River on the west, run through Mambwe district. Although these rivers are mostly dry during the dry season, they contribute to various social, economic and health implications on the communities through fishing and flooding during the rainy season (Banda et al., 2013).

Mambwe district is predominantly occupied by the Kunda speaking people called *aKunda* or the Kundas. Historically, the Kunda people of Mambwe district are believed to be descendants of groups that migrated from the Luba and Lunda kingdom during the 16th century migrations (Pachai, 1973). The Kundas are a breakaway group from the Bisa of Mpika, one of the groups that migrated from the Luba and Lunda kingdom (Banda et al., 2013; Bruwer, 1958). By the 19th century, the Bisa had established their kingdom within the Luangwa valley in present day Mpika (Chondoka & Bota, 2007). However, between 1835

and 1845, the Kunda crossed the Luangwa River and settled in present day Mambwe district as a breakaway group from the Bisa of Mpika (Banda et al., 2013). Over time, the ethnic composition of Mambwe district has been changing due to migrations from surrounding districts and ethnic groups such as the Chewas, Nsengas and Ngonis who have migrated into Mambwe district over time (Bruwer, 1958). Consequently, the Kundas' coexistence with other ethnic groups from the surrounding districts has contributed to 'tribal mixing' and evolution of the Kundas' cultural practices such as livelihood activities, and division of labour, which I will discuss later in this chapter.

Following the Kundas, the Chewa speaking people are another dominant ethnic group in Mambwe district. Like the Kundas, the Chewa speaking people, also known as *aChewa*, were part of the Bantu migrations that characterised the Luba kingdom of Zaire (Marwick; 1965; Yoshida, 1992). Chewa oral tradition shows that they originated from a place called *Uluwa* in the Shaba or Katanga area in Democratic Republic of Congo (Juwayeyi, 2020) and occupied the area lying across the borders between Malawi, Mozambique and Zambia (Yoshida, 1992). In Zambia, the Chewa speaking people settled in the Eastern province around Katete district and the surrounding areas. According to the Zambia Statistics Agency, the Chewas were the largest ethnic group and widely spoken language (34.6 percent) in the Eastern province comprising about 39.7 percent of the total population (CSO, 2012). However, because of the increasing demand for grazing land and cultivation in Chewa speaking areas such as Katete, Chadiza and Lundazi districts, the Chewas have been spreading to other districts including Mambwe district, in search of land for agriculture and grazing purposes (Anderson et al., 2015).

4.2.2 Marriage and social status

Men in this study were aged between 23 years and 84 years. In terms of ethnicity, most participants belong to the Chewa and Kunda ethnic groups. Although most of them are married to one wife, other men like Mike (67 years) and Philip (64 years), both Chewa, are married to three wives. My observations revealed that all men who had more than one wife like Mike and Philip appeared wealthy and influential within their community. For example, Mike was a village headman, and, in his yard, I saw a minibus and an oxcart parked near the main house. In addition to that, Mike had a big herd of cattle and small ruminants such as goats and pigs. In one sense, this implies that marrying more than one wife is a sign of high economic status and masculinity. Women participants' accounts and the researcher's observations and analysis reveal that having more wives may also serve as source of labour that enhanced the agriculture output for men like Mike and Philip.

In contrast, although marrying more than one wife is associated with high status and agriculture productivity (Kudo, 2014; Pike, 2021), my observations and interviews with men aged below fifty years reveal a slightly change in practice. Evidence shows that some men who had almost the same wealth as men married to more than one wife were married to one wife. For example, Lazaro who is aged 37 years has a herd of about seven cattle, small ruminants, and chickens. He also uses his oxcart to earn income by offering transportation services. However, he is married to one wife and together have eight children, suggesting variations in adherence to cultural practices such as polygamy across generations.

Women on the other hand, were composed of a mixture of Kunda (n=7), Chewa (n=10), Ngoni (n=2), and Mambwe (n=1) ethnic groupings. Aged between 23 years and 62 years, women participants were married except for those who were widowed (n=4), single (n=1) and divorced (n=1). However, regardless of marital status, all women had at least two children. Further analysis of participants' accounts reveals that none Kunda women came to Mambwe district because of marriage to a Kunda husband. Further, other women migrated to Mambwe together with their husbands in search of land for cultivation. For example, Rosie, a 45 year old Chewa woman with seven children came from Chief Jumbe's area to Mambwe district under Chief Nsefu's area because of marriage. Rosie's case reflects the experiences of other women in this study who migrated to the areas where they lived to fulfil traditional marital obligations and practice. Although some women revealed that they are not comfortable living in these areas because of the hardships such as lack of healthcare facilities and economic opportunities, they had no option because as Rosie puts it, '*nekonka chikwati*' which translates to 'I came here because of marriage.' This implies that even if Rosie did not want to move to Nsefu chiefdom, the need to fulfil marital roles and obligations compelled her to join her husband. This suggests that shifting traditions in residential patterns among couples, from patrilocal and matrilineal to neolocal arrangements coupled with the growing demand for agricultural and grazing land, indirectly contribute to migration into Game Management Areas (GMAs) and areas near national parks, which may pose direct or indirect risks to the health of individuals and their livestock.

However, as noted by Milika, a 39-year-old Chewa woman of Chilemba village, marriages in her village do not always work and are not as good as they seem. She narrated that most marriages in her village are merely for 'farming purposes' where women and children provide the needed labour but after planting and harvesting seasons, most men would change and desert their families. Milika's observation of the nature of marriages reflects how household power inequalities and decision making affect married women's income, health, and wellbeing due to their reliance on spouses for economic support. Lack of resources

among women limits their ability to make decisions about their own health and that of children, thus perpetuating their experience of vulnerability to diseases and other social vices (Kabeer, 1999).

Turning to the role of marital status on shaping risk of contracting sleeping sickness, Kunda and Chewa systems of marriage show similarities, especially regarding the division of labour within households, management of income and decision making which are enshrined in their cultural and religious teachings. For example, as I will further elaborate in chapter six of this thesis, the Kunda and Chewa religious and cultural teachings on *roles* and *duties* of men and women within the household define and specify duties to be performed by women, men, and children. Married men and women are expected to fulfil certain roles and tasks such as housekeeping, caregiving and cooking while children perform their roles and chores on behalf of their parents. Through prescribed gender roles and cultural practices within households (Butler, 1988; Douglas, 1992; Vlassoff, 2007), participants, especially those in lower positions of power and decision making such as children, are significantly exposed to disease vectors and risk of contracting diseases such as sleeping sickness.

As indicated in the previous section, all male participants I spoke to were married to one wife except for two Chewa men who were married to three wives each. In contrast, out of the twenty-two women I spoke to, fifteen women were married except for four who were widowed, one who was divorced and another who was single. However, regardless of their marital status, all women and men I spoke to had at least two children. Although marital status played a significant role in shaping men and women's community roles, status and privileges (Ayisi, 1979; Magesa, 1998), some participants perceived some forms of marriage negatively. For example, while participants in polygamous married associated it with wealth and social status, some Chewa and Kunda men and women perceived polygamy in a negative sense as merely a source of labour that enhanced the agricultural output and economic position of polygamous men. Accounts from some Kunda and Chewa farmers I spoke to show that more women and children struggled with suffering in polygamous marriage because of increased loads of outdoor tasks which contributed to increased risk of contracting sleeping sickness.

As explained by Milika, a 39-year-old Chewa widow with six children from Nsefu Chiefdom, women and children rarely benefited from their involvement in livelihood activities in most polygamous marriages. To Milika, polygamous marriages in her village were merely 'a means to an end' and not based on companionship. She argued that while marriage brings 'respect' to women, it was used by some men as a source of farm labour.

She observed that women and children in polygamous marriages rarely benefited from the income realised from the sale of crops after harvesting because men, who are responsible for managing income in the household, rarely provided for their families or shared resources with their wives to meet the family needs. With no income and food, most women resorted to risky activities, such as foraging in areas with a high density of tsetse flies and wild animals. Milika's observation of the nature of marriages provides a glimpse of how household power inequalities and decision making affect children and some married women's income, health, and exposure to risk of diseases and suffering. This implies that while marriage of any kind provides status and privileges to men and women in the Kunda and Chewa communities, it also shaped the participants' exposure to areas with high density of vectors such as tsetse flies and mosquitos increasing their vulnerability to diseases through unequal power, access and control over household resources.

However, while women in monogamous and polygamous marriages experience challenges that expose them to vectors and risk of sleeping sickness, single and divorced women such as Mpepo (32 year old single Kunda mother of four) and Anna (26 year old divorced Chewa mother of two), experienced additional challenges compared to other women. While Mpepo and Anna have limited education and no employment like the other women I interviewed, my findings show that single and divorced women experience more hardships with limited resources to provide for their children and access to healthcare compared to their counterparts. This situation reinforced single and divorced women's suffering and experience of illnesses which, if they were economically stable, could be avoided. This finding is consistent with the conclusions made by Smith & Waitzman (1997) in their study on effects of marital status on risk of mortality in poor and nonpoor neighbourhoods.

Thus, my study's findings suggest that Kunda and Chewa farmers' marital status and the type of union reinforced the unequal power relations and distribution of resources within households which created disadvantages for women and children, increasing their risk to sleeping sickness. Analysis of accounts from participants show that similar to women in homes with no cattle, women and children in some polygamous marriages engaged in more outdoor activities compared to women with cattle and in monogamous marriages. This finding suggests that while participants may suffer from the vulnerabilities created by environmental conditions, marital status plays a significant role in shaping women and children's experience of vulnerability to conditions that increase the risk of contracting sleeping sickness and other diseases such as Malaria as explained by Milika.

4.2.3 The role of religion for Kundas and Chewas

Kundas and Chewas believe in the existence of a supreme being called *Mulungu* (God) or *Mulengi* (creator). While the declaration of Zambia as a Christian nation signified the country's strong belief in the Christian faith, as Ziwa et al., (2018), found, it also overshadowed the existence of other religions and beliefs. Although Christianity forms much of the population, African traditional beliefs and other religions form the other proportion (Zambia Statistics Agency, 2025). For this reason, most Zambians in rural and urban areas combine modern Christian beliefs and indigenous Zambian beliefs, which are sometimes perceived by Christian believers as non-Christian practices (Simuchimba, 2001). Like many other Zambians, Kunda and Chewa participants' religion is a combination of a belief in modern Christianity and their indigenous beliefs where ancestral spirits act as intermediaries between *Mulungu* and the people (Simuchimba, 2001). The Kunda and Chewa farmers' cultural and religious situation shows a 'blending' of African cultural traditions and Christian and Islamic beliefs observed in other African countries (Mbiti, 2001; Mbiti, 2015).

Therefore, despite Zambia being a Christian nation, the Kunda and Chewa's religious beliefs reflect both indigenous Zambian beliefs and Western modern religious beliefs. Thus, the Kunda and Chewa farmers' perception of life, fortune and misfortune is shaped by this heterogenous system of beliefs with Kunda and Chewa indigenous beliefs on one hand and modern Christian beliefs on the other. Consequently, the Kunda and Chewa participants I interviewed associate suffering, diseases and misfortune with malignant spirits or men practicing *umfiti* (witchcraft). Although they also believed that changes in the cosmos such as the waxing and the waning of the moon shaped occurrence of good or bad events within the human community, Kundas and Chewas perceive witchcraft and sorcery as the main source of misfortune and unexplained deaths and diseases (Yoshida, 1992). This setting and social structure of the Chewas and Kundas shape their beliefs and practices, perception of illness, its causes and treatment, which ultimately influence their health behaviour explained in more detail later in this chapter.

In terms of religion, all men interviewed are Christian and belong to a Christian denomination, although with varying levels of commitment and participation. For example, some men belonged to the Catholic Church while others belonged to Protestant churches such as the Seventh Day Adventists, Reformed Church in Zambia (Former Dutch Reformed Church), Jehovah's Witnesses and the United Church in Zambia. I noted that men who were married to single women appeared more confident about their denomination and participation in church activities, while those who were in polygamous marriages were not forthcoming on this matter. When I inquired further, it was revealed that although polygamy

is a culturally celebrated form of marriage, it was strongly condemned by the Christian beliefs and denominations (Simuchimba, 2001; Ziwa et al., 2018). As a result, most men in polygamous marriages avoided religion and discussing their marital status to protect themselves from further scrutiny and losing their authority, as one's marital choices reflect their moral standing within rural communities. Furthermore, this topic was avoided for fear of being stigmatised or being pressured to abandon the additional wives, which has the potential of disrupting family structures and economic arrangements (Udelhoven, 2022). For example, Mike explained that he is a Jehovah's Witness, but because he married more than one wife, he was disfellowshipped from the church. For this reason, his involvement in church affairs ends at attending meetings. In terms of religion, like other members of the community, women participants were all practising Christians who belonged to different Christian denominations. Like men, more women participants are Catholics, while others belong to protestant denominations such as the Reformed Church in Zambia, New Apostolic Church, Anglican, and Pentecostal church.

Similar to the role of education, the participants' religious and cultural beliefs shaped their risk of sleeping sickness and overall perception of illness and its causes. As explained earlier, Kunda and Chewa communities are heterogeneous combining both Christian and Zambian traditional beliefs and practices (Udelhoven, 2022). While participants recognise the biological nature of diseases, my findings suggest that Kunda and Chewa participants strongly associate illness, deaths and misfortunes to witchcraft and supernatural forces operating within their communities (Yoshida, 1992). Consequently, Kunda and Chewa participants often turn to traditional methods of disease diagnosis and management before seeking medical care. This implies that the religious and culturally influenced beliefs about the cause of illness and its treatment contribute to delayed access to medical care and treatment of possible cases of sleeping sickness. As a result, participants with symptoms of sleeping sickness may experience prolonged suffering and increased rates of mortality partly due to delayed health seeking and utilisation of the available healthcare services. Therefore, in the absence of correct clinical diagnosis of sleeping sickness, cultural and religious beliefs on the causes of illness and their treatment inadvertently increased the participants' vulnerability and suffering from possible cases of sleeping sickness. Drawing on Douglas (1992), this finding suggests that farmers' religious and cultural beliefs sanctioned some practices that either increased risk or severity of the impact of diseases through relaxed response to symptoms which resulted into delayed diagnosis and treatment of sleeping sickness using the available modern treatment methods. I will return to this matter in the proceeding sections of this chapter.

4.2.4 Understanding political systems

While Kundas and Chewas have different cultural and traditional practices and beliefs, they have many similarities. For example, they are both based on a matrilineal system of inheritance where the descendants trace their ancestry through their mother's clan (Bruwer, 1958; Yoshida, 1992; Banda et al., 2013). Although the core of the kinship systems are women, males dominate in all practical matters of the Kunda and Chewa society (Bruwer, 1958). However, in both tribes, the status and power men practice are derived from women, and their responsibility prioritises their matrilineage (Bruwer, 1958; Yoshida, 1992). Yet, although women are involved in making decisions and are responsible for running all aspects of the home, men influence decision making within households and the community (Bruwer, 1958). Power and decision making disparities between men and women forms the basis of inequalities in resource distribution among Kunda and Chewa communities. These disparities in resources between women and men further contribute to poor health seeking behaviour and delayed response to diseases within these communities, especially among Chewa and Kunda women (Banda et al., 2013). The culturally determined imbalances in power and decision making among Kunda and Chewa men and women ultimately shape how farmers access and utilise the available healthcare resources aimed at controlling the disease burden within the Kunda and Chewa communities.

Despite similarities in their religious beliefs and systems of inheritance, Kundas and Chewas have different political systems. The Kunda political system, for example, is organised using a three-tier territorial grouping namely the tribal, sub-chiefdom and the village (Bruwer et al., 1958). The village level is the lowest and is also considered as the residential unit headed by a headman who is a senior male member of the matrilineage (Bruwer, 1958). Within the village, all families function as independent households called *ng'anda* (house), a domain of married women and are responsible of cultivating the land which is done as a unit where all members are involved in addition to other gendered responsibilities (Bruwer, 1958). The sub-chiefdom is larger than the village and operates under the leadership of a sub-chief (Bruwer, 1958). Mambwe district is under the leadership of His Royal Highness, Senior Chief Nsefu who is assisted by five sub-chiefs who are responsible of the five sub-chiefdoms namely Malama, Jumbe, Mnkhanganya, Msoro and Kakumbi (Bruwer, 1958). Although powers are vested in the senior chief, sub-chiefs have the authority to issue land and resolve various matters in their chiefdoms (Banda et al., 2013). The tribe, on the other hand, is the highest level of organisation within the Kunda political system. The tribe, according to Bruwer (1958), is based on loyalty to the Senior Chief Nsefu and kinship relations of the various sub chiefs. Within the Kunda Chiefdom, all inhabited areas are collectively owned allowing

anyone from respective sub chiefdoms to utilise resources within their reach (Bruwer, 1985), a practice which, as I will explain in the next chapter, contributed to encroachment in areas that have high density of disease vectors and possible conflict with CSOs and law enforcers focusing on conservation of wildlife and the environment.

The Chewas, in contrast, have a centrally controlled political system with *Kalonga* (King) at the helm and villages headed by *Mwine mudzi* (owner of village) at the bottom (Yoshida, 1992). Like the Kundas' three-tier system, the Chewa political system consists of several chiefdoms headed by regional chiefs called *Mambo* who report to the Paramount Chief Kalonga Gawa Undi whose palace is based in Zambia's Katete district of Eastern province (Yoshida, 1992). The regional chiefs are assisted by village headpersons called *Mfummu* who head each village composed of one or more lineage segments (Yoshida, 1992). The Chewas' political structure is based on the dual tradition in which authority is divided between two main Chewa matriclans namely the 'Banda' and 'Phiri' (Marwick, 1965). The Banda clan is responsible for the spiritual aspects of rain calling and fertility of the land while the Phiri clan, where the paramount chief and other regional chiefs come from, is responsible for the political aspect of the Chewa kingdom (Yoshida, 1992).

It should be noted, however, that the political systems of the Chewas in Mambwe district conform to the Kunda political system. However, I would also make it clear that although Chewas and other ethnic groups that migrated into Mambwe district conform to the Kunda political system, practices within their villages and families reflect their indigenous social, economic, and cultural systems which were exhibited in their livelihoods, health behaviour and daily practices. I will return to this matter in proceeding chapters.

4.2.5 Education

Although the Zambia national statistics on national literacy show a 70.2 percent literacy rate, literacy for rural areas such as Mambwe district stands at 60.5 percent compared to 83.8 percent in urban areas (CSO, 2012). As earlier indicated, almost all participants I spoke to had not completed their education and only a few were able to write and read in English and ChiNyanja. For example, out of the twenty-two women I spoke to, none had completed secondary education with some women having had no education and many others having attained grades two, three, four, and six. Similarly, of the nineteen men, two Chewa men had no education, the other men, Kunda and Chewa, stopped in grades two, four, five, six and seven with only one Kunda man who completed grade twelve but did not proceed with tertiary education. While several reasons were given for not completing their education, one common reason for not completing any level of education among Kunda and Chewa men

and women was lack of economic resources to support their education except for Mako, a 58-year-old Chewa man living in Malama, who dropped out of school because of fighting and his belief that he was not good enough.

Others, such as Maiwase, a 56-year-old Chewa woman from Nsefu Chiefdom, could not complete her education because of a lack of support and effort from her family to enable her to get to higher grades. Although Maiwase, like other participants, was willing to pursue her education further, her family's economic conditions and situations made it impossible for her to go beyond the second grade. While low levels of education among the Kunda and Chewa farmers I interviewed reflect their family economic hardships and suffering, structural inequalities perpetuated and reinforced by institutions responsible for distributing resources to areas such as Mfuwe contributed to the inaccessibility and unavailability of school facilities (MDIDP, 2020). Although Mambwe district has about 55 primary schools, eight secondary schools and community schools, accessibility and retention has remained as the main challenge (Banda et al., 2013). This problem has indirectly contributed to high illiteracy and dropout rates among boys and girls who opt to enter early marriages and contracts to herd cattle.

Participants' educational levels varied across the different categories and ethnicities, reflecting a broad range of knowledge and experiences relevant to understanding sleeping sickness within a rural context. Of the participants, eight (n=8) attended secondary education. In contrast, twenty-two (n=22) participants had only attended primary education while six (n=6) have no education. In contrast, all key informants (n=5) held tertiary qualifications. The varying levels of education among participants provided insights into how individuals with different educational backgrounds perceive and experience suffering from sleeping sickness and its consequences. It also shows how education, a key determinant, shape the participants experience of risk of contracting sleeping sickness. Consequently, the varying education levels among participants shaped the occupations and socio-economic positions of my study participants. For example, of the total number, only the five key informants were employed in formal sectors such as healthcare, CSO, conservation and public service, while the rest of the participants were self-employed as small-scale farmers who also engaged in other economic activities such as charcoal burning, and timber harvesting. The varying occupation status of the participants added perspectives on their economic vulnerability and its implications on the risk of contracting sleeping sickness among participants.

The men had varied education levels ranging from no education to those who have done secondary education but could not complete the level due to several reasons (Ministry of Education, 2022; UNICEF & Ministry of Education, 2014; Zambia Statistics Agency, 2025). One common reason for not completing any level of education was lack of resources and support, except for Mako, a 58-year-old Chewa man living in Malama who dropped out of school because he believed he was not good enough and because he fought with other pupils as illustrated in the following excerpt.

“I never really had the brains to learn...well am not sure. For example, if a friend refused to show me his answers, I would grab his book and beat him badly, so I was expelled from school.” Male aged 58yrs, Malama-IDI

Similar to men, women had varied education experience and achievements. None of the women I interviewed had completed secondary education, with some women having not attended school at all (n=4) and many others having attained grades two to seven (n=12), grade eight (n=2), and grade nine (n=3).

Although the participants' low levels of education limited their awareness and understanding of the nature and dynamics of diseases such as sleeping sickness, their indigenous knowledge of zoonotic diseases and treatment revealed the existence of indigenous methods and practices that leverage their understanding of local ecology and herbal medicines. It was common practice among Kunda and Chewa participants to rely on indigenous knowledge to manage disease symptoms before and after seeking medical care. For example, during one interview with Mike, a 67 year old Chewa man of Nsefu, I asked him to explain how they manage illnesses before and after visiting the clinic, the following excerpt illustrates the participant's understanding and reliance on local ecology and herbs.

Ok, so we use a lot of herbs to help us aside from the conventional medicine. For example, for fevers, stomach pain and body pains, we use *mioka* (*mululwe*), and *chikhoswe*.... You take the leaves of that same tree and boil them in water; you sieve the leaves out and store the water in a bottle. If you take the water on the bottle lid, you will be fine from any ailment but to be honest with you, these herbs are very bitter but helpful. Male, 67-year old Chewa, Nsefu- IDI

The above suggests that despite the low levels of formal education among farmers, Kunda and Chewa farmers relied on their indigenous knowledge and understanding of causes of illness and its treatment to manage and treat diseases. Therefore, as I will explain in the next chapter, low levels of formal education among the Kunda and Chewa participants ultimately

shaped their perception, use and response to modern healthcare services to manage disease symptoms.

4.2.6 Livelihoods

On the question of how the Kundas and Chewas earn a living, Banda et al. (2013) argue that Kundas, for example, have mostly practiced fishing, and hunting as their main livelihood activities. As emphasised by some Kunda participants, farming and livestock keeping have not been part of their livelihood activities due to environmental conditions that shaped the types of livelihoods they practiced. Consequently, most Kunda farmers I interviewed relied on hunting, seasonal jobs in safaris and lodges because of the high density of tsetse flies, high temperatures and seasonal droughts and flooding, which hindered their ability to develop their livelihoods based on livestock keeping and agriculture (Anderson et al., 2015; Buyst, 1977). In contrast, the Chewas have lived in areas which, until in recent past, have been conducive for farming and livestock keeping. As noted by Yoshida (1992), the area occupied by Chewas in Zambia receives an average of 1000mm of rainfall annually between November and April. With low density of tsetse flies in these areas, Chewas were able to practice subsistence farming and grow maize and kept livestock such as cattle (*ng'ombe*) and small ruminants such as goats (*mbuzi*), pigs (*nkhumba*), and fowls such as chickens (*nkhuku*) (Yoshida, 1992). Although Chewas hunt and forage, farming and livestock keeping served as their main source of livelihood and income in contrast to Kundas whose livelihood depended on wildlife. This implies that while Kunda and Chewa farmers interact with the natural environment to earn a living, the degree and frequency differed because of variations in their primary systems of livelihood. For example, because Chewa farmers kept livestock, they were at higher risk of some zoonotic diseases compared to Kundas who did not keep livestock. Similarly, because the Kundas engaged in charcoal and timber harvesting, they were at higher risk of contracting sleeping sickness and malaria due to their exposure to habitants of diseases vectors and the natural environment.

Men and boys: Herders, hunters, cultivators, timber, and charcoal producers

While most men have lower primary education, they exhibited understanding and knowledge of various issues regarding their livelihoods and possible challenges. This is reflected in their understanding of crop farming and knowledge in livestock keeping techniques and management which have been passed from generation to another through familial and communal ties. Furthermore, their interaction with government extension and veterinary officers contributes to their knowledge in various aspects of agriculture. Consequently, the men I interviewed are not involved in any formal occupation except for part-time jobs with

researchers, safari companies, licensed hunters, and timber producers. My observations and analysis further reveal that men who identify as Chewa are mostly involved in crop farming, livestock and chicken keeping. Similarly, men who identify as Kunda also engage in crop farming and chicken keeping but rarely keep livestock. I will return and elaborate these observations later in this chapter.

Women and girls: Caregivers, cultivators, firwood and water collectors

However, despite these levels of education, only a few of the women participants were able to write and read. As a result, like the men, none of the women participants worked in any formal institutions, partly due to their lack of formal education and lack of job opportunities within the area. Therefore, women in this study are housewives except for those who are divorced or widowed. Consequently, their primary source of livelihood is agriculture. They work together with their partners to grow crops and earn a living. However, observations also show that some women also engage in other small business activities such as brewing and selling local whisky called *kachasu*. Others bake fritters and scones while others such as Anna, a 26 year old Chewa single mother of two boys is involved in illegal selling of petrol to villagers that have motor bikes. Furthermore, others such as Milika, a 39 year old Kunda woman in Chilembo and Lucy, a 40 year old Mambwe woman in Kadeweale have served as community health volunteers through which they earned some income which was invested in small ruminants and chickens respectively (Sumy et al., 2021). Observations further revealed that almost all women had at least a chicken and small ruminant (n=16) in their homes, only a few kept cattle (n=3). I will return to this matter the following chapter.

The South Luangwa National park's proximity to human settlements provides a platform which indirectly increases the possibility of human animal conflicts and transmission of zoonotic diseases (Dzangirai et al., 2017). As other researchers, such as Alderton et al. (2016), Franco et al. (2014) and Grebut et al. (2001), have found, fields, rivers and bushes where the Kunda and Chewa farmers cultivate, fetch water, collect firewood and forage, respectively serve as the primary points of exposure to tsetse flies in addition to tsetse fly bites within their villages. This suggests that the Kunda and Chewa farmers' risk of contracting sleeping sickness is primarily dependent on the geographical location, environmental conditions, and the livelihood activities that they engage in such as farming, herding, and gathering firewood (Alderton et al., 2016; Franco et al., 2014; Munang'andu et al., 2012). However, although environmental conditions are important determinants of risk, this study's evidence further suggests that gender intersecting with the participants' individual characteristics such as level of education, culture and religion, marital status, role

socialisation, ethnicity, and economic resources compounded the risk and experiences of sleeping sickness among the farmers I spoke to as further elaborated below.

However, despite the low levels of formal education and literacy, the Kunda and Chewa farmers I interviewed exhibited knowledge and understanding of various aspects of their livelihoods (agriculture, livestock keeping), health (human and livestock disease management) and environment. For example, among Chewa farmers, more men than women exhibited knowledge and understanding of livestock, and agriculture techniques (Okwa, 2007). Similarly, more Chewa men than Kunda men exhibited understanding and knowledge of different agriculture techniques, livestock keeping, zoonotic diseases and their management (Majiwa et al., 2024). Similar differences were observed between Kunda and Chewa women with more Chewa women having an understanding and knowledge of farming techniques, livestock diseases and management than Kunda women.

Turning to the farmers' economic position, and education level, none of the Kunda and Chewa farmers, men and women, I spoke to were engaged in formal employment. As earlier highlighted, almost all farmers were primarily involved in agriculture, timber and charcoal production. In addition to agriculture, some participants engaged in grocery business after harvesting as part of their livelihood. Analysis of the participants' accounts further shows that Kunda and Chewa farmers' economic position intersected with their level of education and gender to create another level of vulnerability to risk of sleeping sickness. While the farmers' utilisation and dependence on natural resources maybe perceived as embedded in their culture and traditions (Banda et al., 2013), my findings suggest that existing systemic inequalities in the distribution of resources and economic development is a significant factor contributing to the Kunda and Chewa farmers' dependence on the natural environment for a living. Furthermore, this evidence suggests that the farmers' constant interaction with the natural environment contributes to their continuous interaction with wild animals and disease vectors such as tsetse flies which threaten their health and socioeconomic wellbeing (Munang'andu et al., 2012). This finding implies that while the Kunda and Chewa farmers may perceive interacting with environment as dangerous, the need to survive and earn a living supersede the perceived danger, leaving the farmers with no choice but to live within these areas (Dzingirai et al., 2017a). Furthermore, ethnic based livelihood practices by certain ethnic groups such as livestock keeping, hunting, timber and charcoal production increased their risk of contracting some zoonotic diseases (Ochola et al., 2021).

Although exposure and risk of contracting sleeping sickness is generally high among the participants I interviewed, my findings show that the risk was high among the participants

who kept livestock, harvested timber and produced charcoal (Nambala et al., 2022). This study's evidence suggests that although Kundas, and Chewas I interviewed engaged in different livelihood activities, consistent with Ochola et al.'s (2021) findings, the respective economic activities increased the farmers' risk of contracting sleeping sickness and other vulnerabilities such as human animal conflicts (HACs) but with varying degrees. As will be explained in the next chapter, possession of productive assets such as cattle by farmers contributed to an increase in the level of interaction between farmers and disease vectors such as tsetse flies transmitting sleeping sickness. This suggests that although all participants engage with the natural environment, their social and economic position, livelihood activities and ownership of productive assets such as cattle determined the frequency of interaction with disease vectors such as tsetse flies and mosquitoes transmitting disease such as sleeping sickness and malaria (Scambler, 2018).

These findings indicate that Kunda and Chewa farmers' background characteristics intersect with the existing inequalities in policies and structures to produce their current experiences of HACs and risk to sleeping sickness. This evidence further reveals that the farmers' suffering and vulnerability to NTDs and HAC is a reflection of structural violence which also perpetuates health disparities and reinforces the farmers' experience of ill health and poverty (Farmer, 2004). As a result, the high levels of poverty and continued inequality in access to economic opportunities and development among Kunda and Chewa participants contribute to the shift in their attention from long-term health and wellbeing to prioritising their immediate need to earn a living and survive (Farmer, 2004). Thus, the risk of sleeping sickness among participants I interviewed in Mambwe district reflect the systemic economic marginalisation of rural communities which have inadvertently shaped and contributed to the increased risk of sleeping sickness and other NTDs within the three chiefdoms studied.

