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Review Article

Disease Trends and Reassessment of Knowledge, Attitudes, and Practices of Stakeholders in Trypanosomiasis-Prone Areas of Malawi: A One Health Perspective

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Abstract

Background: Trypanosomiasis is a neglected tropical disease caused by *Trypanosoma* parasites, transmitted primarily by the tests fly vector and, in some instances, by other biting insects. In Sub-Saharan Africa, both the human and animal forms of the disease pose serious challenges, as they hinder agricultural productivity, affect human health, and impede national development. In Malawi, the three pillars of Vision 2063—agricultural productivity and commercialization, industrialization, and urbanization—may be significantly affected by the continued presence of trypanosomiasis, compromising the nation's long-term developmental goals. **Objective:** To review disease trends by comparing prevalence data and assessing stakeholders' knowledge, attitudes, and practices (KAP) in trypanosomiasis-prone areas of Malawi, in order to inform prevention and control efforts. **Methods:** Peer-reviewed articles written in English were retrieved from various databases using targeted search phrases related to trypanosomiasis, disease prevalence, and KAP in Malawi. Retrieved studies were examined to map disease hotspots and characterize each focus area based on stakeholders' KAP. **Results:** This review has revealed that knowledge gaps regarding trypanosomiasis significantly influence stakeholders' attitudes and practices toward its prevention and control. These gaps contribute to sustained disease prevalence across trypanosomiasis-prone areas of Malawi. **Conclusion:** Strengthening community awareness and education campaigns could reduce knowledge gaps, improve attitudes and practices, and ultimately enhance the effectiveness of trypanosomiasis prevention and control efforts in Malawi and other endemic regions.

Keywords: *Trypanosomiasis; Tsetse fly; One Health; Knowledge, Attitude and Practice (KAP); Malawi*

Introduction

Trypanosomiasis has been and continues to be a disease of public health concern by wreaking havoc on the health and economic status of citizens of Malawi (Munthali *et al*., 2023). One key issue in understanding disease dynamics in an area, for instance Trypanosomiasis in Malawi, is to investigate

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disease trends and the knowledge gap, attitude and practice of the stakeholders involved. Trypanosomiasis disease is endemic in communities surrounding wildlife reserves. In recent years, particularly in 2019, Malawi has experienced a resurgence of Trypanosomiasis cases, with the highest reported cases in communities around wildlife reserves such as Vwaza in Mzimba and Rumphi district (Munthali *et al*., 2023), but also Nkhotakota wildlife reserve in Nkhotakota and Kasungu National Park in Kasungu (Chisi *et al*., 2011). The current trend was also experienced in 1970s and 1980s. World Health Organisation (WHO) statistics for the period 1976 -1983, estimated that out of a total population of 6.4 million in Malawi there were 1.2 million people at risk of infection with *T. b. rhodesiense* (Delbaere & Matengele, 1991). This disease is primarily transmitted by the tsetse flies but non- tsetse biting insects such as Tabanids and Stomoxys have also been reported to transmit the disease elsewhere. The prevalent strain in Malawi is *Trypanosoma brucei rhodesiense* which commonly transmit Human African Trypanosomiasis (HAT) (WHO, 2013a; WHO, 2023). A Variety of Trypanosome strains such as *Trypanosoma brucei gambiense, T. vivax, T. Congolese*, *T. simiae* are responsible for Animal African Trypanosomiasis (AAT) (Aksoy *et al*., 2017). Trypanosomiasis is a disease of global health concern looking at its transboundary aspect (WHO, 2013b). The impact of this neglected disease on humans and livestock has a far-reaching bearing on many countries' developmental progress. In Malawi for instance, this disease can hamper developmental progress by negatively impacting the very pillars of 2063 vision, which are agricultural productivity and commercialization, Industrialization and Urbanization (Wood, 2023). This can directly affect human capital but also livestock which are a source of income, food and nutrition security.