However, the changing environmental conditions, migration and increasing population have contributed to the introduction of livelihood activities such as agriculture and livestock keeping in the Luangwa valley (Anderson et al., 2015). Increased clearing of vegetation for settlement, economic and agriculture purposes by farmers has contributed to destruction of wildlife habitats and biodiversity, contributing to the changing ecological outlook of the Luangwa valley (Dzangirai et al., 2016). Consequently, while Kunda participants have been involved in hunting and foraging from time immemorial, their livelihood activities have been changing over time because of their interaction with agriculture and livestock keeping ethnic groups such as the Chewas, as illustrated by Agogo in the following excerpt.

Our lives have been dependent on the national park (hunting and other part time jobs). But we are now learning from the Chewas how to practice agriculture on a larger scale and how to keep livestock. Male-83yrs, Kunda gatekeeper, IDI, Malama Chiefdom

Agogo's explanation suggests that while the Kundas have relied on other livelihood activities for survival, their interaction with ethnic groups such as the Chewas who keep livestock and practice agriculture introduced Kunda farmers like Agogo to subsistence farming involving growing various crops and keeping livestock. Agogo's words may also imply that, while previously it was a challenge to keep livestock and carry out agriculture activities in Mfuwe due to unfavourable conditions, the changing environmental conditions have made it possible for Kundas and Chewas to practice the livelihood activities which were previously not possible to practice due to unfavourable environmental conditions. Similarly, strong anti-hunting and poaching activities and enforcement by law enforcement agencies might also have contributed to a change in livelihoods. Therefore, as I will further explain in later chapters, changes in land use and livelihoods practiced by farmers in GMAs contribute to altering the distribution of vectors such as tsetse flies and mosquitoes contributing to increased risk of contracting sleeping sickness and malaria (Anderson, 2016; Dzingirai et al., 2017a).

Summary

The above categories of community participants and their characteristics reflect how their ages, education, marital status, faith, and occupation shape their experiences of risks, health challenges and how their narratives and perception of sleeping sickness are constructed. The findings also show that limited education attainment and other associated inequalities among men and women have contributed to high levels of poverty in the three chiefdoms because it has limited their ability to engage in better income generating activities apart from subsistence crop farming and livestock keeping. Furthermore, the participants' livelihood activities which involve interaction with their livestock, the bush and farms reflect how interdependent community life is with the surrounding environment and animals and potential for disease transmission. I expand on this interaction on the three interfaces later in this chapter.

So far, I have argued that various intersecting background characteristics of Kunda and Chewa farmers create unique vulnerabilities to diseases and overall experience of vulnerability and suffering to challenges such as HAC in the GMA. Therefore, while several other structural factors such as lack of active screening for sleeping sickness and lack of

active sensitisation campaigns shaped participants' perception of the risk of contracting the disease, their background and individual characteristics influenced by the existing systems of inequality worsened their experience of vulnerability to the disease and suffering from its associated consequences. For example, limited employment opportunities and increased poverty constrained the participants' ability to access healthcare resources to help them reduce their vulnerability to illnesses such as sleeping sickness. Coupled with consequences of climate change such as flooding and droughts, the participants' economic status and food security are further affected leaving them vulnerable not only to the risk of sleeping sickness but also to food insecurity, and hunger which reinforce their vulnerability to ill health.

The participants' situation reflects a form of structural violence where Kunda and Chewa farmers' area of residence, individual and social characteristics shaped their increased experience of health risk (Farmer, 2004). Furthermore, drawing on Crenshaw's (1989) intersectionality theory, the varying individual background characteristics of the Kunda and Chewa participants intersect with the existing systemic inequalities in access to resources and economic development to shape their experience of suffering and risk of sleeping sickness. For example, as other researchers such as Banda et al. (2013), have found, low levels of education in Mambwe district undermines health literacy which inadvertently contribute to high unemployment, poverty, and income inequality. Consequently, the existing gendered disparities in economic resources among Kunda and Chewa farmers contribute to disparities in access to education which perpetuates gendered cycle of vulnerability and poor health outcomes between men and women in Mambwe district (Crenshaw, 1989).

While the participants are able to survive the unfavourable environmental conditions, their experiences are characterised by challenges in accessing and meeting their basic needs. As Galtung (1969) and Farmer (2004) have argued, the Kunda and Chewa farmers' ability to earn a living is impeded by the existing policies governing lives in GMAs and distribution of resources between rural and urban areas. These systems and structures of governance and resource distributions hinder the emancipation of the farmers from poverty and vulnerability to diseases by failing to provide the necessary resources such as education, health facilities and economic opportunities which would enhance the health and socioeconomic wellbeing of the farmers. In the words of Mills (1959), the high levels of illiteracy among participants, high unemployment and pervasive poverty are not merely failings of individual Kunda and Chewa farmers in Nsefu, Malama and Mnkhangya Chiefdoms but reflect deeply rooted systematic inequalities and economic policies that focus more on urban than rural development. These systemic inequalities in health, education and economic opportunities

coupled with the farmers' individual characteristics such as gender, marital status, age, and poverty, the lack of education and disproportionate distribution of healthcare facilities constrain their access to preventive measures such as vector control and screening services contributing to increased risk of contracting sleeping sickness and other NTDs.

Key informants: Veterinarians, medical practitioners, conservation and wildlife specialists

Key informants included individuals with different characteristics. Although I had casual conversations with several gatekeepers within the district who provided very important insights about the community, I focused on five key informants (n=5) within the district who are directly involved in issues related to community health, conservation, wildlife and sleeping sickness. These key informants were aged between 28 years and 60 years old. These are professionals in fields of human and animal health, wildlife conservation and management. Of the five, four (n=4) were men, and one (n=1) was a woman. The only woman key informant, whom I will call Gertrude, had a medical background and was responsible for managing one of the clinics in Mfuwe. She was Tonga by ethnicity, married, in her early thirties and had tertiary education. On the other hand, the four men were aged between 35 and 59 years, who were married, with tertiary education, and were Christians. Of the four men, two were veterinarians while the other two were experts in the fields of human medicine and conservation. These key informants are occupying different positions of power within their organisations. For example, Gertrude, a catholic and a mother of one, was responsible of managing the day to day administrative and operations of health facility where she worked. Similarly, other male participants were involved in more general administrative and planning work. While the other four key informants were government workers whose authority was drawn from the guidelines put forward by the line ministries under which they operated, one participant, who I will call Geoffrey (38 years) worked for a local nongovernmental organisation within the fields of wildlife, conservation and veterinary medicine whose focus was based on the NGO's vision and mission.

Although this gender distribution among key informants was expected, it confirms the argument by Collins (1990) and Keohane (2020) that positions of decision making and power are mostly held by men which has an implication on providing and developing gendered services that consider the gendered differences in the experience of healthcare and risk to environmental hazards such as vectors and wild animals.

4.3 Community construction of sleeping sickness

Within Kunda and Chewa culture and religious beliefs, diseases are perceived as either *matenda yaku bantu* (illnesses from humans-sorcery), or *matenda yakwa Mulungu* (illness from God). Although both types of diseases can be treated, Yoshida (1992) notes that among the Chewas, only illnesses from God can be easily managed and treated without consulting witchdoctors. This implies that all illnesses that cannot be managed at home *ni matenda yaku bantu* (illnesses from humans-sorcery). Consistent with Yoshida's (1992) findings, my findings show that among Kunda and Chewa farmers, despite some diseases being understood as being caused by pathogens, they still believed that these were caused by witchcraft or other supernatural causes. Similar to the findings of Yoshida (1992), accounts by some Chewa farmers in this study show that *matenda yakwa Mulungu* were easy to manage and could be cured by going to the clinic or using herbs within the household. In contrast, *matenda yaku bantu* could not be managed by the clinic as illustrated by Mako, a 58 year old Chewa farmer of Malama Chiefdom, that if an illness cannot be managed at home or at the clinic, it suggests that it was caused by witchcraft. While Mako's account shows how witchcraft and sorcery within the community contributed to disease outcomes, it also reveals the duality of constructing illness among Kunda and Chewa farmers.

If you hear about villages where these things [witchcraft] happen, this is the village... I have seen a lot, but I cannot openly say. But strange diseases have been seen. There is a more recent case.... But we are not sure if that person will survive. The way that disease started is simple, he complained of body weakness. We told him to go to the clinic and get checked, but the clinic did not find him with malaria, so he was given painkillers... To our shock, his body just started swelling. They have now moved him out from the clinic and is now at a traditional clinic. Male 58 years, Chewa, IDI-Malama

Mako's explanation provides insights into how illness and diseases are traditionally and medically constructed within his village. Mako's emphasis on the phrase *this is the village* implies the perceived significant role of witchcraft in causing illness. Although medical care is mentioned by Mako, his emphasis on witchcraft indicates that because *it is the village*, any illness is first perceived as being caused by witchcraft. This also implies that any disease not diagnosed at the clinic is caused by witchcraft, solidifying the farmers' belief that diseases from people are not easily diagnosed or treated at home or at the clinic. Mako's account aligns with the findings of Fottrel et al. (2012) in rural South Africa where they investigated the notion of bewitchment as a lay reported cause of death. Fottrel et al. (2012) established that although medical diagnosis is considered, it is rarely seen as the main cause

of diseases. Similarly, although Mako states that the patient had no malaria, he did not know whether the patient had other diseases such as sleeping sickness which could not be diagnosed using malaria testing tools. This suggests that lack of capacity to correctly diagnose diseases at the health facility indirectly contribute to their mismanagement and reinforces reliance on unclear alternative methods of diagnosis and treatment. This finding also implies that lack of capacity to correctly diagnose diseases including HAT, prevents health practitioners from developing the ‘diagnostic flex’, which develops from knowledge acquired from practice and experience (Palmer et al., 2020).

These findings align with research by Fottrell et al. (2012), who found that participants, such as Mako, mostly pointed to witchcraft despite the presence of a medical diagnosis of diseases. In my study, analysis of the Kunda and Chewa farmers’ accounts reveals a similar pattern where the farmers’ discussion of the causes of illness was based on a dual system which combined the medical and traditional explanations of causes of illness with more emphasis on traditional approaches (Fottrell et al., 2012). These findings suggest that while microorganisms cause diseases such as sleeping sickness, individuals with different cultural and religious beliefs construct the causes and interventions to these diseases differently. This implies that individuals’ vulnerability and risk to NTDs such as sleeping sickness is linked to several social, cultural and structural factors which should be considered when developing interventions to control and prevent its occurrence (Amzat & Razum, 2014).

4.3.1 ‘A death without sickness: Kunda and Chewa construction of illness’

To further illustrate how the Kunda and Chewa culture and religious beliefs shape their perception of illness and its causes, I witnessed a death which further provided insights into the community’s perception of diseases and death. This incident happened in the second week of June 2023 in Mfuwe. It was Friday, 16th June 2023, when a Kunda young man aged between 25 and 35 years collapsed and died. As the following excerpt from a walking interview with a timber harvester shows, the young man was hallucinating and shouting names and running away from *invisible people* who were chasing him. He later collapsed and died near a named lodge which belonged to a known family. Although this death was received with a lot of shock among community members, the conversation was focused on how a person who was *never sick* could die.

It was shocking, the young man was just ok but today, *wafwa chosalwala*, translating to ‘he is dead without getting sick,’ we are very shocked... Male, 47 years, Mfuwe, WI

Rather than attribute this to a biological cause, community members, including the person who narrated the event to me, suspected that it was a case of *unfiti* (witchcraft) because it is not possible for a ‘young’ person to die without getting sick. As everyone else expected, the deceased’s family accused another family of causing the death, and this case was reported to the head person. After heated deliberations, the two families agreed that the burial should go ahead on Saturday, 17th June 2023. On Saturday morning, however, the funeral became more complicated as the accused family counter sued the family of the deceased after it was established that the cause of death was not bewitchment as earlier concluded, rather, the deceased ‘transformed’ into a ‘wild animal,’ a possible indication that the deceased practiced witchcraft. As Yoshida (1992), an anthropologist working among the Chewas, established, transformation into wild animals, such as those that are predatory and snakes, was associated with individuals who practiced witchcraft during their lifetime. For this reason, the deceased’s family were not willing to take the matter further. However, the accused family wanted the matter to be taken to court for defamation.

Although I did not witness the incident first hand, analysis of accounts of Kunda farmers who witnessed the event first hand reveals the community’s strong belief in alternative causes of illness and death. While this death could have been caused by several other factors, the mere fact that the victim was not sick made the community to conclude that it was caused by *unfiti* (witchcraft). While this might be true, other biological causes could be responsible. As observed by Palmer (2020) among the Madi and Dinka people in Sudan, hallucination and evil dreams were among symptoms of sleeping sickness which prompted health seeking. However, in the Kunda and Chewa communities, such symptoms signalled presence of evil spirits and witchcraft, which contributed to reliance on traditional medicine (Bruwer, 1958; Mkunsha, 2014; Yoshida, 1986). This behaviour by farmers reveals the strong influence of their cultural and religious beliefs on the causes of illness and death, which in turn, influence narratives and perception of illness and sudden deaths. Therefore, although the death could have been due to several biological complications including sleeping sickness (Palmer, 2020), emphasis on sorcery and witchcraft in diagnosing causes of serious illness and deaths among Kunda and Chewa farmers overshadowed the alternative causes of the death ‘without sickness’ (Yoshida, 1986, 1992).

However, while the belief in witchcraft as the cause of illness and unexplained death is common, Kunda and Chewa farmers in the three chiefdoms still believed that some diseases such as sleeping sickness and malaria were caused by pathogens. While participants interviewed acknowledged the role of pathogens in causing diseases, they still rely on alternative methods of managing diseases such as the use of herbs and reliance on traditional

healers as their first line of treatment of any disease symptom (Bukachi et al., 2009; Maluma et al., 2017; Odiit et al., 2004). Consequently, while the farmers recognised the role of medical care in disease diagnosis and treatment, Kunda and Chewa farmers' prioritisation of herbal medicine to manage various disease symptoms, including possible cases of sleeping sickness, reflects the existing cultural and religious narratives about illness being caused by witchcraft and evil spirits (Yashida, 1992).

As observed by Douglas (1992), my findings show that the cultural ideas and beliefs Kunda and Chewa farmers receive within their contexts shape their perception of disease origins and how to manage them. This finding implies that while medical interventions may be effective in diagnosing and treating diseases such as sleeping sickness, reliance on indigenous knowledge and methods of diagnosis and treating diseases further contributes to continued risk and vulnerability to sleeping sickness. Therefore, this finding suggests that the construction of multifaceted diseases such as sleeping sickness should not be limited to only one dimension but include other dimensions in order to have a holistic understanding of their nature. While sleeping sickness affects the biological systems of the victims, the causes and consequences are rooted in the social, economic and political dimensions of the societies in which patients live. This evidence therefore shows that while professional experts may perceive sleeping sickness in certain way, farmers' construction of the same disease is different resulting in different approaches to management and control. Consequently, I contend that construction of what sleeping sickness is should not solely be based on biomedical construction but also include other nonbiomedical dimensions of the disease. Doing so contributes to understanding the subjective aspects of sleeping sickness and indigenous knowledge contributing to an effective framework for managing NTDs.

4.3.2 Gender expectations and risk of contracting sleeping sickness

While all Kunda and Chewa farmers I spoke to describe their experiences with tsetse flies in their villages and areas where they carry out their economic activities, almost all suspected cases of sleeping sickness witnessed by participants were in men and not women. For example, the following excerpt from Mevy, a 48 year old Kunda widow of Nsefu reveals that known cases of suspected sleeping sickness were among men.

I also know of another man who died of the disease. He was mostly sick, and his appearance was that of a person who is not feeling too well. He looked weak and pearl. Every time he was taken to the hospital or clinic, they could not find what the problem was for him. Female, 48 years, Nsefu, IDI

Although these findings are consistent with the findings of Mwiinde et al. (2022) and Nambala et al. (2022) who found that more men than women were diagnosed with sleeping sickness in Zambia and Malawi, respectively, my findings may imply two things. Firstly, my findings and those of Mwiinde et al. (2022) and Nambala et al. (2022) suggest that men are more exposed to the risk of contracting sleeping sickness than women because of their engagement in herding cattle, producing charcoal or harvesting timber (Franco et al., 2014). Secondly, these findings may also suggest that although women are similarly exposed to the risk of contracting sleeping sickness through outdoor activities such as collecting firewood, farming and fetching water, the gendered differences in access to healthcare and medical care between men and women may indirectly shape the diagnosis of potential cases of sleeping sickness in women resulting in possible under reporting of cases. In addition to that, lack of early and effective diagnosis for sleeping sickness in Mambwe contribute to the unclear disease burden in men and women. Therefore, the noted variations in cases may not imply that men are more susceptible to sleeping sickness than women due to biological makeup, instead, the findings suggest that differences in culturally determined gender roles performed in areas where the risk of contracting sleeping is high increase the risk of contracting the disease by farmers who perform these roles regardless of sex and age (Franco et al., 2014; Zoller et al., 2008). This evidence suggests that cultural expectations associated with roles women and men play inadvertently shape their experience of vulnerability and risk of contracting sleeping sickness which is reflected in gendered variations in the reported cases in Zambia (Mwiinde et al., 2022) and other countries such as Malawi (Nambala et al., 2022).

Drawing on Goffman's (1959) writing on *The Presentation of Self in Everyday Life*, the above findings suggests that due to the need to fulfil the social expectations of the roles associated with their gender, Kunda and Chewa farmers perform these roles regardless of the conditions and risks associated with specific tasks in order to maintain appropriate social order. This implies that in rural communities of Mfuwe, every time a woman, man, and child engage in various daily chores and activities, they are merely presenting a performance which 'ascribes to the official accepted standards' (Goffman, 1959, p.35). This means that gendered division of labour fulfil this societal value regardless of the risks associated with performing such roles. Therefore, it can be argued that the internalisation of these socialised values about roles impacts the Kunda and Chewa farmers' perception of disease risk and health seeking. This implies that incidence of diseases such as malaria and sleeping sickness within their communities is not merely the farmers' exposure to diseases causing pathogens but rather a culmination of intersecting cultural, economic, and social factors and practices

which influence what farmers do, where, when and the frequency of engagement. This evidence shows that while the risk of contracting sleeping sickness may be high within Mambwe district, gendered differences still persist due to differences in roles and duties performed by the farmers. This implies that gendered roles and age specific tasks influence engagement with environmental conditions, which in turn increase the farmers' interaction with disease vectors such as tsetse flies and the risk of contracting sleeping sickness.

Similar to Douglas and Wildavsky's (1982) conclusions on risk, my findings suggest that participants' cultural and religious beliefs and indigenous knowledge of illness and disease influence both their perception and social response to illness. Shared understandings of risk lead participants to believe that any illnesses that are not diagnosed or treated at the healthcare facilities are caused by witchcraft or spiritual attack. Ultimately, my findings suggest that the lack of active medical diagnosis of sleeping sickness actively reinforces local, non-biomedical conceptualisations of the cause of illnesses, reinforcing participants' reliance on traditional healers for diagnosis and treatment (Douglas and Wankisky, 1982). Therefore, my findings suggest that understanding of diseases such as sleeping sickness within a rural community rich in culture and religious beliefs requires more than biomedical explanations of disease risk and vulnerability. While specialist knowledge is important, non-specialist knowledge from communities can deepen understanding and inform the development of specific disease interventions (Russell & Babrow, 2011). Contextualising social factors helps to understand what puts people such as the Kunda and Chewa participants of Mfuwe at risk of NTDs such as sleeping sickness and how gender intersects with social factors to shape their experience of suffering associated with sleeping sickness. These findings shed light into the role played by structural violence in reinforcing the reliance on alternative methods to disease diagnosis and management. The lack of diagnostic capacity and credible information on the nature of sleeping sickness and the consequences of tsetse fly bites and untreated sleeping sickness among farmers inadvertently contribute to the development of narratives that put more importance on traditional methods of disease management.

4.4. Regime truth and construction of risk of contracting sleeping sickness in Mfuwe

So far, I have focused on how individual characteristics such as gender, ethnicity, level of education and economic position intersecting with social, cultural, religion and institutional factors influence participants' risk, vulnerability and suffering from sleeping sickness. I have also shown that both Kunda and Chewa farmers' construction of illness and diseases is rooted in their culture and religion and affect effective diagnosis management of sleeping sickness. Here, I explore how the risk of contracting sleeping sickness and disease vulnerability in

Nsefu, Malama and Mnkhanya Chiefdoms reflect inequalities in power. Similar to Asaaga et al. (2021) in their study focusing on the role of disease information in shaping the adaptive capacity of smallholder farmer and tribal groups to Kyasanur Forest Disease (KFD), these imbalances have continued to shape perception, response and narratives on NTDs. This, in turn, influences the unequal distribution of economic and health resources between urban and rural communities and inadvertently reinforce vulnerability to NTDs and health (Zyambo et al., 2012). In addition to resource inequalities, my interviews with key informants from the human and veterinary aspects of medicine further show a narrative which categorises diseases according to their economic value to the nation. For example, one key informant explained that existing policy categorises zoonotic diseases like sleeping sickness and rabies as ‘management diseases’ while others such as anthrax and malaria are considered as ‘diseases of national economic importance’. As shown in the following excerpt from my interview with Ben, a 58 year old vet, the two types of disease categorisation are prioritised differently with more attention to diseases of national economic importance.

... disease control in Zambia is in two parts; there is diseases of national economic importance and management diseases. So, when it comes to control, the thrust is on diseases of national economic importance. Tryps (*nagana*) is a management disease... but not disease of national economic importance. Male-58 yrs, KII- Lusaka

Ben’s explanation highlights the existing policy informing decisions on disease control and management Zambia. Categorising diseases as either ‘management disease’ or ‘disease of national economic importance’ reflects institutionalised biases in disease management and response which reinforce the neglect of management diseases. As a result, existing interventions and narratives on disease control are based on biased policy frameworks which inadvertently contribute to the neglect of NTDs such as trypanosomiasis among farmers in rural areas such as Mambwe district. This neglect contributes to low investment in control and diagnosis of ‘management diseases’ such as sleeping sickness leading to farmers’ limited knowledge of the disease’s risk while increasing their vulnerability and suffering from direct and indirect consequences of NTDs.

Therefore, although several intersecting factors such as gender, ethnicity, poverty, and area of residence may influence perception of risk of sleeping sickness among Kunda and Chewa farmers; my findings show that existing policy on disease control and systems that inform knowledge creation, communication and language perform a significant role in the development of narratives professional experts, medical practitioners and individuals have about risk of contracting sleeping sickness (Foucault, 1978). This suggests that risk

construction among Kunda and Chewa farmers is not only influenced by the nonlinear interaction of individual characteristics and cultural, religious and institutional factors, but also by prevailing systems of knowledge and communication developed by professional experts and policies (Russel & Badrow, 2011). While farmers' accounts show the role of medical diagnosis in informing their narratives about risk and treatment of diseases, feedback from the medical practitioners on sleeping sickness is based on prevailing narratives informed by biased knowledge frameworks and communication of the risk of the disease. For example, there is a narrative that tsetse flies in Mnkhanya and Mfuwe around Kakumbi do not transmit the pathogens causing sleeping sickness. This narrative has contributed to a relaxed approach to diagnosis and control of sleeping sickness in Mfuwe.

Although all participants were worried of tsetse flies, their worry was limited to the painful bites and making their livestock sick, thin or reducing milk production. None of the Kunda and Chewa farmers I interviewed were worried of getting sick after getting a tsetse fly bite. Coupled with low levels of education and limited knowledge of the nature of sleeping sickness, Kunda and Chewa farmers were more likely to underestimate the symptoms and severity of the diseases. For example, while I was worried and feared being bitten by tsetse flies, Kunda and Chewa farmers did not perceive a tsetse fly bite as a threat to their health because based on their experience, previous bites did not result in sickness. This finding is similar to conclusions by Davison et al. (1991) in their study on risks people perceived were associated with developing coronary heart disease. Davison et al. (1991) concluded that people based their risk of experiencing coronary heart diseases based on their own experiences.

While this observation may suggest lack of knowledge and awareness among participants, it also reflects institutionalised inequalities in access to health resources such as information which limit the participants' awareness of diseases and overall perception of diseases and health seeking (Young, 2004). Coupled with lack of diagnostic capacity to screen and diagnose sleeping sickness by rural healthcare facilities, Kunda and Chewa farmers are faced with diminished motivation to seek healthcare which in turn increase their vulnerability to diseases such as sleeping sickness and malaria within the farming communities (Brown, 1995; Conrad and barker, 2010). Therefore, Kunda and Chewa farmers, men and women, are faced with the reality of lack of awareness and information on the nature of sleeping sickness and the available services. Limited access to healthcare due to poverty lowers the participants' perception of potential symptoms of sleeping sickness leading to delayed detection and treatment of possible cases of sleeping sickness especially among Chewa farmers who have limited experience and knowledge of the disease.

Therefore, it is important to note that narratives on sleeping sickness play a significant role in shaping how risk is perceived and constructed by the participants. Russell and Babrow (2011) argued that through social discourse, conception of risk pervades social experiences. As illustrated below by a 32 year old female medical expert during a key informant interview, narratives that tsetse flies in the Luangwa valley are not infectious largely shaped how medical practitioners perceived and constructed risk of contracting sleeping sickness.

When I came here, I was scared of tsetse flies, but I was told not to worry because they tested the tsetse flies in the Luangwa valley, and they found that these are safe.

Female 32yrs, medical worker, KII-Mfuwe

This narrative inadvertently creates a perception of low risk among health workers and community members (Figure 4). Furthermore, this narrative contributes to the omission of sleeping sickness on the suspicion index leading to misdiagnosis and missing of possible cases of the disease (Mwanakasale et al., 2013; Mwanakasale & Songolo, 2011). This implies that although participants may experience symptoms of sleeping sickness based on their own daily experiences and interactions with tsetse flies, their reliance on expert knowledge and diagnosis which, as noted by Giddens (1994), is based on available linguistic resources and narrative frameworks, results in omission of the disease due to existing narratives suggesting low risk of sleeping sickness. Consequently, as argued by Foucault (1978), such narratives in turn shape discourse and policy which contribute to reduced official response to NTDs, worsening the participants' vulnerability and suffering from the consequences of undiagnosed and treated cases of sleeping sickness.

The figure below shows awareness posters. While the posters show sensitisation on malaria, voluntary male circumcision and the polio vaccine, no posters were seen sensitising patients on sleeping sickness or available services for those with symptoms. This omission of sleeping sickness points to the influence of institutional and policy biases in communication and control of management diseases. This is evidenced by the participants' poor access to healthcare and information in all the study sites increasing their vulnerability and risk to diseases. These findings suggest that while perception of risk and experience of social suffering is partly due to individual characteristics at a micro level, social structures and institutions operating at a macro level are largely responsible for the experience of vulnerability to sleeping sickness and suffering by Kunda and Chewa farmers.



Figure 4: Health posters and Malaria statistics

However, even though the narrative that the tsetse flies are not a source of worry is common among some key informants and participants I interviewed, accounts from other key informants revealed that three cases of sleeping sickness were recently (2019 and 2020) diagnosed within Mambwe district, a woman, a child and a man as illustrated in the following excerpt from another key informant.

Cases are rare but more recently, it should be 2019 or 2020, the Kakumbi research station detected three positive cases of human African trypanosomiasis. Male 59yrs, KII- Mambwe district

Although such cases may require further investigation in communities where the patients live, reliance on policies and guidelines based on knowledge and evidence which support the existing narrative that sleeping sickness is not risky in Mfuwe (Mwiinde et al., 2022) thwarts such efforts. Consequently, my findings show that the ongoing narrative about sleeping sickness has inadvertently contributed to low suspicion index by health personal, coupled with the lack of diagnostic capacity, the narrative that sleeping sickness is not a problem in Mambwe district persists and is reinforced. As illustrated in Figure 4 above, the narrative about sleeping sickness also influences how medical practitioners package their services to communities, the kind of information and awareness to provide, and resources relevant to Kunda and Chewa farmers' protection against tsetse flies and sleeping sickness (Mwanakasale and Songolo, 2011; Odiit et al., 2004).

However, current evidence on sleeping sickness in Mambwe district suggests that although sleeping sickness might be perceived as a low risk disease due to the presence of non-infectious tsetse flies, tsetse fly bites remain a source of risk due to the presence of human infective trypanosomes in some reservoirs (Lisulo et al., 2024). For example, a study by Lisulo et al. (2024) on domestic dogs as reservoirs for African trypanosomiasis in Mambwe district found that while dogs acted as reservoirs of animal African trypanosomiasis (AAT), they also served as active carriers of human infective trypanosomes. This finding shows that although the cases of sleeping sickness in humans appear low, the risk remains high. This evidence may suggest that while sleeping sickness in Mambwe district has the potential of causing health problems, professional experts responsible for surveillance do not invest adequate resources to estimate its prevalence and the population at risk. This response reflects the existing policy framework which consider trypanosomiasis as a management disease whose control and surveillance is of less priority to government.

These findings suggest that risk to sleeping sickness is a social construct which may be constructed and perceived subjectively by professional experts and the local communities through discourse and their experiences in a particular social and cultural context (Douglas, 1992). This means that perception of whether the risk of contracting sleeping sickness is high or low among Kunda and Chewa farmers is a product of not only their interaction with the environment, livestock and wild animals, but also the broader economic and political structures which shape narratives knowledge and communication frameworks used to communicate policy and health information. Drawing on Bourdieu's (1989) concept of symbolic power and Foucault's (1978) concept of biopower, current narratives suggesting low risk of contracting sleeping sickness in Mambwe district and that it is not a disease of national importance reflects how institutions, through professional experts, shape policies and interventions that do not necessarily reflect the conditions creating risk and the subjective experiences of people. These findings further suggests that while risk does not only mean the structures of relations that are taken to be reality or the probabilistic orientation by which individuals understand the way the world is organised and operates; rather, it refers to how 'choices' or 'decisions' being made whose focus is selective and thereby constructive (Russell and Babrow, 2011, p. 248). This means that the risk of contracting sleeping sickness, as explained in this chapter, is socially and politically constructed. Risk of contracting sleeping is not presented as it is experienced or observed within communities but is constructed through deliberate and selective decisions and choices influenced by institutions, policies and expert knowledge systems (Russell and Babrow, 2011).

Though not conclusive, this finding suggests that professional experts and policymakers are central to shaping correct narratives and perceptions about the risk of sleeping sickness in areas such as Mambwe district. As argued by Douglas and Wildavsky (1982), policy makers and professional experts have the power to frame the *risk* problem, and as suggested by Foucault (1978), create and disseminate knowledge which is used to shape public perception, behaviour and response. Through such discourse and communication, professional experts and policy makers, relying on indigenous and biomedical knowledge to effectively construct and communicate persuasive narratives that ultimately shape health responses by the participants and general public (Douglas and Wildavsky, 1982).

Thus far, I have argued that the Kunda and Chewa farmers' experience of risk of sleeping sickness is a product of structural violence reflected in policy decisions which influence how the Kunda and Chewa farmers access health information about sleeping sickness, its nature and treatment. Based on this evidence, I argue that while participants understand the risk of other diseases such as malaria, lack of deliberate measures to actively screen for sleeping sickness or campaigns to raise awareness of the disease constrain their agency to protect themselves, understand symptoms of sleeping sickness and seek medical care on time. The lack of awareness and knowledge about the possible risk of contracting sleeping sickness contributed to the Kunda and Chewa farmers' non-serious attitude towards the symptoms and their vulnerability to the risk of sleeping sickness. As argued by (Luhmann et al., 2017), knowledge based on experience is important in conceiving risk. This implies that Kunda and Chewa farmers' perception and awareness of risk exist within the confines of their indigenous knowledge which they obtained from their own past experiences (Russell and Babrow, 2011).

4.4.1 Situating risk of contracting sleeping sickness in intersectionality theory

Intersectionality theory, a theory pioneered by Kimberle Crenshaw (1991), emphasises how various social identities intersect and interact to shape individuals' experiences of oppression and privilege (Crenshaw, 1991). Throughout this chapter, I have consistently highlighted the role of gender intersecting with other individual characteristics and social, cultural, and structural factors in shaping experience of vulnerability and risk of sleeping sickness. Reflecting on the third tenet of intersectionality, focusing on the need to understand the role of micro experiences and macro contexts of individuals (Crenshaw, 1991), my findings show that individual characteristics of the participants are a precursor to their experiences of vulnerability and risk of contracting sleeping sickness. However, while individual characteristics such as gender, ethnicity, age and economic positions play a significant role in shaping experiences of social suffering and vulnerability to risk of sleeping sickness, my

findings show that social structures and institutions of power shape the Kunda and Chewa farmers' experiences of suffering and vulnerability to sleeping sickness (McGibbon & McPherson, 2011). Through unequal distribution of resources such as health information on NTDs, adequate healthcare facilities and services, Kunda and Chewa farmers' ability to access health information and care to enhance their agency is constrained, reinforcing their vulnerability to and suffering from sleeping sickness and dangerous environmental conditions.

As will be further explained in the following chapters, participants' social roles and gender norms also influence how risk is communicated and experienced within families and communities, potentially affecting how children, men and women experience and perceive risk of contracting sleeping sickness. For example, more Chewa men than women have knowledge about zoonotic diseases due to variations in education attainment and their gender roles which require them to interact frequently with livestock and veterinary experts. Furthermore, variations in practices and traditions between Chewas and Kundas also shaped how participants' experienced the risk of contracting sleeping sickness. For example, Kundas with a history of living in the Luangwa valley, a region where sleeping sickness is prevalent, perceived tsetse flies to have potential effects on humans though without clear understanding of what this effect might be. In contrast, Chewa farmers perceived the effects of tsetse bites within the context of their livestock with less emphasis on human health. This view by the Chewas is partly because of their background in areas with little or no population of tsetse flies. Consequently, their limited experience of tsetse flies coupled with limited awareness programs constrained their overall awareness of the effects of tsetse flies on humans. In addition to ethnicity, limited access to healthcare due to poverty among participants affected early detection and treatment of sleeping sickness among participants who have limited understanding of the nature of sleeping sickness. Coupled with lack of education and knowledge of sleeping sickness, delayed detection reinforces and perpetuate misdiagnosis and mismanagement of possible cases of sleeping sickness inadvertently contributing to poor health outcomes and negative social and economic consequences for patients.

4.5 Chapter summary and conclusion

Throughout this chapter, I have explored and explained how the risk of contracting sleeping sickness in Mambwe district reflects power biases. I have argued that while biomedical explanations of disease occurrence are available in Mambwe district, Kunda and Chewa farmers' construction of risk of contracting sleeping sickness and other diseases is rooted in their cultural and religious beliefs. I have also shown that although the participants recognise medical diagnosis of diseases, Kunda and Chewa farmers' strong religious and cultural belief

system strongly influenced their belief that illness and diseases are caused by witchcraft and supernatural powers. However, due to tensions between biomedicine and traditional methods of diagnosis and treatment, participants did not openly reveal their use of traditional methods due to the stigma associated with use of herbs.

Interestingly, my findings further show that the risk of sleeping sickness and other diseases and how Kunda and Chewa farmers interpreted the symptoms was partly shaped by absence of screening of sleeping sickness within the rural health facilities in Mambwe district (Mulenga et al., 2015; Mwiinde et al., 2022). Inability to diagnose and treat possible cases of sleeping sickness left room for the participants to attribute causes of undiagnosed diseases such as sleeping sickness to witchcraft and supernatural powers. The diagnostic gap and misconception of sleeping sickness contribute to delayed diagnosis and treatment of possible cases. Furthermore, such gaps increased the farmers' reliance on traditional methods of diagnosis and treatment because of easy accessibility and their perceived effectiveness, ultimately affecting the farmers' overall health seeking behaviour.

In the next chapter, I will explore how the challenges of living in a game management area and unequal distribution of resources shape and contribute to increased vulnerability to risk of contracting sleeping sickness in Mambwe district. I also show how limited capacity of the healthcare system in the country contributes to participants' poor health seeking behaviour and increased reliance on alternative methods of diagnosis and treatment.

CHAPTER FIVE

COMMUNITY HEALTH IN A HUMAN-WILDLIFE-LIVESTOCK INTERFACE

5.0 Introduction

This chapter explores the community's health and wellbeing within the context of Lupande Game Management Area (GMA) in Mambwe district, Eastern province of Zambia, and addresses the first research question: *what are the varying health needs, challenges, impacts and opportunities for women, men, and children in the Luangwa valley, and how are these mediated by gender?* I explore aspects of living in the Lupande GMA discussed by Kunda and Chewa farmers and how they shape their experience of vulnerability, risk and suffering from zoonotic diseases such as sleeping sickness. I will also provide detailed accounts of the Kunda and Chewa farmers' varying health needs and challenges, and impacts for women, men, and children providing context for the next chapter. Throughout this thesis, I use the terms *medical, veterinary, wildlife and conservation workers* to refer to the key informants serving government institutions and Civil Society Organisations (CSOs) in various capacities. Furthermore, I use the term *alimi* (singular *mulimi*) meaning *farmers* in *Chikunda* and *Chichewa* language, to refer to all participants who are part of farming communities in Nsefu, Malama and Mnkhanya Chiefdoms.

I have thematically organised this chapter into three major sections, beginning with a discussion of the capacity of healthcare facilities to offer healthcare to *alimi*. I argue that inaccessibility of healthcare facilities and unavailability of some medical services is a manifestation of 'structural violence' (Farmer, 2004). Then I move to explore the role of community knowledge and perception of sleeping sickness on health seeking behaviour and healthcare utilisation by *alimi* in Mambwe district. Furthermore, I argue that health seeking, and utilisation is indirectly shaped by intersecting individual characteristics and the healthcare delivery system and policy, at a micro and macro level respectively. I conclude with a discussion of the detailed account of challenges and risks faced by *alimi* in the Lupande GMA, and how they affect their livelihoods and health. I argue that *alimi's* challenges and experiences are a consequence of limitations in policy and continued socioeconomic, cultural, and political inequalities. Through a consideration of community experiences of sleeping sickness and health seeking behaviour, I argue that experiences with tsetse fly bites, human animal conflicts and the resulting risk of contracting sleeping sickness may represent a form of suffering; not to imply victimhood, but as people's lived experience of domination and repression (Bourdieu, 2003), and the 'intermeshed components of thinking, feeling, responding, and acting' (Frost & Hoggett, 2008, p.439).

Through these arguments, I suggest that in addition to the material dimensions such as presence of tsetse flies, the experiences of risk involve nonmaterial dimensions such as cultural practices and beliefs which govern how men and women earn a living, where and how this must be done. Furthermore, structural violence manifested in constraints such as inadequate health facilities, shortages of drugs and equipment reinforced Kunda and Chewa farmers' gendered risk and suffering in an interface characterised by constant interaction between humans, animals, and the environment. Although my findings confirm that the risk of suffering is primarily shaped by gender, other overlapping factors such as age, education, ethnicity, marital status and economic resources influenced risk of contracting sleeping sickness. This approach affirms the structural and multidimensional nature of risk of contracting sleeping sickness by the farmers living in the three chiefdoms described in chapter three. This discussion of suffering provides the context for the subsequent analyses in the proceeding chapters of the thesis.

5.1 Healthcare delivery and accessibility

Previous research has highlighted existence and increasing inequality in access to healthcare services between rural and urban areas, women and men (Gwatkin, 2000). While researchers such as Zyaambo et al. (2012), suggest that healthcare needs among rural and urban Zambian population shape healthcare seeking, I indicate in this section that in addition to that, the inadequacy of the available rural healthcare facilities and their challenges such as shortages of drugs, lack of capacity and equipment and trained staff to diagnose and manage diseases largely influence utilisation and healthcare seeking behaviour by rural communities such as the Kunda and Chewa farmers (Young, 2004). Consequently, these limitations coupled with high levels of poverty among Kunda and Chewa farmers contribute to poor healthcare seeking behaviour among farmers and inadvertently the replacement of medical care with alternative methods such as use of traditional healers and medicine. This section also suggests that existing barriers such as lack of capacity to diagnose and manage NTDs including sleeping sickness hinder the ability of rural healthcare facilities to ensure equitable access to sleeping sickness screenings and treatment for all individuals, regardless of gender, socioeconomic status, or geographical location.

5.1.1 Health landscape in Zambia

The healthcare system in Zambia is largely provided and financed by the government (38.3%) with help from donors (42.5%) (Masiye, et al., 2020). In addition, patients' payments and employer based medical scheme contributions account for about 12.2% and 7.8% of the total healthcare expenditure respectively (Masiye et al., 2020). Although the

private sector is involved in providing healthcare services (Masiye et al., 2020), it is the government's primary responsibility to provide healthcare to all citizens (CSO, 2019; MoH, 2014).

Zambia's healthcare system is based on a four-tier referral structure (Figure 5). The first level includes the district health service whose aim is to provide primary healthcare via a network of district hospitals, rural health posts and centres (Masiye et al., 2020). This is followed by provincial hospitals which provide secondary healthcare and act as referral hospitals for district hospitals in the province. The third level hospitals provide tertiary healthcare and receive referrals from provincial hospitals while the fourth level include specialised tertiary hospitals which serve as referral centres for provincial and third level hospitals (Masiye et al., 2020).

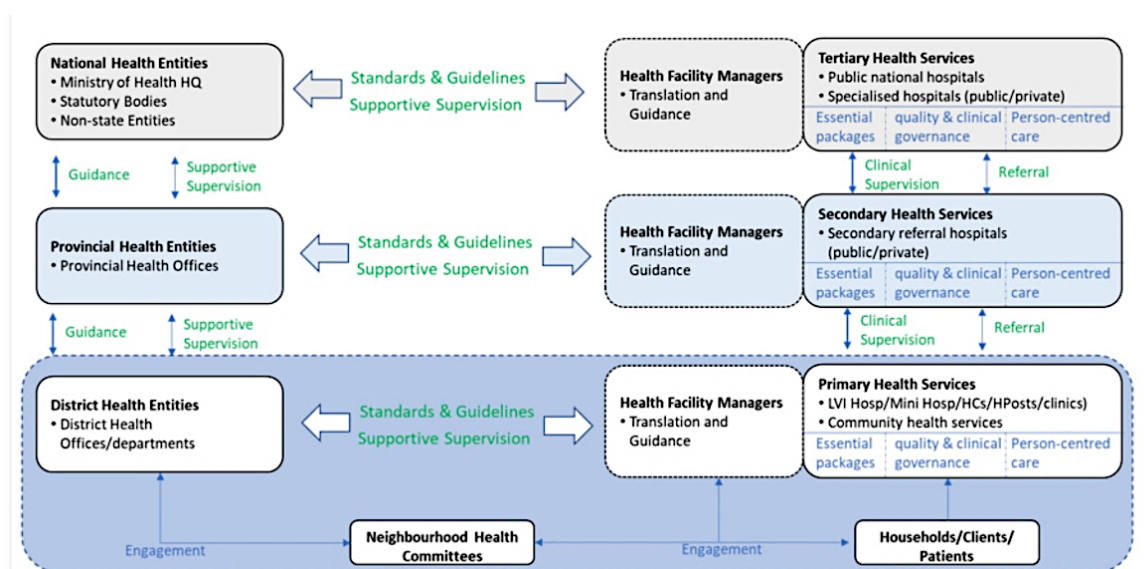


Figure 5: the Zambia health delivery system- levels, roles and responsibilities. Adopted from NHSP M&E Framework (2022-2026)

Like other countries in Sub-Saharan Africa, Zambia is characterised by inequalities in income and access to resources and services such as healthcare, education and job opportunities (Mills et al., 2012; Phiri & Ataguba, 2014). Therefore, to ensure improved utilisation and access to quality healthcare by citizens at reduced costs, several healthcare reforms have been implemented. For example, Zambia has been implementing universal health care (UHC) policy reforms such as the decentralization of health services planning and delivery; nationwide performance-based contracting; introduction and subsequent abolition of user fees in rural areas, peri-urban areas, and all primary health care facilities nationwide (Chitah et al., 2018). However, despite these health reforms, access and utilisation of healthcare is still a problem for most Zambians especially the 'rural poor' (Phiri and Atahuba, 2014). Whereas previous research in Zambia shows that the implementation

of UHC policies and the removal of user fees has improved access and utilisation (Lagarde et al., 2012; Masiye et al., 2010; Rudasingwa et al., 2022), my findings, however, show that access and utilisation among Kunda and Chewa farmers is still a problem. For example, while healthcare facilities are available, they are inaccessible during certain times of the year due to the distance and poor roads. In cases where farmers access the healthcare facilities, their experiences are characterised by drug shortages and inadequate care. This evidence further highlights that the unequal distribution of healthcare facilities between rural and urban areas characterised by inadequate staff, equipment and drugs has negatively affected utilisation and health seeking behaviour among Kunda and Chewa farmers in Nsefu, Malama and Mnkhangya Chiefdoms.

This finding implies that despite the implementation of UHC reforms, disparities in healthcare access based on gender, ethnicity, socio-economic and geographical disparities still exist in rural areas such as Mambwe district (Masiye et al., 2016). While efforts have been made to improve healthcare delivery, especially in rural areas, Zambia's ongoing economic challenges and debt situation has negatively affected the availability of resources to enhance the health sector's ability to function and to provide quality healthcare and diagnostic services for neglected tropical diseases including sleeping sickness (Masiye, et al., 2020).

5.2. Health seeking behaviour among *aChewa* and *aKunda*

Health service utilisation and health seeking behaviour is central to the management and understanding of diseases especially NTDs such as sleeping sickness (Musoke et al. 2014; Westgard et al., 2019). While health seeking focuses on understanding why, when and how individuals seek healthcare services, access and utilisation of healthcare is usually shaped by existing socioeconomic and political processes (Farmer, 1999; Singer & Rylko-Bauer, 2022). To understand their health seeking behaviour and experiences, Kunda and Chewa farmers were asked to describe what illness is to them and what they do when they are ill. The farmers' accounts reveal that although they know that some illnesses are caused by pathogens, they do not visit rural healthcare centres immediately to seek treatment unless their conditions become serious and fail to carry on with their daily activities. As argued by Kamat (2006) and Weller et al. (1997), this finding implies that the perceived severity of illness determined the Kunda and Chewa farmers' healthcare seeking behaviour and overall response to diseases symptoms. As Vele, a 42-year-old mother of Mnkhangya Chiefdom explained, '*healthcare centres are only visited when the symptoms persist and when I cannot continue to work*'. While medical diagnosis is used to define illness, the ability to perform

daily chores and duties was the farmers' basis of illness and healthcare seeking as explained by Vele (Blaxter, 2003). Because of this perception of illness, as Oakley (2016) argued, some farmers, men and women, performed household chores and tasks regardless of their discomforts as explained by Memory, a 42 year old mother of Nsefu Chiefdom.

I feel a lot of discomforts and body pains especially in my neck and backbone, but I still carry on with my daily duties. Female, 42, Nsefu- IDI

Memory's statement shows that she did not look at herself as being ill or needing medical care because she was able to carry on with her daily chores. Similarly, illnesses such as *chifuwa* (cough) and *chimfine* (flu) were considered not serious and were treated using herbs or over-the-counter drugs. Consequently, some farmers, men and women, used phrases such as *tuyenda navo* (we move with the discomforts) to describe an illness that was perceived as not serious. Furthermore, the farmers' use of phrases such as '*mkazi akadwala sagona pansi*' (a woman does not lie down when she is sick) also reveals the cultural perception that one is only considered ill if they lie down.

To the Kunda and Chewa farmers, having body discomforts is not illness as long as one could carry out their daily duties (Blaxter, 2003). The perception that *tuyenda navo* suggests that the Kunda and Chewa farmers consider these discomforts and diseases symptoms as a part of their normal life in the GMA. While the farmers' construction of illness may suggest lack of knowledge on diseases and resources to access healthcare services, this perception of illness may also suggest, as noted by Sauerborn et al. (1996) in Burkina Faso, that Kunda and Chewa farmers' view of illness is based on their continued ability to work, and engage in their livelihood activities such as farming, herding, cooking and cleaning. Thus, this construction of illness and the health beliefs about risk of contracting diseases among the Kunda and Chewa farmers contributed to passive response to disease symptoms and overall approach to health seeking especially among Kunda and Chewa men in Nsefu, Malama and Mnkhanya Chiefdoms. However, it is worth noting that while this construction of illness may contribute to increased disease burden and delayed health seeking, it also reveals the farmers' high level of resilience in circumstances where their access to healthcare facilities and services is constrained not by their choices but by environmental, social, economic and political factors limiting their agency (Putsoane et al., 2024).

In addition to farmers' perception of illness, accessibility and availability of services at healthcare centres also influence the Kunda and Chewa farmers' decision to seek medical care. For example, a Chewa farmer in Nsefu Chiefdom revealed that the available healthcare

facilities are inaccessible especially during the rainy seasons when the roads are impassable due to flooding. As a result of these conditions, the farmers did not use the available healthcare facilities due to accessibility challenges as illustrated in the excerpt below by Anna, a 26 year old Chewa of Nsefu Chiefdom.

It is a challenge getting to the clinic when a child is sick, especially during the rainy season. The facility is far from here and the road itself is impassable, as you can see this place is more of a *dambo*, so water does not easily go down. Because of that, it is difficult to wade through the water. Female, 26 years, IDI, Nsefu

The physical barriers to rural healthcare facilities such as distance and poor roads illustrated in the above quotation reflect the structural barriers that constrain Kunda and Chewa farmers' access and utilisation of the available healthcare resources (Bourdieu, 1989). Coupled with lack of economic resources, the Kunda and Chewa farmers' agency is inhibited as their choices of using or accessing healthcare is constrained by geographical factors that are beyond their control. Although men and women's accessibility were affected, my findings show that the effects of these barriers were more severe on women like Anna than men. My analysis shows that women suffered more because of their role as caregivers and lack of economic resources to aid their ability to access distant health facilities especially during the rainy season. Interviews with key informants who are medical workers reveal that they face reduced utilisation during rainy season with increased home deliveries and use of traditional medicine (Banda et al., 2013). As shown in the excerpt below, Luke, a 58 year old male medical worker explains the implication of poor roads on healthcare access and utilisation among pregnant women.

...But at times, because of the nature of this place, you know, geographical barriers, poor roads especially during the rainy season and so on. We have a lot of home deliveries because of that which is not safe. Male, 59 years, KII- Mkhanya chiefdom

Luke notes that inaccessibility challenges increased use of alternative care such as unskilled birth attendants, and use of herbs which have been a major contributor to maternal complications and loss of life (Maimbolwa et al., 2003; Moyo et al., 2018). This finding is consistent with conclusions by Gabrysch et al. (2011) in their study about the influence of distance and level of care on delivery place in rural Zambia. Their findings show that doubling of distance to the closest delivery facility reduced the odds of facility birth by 29%, while each step increase in level of obstetric care led to 26% higher odds of facility birth (Gabrysch et al., 2011).

Drawing on Foucault's work on power (1982), Kunda and Chewa farmers' lack of economic resources creates power imbalances in which women such as Anna, with limited income, experienced diminished agency to access and utilise the available healthcare services. As expressed by some Kunda and Chewa farmers, their economic situation intersecting with structural problems such as drug shortages, poor roads, and lack of adequate tools to ensure early diagnosis and treatment of sleeping sickness, affected their access and utilisation of the available healthcare services. In addition to that, their situation reinforced the already existing social inequalities that perpetuated the cycle of disadvantage and suffering the farmers, especially women and children, experienced by living in a GMA. As will be explained later in this chapter, Kunda and Chewa farmers' alternative methods to these challenges hindering their access and utilisation of the available healthcare services inadvertently contribute to delayed diagnosis and treatment of sleeping sickness. This reinforces the farmers' suffering to negative outcomes associated with delayed or untreated sleeping sickness, such as weakness and inability to be economically active, reinforcing the poverty levels and vulnerability to social stigma and health conditions associated with the disease (Chuma & Maina, 2012).

5.2.1 Lived experiences of healthcare services in Mambwe district

At the time of my data collection, Nsefu, Malama and Mnkanya Chiefdoms were serviced by one hospital, Kamoto mission hospital and five rural health centres and posts. An ultra-modern hospital was still under construction, which when completed, it would reduce the pressure on Kamoto mission hospital. Kunda and Chewa farmers living in villages around Chulu 2, Chilembo and Kadeweile of Nsefu Chiefdom have access to Nsefu rural health centre and Masumba zonal health centre, while farmers living in villages in Malama and Mnkanya Chiefdoms have access to Nyamaluma, Malama and Kakumbi rural health centres. Although healthcare facilities are available, Kunda and Chewa farmers' accounts of their experiences with healthcare facilities and services within the three chiefdoms studied was punctuated with phrases such as '*vipatala vili kutali*' (clinics are far), '*koma kuliye mankwala*' (but there is no medicine) or '*oyesako kuti thandiza*' (they try to help us) as illustrated in the following excerpt from an in-depth interview (IDI) with Mike, a 67 year old Chewa man of Chulu 2 in Nsefu Chiefdom who believes that the healthcare facility is not providing adequate services.

They [health workers] do what they can do. Some diseases they are able to test and give us treatment which help us. For example, malaria, flu and coughs are treated there but in terms of drugs, they would just give us Panadol [paracetamol] if you are

lucky, or they will ask you to go and buy. If you go complaining about fever and body pains, they will test for malaria and say that you do not have malaria. So, the help that meets our needs is not available. Male, 67 years, Chewa, IDI- Nsefu

Mike's experience reveals that although the clinic offers services which partly meet his health needs and concerns, overall, the help is not adequate. For example, while the healthcare facility was able to conduct tests for malaria, it was not able to provide medication to manage the symptoms of diseases the patients were experiencing. As Mike explained, receiving drugs was a matter of *kuchita mwai* (being lucky); otherwise, patients had to buy the prescribed drugs. Failure by the rural healthcare facilities to provide drugs to manage diagnosed diseases shaped the Kunda and Chewa farmers' perception and dissatisfaction with the available healthcare facilities and the services provided. Furthermore, drug shortages and limited capacity to diagnose diseases inadvertently contributed to increased cases of self-treatment and reliance on indigenous methods such as herbs which ultimately reduce health seeking and utilisation by farmers such as Mikes. As argued by Hausmann Muela et al. (2012), provision of prescription provided Kunda and Chewa farmers a sense of familiarity of the drugs they are asked to buy for specific symptoms.

However, although these challenges with the healthcare facility affected health seeking behaviour among some participants, some farmers such as Maiwase, a 53 year old Chewa woman of Nsefu Chiefdom, still had a positive perception of the healthcare facilities and their services. As illustrated in the following excerpt from our in-depth interview, the healthcare facility's inability to provide drugs and other services did not stop Maiwase from relying on the facility for diagnosis and provision of correct drug prescriptions and dosages.

The hospital does not provide adequate help to be honest, the only help we get from the hospital especially for us people with BP [hypertension], are prescriptions, after checking what the problem is that's all, we are always told to go and buy [drugs] every time. [But] we also fear to go direct to the chemist to buy drugs because you might buy [something] parallel to the disease that is why we first go to the hospital.
Female 53 years, IDI, Nsefu Chiefdom

The above quote further reveals that while drug shortages and limitations to provide adequate healthcare services by rural health care contributed to negative view of healthcare facilities and self-treatment, some farmers were aware of the importance of seeking expert advice before engaging in self-treatment. This view was common among a few Kunda and Chewa farmers who had economic resources and assets which provided them with a source of

money to purchase drugs that were not available at the healthcare facility. In contrast, high levels of poverty and lack of economic assets among most Kunda and Chewa farmers constrained their ability to access drugs and other medical services outside the formal healthcare system. Consequently, these farmers opted to seek alternative methods of treatment including use of herbs and divination which ultimately reduced their health seeking behaviour, perpetuating their diseases burden and poverty (McGibbon and McPherson, 2011).

While all farmers experienced the impact of drug shortages and unavailability of certain services, experience of some challenges such as inaccessibility varied by area of residence and gender. For example, although all farmers experienced accessibility and availability challenges of healthcare services, it was not the case for most Kunda farmers who lived closer to healthcare facilities compared to Chewa farmers who lived further from available basic services and infrastructure. Thus, their experiences and degree of challenges varied by location of residence with farmers such as the Chewas who live further in the GMA facing both accessibility and service-related challenges (Bourdieu, 1979). The Chewa farmers' geographical location constrained their ability to seek healthcare facilities and resources such as information on NTDs leaving them vulnerable to sleeping sickness and the negative effects of NTDs due to delayed diagnosis and treatment (McGibbon and McPherson, 2011).

Similarly, although the inadequacy of the services provided by the health facilities was a source of worry for Kunda and Chewa farmers, more Kunda and Chewa women than men expressed their dissatisfaction with limited services offered by the available healthcare facilities in Nsefu, Malama and Mnkhangya Chiefdoms. Furthermore, although men and women faced healthcare challenges, varying levels of understanding of the available services affected perception and desire to seek medical help. For example, while Kunda and Chewa men noted that healthcare facilities were less helpful, most women noted that despite limited capacity and unavailability of services, healthcare facilities were still helpful to patients within their abilities. Therefore, despite drug shortages and accessibility challenges, Kunda and Chewa women visited healthcare facilities more often than men fulfilling their role as caregivers. As revealed by Anna's experience below, while persistent drug shortages and distance sometimes discourage her from visiting the healthcare facilities, she still has trust in medical care.

Anna, a 26 year old single mother of two boys and resident of Nsefu Chiefdom, explained that geographical, and environmental factors affected her access, and utilisation of the available healthcare services. Like many other women in the study, Anna is a peasant farmer

who went up to the fourth grade and was recently divorced by the father of her two sons. While Anna lived further away from her family, her family has been there for her especially when she is sick or any of her children is sick. However, aside from that support, Anna solely provides for herself and her children. When asked to describe her life and access to basic services, Anna explained that her experiences in Chadiza were better than the life that she found in Nsefu Chiefdom. Although Anna was able to produce her own food in Nsefu Chiefdom, her biggest challenge was inaccessibility of healthcare facilities especially during the rainy season. Anna noted that although distance was the main challenge, poor roads which were impassable during the rainy season hindered her access to the healthcare facility even for those who had *njinga* (bicycle). *‘As you can see’, she explained, ‘this place is a dambo so, during the rainy season, the roads are flooded and become impassable because the water does not go down.’* To make her point, Anna pointed to her waist to show me where the water reaches when the road is flooded. *‘With the water here, even if you have njinga, it cannot move. For us without, it is difficult to walk with a sick child on my back, but what can I do? I just have to do it,’* she explained. Despite all these challenges, Anna explained that she rarely received all the drugs prescribed to her from the healthcare facility as shown in the following excerpt.

When you get there, they will tell you to buy the drugs, *‘uka chita mwayi’* (if you are lucky), they would give you Panadol (paracetamol) and ask you to buy the rest.
Female 26 years, IDI, Nsefu Chiefdom

Anna’s experience in the quote above suggest that inaccessible and distant healthcare facilities do not only leave her vulnerable to sleeping sickness and delayed management of diseases but also hinders her access to information about other health services such as maternal and child health. Poor roads do not only increase Anna and other farmers’ vulnerability to increased disease burden and reliance on herbs but also constrained their right to have access to professional, quality and adequate health services (McGibbon and McPherson, 2011). These findings suggest that Anna and other farmers’ vulnerability and suffering reflect existing institutional inequities and challenges in the distribution of infrastructure and services (McGibbon and McPherson, 2011). While these processes are beyond the Kunda and Chewa farmers’ control, their consequences intersecting with various characteristics of the farmers reinforced their experience of poverty and increased the risks to NTDs such as sleeping sickness.

It is evident that Anna’s experiences are not isolated but are deeply embedded in the power structures of the broader society (Riley, 2008). Anna’s individual characteristics such as

marital status, level of education, social position and gender are at the centre of her experiences of vulnerability and social suffering. For example, her limited education reflects broader societal power imbalances within the village where she was born and bred resulting in gender based inequalities in access to education resources which affected her economic position and access to resources which would enhance her health and wellbeing (Smith, 1990). Anna's failure to afford transportation to the healthcare facility point to how her background and current institutional processes beyond her control affected her economic wellbeing which contributed to her vulnerability to suffering (McGibbon and McPherson, 2011).

Although Anna can make it to the healthcare facility despite the accessibility challenges, her expectations and needs are not met due to the healthcare facility's limited capacity to offer services such as diagnosis of sleeping sickness which she might need based on where she lives. As a result, while Kunda and Chewa farmers such as Anna may be willing to seek healthcare services at healthcare facilities, their previous experiences of the facilities' inability to meet their needs and expectations reinforced the Kunda and Chewa farmers' lack of confidence in the available healthcare services and increase their reliance on alternative methods of disease management such as traditional herbs and divinations (Nolna et al., 2020; Vahekeni et al., 2020). Therefore, I argue that the existing inequalities and barriers to healthcare experienced by the Kunda and Chewa farmers in Nsefu, Malama and Mnkhanya Chiefdoms of Mambwe district reinforce and perpetuate the social inequalities based on gender, ethnicity and economic resources. Ultimately, these inequalities intensify the farmers' vulnerability to ill health and suffering through reduced access to basic services, healthcare services and effective medication. This implies that the vulnerability and suffering of farmers like Anna (26) from structural inequalities and inefficiencies is intensified, inadvertently increasing their reliance on herbs and other non-effective alternatives.