Trypanosomiasis, also known as African sleeping sickness, became more widely recognized with European colonization and with recent extensive research (Aksoy *et al*., 2017). In a recent study by Marsela and co-authors, Polymerase chain reaction (PCR) and nanopore sequencing were used to identify trypanosomes in cattle in Malawi and the findings revealed that cattle in central Malawi had a higher risk of *T. brucei* infection, while *T. congolense* and *T. theileri* were also prevalent (Marsela *et al*., 2020). Interestingly, in this study one cattle sample was confirmed as being infected with the human-infective *T. brucei rhodesiense*, underscoring the potential for zoonotic transmission and the need for a "One Health" approach to disease control with the inclusion of key stakeholders such as the department of parks and wildlife (Marsela *et al*., 2020; Nambala *et al*., 2022). Furthermore, the study by Marsela and others, reported that *T. theileri* was the most prevalent (26%), followed by *T. congolense* (3%) and *T. brucei* (2%). Despite its longevity and endemicity but also initiatives to eliminate it, Trypanosomiasis still maintains a high burden in Malawi because of its zoonotic nature. And this has resulted in its re-emergency even in areas that have been declared Trypanosomiasis free zones (PIIVC, 2020; Barrett *et al*., 2024; Franco *et al*., 2022). This could be attributed to insufficient knowledge of disease dynamics and ecology, but also attitude and practice of the stakeholders in Trypanosomiasis disease prevention and control (Liheluka *et al*., 2023; Kainga *et al*., 2022; Kainga *et al*., 2023; Chiumia *et al*., 2024). Additionally, despite well documented impact of community involvement in boosting up the effectiveness of health programs, there is minimal community involvement in Trypanosomiasis control and prevention (Lubanga *et al*., 2024; Liheluka *et al*., 2023). Therefore, this comprehensive review seeks to re-assess disease trends, Knowledge, attitude and practice gaps of stakeholders in Trypanosomiasis prone areas of Malawi. Relate how one health principles might help to bridge the gap of community non-engagement and non-participation and suggest ways of enhancing the role of community members and all other concerned stakeholders in prevention and control programs.

Methodology

The study used the literature survey approach. This methodology allows inclusion of studies conducted in different geographical regions, allowing for a broader and more diverse perspective on Trypanosome prone area but also analysis of knowledge gaps, attitude and practice of stakeholders towards prevention and control of the disease. Different areas may have different prevention and control frameworks, practices and environmental conditions which affect the presence and distribution of vector and trypanosomes prevalence in their different ecosystems. By examining these studies from multiple locations, the review can provide a bigger perspective on the issue under study, identifying differences

and highlighting potential hotspots and problem areas. Several papers were downloaded from various scientific databases such as PubMed, Google scholar, Google.com and Science direct by searching keywords such as "Trypanosomiasis knowledge , attitude and practice", or "Trypanosomiasis Social and economic impact", or "Animal African trypanosomiasis", or "Human African Trypanosomiasis", or "prevalence", or "tsetse infection", or "biting flies" or 'Trypanosomiasis prone areas in Malawi", or "Stakeholders involved in Trypanosomiasis", or "particular country name" were used to search for peer-reviewed articles published in the mentioned databases and later the list of papers were downloaded and abstracts critically screened and reviewed if they met the inclusion criteria (Ouzzani *et al.*, 2016). Screening and selection of articles were performed according to preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) procedures (Figure 1) (Moher *et al.*, 2009). This was done to ensure that appropriate articles are included in this review. Articles written in English were considered.