5.2.2 Diagnosis and screening of sleeping sickness in Mambwe district

While Kunda and Chewa farmers' accounts show the availability of rural healthcare centres where they access basic services such as maternal and child health, malaria screening, and anti-retroviral therapy (ART), rural healthcare facilities in Nsefu, Malama and Mnkhanya Chiefdoms lack capacity to detect diseases such as sleeping sickness (Mulenga et al., 2020; Mwiinde et al., 2022). For this reason, none of the Kunda and Chewa farmers I interviewed described a situation where they were screened for sleeping sickness at any of the rural healthcare facilities in the district. While the rural healthcare facilities engaged community-

based health volunteers (CBHV) to provide medical care within villages, accounts from Milika, a 39 year old CBHV, revealed that her knowledge and skills are limited to malaria diagnosis and administration of anti-malarial drugs. As a result, while CBHVs helped to screen and manage malaria cases within villages, the possibility of misdiagnosing other febrile diseases such as sleeping sickness which exhibited similar symptoms to malaria was high (Crump et al., 2013). My findings further show that over emphasis on malaria screening by rural healthcare facilities overshadowed and masked the diagnosis and early detection of febrile diseases like sleeping sickness, typhoid and brucellosis indirectly contributing to delayed diagnosis and treatment of possible cases of sleeping sickness and other NTDs. For example, accounts from some Kunda and Chewa farmers in Nsefu and Malama revealed that despite living in an area with a high density of tsetse flies, which are known to carry human infective trypanosomes (Lisulo et al., 2024), CBHVs and healthcare staff rarely establish if the farmers had been exposed to tsetse fly bites to inform their diagnosis.

Although several factors explain this situation, my findings show that this situation is due to two main reasons. Firstly, the lack of skills in diagnosis of sleeping sickness among health workers and limited capacity within the rural healthcare facilities to screen for NTDs especially sleeping sickness contribute to lack of focus on the disease's diagnosis (Mulenga et al. 2020; Mwiinde et al., 2022). Secondly, the narrative that the risk of contracting sleeping sickness in Mambwe district is low contributes to a low suspicion index of sleeping sickness among health workers contributing to lack of efforts to screen for sleeping sickness and exposure to tsetse flies (Mwiinde et al., 2022). As a result, my findings suggest that most health interventions and campaigns within the three chiefdoms omit information on sleeping sickness due to existing belief about low risk and the lack of capacity to control the diseases at a district and national level.

This situation is reflected in Tiku's experience during her last visit to one of the health facilities. Tiku, a 47 year-old Kunda woman from Nsefu Chiefdom explained that her last visit to the healthcare facility with a fever did not include screening for other diseases apart from the usual malaria tests using the rapid diagnostic tests (RDT). Although the malaria test was negative, the health worker gave her two tablets to take immediately without telling her what was wrong. When asked what disease was being treated, *'I do not know but I trust the health worker who understood what my problem is,'* she answered. Tiku's experience is the reality of other farmers living in Malama and Mnkhanya Chiefdoms. While Tiku's experience shows lack of capacity by the healthcare facility to screen her for other diseases beyond malaria, her experience provides insights into the handling of negative disease tests.

Ideally, the malaria test was supposed to be followed by several tests to ascertain the cause of the fever before medication is prescribed to Tiku. However, as indicated earlier, the health worker might not have the necessary skills and tools to carry out the differential diagnosis to establish the cause of the fever partly because of lack of institutional support which is beyond their control. Tiku's experience highlights two important issues. Firstly, possible mismanagement of undiagnosed diseases due to lack of resources to correctly diagnose and secondly, increased risk of anti-microbial resistance due to an increase in mis-prescription of drugs because of misdiagnosis. These findings further indicate that reliance on RDTs for diagnosis of malaria implies that traditional diagnostic methods using examination of blood smears are no longer carried out, denying the opportunity for identification of other blood borne parasitic diseases such as sleeping sickness (Gillet et al., 2013). As illustrated in the following figure (Figure 6), while tested cases of malaria between 2021 and 2022 where more than 11,620, only 1,291 were positive for malaria.

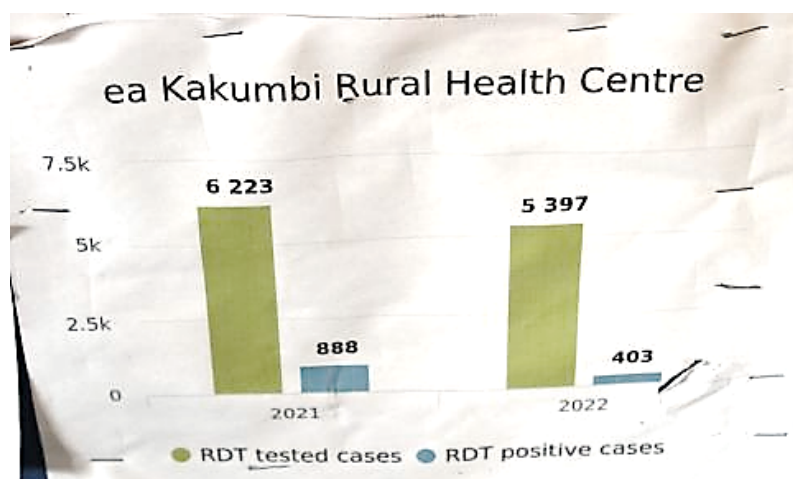


Figure 6: Number of malaria cases at Kakumbi rural health centre for 2021 and 2022

Source: fieldwork data

Therefore, although Mwiinde et al. (2022) suggests that cases of sleeping sickness in Mambwe district are low, my findings show that the lack of screening for sleeping sickness by rural healthcare facilities may conceal the true prevalence of sleeping sickness in the human population. As Luke, a medical expert explained, sleeping sickness is not given similar attention compared to other diseases such as malaria in their surveillance and screening because it is a 'management disease.' Luke further stated that sleeping sickness might be in the community, but because '*we are not doing enough to detect the cases*', he explained, '*the numbers are not significant and subsequently, people are not paying attention, and it is not given priority compared to other diseases.*' While lack of resources is cited as the main reason for lack of surveillance and screening (Mulenga et al., 2020;

Mwiinde et al., 2017), my findings suggest that limited knowledge, skills and understanding of methods of diagnosing sleeping sickness in rural healthcare centres also affected the ability of medical staff to detect the disease (Mwanakasale et al., 2013; Mwanakasale & Songolo, 2011).

Drawing on Foucault's writings on power as a discourse (1982), failure to adequately '*pay attention*' and '*not doing enough*' to detect cases of sleeping sickness by rural healthcare facilities reflects how bureaucratic social structures within decision making control and define the narratives regarding the risk, and incidence of sleeping sickness in Mambwe district. Thus, as suggested by Bourdieu (1979), limitations of the healthcare system in Nsefu, Malama and Mnkhanya Chiefdoms may inadvertently perpetuate power inequalities and continued neglect of the health needs and challenges of rural communities. These findings reveal that although rural communities are associated with poor health outcomes, the overall inability by rural healthcare facilities to provide adequate healthcare services such as disease detection, may hinder the Kunda and Chewa farmers' ability to access and benefit from timely healthcare services within their chiefdoms (Weinhold & Gurtner, 2014).

5.2.3 Current cases of sleeping sickness and other diseases in Mambwe district.

Kunda and Chewa farmers living in Nsefu, Malama and Mnkhanya Chiefdoms in Mambwe district experience a wide range of diseases such as malaria, upper respiratory infections, sexually transmitted infections, diarrhoeal and eye infections. While adults are affected, more children experience frequent episodes of both malaria and diarrhoea, consequently, healthcare services prioritised diagnosis and treatment of these diseases including those that affect the upper respiratory system as reflected in the limited diagnostic tools. However, prioritisation of malaria diagnosis over other diseases such as sleeping sickness has partly contributed to low numbers of confirmed cases of sleeping sickness in Mambwe district. Although official statistics by the WHO are available for Zambia, the data are unreliable due to lack of early and effective diagnosis of sleeping sickness in the country. Furthermore, this data provides limited information on the distribution of sleeping sickness by gender, location, or age.

Whilst estimates from Mwiinde et al. (2022), and WHO (2024) show low and varying cases of sleeping sickness in Mambwe district and Zambia respectively as shown in figure 7 and 8 below, their estimates, nevertheless, still indicate the presence of sleeping sickness in human populations (Mwiinde et al., 2022) and animal populations (Lisulo et al., 2024) in Mambwe district. These findings suggest that although other researchers have found that Mambwe district has low risk of disease occurrence (Mwiinde et al., 2022), failure to present

these cases to healthcare facility by farmers due to inaccessibility and lack of screening and diagnosis of sleeping sickness by rural healthcare facilities further mask the true incidence of the disease (Mwanakasale & Songolo, 2011). The high incidence of negative malaria tests in the district may be indicative of a high prevalence of non-malaria febrile illness some of which could be due to sleeping sickness (Mubemba et al., 2022).

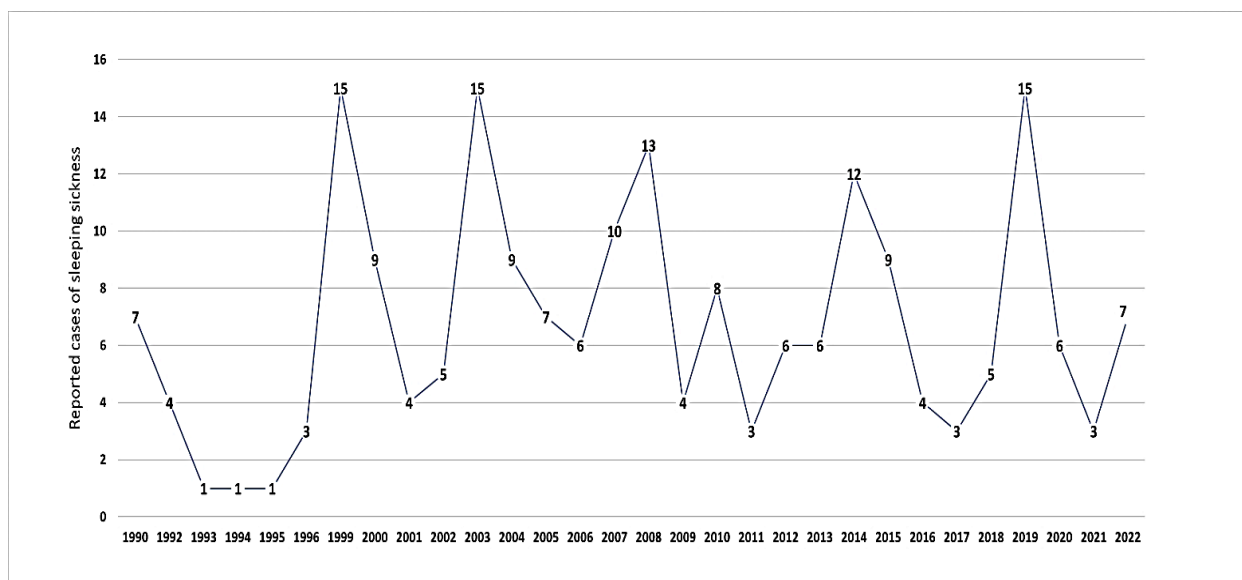


Figure 7 Reported cases of sleeping sickness in Zambia 1990-2022

Data Source: WHO-2024 data

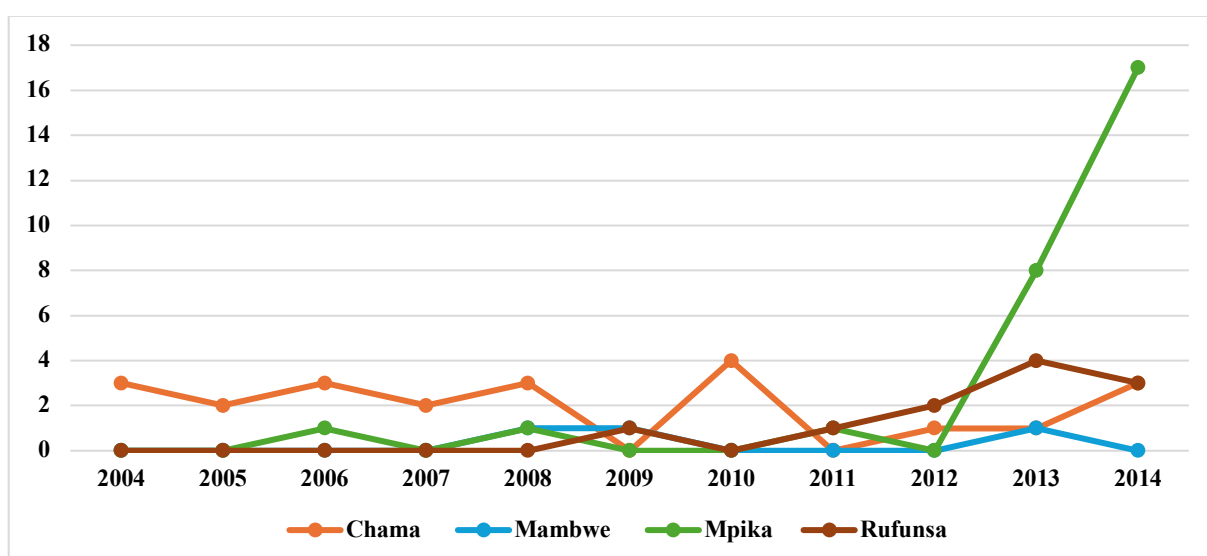


Figure 8: Reported cases of sleeping sickness in four districts (Zambia, 2004-2014)

Data Source: Mwiinde et al. (2022)

Although Mwiinde et al. (2022) reported diagnosed cases of sleeping sickness in men and women in four districts, as shown in Figure 9 below, no official statistics within Mambwe district and Zambia in general show diagnosed cases of the disease by gender or sex,

inadvertently masking the risk and occurrence of sleeping sickness between men and women.

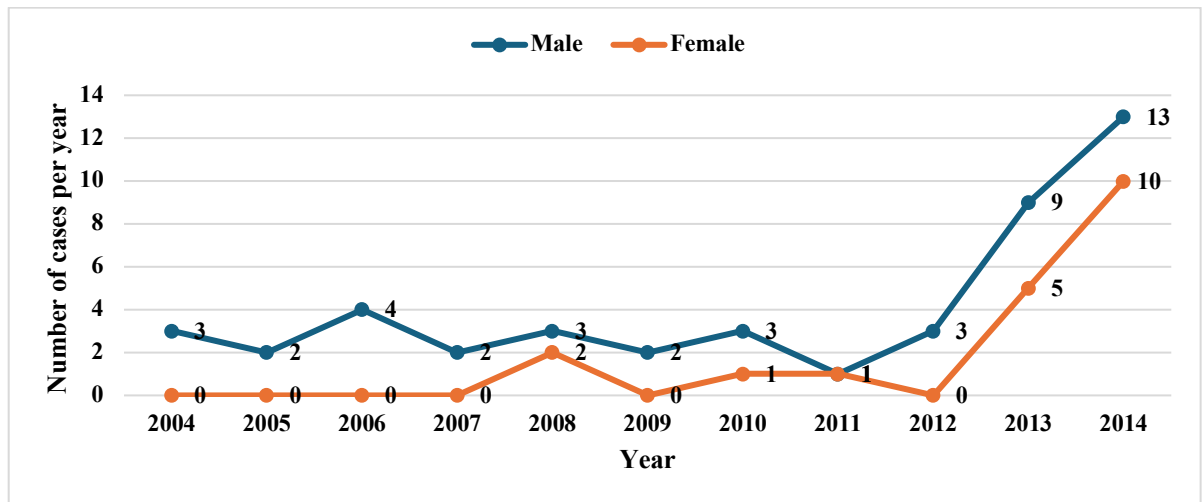


Figure 9 Reported cases of sleeping sickness in four districts (Zambia, 2004-2014)

Data Source: Mwiinde et al. (2022)

However, although the validity of these statistics is not certain, they are still used as official information on which policies shaping the narrative on sleeping sickness in Zambia are based, inadvertently creating a misconception of the true risk and prevalence of sleeping sickness among Kunda and Chewa farmers in Mambwe district. Lack of sex and gender aggregated data at a national level contributes to current gender blind interventions to NTDs especially sleeping sickness further masking the already hidden disease burden in the population and between men and women (Mubemba et al., 2022; Mwanakasale & Songolo, 2011). Although Mwiinde et al. (2022) and Nambala et al. (2022) have highlighted differences in risk between men and women in Zambia and Malawi respectively, their evidence suggests that in addition to gendered roles shaping risk to the disease, variations in screening for the disease persist. Overall, my findings suggest that challenges to collect correct data on sleeping sickness in Mambwe district and Zambia at large is a clear manifestation of structural violence. Drawing on Foucault's (1982) concept of biopower and Bourdieu's (1989) concept of symbolic power, the observed disparities in reporting diagnosed cases of sleeping sickness indicate institutional dysfunctions in reporting of cases, which reinforce and perpetuate the interests of powerful stakeholders. My findings show that these institutional inequalities and inefficiencies contribute to the masking of the gendered vulnerability to sleeping sickness and the health needs of farmers living in different endemic areas, such as Mambwe district. Ultimately, this contributes to the continued weakening of health response and interventions to address gendered risks of contracting sleeping sickness in rural communities.

5.2.4 Disease management and use of alternative methods

The previous sections of this chapter provided insights into the limitations of healthcare facilities to provide diagnostic services for sleeping sickness. While Kunda and Chewa farmers' accounts show reliance on rural healthcare facilities for disease management, self-medication using painkillers and herbs is widespread among the farmers. Although some farmers rely on self-medication using modern drugs to manage disease symptoms, they also spoke of various alternative methods that are used to manage disease symptoms in the absence of medicine from the clinic or pharmacy (Pagán and Pauly, 2005). When asked to describe the alternative sources, Kunda and Chewa farmers' accounts revealed the use of herbs and religious pastors as their main sources of help.

As explained by Mateyo, a 59 year-old Chewa herbalist living in Nsefu Chiefdom, '*kankalamba*', '*mioka*' or '*chikhoswe*' (Figure 10 below) are used to manage malaria symptoms. Mateyo further explained that the three herbs are administered orally by chewing or taking the water where the herbs are soaked until the symptoms disappear. As further explained by Vele, a 42-year-old mother of Mnkhanya Chiefdom, the three herbs are also used to manage colds, and diarrhoea. When asked about the effectiveness of these herbs in managing disease symptoms, Vele explained that the herbs are effective although for some diseases such as malaria, the herbs do not completely clear the parasites from the body. As a result, one still needs to seek medical help to get the malarial drugs to completely 'heal'. On the other hand, Mateyo believed that the herbs were able to completely manage any symptoms unless the '*problem is big*'. When asked to explain why they use herbs instead of seeking medical help to '*completely remove*' the parasites from the body, both Vele and Mateyo explained that they use herbs to manage symptoms because the health facility is very far, and that the healthcare facility is rarely stocked with drugs. However, Mateyo argued that he uses herbs as a safety measure because modern drugs make the body weak and should be avoided at all costs.



Figure 10: Parts of the trees that are used for disease treatment

Vele and Mateyo's experiences show the mixed approach to disease management within the three chiefdoms. Although Vele and Mateyo were aware of modern drugs, they had varying reasons for using herbs in addition to modern drugs. For example, Mateyo's position as a herbalist influenced his negative view of modern drugs while supporting the efficacious of herbs. On the other hand, Vele believed that while herbs help to manage symptoms, one still needed to seek medical care to completely manage some disease, which Mateyo believed were 'a big problem.' While the explanations from Vele and Mateyo highlight the varying beliefs towards medical and traditional medicine, their explanations also suggest that lack of medical care which meets and addresses their health needs such as drug shortages and inaccessible healthcare facilities contribute to their reliance and trust in alternative methods. Like other Chewa farmers, Vele and Mateyo's experiences of herbs effectively managing symptoms enforced their belief in using herbs as their first line of medication, not because they worked, but partly because of inaccessibility of the healthcare facilities.

Although the Kunda and Chewa farmers' belief in traditional medicine also played a role in motivating the use of alternatives, my findings suggest that existing problems within the health sector played a significant role in increasing the farmers' reliance on alternative methods of diagnosis and treatment. Therefore, although Kunda and Chewa farmers' accounts on herbs indicate their belief in alternative causes of illness and trust in indigenous methods of diagnosing and treating diseases, some farmers such as Vele still believed in medical care and the effectiveness of modern medicine. However, existing healthcare challenges such as inaccessibility, limited services and drug shortages indirectly reinforced the Kunda and Chewa farmers' reliance and belief in alternative methods of diagnosing and managing diseases. Consequently, my findings suggest that structural and institutional dysfunctions play a significant role in perpetuating the farmers' use of traditional healers, indirectly reducing the farmers' health seeking and reliance on the formal healthcare system (Desmond et al., 2012).

As Memory, a 42 year old Chewa woman from Nsefu Chiefdom, explained, her husband entirely depends on herbs to manage any symptoms. However, Memory explained that the herbs used are very bitter and, as a result, her children often refuse to take them when they are ill. But in her case, she had to be strong like her husband and take the bitter herbs to feel better because there are no alternatives. When asked to explain why her husband relies on herbs, her response, '*kuchipatala kulibe mankwala*' translating to 'the hospital has no drugs' confirmed the on-going narrative among Kunda and Chewa farmers that the healthcare facility does not provide drugs. This finding suggests that utilisation of herbs is another

manifestation of suffering resulting from lack of drugs, a structural problem and expression of systematic inequality within the health sector (Farmer et al., 2006). Although Memory, like other farmers, used the bitter herbs to manage disease symptoms, her account shows that her reliance on herbs was due to lack of resources to purchase modern drugs. While Memory's economic situation contributed to her inability to purchase modern drugs from pharmacies, structural violence manifested through drug shortages, inadequate healthcare services and inaccessible healthcare facilities ultimately constrained her family's agency to seek better health care services. These findings reflect that utilisation of herbs is another manifestation of suffering resulting from lack of drugs, a structural problem and expression of systematic inequality.

5.3 Community knowledge and perception of sleeping sickness

Resources, in form of knowledge and understanding, contribute to individuals' agency to form opinions and decisions including acting on their desires (Beck, 2008; Kabeer, 1999). While knowledge and understanding are important in shaping perception, other factors such as culture, ethnicity and gender play a significant role (Douglas, 1992). Although previous studies (Mwiinde et al., 2022) in Mambwe district suggest that communities have knowledge of sleeping sickness, this study's participants across the three chiefdoms exhibited limited knowledge and understanding of the nature of sleeping sickness. In addition to that, my findings show that the limited knowledge of the disease differed by gender and ethnicity. For example, most men than women realised that tsetse flies carried disease causing pathogens which affected their livestock. While the farmers were aware of this, their knowledge about the disease caused in humans by pathogens transmitted by tsetse flies was not known. This finding suggests that gendered roles performed by men and women such as herding and caring for livestock influenced awareness and knowledge of the effects of sleeping sickness through contact with veterinary officers. While women performed caregiving roles to sick family members, their knowledge was limited to describing the symptoms of the diseases or reporting the diagnosis offered at the clinic.

Previous studies have shown gender determined health knowledge and practices (Vlassoff, 2007). Anaam and Alsahali (2023) in their study on gender differences on knowledge, attitudes, and practices toward COVID-19 in Saudi Arabia found significant differences in both knowledge and practices toward COVID-19 between women and men, with more women achieving better scores than men. Although my findings are broadly consistent with findings by Annam and Alsahal (2023), my conclusion differs from theirs when sleeping sickness is considered. For example, while more women participants were more

knowledgeable about other diseases and health practices than men, men were more knowledgeable on sleeping sickness and some zoonotic diseases than women, regardless of ethnicity.

This finding reflects how access to information and knowledge about diseases varies between men and women due to variation in literacy (Okwa, 2007) intersecting with other factors such as their ethnicity and possession of livestock. Due to women's disadvantages such as early marriages, teen pregnancies within rural communities such as Mfuwe, their chance of getting formal education is limited; thus, coupled with gendered division of labour, their ability to access and understand information about diseases such as sleeping sickness is further constrained. Therefore, as will be explained in later sections, limited health literacy and awareness about sleeping sickness may worsen existing disparities in access to screening and treatment by farmers. Female farmers, with lower levels of knowledge of zoonotic diseases may be less likely to recognise symptoms of sleeping sickness or understand the importance of seeking medical care, contributing to delayed health seeking, diagnosis and treatment of possible cases the disease (Mwiinde et al., 2022).

Turning to the role of ethnicity on shaping knowledge and awareness of sleeping sickness, my findings show that Kunda farmers were more aware of sleeping sickness than Chewa farmers. However, whereas Kunda farmers have knowledge of sleeping sickness, their awareness was limited to one of the symptoms '*kulala-lala*' (dozing). But when asked to describe how sleeping sickness is contracted, some participants, like Toliwe, a 31 year old Kunda woman of Malama Chiefdom, responded by saying '*nuziba lini*' (I do not know); while Ambuya, a 59 year old married Kunda woman of Malama Chiefdom, mentioned in passing that '*si ivi vuluma*' (is it not these things that bite) without specifying exactly the vector or the symptoms of the disease apart from dozing.

In contrast, Chewa farmers, were mostly unaware of sleeping sickness. For example, when Memory, a 42 year old Chewa woman was asked about her knowledge and awareness of sleeping sickness, '*I am not sure of that disease*' she replied. '*I have heard of people talk about people who sleep, but personally, I have not seen any*' she explained. Although the local name '*matenda ogona*' imply a disease involving sleeping, Chewa participants did not know the symptoms of sleeping sickness and how it is transmitted. It should be noted that Chewa participants understood that tsetse flies caused diseases in their livestock, however, they were not aware that tsetse flies transmitted sleeping sickness in humans. As noted by Robinson and Howland (2021) in Kenya, this study's participants were not aware of the

potential of disease transmission between the farmers and their livestock, and possible impact of tsetse flies on their health.

It can be argued that while various factors shape knowledge and awareness of diseases, my findings suggests that ethnicity and area of residence shaped knowledge and awareness of sleeping sickness among participants (Bukachi et al., 2018). For example, as explained by Banda et al. (2013), Kundas have lived in the Luangwa valley and interacted with tsetse flies for a long time. Therefore, their awareness of tsetse flies and sleeping sickness, although informal, is based on their experiences and stories that have been passed from generation to generation (Kabanga et al., 2022; Palmer, 2020). Similar to Palmer's (2020) observation among the Dinka who learned about sleeping sickness during their displacement, the Chewa farmers, men and women, only learnt about sleeping sickness and the effects of tsetse flies on humans after settling in Mambwe district. This evidence suggests that limited knowledge about tsetse flies and sleeping sickness among Chewa farmers reveals the geographical nature of the disease (Malvy & Chappuis, 2011; Simarro et al., 2010). While some Kunda farmers, men and women, might have some lived experiences of tsetse flies and possible effects on their lives despite limited knowledge of sleeping sickness, Chewa farmers in contrast, have had no source of awareness of sleeping sickness, its nature, transmission and treatment. This implies that Chewas rely on healthcare centres to acquire knowledge of sleeping sickness in Mambwe district. However, lack of diagnosis and awareness campaigns by the rural healthcare facilities constrained the Chewa farmers' access to information on sleeping sickness, leaving them with a higher risk of contracting the disease due to limited knowledge and awareness of its nature, symptoms and dynamics.

As illustrated in the previous chapter, perception of illnesses is shaped by several micro and macro factors. While knowledge is key, factors such as culture, religion, environmental and economic factors influenced understanding of illness and risks (Douglas, 1992; Kleinman, 1997). When Kunda and Chewa farmers were asked to describe how they perceived illness and how it is caused, their responses revealed a strong belief in witchcraft and spirituality as the main cause of illness. For example, among Kunda farmers, persistent and undiagnosed illnesses were mainly perceived as being due to AIDS or witchcraft. However, for most Chewa participants, despite presence of medical diagnosis, persistent illnesses were always associated with witchcraft (Fottrel et al., 2012). Although both women and men believed that persistent and undiagnosed diseases are caused by witchcraft, the study found that most men than women associated any disease with witchcraft regardless of whether there is clinical diagnosis or not (Fottrel et al., 2012). This finding suggests that although medical

diagnosis formed the basis of knowledge about diseases, Kunda and Chewa farmers still rely on alternative views on the cause of diseases which also informed the farmers' approaches to treat and manage diseases including possible cases of sleeping sickness.

It can be argued that the knowledge gap created by the lack of diagnosis of suspected cases of sleeping sickness contribute to misconception of its symptoms as 'stubborn malaria', AIDS or illness caused by witchcraft. As a result, possible cases of sleeping sickness might have been treated as febrile or witchcraft induced illnesses by the farmers and medical staff. Therefore, it can be argued that inability to offer correct diagnosis by the rural healthcare facilities created a knowledge gap of undiagnosed diseases such as sleeping sickness contributing to their mismanagement. For example, when asked to explain how undiagnosed diseases are managed, it was noted that several methods such as painkillers, herbs and 'holy water' were used to manage symptoms. Consequently, these challenges contribute to worse health outcomes among the farmers especially women and children who have limited resources and knowledge of sleeping sickness.

5.3.1 Community practices and risk of contracting sleeping sickness

As suggested by other researchers such as Lindstrand et al. (2006) and Semenza et al. (2016), risk of contracting diseases is shaped by many factors. In Nsefu, Malama and Mnkhanya Chiefdoms of Mambwe district, the risk of contracting sleeping sickness is shaped by gender roles and other intersecting social factors such as livelihood practices, economic resources, age, and ethnicity which shape exposure to vectors (McGibbon et al., 2011). However, it is worth noting that the importance and influence of these factors on Kunda and Chewa farmers' practice and experience differs according to context (Armstrong & Connelly, 1989), as discussed in the following subsections.

Livelihood activities, economic resources and gender role flexibility

As explained in the previous chapter, this study's participants are engaged in livelihood activities that involve constant interaction with the natural environment (Banda et al., 2013). During the rainy seasons for example, Kunda and Chewa farmers in all three chiefdoms are involved in farming, which involves spending days in their farms planting crops. This is followed by weeding in early December and later starting in April through to June, harvesting. During this period, women, men, and children leave their homes and camp in the bush where they are more exposed to disease vectors like mosquitoes or tsetse flies (Torr et al., 2012). Others, especially men and some women, also engage in timber and charcoal business during the dry season. These livelihood activities, as shown by Kabanga et al.

(2022), Ochola et al. (2021) and Torr et al. (2012), serve as sources of exposure to tsetse flies bites and risk of contracting sleeping sickness.

As Memory, a 42 year old Chewa woman explained, she gets bitten together with her two children while working at her farm and when she goes to collect firewood. Others such as Rosie, a 45 year old Kunda woman of Nsefu Chiefdom, get bitten when fetching water from streams and lagoons. Similarly, Villi, a 47 year old Chewa man of Mnkhanya Chiefdom stated that he gets bitten while grazing his cattle. Although Kunda and Chewa farmers I spoke to know about when and where tsetse fly bites are high, their accounts showed that tsetse fly bites have been accepted as a ‘harmless’ part of life in a game management area (GMA). While these findings are broadly consistent with findings by other researchers such as Kabanga et al. (2022) and Torr et al. (2012), women and men I spoke to, especially those with a Chewa background, were aware of tsetse fly bites but did not take them as a source of concern. Similarly, they performed their livelihood activities in areas infested with tsetse flies, but they did not consider themselves at risk of contracting sleeping sickness or any other disease. This finding indicates that the need to earn a living inadvertently shapes the farmers’ perception of risks associated with their livelihood activities such as herding cattle, timber harvest and charcoal production.

Despite the significant role of the farmers’ livelihood activities on enhancing their economic position and ability to access healthcare, the nature of economic resources farmers possess shapes their exposure and frequency of exposure to areas that had higher density of tsetse flies. As Maiwase, a 53-year old married Chewa woman of Nsefu Chiefdom explained, having cattle reduced her involvement in chores outside her home. Apart from farming and harvesting, Maiwase stated that her older sons helped to fetch water and collect firewood for the family using their oxcart (Figure 11 below). This, however, did not imply that women with cattle are not at risk of contracting sleeping sickness. This finding implies that although some women with cattle rarely visited areas with tsetse flies, they got exposed to tsetse flies which followed cattle from the bush to their villages but to a lesser extent compared to men and women who visited the bush where the tsetse fly density is high (Torr et al., 2012).

For example, I observed that although the density of tsetse flies was generally low in Malama village, I encountered more tsetse flies within the yards of livestock keeping farmers especially the Chewas compared to Kunda farmers. This finding suggests that although Chewa farmers lived in the same area as the Kunda farmers, their different social and economic characteristics such as keeping of livestock increased their risk of contracting some zoonotic diseases due to their exposure to vectors that followed their livestock. This

finding indicates that it is not only wildlife that attracts tsetse flies to human villages, but livestock also attracts tsetse flies during grazing, inadvertently increasing the density within human villages. Therefore, my findings shows that while women and girls with cattle are less exposed to areas with high density of tsetse flies, confinement to domestic chores reinforced the existing gender disparities in workload and limited their opportunities to participate in activities outside the home, potentially affecting their autonomy and empowerment (Vlassoff, 2007).



A girl and a boy on an oxcart filled with firewood. A man carrying firwood on a bicycle

Figure 11: Gender role flexibility.

In contrast, as concluded by Ochola et al. (2021) in Kenya, women with young or no children performed outdoor tasks with little or no help from their husbands. Similarly, children in homes with or without livestock were also exposed to the risk of tsetse bites because they performed outdoor tasks on behalf of their parents. While men in homes without livestock rarely performed household chores, some Kunda men stated that they engaged in timber and charcoal production which was carried out in the bush where they constantly interacted with various disease vectors including tsetse flies.

Although other researchers such as Lindstrom et al. (2006) suggest that economic resources improve health outcomes by reducing exposure to risky environmental conditions, my findings suggest that while this is true for urban areas, economic resources in rural areas may have more positive health influence on adults compared to children. In all three chiefdoms, children performed most outdoor activities such as fetching water, collecting firewood and helped their parents with farm work. Through gender role socialisation, children were more exposed to areas where the risk of tsetse fly bites is high, increasing their risk of contracting sleeping sickness as shown in Figure 12 below.



Figure 12: Gender role socialisation of children

Therefore, understanding such cultural practices helps to explain and understand why certain categories of individuals experience suffering and vulnerability more than others despite improvements in economic conditions. While these practices seek to socialise children, such cultural practices may inadvertently increase the vulnerability and suffering of children to the risks of sleeping sickness and schistosomiasis. It can therefore be noted that although all farmers I spoke to are exposed to tsetse fly bites, economic resources, age, and gender and ethnicity shape the frequency and degree of exposure to tsetse flies and risk of contracting sleeping sickness.

5.4 Understanding the role of game management areas as a source of livelihoods and risk to sleeping sickness

Although research has been done on protected areas (Chakuya et al., 2024; Chomba, 2012; Gandiwa et al., 2011; Gusset et al., 2009), focus has been limited to human animal conflicts and its impacts on the social, economic and health impacts of communities (Chomba et al., 2012; Gusset et al., 2009). While some studies have noted the possible implications of human animal interaction and living in or near protected areas and GMAs (de Vos et al., 2016; Nakamura and Hanazaki, 2017; Nyamwamu, 2016), limited research has explored the role of human animal conflicts, and other challenges such as lack of roads, water sources and health facilities on women, men and children's risk of contracting neglected tropical diseases such as sleeping sickness. Therefore, in this section, I contend that while living in the GMA increased vulnerability to human animal conflicts, which contributed to the Kunda and Chewa farmers' economic loss, constant interaction with livestock, wild animals and environmental conditions such as high density of vectors also increased the farmers' risk of contracting zoonotic diseases such as sleeping sickness. As my analysis and experiences in Mambwe district suggests, Kunda and Chewa farmers' awareness of the negative effects of

living in the GMA was limited to crop raids, livestock predation and sporadic attacks on humans. On whether they were exposed to risks of contracting diseases such as sleeping sickness, most farmers, especially those with Chewa background, seemed unaware of such risks as will be further explored later in this section.

While I was aware of the occurrence of human-animal conflicts in Mambwe district and had expected to encounter some wild animals, my courtesy call to the District Commissioner (DC) for Mambwe district on the morning of 8th June 2023 changed my perception of the situation. During my brief but informative meeting with the DC in his office at Mambwe Boma, I was advised to seek help from the Department of National Parks and Wildlife (DNPW) to protect me and the research assistants from wild animals on our way to Malama Chiefdom as people, locals and visitors, have suffered attacks from wild animals. Although I was initially worried about my safety and that of the research assistants, my conversation with the DNPW senior warden clarified and cleared my worries. However, a thought of how the communities coped with attacks from wild animals lingered on my mind throughout my stay in Mambwe district. Two days after my visit to the DC's office, I visited Malama Chiefdom to familiarise myself with the area and to seek access from the local gatekeeper to conduct my research. After interacting with the local farmers in Malama Chiefdom, I learnt that on the night before my visit, a lion had attacked a herd of cattle injuring two cows belonging to a Chewa farmer. Besides attacks from wild animals, my own observations and interviews with *alimi* in Malama, Nsefu, and Mnkhanya Chiefdoms further revealed their challenges with tsetse flies and access to basic services.

Despite the challenge of living alongside dangerous animals, and the risk of irritation, infection and disease from biting insects, more people were still migrating into Mambwe district from the surrounding chiefdoms due to increasing population and demand for fertile land (Anderson et al., 2015; Chomba et al., 2012). When I asked why, more Chewa farmers than Kunda farmers gave reasons that led to their migration into Mambwe district. As Memory, a 42-year-old married Chewa woman who migrated from Chief Nzamene's area explained, the need for fertile land to meet the needs of her growing family and livestock initiated her migration. Similarly, Mike, a 66-year-old married Chewa man, migrated from Chief Msoro's area in search of fertile land and good pasture for his livestock. Like Memory and Mike, many other *alimi* migrated to Malama, Nsefu and Mnkhanya Chiefdoms in search of fertile land and pasture, which would increase their yields and translate into increased income and enhanced wellbeing.

Accounts from wildlife workers, however, revealed that increased migrations into the district and absence of the game management plan contributed to habitation and introduction of agriculture and livestock keeping in previously uninhabited areas in the GMA. For example, areas such as Chulu 2 of Nsefu Chiefdom which served as animal corridors are populated by *alimi* from different parts of the province. Although livelihood activities such as farming and livestock keeping were permitted in the GMA, Yohane, a 53 year old wildlife worker noted that such livelihood activities attracted wild animals from the nearby South Luangwa National Park (SLNP) especially during seasons when there is limited food in the park. As a result, farming and livestock keeping by *alimi* contribute to cases of human- animal conflicts. As will be elaborated in the following section, Chewa farmers such as Memory and Mike experienced increased interaction with wild animals (Simasiku et al., 2008), and related challenges partly due to the location of their settlements and unavailability of services to ameliorate their vulnerability and suffering.

5.4.1 Challenges in the Lupande Game Management Area

Primarily, as suggested by Richardson et al. (2012), GMAs were established to serve as buffer zones between national parks and human communities while meeting the livelihood needs of settlers. Whilst living in the Lupande GMA presented Kunda and Chewa farmers with several benefits stated earlier such as hunting, smallholder farming, trading, and providing tourism hospitality services (Bwalya & Kapembwa, 2020), it also offered them several challenges which I categorised into human-animal conflicts, and access to basic services and infrastructure which are discussed further below.

5.4.1 Human- animal conflicts and risk of sleeping sickness

Researchers such as Rock et al. (2009) argue that humans, animals, and the environment have always existed side by side and depended on each other for survival through a balanced system of reciprocity. However, as noted by Messmer (2009) and Simasiku et al. (2008), human and wildlife interaction in some cases has had negative consequences on human communities and their livelihoods and negative consequences on wildlife (Becker et al., 2013). Other researchers such as Dzingirai et al. (2017a), have found that human-wildlife interaction also increases the overlap between humans, animals and pathogens creating a shared risk environment. While the interaction between humans and wildlife has yielded positive results as in the case of tourism in Mambwe district, continued presence of wildlife near human communities increases the presence of vectors such as tsetse flies within human dwellings, increasing the risk of contracting sleeping sickness. My findings suggest that Kunda and Chewa farmers experience three forms of human-animal conflicts (HACs) which

can be categorised as crop raids, livestock predation, and threats on human life and wellbeing. Regardless of form of HAC, Kunda and Chewa farmers' experience of HAC increased their vulnerability and risk of contracting some zoonotic diseases especially sleeping sickness due to increased interaction with wild animals which also attract tsetse flies.

Food insecurity and poverty

In Mambwe district, low levels of economic activities and development result in most of the population to rely on farming as the main economic activity with most farmers growing maize, groundnuts, soybeans, cotton, and rice for food and income (Banda et al., 2013). However, due to raids by wild animals such as elephants, baboons and hippos, Kunda and Chewa farmers I spoke to rarely achieved good harvests. This research finding is consistent with conclusions by Chomba et al. (2012) that elephants, hippos, and baboons are the main culprits behind crop raids and destruction, which contributes to food insecurity among participants in all GMAs in Zambia. As a result, Kunda and Chewa farmers remained vulnerable to food insecurity and low incomes due to low farm yields (Chomba et al., 2012). Although wildlife managers are aware of these challenges, absence of the game management plan and conflicts between traditional leaders and governmental institutions on management of land contributed to lack of immediate interventions by the DNPW. As concluded by Bwalya and Kapembwa (2020), lack of deliberate interventions to protect farmers and their crops discouraged most Kunda and Chewa farmers from engaging in agricultural activities due to fear of making losses, which would worsen their vulnerability to hunger and poverty.

However, while some *alimi* decided to stop growing crops, others whose lives depended on agriculture chose to adopt several strategies to protect their crops. As Rosie, a 45-year-old Kunda mother of six girls and one boy quoted below explained, her '*life*' (livelihood) and that of others within the Nsefu Chiefdom depended on spending nights in their fields guarding crops. Although, some *alimi* used chili pepper to protect their crops, this was proven ineffective.

When our crops grow, *nimabvuto* (problems)... we spend the whole night seated at our fields *kutandila* (making noise) to scare the *njovu* (elephants) away from our crops.... Without watching, then you would not harvest anything. Female, 45 years, IDI- Nsefu Chiefdom.

This illustrates how *alimi*'s food security and possible income are dependent on spending nights in their fields. Rosie's account shows that while she manages to guard her crops from

raids by spending nights in the maize fields, she and her husband remained vulnerable to mosquitoes at night and tsetse flies during the day. Consequently, these disease vectors exposed Rosie and her husband to the risk of contracting malaria and sleeping sickness respectively which threatened their health and productivity in other tasks (Nyirenda et al., 2018). Therefore, while guarding crops during the day and at nights partially guaranteed food security and income, it increased the risk of experiencing attacks by wild animals and contracting diseases such as sleeping sickness.

Rosie's experiences illustrate the vulnerability and risk associated with *alimi's* sources of livelihood and the negative effects it has on their health, social and economic wellbeing (Ochola et al., 2021). Whereas *alimi's* suffering and vulnerability to wild animal attacks and tsetse fly bites is rooted in broader environmental factors, these findings suggest that limited political will and existing tensions between stakeholders such as traditional leaders and government institutions hinder government's support to communities living in GMA to reduce crop loss and risk to zoonotic diseases such as sleeping sickness.

Livestock depredation

Besides crop raiding and destruction, *alimi* in the three chiefdoms also suffer from livestock depredation by lions and hyenas, another form of human animal conflict (Hazzah et al., 2009). As other researchers, such as Dabasso et al. (2022), have found, livestock serve socio-cultural roles and are a source of meat for farmers. Although these findings are compatible with Dabasso et al. (2022), my findings further suggest that among the Kundas and Chewas in the three chiefdoms, cattle formed the basis of agricultural production and a source of income. Whilst Lamarque et al. (2009) and Patterson et al. (2004) concluded that livestock depredation only affects farmers' economic resources, my findings further suggest that depredation also reduces Kunda and Chewa farmers' ability to practice farming on a large scale. Reduced ability to practice farming contribute to *alimi's* inability to meet their socioeconomic and health needs, such as purchasing drugs and other necessities. As Mako, a 53-year-old man of Malama Chiefdom explained, his savings and ability to earn a living were under threat due to persistent attacks from lions and hyenas. '*Just last night, two of my cows were attacked by a lion,*' he explained. '*Losing my animals means I cannot do anything here.*' This finding suggests that livestock depredation not only leads to loss of livestock, but also livelihood and ability to meet basic needs such as health among farmers, such as the Chewas who rely on cattle to cultivate. However, while Barua et al. (2013) acknowledges the existence of compensation payments for livestock lost to depredation, my findings indicate that Kunda and Chewa farmers did not receive any compensation to compensate

losses resulting from HAC, similar to findings by Chomba et al. (2012) in their study on causes, consequences and management of responses of human wildlife conflicts in Zambia between 2002 and 2010.

Therefore, to prevent attacks on livestock, men such as Maliseni, a 73-year-old retired untrained teacher of Mnkhanya Chieftdom, spend nights guarding their kraals from lion and hyena attacks. Although Maliseni can guard his livestock from lion and hyena attacks, like Rosie who spend nights guarding her crops, he remained vulnerable to disease vectors such as mosquitoes at night and tsetse flies during the day. This finding further suggests that similar to guarding crops from wildlife, protecting livestock increased exposure to disease vectors and risk of contracting diseases such as malaria and sleeping sickness. However, my analysis further indicates that while living in these areas pose these dangers, invasion of areas which were considered wildlife corridors has exacerbated these challenges. As Yohanne explained, pressure for land has driven immigrants to occupy and create their fields in wildlife corridors, which would be avoided if different stakeholders collaborated. This suggests that while HAC is a direct consequence of occupying certain areas, lack of collaborations among stakeholders contribute to the persistence of the problem. While *alimi* from other chieftdoms may not know the consequences of occupying certain areas, lack of deliberate policy to guide how land is used and distributed would help minimise these challenges.

5.4.2 Loss of human life

It is worth noting that while farmers, as shown in the previous section, engage in various activities to reduce the impacts of these conflicts, some strategies leave their lives at risk. As explained by Milika, a 39-year-old single mother of Nsefu Chieftdom, a herd of six elephants was provoked after she tried to chase them away from her maize field. Although two elephants charged towards her, Milika was not injured because the elephants stopped and left her field. Similarly, Mailesi, a 22-year-old Kunda mother of two lost her father who was attacked by a herd of elephants on his way to church in Malama Chieftdom. Mailesi described the anger she has for *nzovu* (elephants) but feels powerless to do anything. *‘I am so angry with nzovu, they killed my father, but nothing was done to them’* she explained, *‘but I have no power to do anything.’* While Mailesi expected immediate intervention from authorities, nothing was done. To support Mailesi’s conclusion, as researchers such as Chomba et al. (2012), have found, existing interventions on GMAs in Zambia do not prioritise human life and wellbeing. While human communities lived in designated areas, many a time wild animals encroached into human communities from the nearby south

Luangwa national park in search for food which in many cases resulted in conflicts and deaths (Gandiwa et al., 2011; Nyamwamu, 2016). However, such cases were treated as incidents by the DNPW and only offered support by killing the wild animal responsible for causing a death and the needed resources for the funeral.

While Milika and Mailesi's experiences show how lack of institutional support shaped intensity and experience of vulnerability and suffering, it also reveals how competing narratives and tensions between stakeholders increased the risk of suffering and vulnerability to attacks from wild animals and risk to zoonotic diseases such as sleeping sickness. For example, while Kunda and Chewa farmers expected authorities to provide resources to protect their wellbeing and livelihoods, Yohane, a 59 year old wildlife worker on the other hand, sees these challenges to be due to occupation of areas that are not designated as conducive for human settlement and practicing of livelihood activities such as farming and livestock keeping. However, by excluding farmers' experiences in policies on land use, compensation, and conservation, government institutions and nongovernmental organisations reinforce and perpetuate marginalisation and inequalities of individuals living in GMAs. Ultimately, this tension among stakeholders and omission contributes to negative perception of conservation programmes and increasing unsustainable practices such as illegal hunting, charcoal, and timber production (Bwalya & Kapembwa, 2020).

Therefore, although Kunda and Chewa farmers performed their daily duties and roles, their lives are filled with uncertainty and fear (Gandiwa et al., 2011; Nyamwamu, 2016). Yet their economic vulnerability and desire to meet their needs exceeded their fear of risks associated with living in the GMA (Weyman and Kelly, 1999). Reflecting on Goffman's (1959) impression management, participants, though in fear, merely put up an act to show normalcy in order to earn a living (Weyman & Kelly, 1999). This finding suggest that economic vulnerability and other intersecting factors make it inevitable that people will come in contact with wildlife. While the continued human wildlife contact increase chances of spillovers of some zoonotic diseases from wild animal hosts to human and livestock populations, this interaction also leaves the farmers at risk of other harms (Daszak et al., 2000). Therefore, these findings suggests that human animal conflict does not only expose farmers to economic and social vulnerability and suffering but also increases their vulnerability to health risks due to continued contact and interaction with wildlife.

5.4.3 Access to basic services and infrastructure

Water

Beyond the challenging experiences and misfortunes Kunda and Chewa farmers have with wild animals in the GMA, their accounts further revealed challenges with access to basic services and infrastructure especially water. While global evidence shows gains in access to improved water sources, these gains are more in urban areas (2.1 billion) compared to rural areas (703 million) where people still rely on unimproved and unsafe water sources (WHO & UNICEF, 2023). Similarly, about 72 percent of Zambian households have access to improved water (Zambia Statistics Agency and ICF, 2019). Yet, access is still a problem in rural areas where only 58 percent have access to improved water sources compared to 92 percent in urban areas (ZSA, 2019). Farmers' accounts and descriptions of water challenges within their villages included phrases such as '*tikhala ngati nyama*,' (we live like wild animals), and '*manzi si alibwino*' (water is not safe). These phrases imply that although water is available, farmers still 'lived like wild animals' with no access to clean and safe sources of water.

While farmers spoke about the available water sources near their villages, I observed that while available, water was either inaccessible or unsafe to use. It was also observed that improved sources such as boreholes were available, they were located further from the farmers' villages. For example, in Katemo of Mnkhanya Chiefdom, the nearest borehole was in Chota village, approximately six kilometres away. Therefore, clean water was collected from the borehole twice or thrice a week by children aged between nine and thirteen years using ox carts and bicycles (Figure 9), an activity which exposes them to tsetse flies and sleeping sickness (Ochola et al., 2021).

However, for other water needs such as washing, cleaning, and bathing, farmers relied on unimproved sources such as lagoons, and the nearby streams where children and women collect water for home use despite associated risks. While other researchers, such as Robinson and Howland (2022), have found that women in Kenya were not aware of the risk posed by clear but stationary water, women I spoke to were aware of the risks of clear but contaminated water, and risk of sharing water sources with their livestock and wild animals. For that reason, specific measures such as sieving and boiling were implemented to make the water safe. Yet, despite the awareness and measures adopted to make the water safe for use, farmers, especially women and children, remained at risk of contracting waterborne and zoonotic diseases such as schistosomiasis and sleeping sickness respectively. Firstly, because of their reliance on contaminated water to carry out chores such as washing, and

secondly, because of limited awareness of possible transmission of zoonotic diseases when walking through the bush and during their interaction with livestock at water points (Figure 13). Therefore, while all farmers are at risk of contracting waterborne diseases, the risk was higher among women and children due to their constant contact with contaminated water.



Figure 13: Water sources

These findings further suggest that while water challenges affected all farmers in Nsefu, Malama and Mnkhangya Chiefdoms, farmers without cattle or a bicycle faced more accessibility challenges compared to farmers with livestock. Although farmers without any means of transportation relied on the good will of those with ox carts to access clean water, their main source of water was still limited to unimproved water sources such as lagoons and rivers like the Lusangazi and Mwangazi which served both livestock and wild animals. As other researchers, such as Aagaard-Hansen et al. (2009) and Ochola et al. (2021), have found, reliance on unsafe water sources leaves Kunda and Chewa farmers vulnerable to diarrheal diseases. As Maliseni, a 73-year-old man of Mnkhangya Chiefdom quoted below explained, dependence on unsafe water sources by his village contributed to frequent episodes of diarrhoea in his household and the village at large.

‘Kuno nkani ya manzi ndiyo bvuta (Here the issue of water has been a problem), we drink unsafe water. So, you can’t go for 2 weeks *osadwalako mumimba* (without any stomach problems) because the water is not safe. Male, 73 years, IDI- Mnkhangya Chiefdom

While official figures on access to clean water in rural Zambia show an improvement (58%) (ZSA, 2019), Maliseni’s experiences revealed inequities in provision of clean water between urban and rural areas, resulting in increased occurrence of waterborne diseases among rural communities. These findings are consistent with those by other researchers who observed that continued use of unimproved water sources expose individuals especially women and girls to risk of waterborne diseases (Bain et al., 2014; Ochola et al., 2021; Shomuyiwa et al.

2023). In addition, my findings reveal that use of unimproved sources such as lagoons and rivers exposed all farmers to vectors such as tsetse flies which increases their risk of contracting sleeping sickness.

However, due to gender role socialisation, both girls and boys in homes with or without cattle performed outdoor chores on behalf of their parents. This finding implies that while women and men are exposed to tsetse fly bites in both homes with or without cattle, children get more exposed to tsetse flies and risk of contracting sleeping sickness and waterborne diseases regardless of their family's economic resources. Similarly, while Ochola et al. (2021) and Shomuyiwa et al. (2023) suggest that outdoor tasks such as collecting water and firewood increased women and girls' exposure to vectors and risk of contracting NTDs such as sleeping sickness; my findings posit that while this observation is true for women and children in homes with no cattle, women who have cattle rarely engage in outdoor activities such as fetching water and collecting firewood. Due to inaccessibility of clean water and firewood sources, some men with cattle, especially Chewas, performed outdoor tasks on behalf of their women in addition to herding cattle in the bush (Dernberger & Pepin, 2020). As a result, some women, especially those with Chewa background, only encountered risk of tsetse fly bites during farm work, sporadic collection of wood and water and from tsetse fly bites within their villages.

This study's evidence contributes new insights into the established assumptions about the role of water accessibility and economic resources in influencing gender role performance and exposure to risk of contracting diseases by children, men, and women. While women and children in homes without cattle are exposed to tsetse fly bites (Ochola et al., 2021), this study posits that availability of economic resources such as cattle does not change the risk to children; but only contributes to gender role flexibility among men which results in reduced exposure of some women to areas with tsetse flies. As other researchers, such as Glass et al. (2014), have found, possession of livestock improves women's health in areas with limited access to quality health and social services while increasing the exposure of men and children to risk of diseases.

Roads and healthcare infrastructure

Although rural roads serve a pivotal role in alleviating poverty, gender equality and creation of sustainable livelihoods among the rural populations (Sewell and Desai, 2016), the three chiefdoms are yet to see the benefits of improved roads. I asked the farmers to further describe the implication of these challenges on their wellbeing, both men and women spoke

about how the lack of developed roads hindered their access to markets and healthcare facilities especially during the rainy season. As Anna, a 26-year-old mother of two explained, walking to Nsefu or Masumba zonal rural health centres (20km) was challenging for her because of the distance and impassable roads especially during the rainy season. As a result, Anna, like other farmers, opted to stay back at home especially when she was too sick to walk. These experiences by farmers like Anna reflect how geographical limitations and institutional challenges to equitably distribute resources and infrastructure reinforced and perpetuated the vulnerability to diseases and suffering of Kunda and Chewa farmers. As Hierink et al. (2021) have found, poor accessibility to healthcare facilities contributes to a higher disease burden among farmers, reliance on alternative methods such as herbs, and lower disease diagnosis and reporting.

Kunda and Chewa farmers' experiences of challenges in the Lupande GMA reflect the existing societal structures and process which worsen their struggles and misfortunes. Drawing on Giddens (1994) structuration theory, participants' suffering and vulnerability in the GMA is embedded in the inadequacies within the existing power structures and policy on GMAs. Although current regulations permit human settlements in the GMAs, lack of basic services such as roads, accessible healthcare facilities and safe water is another way of suggesting to settlers like Maliseni and other farmers that they are 'on their own'. This may imply shifting the blame to the farmers, and that they were responsible for their experience of suffering and vulnerability (Douglas, 1992).

5.5 Chapter summary and conclusion

This chapter set out to explore the community's health dynamics within the context of Lupande Game Management Area (GMA) in Mambwe district. I have indicated that community challenges such as human-animal conflicts, water and health facility problems influenced Kunda and Chewa farmers' exposure to tsetse flies and the risks of contracting diseases. The findings suggest that risk of contracting sleeping sickness reflects a complex intersection of factors that influence and relate differently with participants' social positions such as gender, ethnicity, age, and their economic status. This means that in addition to participants' culture and established system of livelihood, their exposure to areas with tsetse flies and risk of contracting sleeping sickness may reflect the existing institutionalised inequalities in resource distribution and provision of infrastructure in rural communities such as Mfuwe (Hankivsky, 2014). It can be argued that although use of herbs is associated with cultural traits, the unequal distribution of healthcare facilities combined with geographical

locations inadvertently contributes to use of herbs by impeding certain groups from accessing medical care.

Throughout this chapter, I have highlighted the role of gender and ethnicity in influencing exposure to vectors and risk of contracting sleeping sickness, disease awareness, health seeking and use of herbs among participants in all the three chiefdoms studied. While the chapter presented individual experiences reflecting the existing structures they live in (Bowleg, 2012), it also highlighted the social realities of inequality and power in the three chiefdoms which shape, and influence participants experiences of suffering and vulnerability. Therefore, participants' experiences and vulnerability can be linked to broader discussion on structural violence and social suffering which results from political, economic, and institutional power (Kleinman et al., 1997).

Thus, this study's findings are broadly in line with those of previous researchers such as Ochola et al. (2021) and Neema et al. (2021) on the role of gendered roles on exposure to risk of NTDs. Although these findings are broadly consistent with the previous research (Ochola et al., 2021; Neema et al., 2021; Mwiinde et al., 2022), there are several areas in which they differ. For example, while my findings confirm that gender disparities play a significant role in shaping risk of exposure to vectors, age, ethnicity, lack of education, and limited access to resources influence how women and men experience vulnerabilities to risk of NTDs and barriers to healthcare. Therefore, my findings support the need for gendered understandings of diseases and a One Health approach which applies intersectionality thinking to understand and improve rural populations' health (Woldehanna and Zimicki, 2015).

Building on this chapter's discussion, the next chapter, where I discuss the gendered realities in Mambwe district, will situate how gender is embedded in the various aspects of life of the farmers and why it is important to consider gendered understanding of sleeping sickness in its management and control.

CHAPTER SIX

UNDERSTANDING RISK OF SLEEPING SICKNESS THROUGH EVERYDAY LIFE AND POLICY DISCOURSE

6.0 Introduction

This chapter builds on the previous chapters to establish that gender and gendered roles in *alimi's* everyday life intersecting with policy discourse significantly contribute to experiences of vulnerability and suffering among Kunda and Chewa farmers in Mambwe district. I explore how gender and gendered practices shape farmers' experiences of healthcare and risks of sleeping sickness. By focusing on social factors such as gendered roles, household decision making and economic resources, my findings provide insights into how gender shape the Kunda and Chewa farmers' exposure to disease risk, health seeking behaviour, and outcomes. I also consider how the existing policy and legislation landscape on health and on issues of gender in Zambia contribute to current health challenges related to sleeping sickness. Ultimately, I will address the third research question: *How can these gendered One Health understandings inform national policy for controlling neglected tropical diseases (NTDs) such as sleeping sickness in Zambia through policies, and programme implementation that promote gender equality and health equity among different categories of people in rural communities?*

Thus, I have organised this chapter in four main sections. In the first section, I explore how gender intersecting with background characteristics of Kunda and Chewa farmers create varying identities that influence their exposure to sleeping sickness. I argue that the unwritten social norms and expectations influence how women and men in Mambwe's Nsefu, Malama and Mnkanya Chiefdoms engage in livelihood activities and distribution of resources within households. I contend that gendered roles and responsibilities among Kunda and Chewa farmers translate in variations in economic resources, socioeconomic status, access to healthcare and overall wellbeing of the farmers.

I then proceed to show that while gender shapes health seeking and utilisation of healthcare, ethnicity intersecting with economic resources such as possession of cattle play a significant role in shaping perception of medical care, illness, and health seeking. I contend that farmers with characteristics such as being Chewa, having low education level, and lack of cattle face compounded barriers to accessing diagnosis, and treatment of possible cases of sleeping sickness. The third section shows that gender related differences in health behaviour and risk to sleeping sickness is rooted in traditional gendered roles and responsibilities children,

women and men perform. I further argue that domestic duties and livelihood activities shape the farmers' experience of risk of contracting sleeping sickness.

The fourth section shows the policy and legislation landscape on health and on issues of gender in Zambia. I argue that despite this rich policy framework, there are gaps that exist especially regarding the gendered understandings of NTDs such as sleeping sickness, access, and utilisation of health services. I further contend that the current policy framework does not consider interdisciplinary collaborations towards management and control of sleeping sickness. I indicate that current frameworks inadvertently contribute to limited understanding of neglected tropical diseases especially sleeping sickness due to lack of support for interdisciplinary collaborations needed to have an effective approach to manage sleeping sickness in Zambia. Consequently, I argue that such policy gaps play a significant role in perpetuating and reinforcing farmers' vulnerability to sleeping sickness and its consequences. Therefore, through a gender lens, this chapter explores how individual farmers' experiences of risk and vulnerability are rooted in policy, the broader community norms, cultural expectations, and environmental dynamics in which they live every day.

6.1 Intersecting identities and risk of contracting sleeping sickness

As highlighted in chapter four and five, unequal power relations and decision making within Kunda and Chewa households contribute to unequal economic resources between women and men which has contributed to disparities in the ability of women and men to access and utilise the available healthcare services. Although I indicated that livestock serve as an important source of income for both men and women in Mambwe district, I argued that women are disadvantaged in terms of income due to the low market value of the type of livestock they keep and own (Badstue et al., 2020). For example, although men owned cattle in addition to small ruminants in their own capacities, most Kunda and Chewa women I interviewed were limited to small ruminants such as goats, pigs, and fowls such as chickens which they kept in their own capacities. In contrast, of the men interviewed, only Chewa men owned cattle and some small ruminants such as goats and pigs while Kunda men only owned chickens. Consequently, variations in the value of economic resources owned between Kunda and Chewa farmers, men and women, contributed to differences in how the farmers accessed healthcare facilities and treatment, resulting in varying levels of suffering and vulnerability due to structural violence. This evidence suggests that unlike Chewa men who owned cattle, Kunda men and women who owned small ruminants and fowls with less economic value were likely to have limited resources to enhance their urgency and ability to access the available healthcare services in their area (Agarwal, 1997; Kabeer, 1999).

Furthermore, among Chewa women and men who co-owned cattle and other small ruminants with their spouses, men and boys in the household managed and handled all income and economic aspects of the livestock as illustrated in the following excerpt by Juliet, a 49-year-old married Chewa woman living in Mnkhanya Chiefdom. This finding is consistent with the findings of Bukachi et al. (2023) in their study on gender linked dynamics and sustainable smallholder poultry value chains in Kenya. Their findings show that while women managed and contributed to the poultry business, men managed and made decisions on all income realised from the business.

Well, the boys or my husband are responsible for charging and collecting the money from those who come to hire the oxcart because they are the ones who look after the animals. Female, 49 years, IDI-Katemo, Mnkhanya Chiefdom

Juliet's narrative reveals how gendered roles and expectations shape management of income and economic resources within her household. Although Juliet, like other women, jointly owned the livestock with her husband, the gender roles associating men with decision making and management of livestock and economic proceeds earned from hiring the cattle hindered her access to income which would enhance her wellbeing and agency to make decisions on various matters including her health and access to services (Badstue et al., 2020; Bukachi et al., 2023). This finding provides insights into how traditionally determined decision making and power imbalances between men and women within Chewa and Kunda households contribute to women's limited economic resources and inability to access services such as healthcare. As other researchers, such as Rilkoff et al. (2013) have found, gender based economic barriers within the three chiefdoms reflect deeper gendered economic gaps between men and women, a contributor to the observed differences in agency to access healthcare and treatment among Kunda and Chewa farmers, women and men. This finding confirms results of a study by Okwa (2007) who found that although poverty and illiteracy and lack of information on NTDs affects both men and women, women are more affected because of their limited economic status, low education and usually lack ownership of resources compared to men.

These findings reveal that economic inequalities within Kunda and Chewa households limit the farmers' ability to access distant healthcare services and purchase prescribed medicines, inadvertently contributing to their increased vulnerability to ill health and poverty. Driven by the desire to enhance their well-being and productivity by settling in areas offering better farming and livestock keeping opportunities such as the Lupande GMA, many Kunda and Chewa farmers are left vulnerable to poverty and increased risk of sleeping sickness, forms

of suffering resulting from their reliance on the natural environment for a livelihood and survival.

Drawing on Parsons' (1959) writing on social systems, my findings suggest that while culturally and religiously determined gender, economic and education inequalities among the Kunda and Chewa farmers contribute to community stability, the system of roles and responsibilities also hinders the Kunda and Chewa farmers from achieving better health and wellbeing. For example, because of their gender roles and responsibilities, individual farmers with varying characteristics experience suffering from systemic inequalities and risk of diseases differently. Furthermore, as explained by Juliet, the Kunda and Chewa system of roles and responsibilities also indirectly reduced involvement of certain groups such as women in activities that would enhance their economic wellbeing. Consequently, the existing systems of gender division and economic resource distribution contribute to the farmers' vulnerability to poverty and risk of contracting sleeping sickness through established systems of earning a living.

As argued by Butler (1988) in her essay on performative acts and gender constitution, gendered division of labour among the Kunda and Chewa farmers reinforce power imbalances and unequal access to resources which constrain the farmers' ability to access healthcare services and economic opportunities, indirectly increasing their vulnerability to illness and suffering to ill health and poverty. These findings suggest that the Kunda and Chewa farmers' vulnerability to suffering and risk of sleeping sickness is shaped by their livelihood roles, and where these are performed. Thus, my findings indicate that Kunda and Chewa farmers' individual characteristics such as gender, education, ethnicity, marital and economic resources intersect with their cultural and religious system of roles and responsibilities to create identities that contribute to their vulnerability to sleeping sickness, poverty and consequences associated with their livelihoods such as human wildlife conflicts.

As Mako, a 60 year old Chewa man of Malama, explains, the unwritten social norms and expectations among farmers in Mambwe district shape the duties and activities performed by women and men. Having migrated from Katete three years ago in search of fertile land and water resources, Mako, like other Chewa farmers in other chiefdoms, perform roles and duties based on his gender and the cultural norms, which also determine the responsibilities of women, and children. For example, as shown in figures (14 and 15) and the excerpt below, women and girls clean, cook and fetch water while men and boys, herd cattle, and construct houses in their villages among other tasks.

The daily chores that women and girls do here is mostly cooking and washing, cleaning, fetching water. Herding of cattle is done by the boys or me. The girls do not take part in that, only the boys do. Male, 60 years, IDI- Malama Chiefdom

In addition to the above chores, Mako and his family, like other farmers in the three chiefdoms, are also involved in field preparation and cultivation, a critical component of their livelihood. While the whole family is involved in cultivation, like other Kunda and Chewa farmers, Mako's account revealed that men and women performed different roles. For example, during farming season, men, women and children labour in the fields from dawn until midday when women are excused to go and prepare the midday meal. In the afternoon, Mako continues to work while the women and children are excused to go and fetch water and prepare for the evening. Mako, sometimes accompanied by his eldest son, spend time guarding his crops or his livestock depending on the season, an activity which he described to be very dangerous. While cultivation exposed both children, men and women to tsetse fly bites and other health risk such as attacks from wild animals, gendered role division such as protective roles performed by men, and caring roles performed by women shaped the farmers' exposure to various health risks which contributed to their suffering from the outcomes of illness such as poverty and stigma in the case of sleeping sickness (Mwiinde et al., 2017).



Figure 14: A woman carrying water containers and a girl washing dishes



Figure 15: Herders and a herd of cattle

These gendered tasks, while important towards their economic livelihood, expose Kunda and Chewa men and boys like Mako to the dangers posed by wildlife and disease vectors such as tsetse flies and mosquitoes (Franco et al., 2014). Equally, as observed by Ochola et al. (2021) in Uganda, women and children, including Mako's wife and daughters, who are responsible for various chores including fetching water from the nearby stream as well as caring for the sick in the family remain vulnerable to waterborne diseases.

Although roles and responsibilities within households are divided along gender lines as illustrated above, my findings show that Kunda and Chewa men dictated what roles family members performed regardless of their gender. For example, while men and women have clear cut roles, children below the age of 10 years mostly carry out chores and task that women do. Further, older children aged above 10 years but not yet married were assigned roles and responsibilities by the men. It should be noted that while there is this flexibility in roles and responsibilities for children, they were still socialised in gendered roles with girls intensifying in what are termed *feminine responsibilities* such as cooking, cleaning, washing, fetching water and collecting firewood while boys focus on *masculine responsibilities* such as herding and cultivating, and constructing huts (Yoshida, 1992). While these findings clearly show how roles are divided according to gender, Kunda and Chewa men are the main decision makers who control all resources within their households. My findings are consistent with conclusions from previous researchers who have found that regardless of ethnicity, economic resources and age, men control household resources (Badstue et al., 2020b; Bukachi et al., 2023). These power imbalances and unequal access to household resources indirectly limit most married Kunda and Chewa women's ability to control and utilise household resources to access healthcare services when they needed them (Kabeer, 1999). As a result, unequal access to household resources and income between men and women within the Kunda and Chewa villages perpetuate and reinforces the already existing variations in risk and delayed detection of NTDs such as sleeping sickness among different categories of farmers, children, men and women.

These findings suggest that while gender roles and division of labour shape frequency and exposure to risk of contracting sleeping sickness, risk of contracting sleeping sickness is fluid when other intersecting factors such as age, marital status, ethnicity and economic resources are considered. While my findings are consistent with conclusions by Ochola et al. (2021) and Neema et al. (2021) that women and children perform most outdoor tasks and thus face higher risk of contracting sleeping sickness, my findings further suggest that men also experience risks through the outdoor tasks such as hunting, timber harvesting, and

charcoal production, which are performed in areas with high densities of tsetse flies and other disease vectors. Therefore, as observed by Ssali et al. (2023) that traditionally determined gender roles men and women perform expose them to schistosomiasis in Pakwach district in Uganda, my findings suggest that culturally determined gender roles such as herding and protective roles for men, and caregiving roles for women, shape their risk of contracting sleeping sickness and other NTDs.

6.2 Gendered barriers to healthcare among *aKunda* and *aChewa*

Multiple social factors contribute to unequal access and utilisation of healthcare between men and women among Kunda and Chewa farmers. Because of their individual characteristics, Kunda and Chewa farmers face compounded barriers to accessing preventive, diagnostic, and curative care of possible cases of sleeping sickness (Ssali et al., 2023). The varying but similar characteristics of Kunda and Chewa farmers, women, men and children, play a significant role in determining their identity, experience of risk and utilisation of healthcare facilities available to them. Factors such as gender, marital status, ethnicity, age, education, geographical location and economic resources such as possession of cattle provide insights into the farmers' social, economic and cultural context which also influence their experiences of risk of contracting sleeping sickness and overall health seeking behaviour (McGibbon & McPherson, 2011). Several studies in both low and high income countries highlight how access and utilisation of health services and care is shaped by individual characteristics and institutional factors. For example, a study by Bielińska et al. (2022) on equal access to healthcare in national legislations in four European countries (Croatia, Germany, Poland, and Slovenia) found that despite the existence of legislation to enhance access to healthcare, legislative barriers for individuals with diverse race, religion, sexual orientation and based on individuals' gender identity in all countries of study still exist (Bielińska et al., 2022). Similarly, as argued by Ruger (2006) in their study on rethinking equal access- agency, quality, and norms, differences in healthcare quality, agency and norms lead to injustice within healthcare. As noted by other researchers such as Bielińska et al. (2022), Ruger (2006), and Ssali et al. (2023), access and utilisation of healthcare is determined by institutional factors intersecting with individual characteristics. This suggests that while individuals are expected to meet requirements to access and utilise healthcare, ultimately, institutions are responsible of ensuring that individuals' ability to access and utilise the available healthcare services is enhanced.

Similarly, in terms of health utilisation between men and women from the Kunda and Chewa ethnic groups, my findings show that both women and men rarely visited the healthcare

facilities. When asked to explain lack of health visits when sick, Kunda and Chewa participants gave several reasons for this health behaviour. As indicated in chapter four, Kunda and Chewa tradition and culture consider diseases to have both biological and supernatural causes such as witchcraft. Because of the cultural and religious beliefs, the Kunda and Chewa farmers' health seeking behaviour and utilisation of the available health services is shaped by their reliance on indigenous methods of diagnosis and treatment. For example, all farmers I interviewed confirm the use of herbs as their first line of treatment or as an alternative used parallel to modern medication. Although accessibility and trust in the effectiveness of herbs by farmers may be deemed as a contributing factor as suggested by Galabuzi et al. (2010) and Mutola et al. 2021), my findings further suggest that Kunda and Chewa farmers' cultural practices and beliefs that illness is caused by witchcraft, or supernatural powers shaped their belief and trust in herbs. While the farmers acknowledge the existence of communicable and non-communicable diseases, their strong belief in witchcraft superseded the role of pathogens in the process of causing diseases. While diseases from God would easily be managed as highlighted in chapter four, diseases from humans were difficult to manage and control (Yoshida, 1992). This belief shaped how farmers perceived undiagnosed diseases and possible cases of sleeping sickness as diseases caused by witchcraft. As reflected in their conversations, the farmers' approach to management of undiagnosed diseases involves either complete reliance on herbs or a combination of herbs with religious interventions informed by prayers and use of holy water.

As a result, Kunda and Chewa farmers' belief in dual cause of illness and diseases shapes their response to symptoms, and utilisation of the available healthcare services. This position is similar to the views and experiences of key informants working within the field of human medicine who observed rampant use of herbs among farmers in Mambwe district. Although the key informants in the field of human medicine acknowledge that herbs used by the farmers have worked in some instances, their overall position is that use of such herbs has mostly contributed to life threatening complications, especially for pregnant women trying to hasten the process of labour (Nyirenda & Maliwichi, 2010). Similarly, farmers, from both ethnic groups, also rely on traditional herbs such as *geza*, a combination of herbs used to manage symptoms of STIs despite the availability of modern drugs. However, the medical experts noted that despite the perceived effectiveness of these herbs, ultimately, the use of such herbs caused side effects which threatened the lives of the farmers, such as dehydration caused by excessive vomiting and diarrhoea.

These observations suggest that the farmers' current health behaviour and practices reflect the existing cultural knowledge and narratives about diseases and their management. This implies that limited awareness and screening for diseases such as sleeping sickness at the healthcare facilities constrain the Kunda and Chewa farmers' knowledge and understanding of sleeping sickness leaving them at risk and vulnerable to the disease. Furthermore, lack of screening of patients with symptoms of HAT also contributes to the Kunda and Chewa farmers' continued reliance on less effective traditional systems of diagnosis and treatment of possible cases of sleeping sickness (Mwanakasale & Songolo, 2011). In addition, the inaccessibility of the available healthcare facilities and shortages of drugs hinder the farmers' visits to healthcare facilities. While this was a challenge to all farmers, my findings also show that most single women, despite acknowledging the challenges highlighted by men and some married women, emphasised their challenges with accessibility as they lacked resources to facilitate their access to the healthcare centres. Consequently, in addition to their poverty, low education and lack of economic resources such as livestock, most Kunda and Chewa single women, like men, were susceptible to using herbs which are less effective and are at risk of experiencing diseases complications due to lack of access to professional care. This observation suggests that while all farmers faced challenges in accessing healthcare, single women suffered more from inaccessibility of healthcare facilities. This finding illustrates that despite gender, economic resources and ethnicity being significant contributors of experience of risk and suffering, farmers' marital status in the rural areas intersect with existing healthcare challenges to create barriers to access healthcare and health resources such as effective diagnosis and treatment thereby increasing their vulnerability to sleeping sickness and its consequences.

Therefore, the existing cultural and institutional inequalities in the distribution of economic opportunities, health resources such as healthcare facilities in rural areas, and the lack of financial support prioritising NTDs such as sleeping sickness reflect structural violence experienced by the Kunda and Chewa farmers in the three chiefdoms (Kleinman, 1988). This structural violence further contributes to disparities in awareness of the nature and dynamics of sleeping sickness between men and women living in Mambwe district; the available medical care and treatment, indirectly reinforcing delayed diagnosis and treatment of possible cases of sleeping sickness and other NTDs (Musoke et al., 2014). Structural violence contributes to policy and interventions that overlook the gender specific risks associated with sleeping sickness, restricting the ability of men and women to access health information and services on sleeping sickness and other NTDs. While other diseases such as malaria are accorded adequate resources and priority, sleeping sickness and other NTDs have

not been given high priority as observed in limited equipment to diagnose, limited training and capacity building and research in humans in Mambwe district and Zambia at large.

While these limitations within the healthcare system reflect structural violence, the inability to diagnose NTDs inadvertently influence the overall health behaviour and health seeking of Kunda and Chewa farmers and reinforces the existing gendered risk of contracting sleeping sickness. As a result, inequality is perpetually embedded in health and political systems which are entrusted with the responsibility of providing interventions to health problems. However, biases towards certain diseases have contributed to lack of gender specific interventions targeting risks experienced by men and women, contributing to poor health seeking and utilisation of the available healthcare services by the Kunda and Chewa farmers in Mambwe district. Therefore, Kunda and Chewa farmers' reliance on traditional medicine, their limited awareness of the nature of sleeping sickness and other neglected tropical diseases in Mambwe district does not only reflect individual characteristics and conditions, but challenges and dysfunctions of institutions responsible of decision making and distributing resources to rural communities (Farmer, 2004; McGibbon & McPherson, 2011). The findings suggest that structural violence, intersecting with cultural norms and gender, produce advantages and disadvantages among Kunda and Chewa farmers which contribute to the observed variations in roles and tasks performed and overall risk of contracting sleeping sickness.

6.3 Gender roles, responsibilities and risk of sleeping sickness in Mfuwe

Gender roles and the division of labour between men and women among rural communities in developing countries have been central in studies focusing on health and wellbeing. Researchers, such as Allen (1988) and Ochola et al. (2021), have further suggested that the division of tasks and roles between men and women is unequally done and results in women and children performing more work than men, contributing to variations in disease risk and health outcomes between men and women. Among the Kunda and Chewa farmers, for example, I identified various categories of tasks that are performed by women, men, and children and the associated risks. As observed by Whitehead (1999) among the Lamba people of Copperbelt province of Zambia, the main tasks among the Kunda and Chewa households included farming, food preparation and cooking, household chores, foraging, herding, building, and casual work in other farms, which I further categorised as food production, economic activities, and household activities.

Although Kunda and Chewa farmers referred to all these tasks as '*nchito*', which translates to '*work*', these tasks were differentiated from each other based on the value to the family

and whether the whole family or specific members were involved. For example, food production, which involved cultivation, and any farming related activity, was considered the main source of livelihood for families, and every family member was involved. However, household chores such as collecting firewood, collecting water and herding livestock are divided by gender and women and children were expected to perform these tasks in the household. Among Chewa farmers for example, men were limited to herding livestock and constructing structures within their household in addition to sporadic errands. However, although men performed fewer household chores, as observed by Whitehead (1999) among the Lamba of Copperbelt province in Zambia, Kunda and Chewa men engage in other non-agriculture activities such as piece works in safari camps, hunting and charcoal and timber production. However, as argued by Whitehead, (1999), these non-agricultural activities are usually omitted as part of men's daily gender roles and tasks they perform to earn additional income besides their primary sources of income.

Therefore, while other researchers such as Ochola et al. (2021) argue that risk of contracting NTDs among women is high because they perform more chores and outdoor tasks in areas with tsetse flies, my finding suggests that although men perform their tasks such as herding and hunting in different areas, the risk and frequency of interaction with tsetse flies is the same. This finding is consistent with conclusions by Allotey and Gyapong (2005) and Nambala et al. (2022) who reported cases of sleeping sickness among men and women due to gendered roles and tasks which increased their interaction with tsetse flies. These findings show that even if variations in cases diagnosed between men and women may exist, both genders are exposed to the risk of sleeping sickness. For example, among Kundas and Chewas, socialisation of young children is always done to fulfil the gender roles and responsibilities (Banda et al., 2013; Yoshida, 1992). Boys aged between 8 and 16 years are tasked with outdoor activities such as herding cattle in the bush and maize fields while girls of the same age are tasked with household responsibility of fetching water and picking firewood in addition to cooking and cleaning. Differences in duties between boys and girls as well as where the duties are performed, shows how gendered socialisation of roles shaped variation in exposure to tsetse flies between boys and girls.

I will consider firewood collection as an example. Although firewood serves an important cultural and economic role in preserving the taste and cost of energy among Kundas and Chewas, its acquisition is gendered and associated with increased risk to exposure to wild animals and tsetse flies. The daily visits to these sites by women and children increased their risk of getting tsetse fly bites and contracting sleeping sickness (Ochola et al., 2021).

Although the Kunda and Chewa farmers are aware of the possible dangers and health risks associated with the collection of firewood (Fathallah & Pyakurel, 2020), the farmers, especially women and children, still perform this task to fulfil social expectations associated with their status as women and children within the community. The need to fulfil social expectations changes the women and children's perception of risks and dangers associated with collecting firewood. While acknowledging the possible effects of tsetse fly bites on their wellbeing for example, the women accepted their suffering from the tsetse fly bites and risk as part of their lives in the game management area (GMA). As illustrated in the excerpt below from my interview with Maiwase, a 53 year old Chewa woman, her account like that of other Kunda and Chewa women in Nsefu Chiefdom reveals how going to collect firewood *kusanga* (in the bush) is merely visiting tsetse flies' home, as a result, the farmers knew what to expect.

Kuluta kusanga kuyotola nkuni nikuzipeleka ku n'anda ya kamzembe na nyama
(Going in the bush to collect firewood is taking ourselves to the home of tsetse flies and wild animals). So, we expect to find these, there is nothing we can do. Woman, 53 years, IDI-Nsefu Chiefdom.

The quote above illustrates these women's awareness of the risks and dangers of performing tasks such as collecting firewood in the bush. However, participants appear to accept this as an aspect of their daily lives. The report of the participants' adoption of protective measures, such as the use of traditional medicine to protect themselves from snakes and other animals, suggests two things. Firstly, it highlights that the participants (as Kunda and Chewa farmers) were aware of the challenges and risks associated with the environment where they perform their livelihood activities, such as herding cattle, charcoal production, timber harvesting and collecting firewood. Secondly, it also points to the resilience that they have developed to survive the conditions found in the GMA. However, despite these participants' awareness of the risk and survival strategies, their limited knowledge of the risks of tsetse fly bites in humans influenced them to focus more on the effects of tsetse fly bites suffered by their livestock than responding to the potential risk from sleeping sickness.

While the Kunda and Chewa farmers acknowledged that their experience of the negative consequences of the challenges associated with performing livelihood task such as collecting firewood was suffering, poverty due to low levels of economic activities and disparities in resource distribution, their religious beliefs and faith about the importance of suffering and simplicity shaped their perception of suffering and vulnerability to sleeping sickness and poverty (Kleninman, 1988). While the farmers felt and suffered from the negative

experiences that accompany poverty and inequality in distribution of health and economic resources, such as poor health and drug shortages, poor infrastructure and inability to meet their basic needs, their religious beliefs changed the meaning of their suffering from something undesirable to something valuable and acceptable for Christian believers.

Similarly, challenges associated with healthcare such as limited attention and lack of prioritisation of diagnosing sleeping sickness in Mambwe district by relevant authorities were not perceived to be as a result of structural violence and inequality but in most cases, farmers blamed themselves for living in these ‘neglected’ areas and believed that ‘God’ will come through for them one day. This finding reveals internalisation of negative beliefs which contributed to farmers blaming themselves by shifting the blame from structural inequalities within the existing policy framework and decisions (Ishikawa, 2023; Pyke, 2010). Furthermore, the Kunda and Chewa farmers’ perception reveals the invisible nature of structural violence which limits the farmers’ understanding that their suffering and experiences such as health challenges, risks to diseases and poverty are shaped by the broader social, economic and institutional processes such as limited support to the health sector and awareness campaigns on the risks of sleeping sickness.

As observed by Njenga et al. (2021), my findings suggest that the gendered nature of performing livelihood activities and daily chores such as collecting firewood in the bush increase the risk of the firewood collectors to various dangers including attacks from wild animals, tsetse fly and snake bites. Thus, my findings contend that the risk of sleeping sickness and experiencing physical harm is high among Kunda and Chewa farmers performing livelihood activities and daily chores such as herding cattle, harvesting timber or producing charcoal regardless of age and gender. This finding implies that while gender plays a significant role in who performs daily chores, structural violence, reflected in lack of deliberate measures to protect people living in ecological systems which are usually habitats for vectors such as tsetse flies and mosquitoes, contribute to increased vulnerability and risk of contracting sleeping sickness by farmers regardless of their gender roles. Thus, my findings contribute to the body of knowledge by demonstrating that processes beyond the cultural practices and individual characteristics such as lack of active vector control programs, screening and sensitisation ultimately shape and influence the Kunda and Chewa farmers’ vulnerability and suffering from sleeping sickness. This means that cultural practices and institutional factors intersecting with individual characteristics shaped children, men and women’s risk of contracting sleeping sickness by determining how, when, and where certain activities are done and by whom.

6.3.1 Who does what, when and where?

Throughout my interaction with the farmers, one thing was evident, all Kunda and Chewa farmers, men and women, performed their chores based on their gender. I further observed that although the farmers were all at risk of getting bitten by tsetse flies, the tasks they performed, their gender, ethnicity, age, marital status and economic resources determined the frequency and degree of interaction with tsetse flies. As highlighted in chapter four of this thesis, Kunda and Chewa farmers share similar cultural practices and beliefs. For this reason, while small variations exist in how chores and responsibilities are divided between men and women from Kunda and Chewa ethnic groups, division of labour, roles and responsibilities among the farmers was generally similar.

Among farmers with Chewa background for example, men did more physical work such as herding, cultivating, clearing land for cultivation, building and sporadically harvesting timber and producing charcoal. In contrast, while Chewa women participated in cultivation, they were mostly concerned with household chores such as cooking, washing, fetching water and collecting firewood. As noted by Phiri (1983) and Yoshida (1992), the division of labour among Chewa farmers is rooted in the uxorilocality in which Chewa men were expected to perform tasks such as herding, cultivating, clearing land for cultivation, and building on behalf of their in-laws. Failure to show wisdom and hard work among uxori-local husbands, as observed by Phiri (1983), attracted negative sanctions such as being described as ‘a stranger’ in his wife’s village which, as Schoffeleers (1968) observed, discouraged most uxori-local husbands from economically investing in their wives’ village because of control from the matriarchy which implied that they would leave back their investments in cases of dissatisfaction from the wife’s family. Therefore, before young Chewa men could marry, they needed to acquire these skills to perform such tasks (Phiri, 1983). Similarly, young Chewa women were expected to acquire the housekeeping skills before marriage. Consequently, this belief and practice reinforced and perpetuated the gendered performance of outdoor and household tasks among the Chewas. In contrast, as observed by Banda et al. (2013), among Kunda farmers, women did most of the work including chores as their husbands were usually away performing non-agriculture activities such as harvesting timber, producing charcoal or working as part-time workers in private safaris and lodges.

While all farmers kept livestock, more Chewas than Kundas kept cattle, small ruminants and fowls such as chickens. This difference is partly due to differences in cultural practices that shaped the Kunda and Chewa farmers’ livelihoods. Chewa farmers for example, relied on livestock especially cattle to carry out subsistence agriculture while Kunda farmers relied on

human labour to cultivate smaller pieces of land (Bruwer, 1958; Banda et al., 2013). Therefore, variations in the types and quantity of livestock kept by Kunda and Chewa farmers influenced the degree and frequency of interacting with livestock and exposure to vectors transmitting some zoonotic diseases. For example, more Chewa men and boys than Kunda men and boys herded cattle. While other researchers such as Pitikoe and Preece (2017), have associated herding with men because of the protective role which they perform, evidence among Chewa farmers show that in addition to protective roles, herding was used as platform for role socialising young boys aged between 9 and 14 years into adult roles such as cultivation, and transportation they would be expected to perform in adult life (Phiri, 1983).

This finding suggests that both Kunda and Chewa farmers are at risk of contracting sleeping sickness because of the gender roles and chores they perform. However, Chewa farmers' frequent contact with livestock and tsetse flies in places where they take cattle for grazing increases their exposure to risk compared to Kunda farmers. While tsetse flies are common in the villages and water collection points especially streams and rivers, the density was higher in the bush and farms where herding, farming, charcoal and timber production took place. This finding implies that regardless of ethnicity, children, men and women collecting firewood, herding, collecting water and harvesting timber in areas infested with tsetse flies were at increased risk of contracting sleeping sickness compared to farmers who performed daily chores within their villages. As other researchers have found, my findings suggest that while women and men perform tasks in areas with high density of tsetse flies, more men and boys, particularly hunters, herders, timber harvester and charcoal producers, were at higher risk of contracting sleeping sickness and malaria due to prolonged interaction with tsetse flies and mosquitoes (Nambala et al., 2022). Furthermore, the observed variations in frequency and degree of interaction with tsetse flies between men and women contribute to variations in risk and cases of sleeping sickness recorded between women and men in some studies conducted in Zambia (Mwiinde et al., 2022) and Malawi (Nambala et al., 2022).

To further illustrate my point, I will turn to one of my walking interviews with a 40 year old Kunda carpenter and timber harvester who I will call the Carpenter. It was a Saturday afternoon, 17th June 2023, when we had a conversation in his workshop (Figure 16) on his experiences while doing his carpentry business. Although our conversation touched several interesting issues about life in Mfuwe, I mostly focused on his experiences and the whole process of harvesting timber, where I found out, how long it takes to harvest and what is involved. In terms of the sources of timber, the Carpenter explained that he harvests timber

from Chief Nsefu and Chief Jumbe's areas. However, he made it clear that before he goes to the 'bush', he needs permits from the Department of Forestry, the local chief and Local Community Resource Board (CRB). When asked if these permits were free, the Carpenter responded by saying, *'there is nothing for free, we pay at all these levels.'* While he explained that the permits outlined how much timber could be harvested and the period of its validity, timber harvesters like him suffered from prosecution from law enforcers especially those that operate under non-governmental organisations focusing on conservation. In some instances, timber harvesters lost their tools, livestock and timber despite having a valid permit as illustrated in the excerpt below.

‘...even if you have permission from the chief and CRB, or just from Forestry, you can lose your timber or get arrested by the entity whose permission you did not get’,
Male, 47 years, WI- Nsefu Chiefdom.

While confiscating tools, cattle and oxcarts by law enforcers was done to deter farmers from engaging in illegal timber harvesting, the act indirectly robbed the farmers of their means of earning a living to survive and get emancipated from poverty. As noted by Nakamura and Hanazaki (2017), farmers engage in such economic activities due to prevailing conditions beyond their control. However, they are blamed for contributing for climate change by engaging in timber or charcoal production (Bisoffi et al., 2009). Such practices contributed to increased suffering among farmers and vulnerability to animal attacks and tsetse flies in the process of avoiding law enforcers. Consequently, while timber production serves as a source of livelihood, the process of acquiring and transporting it using livestock increases the harvesters' susceptibility to risk of contracting sleeping sickness and the potential of reinforcing their poverty and suffering. The carpenter's account show that the risk of getting bitten by tsetse flies and contracting sleeping sickness is higher for farmers who spend longer periods of time working in areas with high density of tsetse flies compared to those who make sporadic visits to collect firewood.



Figure 16: Carpentry workshop showing furniture

When asked about his experiences, the carpenter explained that of the challenges he faced, issues of wild animal attacks and tsetse flies were common and serious. *'We have a challenge of wild animals especially nzovu and lions. It is very scary to be honest, but we have no option but must do this,'* he explained. *'During the day, tsetse flies bite us while mosquitoes bite at night.'* In addition to tsetse fly and mosquito bites, the Carpenter also suffers from muscular and sometimes skeletal problems. The Carpenter's experiences are consistent with the findings of other researchers who found that forest workers, such as the Carpenter I spoke to, also suffer from occupational diseases of the muscular, and skeletal systems in addition to experiences of wild animal attacks and risk of biting insects (Albizu-Uriónabarrenetxea et al., 2013; Gallis, 2006). However, despite the dangers posed by the environmental conditions where the Carpenter harvested the timber from, he repeatedly visited the area in order to earn income in order to meet the needs of his household and enhance their wellbeing.

The above account suggests that timber harvesting, like other outdoor activities such as herding and firewood collection, expose farmers performing such tasks to the risk of contracting sleeping sickness and attacks by wild animal. While the carpenter's experiences maybe perceived to be due to cultural practices shaping his livelihood activities, like other Kunda and Chewa farmers working in similar conditions, his experience of vulnerability and suffering from the challenges such as human animal conflicts and tsetse fly bites are largely due to structural violence and economic inequalities within Mambwe district and the country at large. These conditions have reinforced and perpetuated the unequal distribution of economic opportunities, resources and facilities that would reduce disparities in experiences of health risk and suffering due to activities related to the Kunda and Chewa farmers' livelihoods and gender roles.

Moving to the role of socialisation on shaping the risk of children, my study's findings reveal that gender role socialisation of children reflected in their involvement in outdoor tasks such as herding and collecting firewood, increase their risk of contracting sleeping sickness. As illustrated in the following narration from my walking interview on 9th June, 2023 with three Chewa boys herding their families' cattle in Malama Chiefdom, it was evident that herding cattle, a gendered responsibility, increased the boys' risk of contracting sleeping sickness due to prolonged interaction with tsetse flies. Although the boys were almost of the same age, only one boy, who I will call Lameck (Figure 17), was able to talk to me while the other two were too shy to talk. I found them standing on the other end of the village near the fields where a herd of cattle of about 15 to 20 was grazing. He was wearing a navy blue short and a red polo neck shirt. He had no shoes, and a pair of slings were hanging around his neck

together with a small side sack bag which looked like a Shepard's bag. Lameck was shy and mostly gave short answers without looking at me. He either looked at the cattle grazing or faced the ground. Although he appeared to be aged between 9 and 11 years, Lameck did not know his exact age, but he was able to tell me that he was in grade three. However, I wondered why he was not in school at 09:00hrs, a time of the day when most children that are below the fifth grade are supposed to be attending class. But I did not want to speculate on what made Lameck to be at home.



Figure 17: Herders looking after a herd of cattle near the village fields

When asked to explain what he does in the home, Lameck explained that apart from schoolwork, he helps his father and mother to carry out household chores such as going to the hammer meal, collecting firewood, fetching water, and herding cattle. But mostly, Lameck's main tasks around the home involve looking after *ziweto* which translate to 'livestock.' In the morning, Lameck takes *ziweto* out for grazing at 09:00hrs and comes back around 15:00hrs. When asked to explain the timing of grazing, Lameck replied by saying '*kuno kuli vanyama vukata ng'ombe*' translating to '*there are wild animals that attack cattle here.*' So, to graze the cattle to satisfaction, he had to leave his home early. However, when asked about the dangers he faced, Lameck explained that lions, hyenas and snakes were very common. I asked him whether he was scared of these wild animals, Lameck confidently replied that as a boy, he was expected to learn how to manage these challenges in advance. He went on to explain that most of these wild animals especially hyenas and snakes feared humans, so, he was not very worried. As other scholars such as Phiri (1983) have found,

gender role socialisation contributes to gendered experience of risk through interaction with environments that posed danger to individuals found in such areas. In the case of Lameck and other herders, their constant and frequent visit to the bush increased the risk of experiencing physical harm from attacks by wild animals such as lions, hyenas and snakes. While the herders are aware of the risk of herding cattle in areas where lions were roaming, to them, fulfilling their social expectations as herders and providers of meat for their family was more important than the perceived risk associated with the social expectations (Goffman, 1956).

When asked about his experiences with tsetse flies and if he knows what it is and does, Lameck responded by saying, '*Ah! Tu kamzembe nituziba, nitu nyinji kuno... Ndipo tuti luma ngako!*' Translating to 'Ah! you mean tsetse flies, I know it. It is a lot here. It bites us a lot!' '*The tsetse fly is smaller and appears grey sometimes, but very painful and difficult to kill*' Lameck explained. But on the effects of their bites, Lameck was not sure because he took time to respond, but when he responded, he said, '*they make our cattle and pigs sick and thin.*' Lameck's response was unexpected, given his age. However, I wondered how Lameck, a third grader, knew that tsetse flies made his cattle sick and thin. Although I did not expect him to know the effects of tsetse bites on humans and animals at his age, Lameck's level of knowledge on the impact of tsetse flies on livestock showed how the gendered role socialisation contributed to varying levels of knowledge about zoonotic diseases, risk and possible impacts on humans and livestock between men and women (Okwa, 2007; Wharton-Smith et al., 2019).

Although tsetse flies affect humans, prevailing community knowledge about tsetse flies and their effects is reflected in Lameck's knowledge that tsetse flies only affect cattle. This finding, as highlighted in chapter 5 of this thesis, reveals that community knowledge influences the existing narrative and perception of the effects of tsetse flies on humans and livestock. Furthermore, this finding indicates that gender role socialisation and gendered division of labour among Kunda and Chewa men and women contribute to differences in knowledge of tsetse flies and their role in the occurrence of sleeping sickness in humans and animal African trypanosomiasis in animals (Okwa, 2007; Wharton-Smith et al., 2019). This implies that despite having similar characteristics as women and girls, men and boys, through their interaction with livestock and veterinary officers, had an opportunity to access information on the effects of tsetse flies and their bites. Consequently, persistent disparities in awareness of risk and knowledge of sleeping sickness between Kunda and Chewa men and women indirectly contribute to varying levels of concern about the effects of tsetse flies

and their bites on humans, inadvertently negatively affecting the Kunda and Chewa women and men's response to disease symptoms and healthcare seeking (Okwa, 2007).

Similarly, as shown in Figure 18 below, Kunda and Chewa women and girls performed several tasks including collecting firewood, fetching water, cleaning and cooking among other chores. Similar to men and boys, women and girls experienced risks associated with performing the gendered roles within their households and farm. Although women's involvement in chores depended on their ethnicity, marital status and possession of economic resources such as cattle, my findings suggest that like men, women and girls also experienced the risk of contracting sleeping sickness through exposure to tsetse flies within their compounds. Furthermore, women and children in households without cattle were exposed to tsetse flies in areas where they collect water and fetch firewood, and in the farms where women and men, regardless of the economic possession, spent more time during the farming season. During the farming season, women and the children were expected to take part in the planting, weeding, and harvesting of maize, soybeans and cotton (Banda et al., 2013). In addition to that, Kunda and Chewa women and children were also expected to perform other roles within their households such as housekeeping, caregiving, cleaning, and cooking.



Figure 18: Woman carrying water

As explained by Mercy, a 25-year-old married Kunda woman of Malama Chiefdom, her role as a woman is to manage the home and ensure that everything runs smoothly. She believed that these were the basic roles and responsibilities of women, and all girls within the Kunda and Chewa villages were socialised towards these responsibilities. Although I found Mercy washing (Figure 19), I was interested in knowing what else she does as a woman in Malama village. However, when I asked her this question during our walking interview, Mercy replied by asking me whether I was married. I replied in the affirmative, and Mercy was interested in knowing what my wife does. I explained to her but to Mercy, my answer was

not adequate and satisfying. *'Here, that cannot happen, life in the village is different,'* she explained. *'Women in the village are responsible of everything that happens at home.'* I asked her to explain what she meant by that, Mercy smiled and said to me, *'you seem you have never lived in a rural area before, so you might not know what women do here, but I will explain so that you understand.'* While I grew up in the village and urban setting, rather than rely on my own positionality and knowledge, I encouraged Mercy to give her own interpretation, reflecting her unique, gendered positionality.

Mercy's explanation stressed that for women like her, a day starts with ensuring all household chores are done followed by collection of water. Preparation of meals is usually done once all chores are done. *'If I have a bit of money,'* she explained, *'I would buy some vegetables and kapenta (Tanganyika sardine) from the market.'* However, in instances where Mercy has no money, she collects some wild vegetables such as *katate* (wild okra) and *chiwawa* (some squash or pumpkin leaves) which could be cooked in cooking oil, mixed with groundnuts, or by boiling in water. Mercy used this time in the fields to pick firewood to supplement quantities at her home. Afternoons were used to clean utensils, fetching water, and preparing for the evening meal. *'During the farming and harvesting season like this one,'* Mercy explained, *'I accompany my husband to the field to plant, weed, apply fertilisers and also harvest.'* Like other women in the other chiefdoms, Mercy took part in the farming activities because farming served as the farmers' primary source of food and income. As a result, regardless of gender and age, all family members were involved with varying responsibilities.



Figure 19: Woman washing near a water point

However, although Mercy believed that it was a woman's task to ensure that all household chores were done, as Ochola et al. (2021) and Ssali et al. (2023) have found, Mercy and other Kunda and Chewa women in the three chiefdoms performed more chores which, when combined with lack of adequate nutrition and rest, contributed to increased risk of physical and mental health problems among Kunda and Chewa women. Therefore, although women

did not spend more time in the bush like herders, Mercy's account reveals how like other women, she experienced tsetse fly bites during the collection of *Chiwawa* (pumpkin leaves) *muminda* (in the fields/farms), firewood in the bush and when fetching water at the water pump and stream where livestock drink from. This finding illustrates that while risk varies by gender and roles performed, both women and men and children are at risk of contracting sleeping sickness.

However, although Kunda and Chewa women are expected to perform these task as explained by Mercy, other factors such as economic status, marital status and age of children determined a woman's involvement in outdoor tasks and some household chores. This suggests that although Kunda and Chewa women were involved in activities such as farming and harvesting, women who possessed cattle and had older children were rarely involved in outdoor chores such as fetching water or collecting firewood. This implies that while women with cattle were at risk of contracting sleeping sickness, their risk was limited to time spent in their fields and to tsetse flies that followed their cattle from the bush to their homes. In contrast, women who have no cattle would get involved in collecting firewood and water regardless of the age of their children. However, my observations highlighted that while this is true, in some Kunda and Chewa households, children performed all household chores such as collecting firewood, collecting water, cleaning and cooking with little help from their mother as shown.

These findings suggests that while gender roles and responsibilities are responsible for what tasks one does and where these are done, risk and exposure is shaped by several other factors acting together with gender which inadvertently contribute and reinforce vulnerability of men, women and children to environmental conditions that have potential health risks. Reflecting on Bulter's (1988) writing on gender as performance and subversion and resistance, my findings illustrate that the gender roles among Kunda and Chewa farmers are performed daily through specific tasks and responsibilities. Men's involvement in herding and protection and women's involvement in water collection, farming and collection of firewood reflect performances of socially constructed gender norms and roles (Goffman, 1956).

While the findings show clear division of labour by gender, role flexibility characterises most tasks such as fetching water and collecting firewood especially among Chewa men, reflecting subversions of possibly rigid gender norms. However, the intersection of gender, economic status and ethnicity reveals how the farmers' varying characteristics create their unique experience of suffering and vulnerability to tsetse fly bites and sleeping sickness. The

farmers, therefore, face compounded risk of contracting sleeping sickness due to their gender roles and tasks which are performed in an environment characterised by conditions that increase risk and vulnerability to tsetse fly bites (McGibbon & McPherson, 2011). In addition to the gender roles and chores, the unequal distribution of economic development and job opportunities in Mambwe district contribute to the Kunda and Chewa farmers' reliance on the natural environment for a living and their vulnerability to sleeping sickness and other NTDs.

6.4 National policy and response to sleeping sickness

In the previous section, I have explored how the gendered roles and tasks performed by Kunda and Chewa men and women in varying conditions contribute to the risk of contracting sleeping sickness in Mambwe district. I have considered the role of ethnicity, economic position and gender role socialisation in determining who performs what task, when and where, contributing to gendered risk of contracting sleeping sickness. In this section, I turn to existing policies on gender and health in Zambia and how this policy framework shape risk and overall response to sleeping sickness. Furthermore, I explore how the existing policy framework serves as an important determinant of addressing the biomedical and nonbiomedical causes of sleeping sickness in Mambwe district.

6.4.1 'The game management plans- GMPs'

Mambwe district, as earlier established, is located in game management area. This means that several policies and regulations guide how individuals live and conduct business within the GMA. Several policies and legislation on wildlife, national parks and game management areas (GMAs) exist. Overall, the aim of these policy frameworks is primarily to protect biodiversity and manage wildlife. In addition to that, the existing policy framework also focuses on empowering local communities through resource management, tourism and also protection from wild animals (Ministry of Tourism and Arts, 2018; Zambia Wildlife Act, 2015). The Zambia wildlife act of 2015 for example, provides the legal foundation for the management of wildlife and natural resources (Zambia Wildlife Act, 2015). Similarly, the National Parks and Wildlife Policy (2018) provides guidance on conservation and sustainable use of wildlife by providing areas where social economic activities can be carried out by the communities and how proceeds from overall tourism activities managed by the local community boards benefit the communities, balancing conservation of wildlife with economic needs of local communities (Ministry of Tourism and Arts, 2018). In addition to that, these policies control and regulate use of wildlife and provides mechanisms for addressing human-wildlife conflicts.

While this policy framework provides clear guidance on how wildlife and natural resources can be utilised and conserved, my findings suggest that focus is more on the wellbeing of the natural resources and economic benefits for the community. Although the policies have established mechanisms of addressing possible challenges such as human wildlife conflicts (Ministry of Tourism and Arts, 2018), my findings show that the health risks of communities living in designated areas are not considered primary in the existing legislation. Consequently, while some challenges that farmers face need clear policy direction to enhance safety, lack of such direction within the existing policies have indirectly contributed to the neglect of communities. To clarify this point further, I will turn to my key informant interview with Yohane, a 58 year old key informant working with wildlife. When asked about the challenges and risks that communities face especially within the context of health, the response given was *‘the absence of the game management plan (GMP) is one of the main causes for these problems.’* Yohane’s argument was that while several factors contribute to increased frequency of tsetse fly bites and risk of contracting sleeping sickness within the GMA, but the absence of the GMP contributed significantly as individuals settled anyhow including in areas that were considered corridors for wild animals and were mostly infested with tsetse flies. The following excerpt further show that uncontrolled habitation of areas contributes to the current challenges that Kunda and Chewa farmers are facing.

Ideally, a protected area such as this one is supposed to be managed by what we call a Game Management Plan (GMP). The GMP shows where people can live, do farming, fetch water and participate in recreational activities. This would help people not to build their homes in animal corridors. For example, in the Lupande GMA, there is no GMP. For this reason, it becomes practically impossible to manage the GMA, community’s activities, and settlements cannot be coordinated or managed to ensure safety and efficient use of resources. Male, 58 years, KII2- Mfuwe

Yohane’s argument shows that while the existing policy framework provides for most issues within the GMA, gaps such as difficulties to implement GMPs contribute to challenges communities living in GMAs face. When asked to explain why the Lupande GMA has no GMP and the possible consequences, Yohane replied by saying,

‘Here, the chiefs and their subjects have refused to develop and sign the GMP for fear of losing land, so people are at liberty to settle anywhere, do anything without control.’

Consequently, there is persistent conflicts between law enforcers from the Department of National Parks and Wildlife and some local CSOs with the communities. While these organisations aim to foster conservation, controlled and sustainable use of resources, local communities perceive them as hinderances to their access to natural resources. This further highlight the ongoing tensions and competing interests among stakeholders interested in environment, and wildlife management. Although these tensions and conflicts focus on control and utilisation of the natural resources (Bwalya & Kapembwa, 2020), my findings also show dissatisfaction with wildlife benefits among the chiefdoms. For this reason, collaborations to ensure conservation, safety of both the wildlife and communities is difficult to build due to this ‘misunderstanding’ and ‘mistrust’ between local leaders, communities and organisations working in wildlife and conservations. My findings show that the differences in interests and focus between the local leadership, communities and stakeholders such as Yohane inadvertently contribute to the local community’s vulnerability to tsetse fly bites, sleeping sickness and consequences of human wildlife attacks.

Therefore, it can be noted that while control and management of challenges related to tsetse flies, human wildlife conflict and NTDs such as sleeping sickness require multisectoral collaborations to resolve, my findings suggest that ongoing misunderstanding, competing interests and tensions among key stakeholders in wildlife management contribute to the persistence of these challenges within communities. For example, while communities are expected to benefit from proceeds from wildlife and tourism, my findings show conflicting narratives. Key informants argue that of the revenue collected, 5% goes to the chiefs, 45% goes to the community, a 20% is used for administration, and the remaining 30% is for the community resources boards (CRBs). However, Kunda and Chewa farmers I spoke to belief that these benefits rarely reach their communities, and lack of infrastructure such as roads, water facilities and health facilities. These findings are consistent with findings of other scholars who found that some local leaders and communities were dissatisfied with the distribution of wildlife benefits (Bwalya & Kapembwa, 2020).

The competing interests and conflicting narratives among stakeholders within Mambwe district reduce focus and investment in issues related to the health and wellbeing of communities. Furthermore, while cultural and religious norms shape risk and exposure to the risk of contracting sleeping sickness, the existing policies regarding wildlife and conservation coupled with conflicts among stakeholders further perpetuates the Kunda and Chewa farmers’ vulnerability to sleeping sickness and challenges associated with living in a GMA.

Turning to national policies and legislation on health and gender, evidence shows that Zambia has a several policies (Table 7 below) and legislation on gender, and health. These policies include the National Gender policy (NGP) of 2014 and the National Health Policy (NHP) of 2012 (Table 7). The NGP's overall goal is to facilitate effective and equitable participation of both women and men in the social economic development of the country (Ministry of Gender, 2014). Similarly, the NHP focus on ensuring equitable access to healthcare for all the people of Zambia, regardless of their geographical location, gender, age, race, social, economic, cultural or political status (Ministry of Health, 2012).

Table 7: Zambia national gender (2014) and health policy (2012)

Policy	Goals	Gaps
National gender policy of 2014/2023	Gender equity, women's participation in economic activities, and eliminating gender-based violence	Lack of focus on health-related gender disparities
National health policy 2012	Reduce the burden of disease, maternal and infant mortality and increase life expectancy through the provision of a continuum of quality effective health care services as close to the family as possible in a competent, clean and caring manner.	Lack of focus on health-related gender disparities.

These policies are complimented by several Acts and Strategic Plans being implemented to ensure gender equity, and equality in health. Table 8 below shows the various Acts and Plans focusing on health.

Table 8: Acts of parliament and plans on gender and health

Act	Goal(s)	Policy Gap(s)
The gender equity and equality Act no 22 of 2015	Protection and promotion of sexual and reductive health rights of women and states (1): "A woman has a right to adequate sexual and reproductive health, which includes the right to (a) access sexual and reproductive health services; (b) access family planning services; (c) be protected from sexually transmitted infection; (d) self-protection from sexually transmitted infections; (e) choose the number of children and when to bear those children and (f) control fertility.	Lack of focus on health-related gender disparities Lack of focus on NTDs Gender not clearly addressed
The Anti-Gender-Based Violence Act No. 1, 2011	To prohibit GBV by empowering any citizen to report GBV.	Lack of focus on health-related gender disparities Lack of focus on risk to NTDs
The Zambia Police (Amendment) Act No. 14 of 1999,	Establishes the Victim Support Unit (VSU) to protect citizens from various forms of abuse and to provide professional counselling to victims of crime and to offenders	Lack of focus on health-related gender disparities

Penal Code Act, Chapter 87, Sections 132 and 138.	Prohibit the rape of a woman above the age of 16 years and defilement of a child below 16 years of age. Section 247 prohibits common assault, Section 248 prohibits assault occasioning actual bodily harm, and Section 248A prohibits battery including battery of children.	Lack of focus on health-related gender disparities
Plan	Goal(s)	Policy Gaps
2022-2026 National Health Strategic Plan	Five priorities are to strengthen: (1) health service delivery for prevention and primary health care; (2) maternal, neonatal, child and adolescent health and nutrition; (3) control of communicable diseases (malaria, HIV, tuberculosis, sexually transmitted infections); (4) control of noncommunicable diseases; and (5) integrated health support systems	Lack of explicit gender focus: The plan doesn't specifically outline gender-related interventions. Gender norms and cultural context: The plan does not plainly address the role of gender norms and cultural context shaping health
Zambian One Health strategic plan	Integrate and strengthen the health systems across sectors. Promote interdisciplinary research and surveillance. Enhance preparedness and response to diseases and health events. Improve overall health outcomes by recognizing the interdependence of people, animals, plants, and their shared environment.	Focus on biomedical fields Nonbiomedical fields not represented Lack of explicit focus on the role of gender in One health

However, as Table 7 and 8 above shows, although these policies, acts and plans seek to enhance gender equality in health access, the existing framework has several gaps especially regarding NTDs such as sleeping sickness which contribute to gendered inequalities in health access and continued variations in experience of vulnerability to NTDs and poverty by rural communities such as Mambwe district. Therefore, although the current policy and legislation frameworks highlight the need for equitable health access by gender in Zambia, my findings show that the focus of current policies is women and girls' health in the areas of family planning, early childhood mortality maternal care services, child health and nutrition of children and women, diagnosis, and prompt treatment of fever among children, HIV/AIDs awareness, knowledge, and behaviour change services including comprehensive knowledge of HIV prevention among young people. While important, the current frameworks omit the relevance of other aspects of health such as NTDs whose risk and exposure are highly influenced by gendered roles and responsibilities performed by women and men, boys and girls (Okwa, 2007). Therefore, it can be noted from Table 7 and 8 above that despite the existence of policy and legal framework, equal and equitable health access and utilisation for rural populations such as Mambwe district is still a challenge.

Furthermore, my analysis shows that the current policy and legal framework consider gender and health within the context of gender-based violence and maternal and reproductive health among women and girls. Although health concerns for men and women are considered, the framework does not explicitly address issues relating to how existing gendered disparities in healthcare access and utilisation between men and women are shaped by both cultural and

institutional factors. While the country's health policies recognise the existence of NTDs such as sleeping sickness in humans, NTDs still receive less priority in terms of research and funding compared to malaria and other noncommunicable diseases as shown below in figure 20, an excerpt from the Zambia National Health Plan 2022-2026. Therefore, my findings indicate that in addition to lack of policies on wildlife management and conservation which explicitly address the health and social wellbeing of communities living in GMAs, the lack of deliberate policy framework specifically to address sleeping sickness and the role of gender in shaping risk in humans contribute to low awareness, delayed diagnosis and treatment of cases among the Kunda and Chewa farmers.

Health Service Delivery Priorities	Health System Priorities
i. Health Promotion and Education. ii. Primary Health Care (PHC) and Community Health. iii. Maternal, Neonatal and Child Health, Youth and Adolescent Health. iv. Communicable Diseases, Especially Malaria, HIV/AIDS, STIs and TB. v. Non-Communicable Diseases (NCDs), including Cancers, Cardio-Vascular Diseases, Diabetes and Mental Health. vi. Public Health Security. vii. Environmental Health and Food Safety. viii. Health Service Referral Systems. ix. Hospital Services.	i. Health Workforce, ii. Essential Drugs and Medical Supplies, iii. Infrastructure, Equipment and Transport, iv. Health Information, Research and Innovation, v. Health Care Financing, vi. Leadership and Governance,

Figure 20: National Health Priority Areas

As illustrated in Figure 20 above, sleeping sickness and other NTDs are not among the list of health service delivery and system priorities for Zambia between 2022 and 2026. This finding suggests that while availability of resources shape response towards diagnosis and treatment of sleeping sickness, lack of prioritisation points to how the disease in humans is still under researched compared to animals. Furthermore, as illustrated in the excerpt below from a 58 year old male key informant, lack of research on sleeping sickness in humans contributes to the limited understanding by human medicine experts on how the disease has evolved overtime, and how reliance on alternative methods of treatment such as use of herbs would have shaped the prevalence of sleeping sickness in humans the Luangwa valley.

From experience, there is limited knowledge about sleeping sickness on the human side. There is more research that has been done in the animal side especially here in Zambia. Male, 58 years, KII1- Lusaka

Although this gap in knowledge of sleeping sickness in humans can be partly attributed to limited resources and support towards research on sleeping sickness and other NTDs on humans, it reflects biases in disease prioritisation and resource distribution based on narratives that portray certain diseases as more important than others and need urgent support (Foucault, 1978; Douglas and Wildavsky, 1982). Therefore, my findings show that the lack of equipment, skills and capacity to accurately diagnose cases of sleeping sickness by health staff in rural healthcare facilities in Mambwe district reflects lack of policy to provide financial support towards research on sleeping sickness in humans. Consequently, the lack of support has contributed to limited awareness of sleeping sickness among health workers and rural communities, indirectly perpetuating limited understanding of the nature and effects of the disease in humans. Therefore, this finding suggests that the absence of deliberate and explicit policies to enhance diagnosis of sleeping sickness in humans reinforce the absence of accurate diagnosis for the disease in areas where it is endemic such as Mambwe district. Consequently, possible cases of sleeping sickness get mis-diagnosed, and mis-managed contributing to complications and death in patients. Therefore, policy gaps, a reflection of structural violence, contribute to the Kunda and Chewa farmers' suffering through delayed diagnosis and treatment of possible cases of sleeping sickness (Farmer, 2004).

Drawing on Foucault's (1978) concept of power as discourse, the power imbalance among farmers, health experts and decision makers result in misplaced policies and decisions based on evidence that does not reflect the suffering experienced by the rural poor. The lack of adequate mechanism to actively screen and diagnose cases of sleeping sickness and drug shortages reflect how structural violence ultimately hinder the Kunda and Chewa farmers in Nsefu, Malama and Mnkhangya Chiefdoms to receive adequate health services including drugs. For example, my findings show that of the five healthcare facilities visited in Mambwe district, only Kakumbi clinic had a functional laboratory with a microscope. The remaining four relied on rapid diagnostic tests (RDTs) to test for malaria and other febrile diseases. These findings indicate that while cases of sleeping sickness maybe there, inability to diagnose makes them non-existent and invisible.

6.4.2 Is a One health approach the solution?

Throughout this thesis, I have contended and indicated that sleeping sickness is a multidimensional disease that involves both biomedical and nonbiomedical dimensions. Furthermore, I have, through the preceding chapters, explored the various nonbiomedical factors that shape risk of contracting sleeping sickness among Kunda and Chewa farmers in

Mambwe district. While doing this, my thesis has highlighted the importance of considering both dimensions in managing and controlling sleeping sickness. Having discussed the role of gender and policy frameworks on shaping the risk of sleeping sickness, I will now turn to demonstrating the need for a One health and interdisciplinary approach that does not only consider non-biomedical research but also draws on sociological theories to develop interventions.

While One Health and interdisciplinary research has been gaining momentum in Zambia, collaborations favour more biomedical sciences with limited inclusion of social sciences such as sociology. For example, more recently, Zambia launched its first National One Health Strategy to ensure collaborations among different stakeholders to address various issues of health and climate change. However, while this is a right step in the right direction in developing collaborations, my findings show that National One Health Strategy is focussed more towards promoting collaborations among biomedical disciplines. As highlighted throughout this thesis, non-inclusion of nonbiomedical disciplines such as sociology contributes to the continued omission of gendered understanding of sleeping sickness and how risk of contracting it is embedded in the social and cultural processes of communities. Thus, my findings highlight the technical, and strategic challenges that the current national response and framework to manage sleeping sickness in Zambia faces. Accounts from experts in human medicine, veterinary medicine and wildlife management suggest that limitations of the existing policy framework on sleeping sickness in humans has affected the ability to consider how poverty, gender and the associated roles shape risk of contracting sleeping sickness among Kunda and Chewa farmers living in Nsefu, Malama and Mnkhangya Chiefdoms.

Therefore, my study identified three main policy gaps. Firstly, the absence of policy on gendered awareness on neglected tropical diseases. Although previous research has studied gender, the context and focus were not informed by intersectionality and role of inequalities on risk of contracting sleeping sickness. Secondly, the lack of policy to ensure interdisciplinary collaborations on NTDs considering the role of social sciences. While most evidence is based on biomedical approaches, evidence based on human medicine research is limited. Thirdly, there are no efforts to incorporate indigenous knowledge and understanding of NTDs in existing frameworks to understand sleeping sickness and how risk and management is shaped by cultural and religious beliefs and practices.

Overall, my findings show that the Kunda and Chewa farmers' experiences of vulnerability and suffering in Lupande GMA is based on gender intersecting with several individual,

social, cultural, economic and institutional factors which, while accounted for by previous research, were presented in a manner that did not reflect that the farmers' experiences of risk of contracting sleeping sickness is indirectly shaped by cultural systems which determined roles, who performed them, where and when. Furthermore, as highlighted in this section, the existing gaps in policy and failure to support interventions that would reduce experiences of vulnerability and suffering from tsetse flies, inaccessible healthcare facilities and human wildlife attacks perpetuates the participants' poor health and poverty.

6.5 Chapter summary and conclusion

In my discussion of gendered realities and risk of contracting sleeping sickness in Mambwe district, I have argued that Kunda and Chewa farmers' characteristics create identities which shape their experience of risk of contracting sleeping sickness (Crenshaw, 1992; McPherson and McGibbon, 2011). Using accounts from participants and key informants, it can be noted that the Kunda and Chewa farmers' exposure to risk of sleeping sickness is embedded in their daily routines, the duties that they perform in addition to their gender roles. Furthermore, poverty and ethnicity, while interacting with gender and age, shape how the Kunda and Chewa farmers interact with the physical environment which translated in constant interaction with tsetse flies and possible attacks from wild animals.

I have also presented the existing policy and legal framework in Zambia on wildlife, health, gender and One Health. While the policy landscape is favourable, I have indicated that challenges with implementation of the existing policies on gender and health has contributed to challenges in actively screening for sleeping sickness. Turning to neglected tropical diseases and One Health, I have indicated that the existing policy framework has no deliberate policies to enhance interdisciplinary collaborations between biomedical and nonbiomedical disciplines. Further, I argued that the existing framework does not explicitly show the role of nonbiomedical sciences such as social sciences in One Health in Zambia.

Therefore, my findings show that unclear policy frameworks on sleeping sickness in humans have contributed to increased risk in rural communities. While gender roles and chores contribute to increased risk, lack of resources supporting diagnosis of the disease and investment in equipment ultimately shape Kunda and Chewa farmers' vulnerability to sleeping sickness. Similarly, my findings also show that while One Health and interdisciplinary collaborations are being supported, there is still over emphasis and reliance on biomedical sciences, contributing to limited understanding of the experiential and subjective factors that shape vulnerability and risk to sleeping sickness. This chapter,

therefore, has explored the significance of considering social science evidence in One Health and the study of sleeping sickness.

CHAPTER SEVEN

DISCUSSION AND CONCLUSION

7.0 Introduction

This chapter discusses the study's main findings in relation to existing literature and theoretical frameworks on sleeping sickness. Throughout this thesis, I set out to explore the experience of risk and vulnerability to sleeping sickness, also known as human African trypanosomiasis (HAT), in the context of gender roles, structural inequalities and socio-ecological factors. While sleeping sickness is often framed in biological and ecological terms, my findings presented in this thesis show that the burden and risk of contracting sleeping sickness is embedded in the systems of inequality and power. Therefore, I argue that sleeping sickness, specifically *Trypanosoma brucei rhodesiense* (rHAT), is not only a public health issue but a manifestation of broader socio-cultural, political, and economic processes that leave certain populations disproportionately vulnerable to sleeping sickness which are invisible to policy and interventions.

Ultimately, the evidence I present in this chapter points to broader systems of structural violence across sectors that produce and maintain conditions shaping risk of contracting rHAT and experience of social suffering among marginalised populations living in rural areas which are often characterised by lack of basic services and infrastructure (Dzingirai et al., 2017a; Zyaambo et al., 2012). Therefore, drawing on intersectionality and gender performativity, vulnerability and social systems theory, I critically engage with the following three themes reflecting the main findings of my study: the gendered roles, role socialisation of children and its contribution to risk exposure to sleeping sickness; the role of macro-level inequalities on participants' risk to the disease, and the invisibility of sleeping sickness in national policy frameworks; and the influence of the changing environmental and climatic conditions on HAT transmission and participants' access to healthcare.

In the next section, I explore the gendered roles, role socialisation of children, showing the role of socially and cultural determined roles in shaping risk of contracting sleeping sickness (Odiit et al., 2004). I then consider the effect of macro level inequalities on the participants' vulnerability and the invisibility of sleeping sickness in national policy frameworks, interventions and current discourse among experts on health issues. I then argue that changing environmental and climatic conditions intensify seasonal access barriers by affecting mobility of farmers further affecting their overall access to healthcare in rural communities. While I discuss risk, vulnerability and suffering as being a result of structural violence, I would like to argue that these experiences relate to the Nsefu, Malama and Mnkanya chiefdoms of Mambwe district.

7.1 Gendered roles, role socialisation, and risk of sleeping sickness

The first main finding highlights how the gendered roles and gendered socialisation of children contribute to the variations in the experience of risk of contracting sleeping sickness. Because of the culturally determined roles, men, women and children perform different tasks in different areas (Ochola et al., 2021; Okwa, 2007). As a result, their interaction with tsetse flies varies as some tasks such as herding and cultivation happen in areas with more vectors compared to areas where chores such as cooking take place (Nambala et al., 2022).

Children, particularly boys, are assigned tasks such as cattle herding, firewood collection and farming, activities that take place in environments that have a high density of tsetse flies and mosquitoes (Nambala et al., 2022). Similarly, girls, while generally assigned more domestic roles, are still involved in firewood collection, fetching water from sources where wild animals drink from and farming, placing them at periodic risk of tsetse fly bites and sleeping sickness (Ochola et al., 2021). This finding aligns with Butler's theory of gender performativity in which gender implies repeated series of performances that are influenced by social norms and values (Butler, 1988). Consequently, as a way of learning these roles, children are taught to 'do' gender through the specific chores associated with their gender. For example, roles such as herding cattle, farming, and fetching water from tsetse infested areas such as riverbanks, and grazing lands increase boys' and girls' vulnerability to tsetse flies (Alderton et al., 2016; Ochola et al., 2021). These roles and chores, in turn, shape what the children do, when and where, indirectly shaping their vulnerability and exposure to health risks (Butler, 1988; Goffman, 1956). Therefore, this gendering of risk is not merely biological or behavioural but deeply cultural and institutional. To fulfil the cultural and traditional expectations associated with their roles, young boys and girls living in areas with high density of tsetse flies may be burdened by the expectation to fulfil these expectations and contribute towards household labour (Bukachi et al., 2018; Ochola et al., 2021; Okwa, 2007).

Therefore, my findings point to how power and cultural practices shape children's susceptibility to health risk such as NTDs through gender role socialisation. Their limited ability to negotiate their roles, coupled with the absence of knowledge on risks associated with performing tasks such as herding in areas with high density of tsetse flies, makes the children very vulnerable (Bukachi et al., 2018; Ochola et al., 2021). This everyday gender role socialisation of children indirectly and silently contributes to social suffering, normalised through culture and is invisible to policy (McGibbon and McPherson, 2011).

Similarly, men and women who perform outdoor activities such as herding roles, farming, collecting firewood, hunting, timber and charcoal production are also highly exposed to the risk of contracting sleeping sickness (Nambala et al., 2022; Wharton-Smith et al., 2019). Although women are exposed to risk of sleeping sickness, my findings show that exposure varies by ethnicity and economic possessions of the participants. Some married Kunda and Chewa women who own livestock were rarely involved in outdoor chores such as firewood collection and water collection as these roles were performed by their children. However, women without cattle or a form of transport and single were involved in these chores with their children. This finding shows that while women are at risk of sleeping sickness, their risk is shaped by several factors acting together compared to children and men. Furthermore, poverty and ethnicity, while interacting with gender and age, shape the Kunda and Chewa farmers' contact with the physical environment which translated in constant interaction with tsetse flies and possible attacks from wild animals.

While these findings are consistent with other researchers (Ochola et al., 2021; Vlassoff, 2007), my findings provide additional insights into the dynamics that cultural processes such as gendered division of labour, gender role socialisation of children, possession of cattle, and marital status shape the risk of contracting sleeping sickness in rural communities. While it is expected that wealth would benefit men only, among the Kunda and Chewa farmers, wealth in form of livestock benefited women but increased the load of chores performed by boys and girls. While previous research suggests improved health outcomes when there are improvements in income (Emerson et al., 2006), my findings suggest that regardless of wealth in the form of livestock, children from homes with livestock and those without spend more time performing outdoor activities and interacting with tsetse flies.

Therefore, risk and exposure to sleeping sickness is a product of prevailing cultural practices and gender intersecting with ethnicity, economic resources and age to create varying identities of the participants which create different forms of perpetual disadvantages in social, cultural, and economic terms for the farmers (Crenshaw, 1991; McGibbon & McPherson, 2011). Thus, my findings show that risk of sleeping sickness is not entirely biological and about the vector, intersecting social, cultural, economic and institutional factors shape risk of contracting the disease by defining what they do, where and when (Ochola et al., 2021; Okwa, 2007; Vlassoff, 2007).

Therefore, my findings show that the participants' gender and ethnicity intersecting with their levels of education, employment and location create identities which situate them differently within the physical, social and political environment (Crenshaw, 1992;

McPherson and McGibbon, 2011). These identities in turn shape the participants' degree of vulnerability resulting from limited access to opportunities, resources and information about health, increasing risk of contracting sleeping sickness and suffering from its outcomes (McGibbon and McPherson, 2011). Although previous research has acknowledged that gender shapes health access, utilisation and health seeking behaviour (Vlassoff, 2007; Okwa, 2007), their focus was on NTDs in general without specifically focusing on its role in shaping risk of contracting sleeping sickness, a disease with so many dimensions (Okwa, 2007; Rilkoff, et al., 2013; Wharton-Smith, et al., 2019; Woldehanna, et al., 2015).

Thus, this study's findings are broadly in line with those of previous researchers such as Ochola et al. (2021) and Neema et al. (2020) who found that gendered roles shape risk of contracting NTDs such as sleeping sickness. However, while aligning with the findings of previous studies, my conclusion that all participants are at risk but with varying degrees differ from other researchers who concluded that women and children are more at risk of NTDs such as sleeping sickness due to their involvement in chores such as collecting firewood, water and cultivation (Ochola et al., 2021; Okwa, 2007; Vlassoff, 2007).

7.2 Structural inequality, vulnerabilities and suffering

The second finding points to the role of macro-level processes in shaping participants' vulnerability and the persistent invisibility of sleeping sickness in national health, and conservation, policies (Mwanakasale and Songolo, 2011). The study found that the risk of rHAT is closely shaped by the unequal distribution of economic infrastructure such as roads, and healthcare facilities which reflects developmental inequity, reinforcing spatial disparities in disease burden and service access (Mulenga et al., 2015, 2022; Mwanakasale and Songolo, 2013). Furthermore, the study findings show that structural inequalities are neither neutral nor incidental but that they are the outcome of prevailing political and economic choices that marginalise certain categories of populations (Farmer, 2006).

The absence of consideration of rHAT in health and conservation policies suggests a form of 'epistemic erasure' rooted in the failure to recognise zoonotic diseases like rHAT as inherently socio-political phenomena whose dynamics are largely shaped by institutional policies and interventions (Thomas, 2020). Consequently, rHAT becomes doubly 'invisible' through weak surveillance and data systems (Mwanakasale and Songolo, 2011), and through the absence of sleeping sickness in broader planning frameworks and discourse that shape health resource access, distribution, and ecological management (Foucault, 1978).

This invisibility of sleeping sickness is reflected in the absence of targeted education, prevention programmes, and active surveillance of the disease in Mambwe district and Zambia as a whole (Mulenga et al., 2022; Mulenga et al., 2022). Furthermore, as observed by Mwanakasale and Songolo, (2011) and Mwanakasale et al. (2013), health workers in rural healthcare facilities lack training and resources to correctly diagnose rHAT, contributing to increased possibility of misdiagnosis and mismanagement of possible cases of sleeping sickness. The continued lack of attention to rHAT at national and policy level further affects public levels of knowledge of the disease. While community members in my study knew that there is a disease called *chikusila* (sleeping sickness) (Mwiinde et al., 2022), they did not know the early symptoms of sleeping sickness. This absence of knowledge and the disease's relative neglect in national discourse suggests that sleeping sickness remains underreported, misunderstood, and inadequately addressed in broader health and policy frameworks in Zambia (Foucault, 1978).

As highlighted in chapter four and five of this thesis, inability to diagnose and treat possible cases of sleeping sickness left room for the participants to attribute causes of undiagnosed diseases such as sleeping sickness to witchcraft and supernatural powers (Yoshida, 1992). The diagnostic gap and misconception of sleeping sickness contributed to delayed diagnosis and treatment of possible cases of sleeping sickness. Furthermore, this gap contributes to the participants' reliance on traditional methods of diagnosis and treatment which are easy to access, ultimately affecting the participants' overall health seeking behaviour. The Kunda and Chewa farmers' strong religious and cultural belief system strongly further shaped their belief that illness and diseases are caused by witchcraft and supernatural powers in the absence of medical diagnosis and treatment. A study by Palmer (2020) in Sudan, shows that active screening increased the farmers' awareness and sensing of symptoms which prompted them to seek medical attention on time. However, my findings reveal that while sleeping sickness and other NTDs are acknowledged in Zambia, there is no national plan encouraging early diagnosis of sleeping sickness. For this reason, participants' levels of knowledge did not help them to seek medical attention.

While Palmer (2020) found that the Madi and Dinka sensed the symptoms based on the discourse and knowledge they had obtained from their interaction with medical and community based health workers, due to lack of enhanced diagnostic procedures and training in rural healthcare facilities to detect sleeping sickness, Kunda and Chewa farmers interpreted the symptoms based on their ethnicity and previous experiences of symptoms and treatment which managed the symptoms (Mulenga et al., 2015; Mwiinde et al., 2022).

This neglect of rHAT in national policy reflects structural violence, manifested as the ability of institutions of power to decide whose health is ‘visible’, and whose voices are heard and integrated in health policies and interventions (Farmer, 2004). Consequently, a cycle of ‘invisibility’ and abandonment in which poverty and the disease burden of sleeping sickness continues to affect the rural populations living near protected areas, is reinforced. Drawing on the concepts of power as a discourse (Foucault, 1982), inaccessibility and unavailability of health resources such as healthcare facilities, adequate drugs and services indirectly normalise healthcare inequalities and inequities among the participants. This evidence shows that social suffering from the risk of rHAT and its consequences is sustained by current institutional practices and policies (Kleinman, 1997).

Consequently, while other diseases such as malaria are prioritised, sleeping sickness remains neglected and lacks support toward its control and management (Mwanakasale et al., 2013; Mwanakasale & Songolo, 2011). This policy position contributes to gaps in service provision which indirectly reinforce participants’ reliance on alternative methods of disease diagnosis and treatment such as traditional medicine. Reliance on non-effective diagnosis and treatment methods increase the disease burden among rural communities and also hinders their emancipation from poverty and economic suffering (Kleinman, 1997).

Therefore, my findings suggest that risk of contracting sleeping sickness is embedded in the social, cultural and institutional processes (Rutto et al., 2013, Anderson et al., 2015). By that, I mean that while occurrence of sleeping sickness is based on biological and ecological conditions, the underling factors that predispose individuals to these conditions relate to power relations, distribution of resources and policy which ultimately shape participants’ social positions. This means that in addition to the participants’ culture and established system of livelihood, their exposure to areas with tsetse flies and risk of contracting sleeping sickness reflect the existing institutionalised inequalities in resource distribution and provision of infrastructure in rural communities such as Mambwe district (Hankivsky, 2014). While certain health behaviours such as use of herbs is associated with cultural traits, the unequal distribution of healthcare facilities combined with geographical locations inadvertently contributed to use of herbs by impeding the participants from accessing medical care.

7.3 Environmental and climatic factors driving unequal risk and access to healthcare services

The study found that climate change and environmental conditions manifested through droughts, flooding, and rising temperatures in Mambwe District reshape the ecological,

animal and human landscapes in which rHAT emerges (Longbottom et al., 2020). These changes also influence the risk of rHAT transmission and people's ability to access and utilise health services within the district. These environmental changes influence both the habitats of the tsetse fly and the movement patterns of livestock and people, increasing human-vector contact (Dzingirai et al., 2017a). Furthermore, as argued by Dzingirai et al. (2017a), my findings suggest that climate change not only creates ecological conditions favourable for disease emergence but also increases social vulnerability through displacement, food insecurity, and failure to access public infrastructure such as healthcare facilities. For example, in response to droughts, farmers and herders are often forced to move deeper into GMAs to areas which have abundant water and pasture (Nakamura and Hanazaki, 2017). However, these areas also serve as habitat for tsetse flies and wildlife, leaving the farmers and their livestock vulnerable to human wildlife conflicts and risk of HAT.

These findings align with the findings of other researchers such as Simasiku et al. (2008), Nyirenda et al. (2013) and Richardson et al. (2014) who concluded that game management areas (GMA) such as the Lupande GMA are faced with several environmental challenges such as floods, droughts, human wildlife conflicts, poor roads, and inadequate and inaccessible healthcare facilities during rainy seasons. Similarly, other researchers, such as Mwiinde et al. (2017) and Banda et al. (2013), have found that GMAs also suffer from low levels of economic, infrastructure and social development. These findings align with my findings by showing that vulnerability and risk to rHAT and consequences of climate change are mediated by social position, geography, and economic factors. For example, the three chiefdoms where my fieldwork was conducted in Mambwe district, face unequal exposure to climate driven ecological changes causing floods and droughts. In addition to that, seasonal floods destroy roads and bridges, isolate villages, and cut off access to already distant and under resourced rural healthcare facilities (Mulenga et al., 2015, Mwanakasale and Songolo, 2011, Mwanakasale et al., 2013). In addition, floods and droughts intensify food insecurity and economic pressure, forcing the Kunda and Chewa farmers to seek livelihoods in risky environments in a bid to meeting their daily needs (Nakamura and Hanazaki, 2017).

These findings show that vulnerability to sleeping sickness and socio-economic suffering by the participants is both socially produced and structurally maintained (Farmer, 2004). This suggests that participants' unequal exposure to environmental risk is not simply a matter of geography, but it reflects long standing infrastructural gaps that have left rural communities such as those of the Kunda and Chewa farmers in Mambwe District, with little capacity to

buffer environmental shocks (Cassidy et al., 2025). In this way, these findings show that environmental conditions and climate change amplify the existing risks of contracting sleeping sickness and suffering from consequences of the disease by participants from the three chiefdoms, populations already struggling with poverty and underdevelopment.

Although the above challenges contribute to economic problems and poverty as other studies such as Mwiinde et al. (2017) and Bukachi et al. (2018) have found, my findings further suggest that changing environmental conditions and climate change induced challenges especially droughts within the GMA indirectly increase the participants' risk of contracting sleeping sickness through their increased interaction with tsetse flies within their villages and areas where they practice their livelihood activities (Dzingirai et al., 2017a). For example, similar to the findings of Alderton et al. (2018), my findings show that during droughts, wild animals such as buffalos, elephants and impalas frequently visited the villages in search of food, thereby creating a constant presence of tsetse flies within villages, farms and water points, suggesting that the risk of contracting sleeping is within the participants' own villages and places where they earn a living.

Ultimately, my findings show that environmental, climatic and ecological factors such as the changing environmental conditions, rainfall patterns, and density of tsetse flies in a geographical location is but a part of the factors contributing to risk of contracting sleeping sickness among Kunda and Chewa farmers. While my findings support the role of climate change, environmental and ecological factors in risk of contracting sleeping sickness (Longbottom et al., 2020; Simasiku et al., 2008), I argue that the Kunda and Chewa farmers' social, cultural and economic characteristics intersect with the environmental factors to create conditions which further increase the participants' vulnerability to ill health, poverty and food insecurity which reinforce their social suffering in the GMA. This pattern reflects structural violence, not as an act of intent, but as a result of institutional decisions that systematically disadvantage some populations (Farmer, 2010). Similar to Farmer's (2004) observations, these findings suggest that changing environmental conditions intersect with weak public policy on health and surveillance systems, reinforcing a cycle of exposure, delayed diagnosis, and prolonged suffering of the rural population. While my findings highlight the considerable challenges faced by participants living in the Lupande GMA mediated by gender and their background characteristics, as observed by Banda et al. (2013), they also reveal that Kunda and Chewa farmers benefit from several opportunities. For example, opportunities for small-scale farming, regulated hunting, safari business and access to other natural resources such as timber that contribute to household livelihoods.

7.4 Invisibility of sleeping sickness in policy, healthcare and community discourse

The final finding relates to the structural and institutional conditions that enable sleeping sickness to persist while remaining largely invisible in the eyes of policymakers and health practitioners especially in rural healthcare facilities (Mwanakasale and Songolo, 2011). Farmers and community members repeatedly pointed to impassable roads during the rainy season, unreliable transport, poorly equipped clinics, and the absence of active vector control services. These challenges are noticeable in all the three chiefdoms, Nsefu, Mnkhanya and Malama which are near the South Luangwa National Park, where people, livestock, and wildlife frequently interact (Lisulo et al., 2024). Despite these conditions, as observed by Mwanakasale and Songolo (2011) and Mulenga et al. (2015), sleeping sickness receives little attention in health system planning, disease surveillance, or public awareness campaigns. This institutional silence contributes to the invisibility of sleeping sickness, not only as a disease but as a lived burden affecting marginalised populations.

Farmers and community leaders frequently reported that sleeping sickness is not a priority in national or local development agendas. This invisibility is reflected in the absence of targeted awareness programmes, and better screening of sick people within the rural healthcare facilities. Similar to Mwanakasale and Songolo's (2011) conclusions, my findings show that health workers in rural healthcare facilities lack training or resources to correctly identify sleeping sickness resulting in frequent misdiagnosis which indirectly contribute to low public awareness in settings that rely on health workers to know diseases. This invisibility of sleeping sickness in policy is not accidental, but a reflection of broader power dynamics, where decisions about health resources such as infrastructure, surveillance systems, and screening services reflect uneven political priorities and resource allocation (Douglas, 1992; Douglas and Wildavsky, 1982). This structural violence results in a cycle of invisibility in which the burden of sleeping sickness continues to impact the livelihood and wellbeing of people living within the Lupande GMA, while the disease itself is rendered unimportant in policy and expert discourse (Craddock and Hinchliffe, 2015; Douglas, 1992). This suggest that social suffering from the risk and consequences of sleeping sickness is a collective experience, rooted in historical disadvantage of rural populations and sustained by current institutional practices and discourse (Douglas, 1992; Douglas and Wildavsky, 1982). For example, in Zambia, the limited inclusion of non-biomedical aspects of sleeping sickness and lack of prioritisation by policy makers and professional experts has largely contributed to the disease's invisibility among communities, medical researchers, conservationists and in policy discourse. This finding is consistent with Mwanakasale and Songolo's (2011)

conclusion in their study on the disappearance of HAT transmission foci in Zambia in the absence of a tsetse fly and trypanosomiasis control programme.

Taken together, the study's findings reveal a pattern of interconnected drivers that produce both vulnerability to infection to sleeping sickness and obstacles to healthcare services in Mambwe District. Change in climate and environmental conditions also create ecological imbalances which alter the behaviour, location and density of tsetse flies influencing the dynamics of contracting sleeping sickness (Gbetnkom 2009; McKinnon et al. 2016; Longbottom et al. 2020). Furthermore, gendered roles and gender role socialisation of children also shape everyday interaction of men, women and children with tsetse flies (Bukachi et al. 2018; Ochola et al., 2021). As argued by McGibbon and McPherson (2011), challenges such as inaccessible healthcare facilities, drug shortages, lack of accurate diagnosis, lack of campaigns and prioritisation of sleeping sickness are not separate issues, rather, they interact and reinforce each other.

Therefore, although climate and environmental change may worsen the transmission conditions of sleeping sickness within Mambwe district, the failure of public healthcare facilities and institutions to protect, educate, and provide healthcare services to communities at risk of sleeping sickness contribute to the disease's persistence within rural communities. Consequently, I argue that the suffering associated with rHAT is not only biological but social, economic and political (Douglas, 1992; Douglas and Wildavsky, 1982; Kleinman, 1997). It involves not only the symptoms of illness but the frustrations of delayed diagnosis, the stigma and exclusion from socioeconomic activities because of the long term effects of the disease such as body weakness (Mwiinde et al., 2017). Such suffering, therefore, is not only a private matter but a public and structural issue requiring an interdisciplinary one health approach which accounts for both the biomedical and non-biomedical aspects of sleeping sickness.

7.5 Study Contributions

To date, most research on sleeping sickness particularly in Zambia has been grounded in positivist paradigms, relying on quantitative methodologies to examine various aspects of the disease, including its economic impact (Mwiinde et al., 2017), challenges to its control (Alderton et al., 2016; Mwanakasale et al., 2013), and its wildlife reservoir (Anderson et al., 2011). While these approaches have yielded valuable insights into the biomedical characteristics of sleeping sickness and some of its effects on patients, the approach offers a limited account and understanding of macro process such as the socio-cultural and political dynamics that shape risk of contracting sleeping sickness in rural areas such as Mambwe

district. Specifically, the available evidence on sleeping sickness in Zambia under-emphasise how gender intersecting with broader structural processes influence risk and vulnerability to the disease. In the following section, I discuss the study's theoretical and methodological contributions to the growing body of knowledge on sleeping sickness, gender, One Health, and NTDs in Zambia.

7.5.1 Theoretical contributions

Throughout this thesis, I sought to explore risk, and vulnerability to contracting sleeping sickness and suffering to conditions in the Lupande GMA through a sociological theoretical framework. Specifically, I rely on the intersectionality theory (Crenshaw, 1991), gender performativity theory (Butler, 1988) and vulnerability theory (Zakour, 2010), to explore the role of gender in shaping vulnerability and suffering from sleeping sickness and its associated challenges in the GMA. Similarly, I rely on Parson's (1969) and Luhmann's (1980) social systems theory to show the relevance of interdisciplinary collaboration and inclusion of social sciences in the One Health approach seeking to understand and control sleeping sickness (Calhoun et al., 2012).

This study's findings contribute to theory on sleeping sickness by showing that gendered understanding of sleeping sickness, the role of cultural and religious factor play a significant role in shaping risk, response, access and utilisation of healthcare resources especially by marginalised populations living in rural communities such as the three chiefdoms I studied. Furthermore, these findings emphasise that a sociological theoretical framework rooted in intersectionality, gender performativity, social systems and vulnerability theory act as a good platform for interdisciplinary One Health collaborations on sleeping sickness which would allow a comprehensive, context specific approach to the underlying factors that shape experiences of risk to sleeping sickness by rural communities (Bardosh, 2014; Craddock and Hinchliffe, 2015). Adopting sociological theoretical approach would help to address sleeping sickness not just as a health problem but also as a reflection of deeper social inequalities and systemic injustice (McGibbon & McPherson, 2011). Therefore, my thesis shows the value of considering social science theories in understanding the multidimensional nature of sleeping sickness and how these nonbiomedical factors shape risk of contracting the disease, response to symptoms and policy to control it.

7.5.2 Methodological contributions

Turning to my thesis's methodological contribution to One Health and the study of sleeping sickness, it has shown the value of social science methods, especially, sociological and anthropological approaches to understanding the nonbiomedical aspects of sleeping sickness

and its risk in different settings (Craddock and Hinchliffe, 2015). Therefore, the methodological contribution of my thesis lies in its interdisciplinary application of sociological and anthropological methods and theories to sleeping sickness, a biomedical issue. For example, the qualitative methods rooted in interpretivism used in my study provided a subjective and experiential understanding of how risk of contracting sleeping sickness is shaped by socio-cultural, economic, environmental and political factors. Although these findings show that risk of sleeping sickness is shaped by several macro processes and actors intersecting with individual characteristics of the farmers, the findings also reveal the opportunities of how sociological theory and methodology can enhance understanding of the different dimensions of sleeping sickness (Robinson & Howland, 2021). This finding emphasises the need for, and importance of a critical One Health approach which goes beyond human, animal and environmental health to include interrogation of power relations and social structures that shape who suffers from sleeping sickness, who acts and who decides (Bardosh, 2014; Craddock and Hinchliffe, 2015). Overall, these findings suggest that elimination of rHAT transmission in Zambia, requires moving beyond predominantly biomedical and vector control interventions to gender responsive and interdisciplinary One Health approaches that consider gender and governance dynamics in the development of interventions.

7.6 Conclusion

In this thesis, I explored the multidimensional non-biomedical nature and factors that shape human vulnerability to sleeping sickness in Mambwe District. Drawing on intersectionality theory, gender performativity, vulnerability, and social systems theory, I have analysed how risk, exposure, and response to sleeping sickness are shaped by structural inequalities rather than merely individual behaviours and changing climatic and environmental conditions.

A key finding is that gendered experiences of sleeping sickness are embedded within broader economic, environmental, social, and political processes. For example, men, women and children perform chores and engage in gendered roles which expose them to tsetse flies and risk of sleeping sickness. These findings highlight the many disadvantages faced by the participants, Kunda and Chewa farmers, whose roles expose them to increased risk and reflect deep structural violence that remains unaddressed within existing policy frameworks and approaches (Sambo et al., 2014, Craddock and Hinchliffe 2015).

I have also argued that understanding sleeping sickness through a gendered lens illuminates the unequal power relations shaping perceptions, awareness, and experiences of illness and suffering (Morgan et al., 2016; Sheikh, Ranson and Gilson, 2014). Social and cultural

conditions not only construct the meaning and causes of illness but also determine access to resources necessary for prevention and care (Link & Phelan, 1995). Risk is thus embedded in local political, institutional, cultural, and religious contexts. I argue that challenges in healthcare service delivery and institutional systems also contribute to the exclusion of rural communities from zoonotic disease knowledge, increasing their vulnerability (Nyamwamu, 2016; Zakour & Gillespie, 2013). Despite evidence that risk is gendered and linked to livelihood patterns, detection and diagnosis efforts remain inadequate (Mwanakasale & Songolo, 2011). While some recognition of inequality exists, the role of gender and power relations in shaping these inequalities is largely overlooked (Gore & Parker, 2019; Østebø et al., 2018).

In light of these findings, there is a clear need to reorient sleeping sickness interventions and policies to broaden its focus to include the non-biomedical dimension of sleeping sickness (Craddock & Hinchliffe, 2015). Although the One Health framework has historically focused on biomedical factors, incorporating gender and social science perspectives would enhance its ability to understand complex, multidimensional health issues as revealed in this thesis. Throughout this thesis, I have highlighted that effective interventions against sleeping sickness require more than drugs to include equity, equality and transformation of barriers to health and economic development.

Ultimately, I argue that sleeping sickness is not merely a parasitic disease, but also a social condition perpetuated by intersecting individual, environmental and institutional processes. Thus, understanding and addressing sleeping sickness and other NTDs requires a fundamental shift towards a combination of biomedical and nonbiomedical, and context-specific informed responses. This would ensure the development of effective interventions that move beyond medical treatment to address structural barriers to health. This thesis, therefore, adds to growing calls to consider the One Health approach not only as a biomedical model to NTDs and the environment, but as a socially engaged framework capable of confronting the inequalities that shape human, animal and environmental health.

7.7 Study limitations

This thesis makes an important contribution to the gendered understanding of sleeping sickness among Kunda and Chewa farmers in Mambwe District. One of the key strengths of this study lies in its methodological and theoretical approach, which enabled the exploration of the farmers' lived experiences of vulnerability, risk, and healthcare seeking practices in relation to sleeping sickness within a specific socio-cultural and institutional context. However, the thesis is not without limitations, which should be considered when interpreting

the findings. For example, the study's findings may not be generalised beyond the field site to other parts of Eastern Province or Zambia as a whole. While experiences may be similar in comparable contexts, this thesis reflects the experiences of vulnerability and suffering related to the risk of sleeping sickness and associated challenges among Kunda and Chewa farmers living in Nsefu, Malama, and Mnkhanya Chiefdoms of Mambwe District. Furthermore, cultural norms governing interactions between men and women restricted the areas I could access with women and shaped the level of interaction and engagement I had with Kunda and Chewa women during walking interviews. The lack of sex-disaggregated data in official records also limited the ability to fully explore gendered patterns of exposure, vulnerability, and care seeking.

Lastly, lack of capacity to diagnose possible cases of sleeping sickness, and lack of clinically confirmed cases, made it difficult to confirm health seeking behaviour and understanding for the disease among the farmers. Although accounts from Kunda and Chewa farmers included symptoms of sleeping sickness, the local health facilities did not offer further diagnosis in cases where malaria tests are negative. This implies that whether these were true or false malaria cases, the opportunity to confirm this was not available. Therefore, the lack of diagnosis was a hindrance to verifying the healthcare and farmers' experiences and responses to suspected and confirmed cases of sleeping sickness in the three chiefdoms. For this reason, the low number of diagnosed cases constrained the sample characteristics thereby reducing opportunities to capture the lived experiences of rHAT and its treatment pathways.

7.8 Policy recommendations

My analysis in this thesis has shown that Zambia's policy framework on trypanosomiasis is fragmented coordinated across human, animal, and environmental sectors. I have shown that, despite previous notable gains in vector control, national strategies largely pay limited attention to the ecological and climatic dynamics driving tsetse fly habitat and disease transmission. Climate variability marked by shifting rainfall, rising temperatures, and land use change has reshaped wildlife movement and vegetation, creating ideal conditions for the persistence and resurgence of trypanosomiasis in humans and animals. At the same time, gendered divisions of labour and unequal access to health care intensify exposure and delay treatment. These intersecting challenges suggest a need for policy shift from narrow biomedical focus to approaches that integrate sociocultural, environmental, climatic, economic, and political dimensions of trypanosomiasis. Therefore, I make the following recommendations:

1. Mainstream gender analysis. There is need to apply gender analysis across all programme stages, planning, implementation, and evaluation, to reduce disproportionate exposure and improve timely diagnosis and treatment for marginalised groups, while explicitly addressing structural and gendered vulnerabilities.
2. Institutionalise One Health coordination. Government should establish a statutory One Health platform with clear authority to integrate conservation, health, social and development policy to address existing structural gaps. Within the current framework, competing interests among gatekeepers and policy makers leave communities vulnerable to disease because attention centres on the actors' interests rather than the wellbeing of communities.
3. Integrate planning for mobility and healthcare access constraints. Findings show that changing climatic conditions shape the farmers' seasonal mobility and access to diagnostic and treatment services. Disease control programmes should account for physical and seasonal barriers to healthcare, reducing delays in diagnosis and treatment.
4. Strengthen diagnostic systems and clinical capacity. Enhancing diagnostic infrastructure and providing continuous clinical training, particularly at primary and district levels, is important for timely diagnosis and treatment of sleeping sickness.
5. Strengthen community centred surveillance. The study also shows that embedding community knowledge and lived experiences within formal surveillance systems through participatory approaches can improve early case identification, build trust, and enhance responsiveness to risks shaped by livelihoods and environmental change.
6. Expand ecologically and socially informed vector control. Vector control strategies should reflect local ecological and livelihood patterns, with targeted deployment of tsetse fly traps near grazing areas, water points, agricultural fields, and village peripheries to reduce vector density in high-exposure spaces.

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Appendices

Appendix 1: UNZA HSSREC Ethics clearance letter

Appendix 2: Permission letter from the ministry of Health

Appendix 3: Permission letter from the ministry of Fisheries and Livestock

Appendix 4: Permission letter from the Ministry of Health

Appendix 5: Map of the study areas