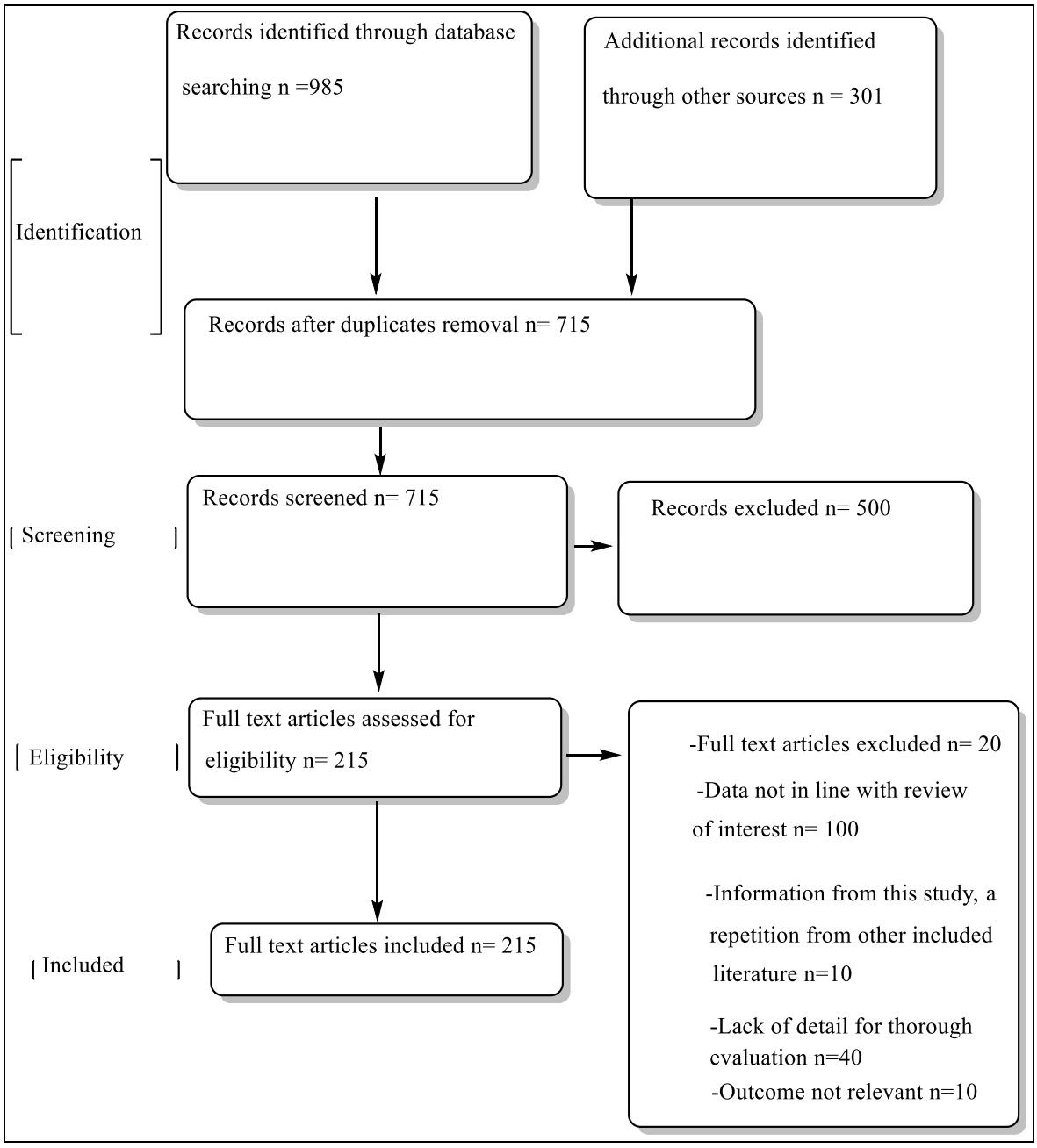

Figure 1: Showing PRISMA Process of Literature Selection

Quality Assessment

Assessment of quality of articles was done with major considerations on articles that were published in peer reviewed journals.

Data Extraction

Included articles were used for data extraction. Extracted data included main author and year of publication, total number of samples and overall prevalence rate.

Results and Discussion

Disease Knowledge and Terminology

Trypanosomiasis being a neglected disease affects the marginalized, vulnerable individuals, those having no political influence in a country (Papagni *et al*., 2023). Sadly, the implications are felt at all levels due to the gravity of impact imposed on the developmental aspects of the nation. Resources are channeled to buy medicines of both livestock and humans, and the livestock and human capital as work force is reduced impacting production. The burden is especially heavier in poor and marginalized communities surrounding wildlife reserves (Reid *et al*., 2012; Papagni *et al*., 2023). Malawi has seen a resurgence in trypanosomiasis cases, with the highest reported numbers in communities around wildlife reserves and national parks such as Vwaza marsh wildlife reserve in the Rumphi and Mzimba districts (Munthali *et al*., 2023; WHO, 2013b), Nkhotakota wildlife reserve in Nkhotakota district and Kasungu National park in Kasungu district (Chisi *et al*., 2011; NTD, 2014; Munthali *et al*., 2023). These communities are occupied by different tribes of people with different languages hence terminology used in identifying the disease and the vector differs (Table 1). In areas around the Vwaza Marsh Wildlife Reserve (VMWR) in both Rumphi and Mzimba districts occupied by large population of Tumbukas, "*kaskembe"* is the local term used to refer to both the tsetse fly and the disease (Munthali *et al*., 2023). This is different from other provenances. Human African Trypanosomiasis, in communities occupied by the Chewa and Sena depending on individual's ethnic background, is known as "*Kawodzera*" and "*kawojiwoji*" respectively (Nambala *et al*., 2022). These literally translate to the disease of Sleeping sickness or Trypanosomiasis and not, the vector (Tsetse fly) as is the case in the Tumbuka ethnic background provenances of Rumphi and Mzimba (Table 1). Knowledge of the disease is of paramount importance if it comes to its prevention and control (Munthali *et al*., 2023). For instance, poor Knowledge, Attitude and Practice was detected among the population in studies that involved Covid and Veterinary drug dispensers (Li *et al*., 2021; Kainga *et al*., 2023). People faced challenges due to lack of necessary preventive resources and formal information channels. The situation was worse considering vulnerable population who had low economic status (Li *et al*., 2021; Kainga *et al*., 2023). This present study revealed that most community members surrounding Trypanosomiasis prone areas were conversant with different terminologies hence standing a better chance of preventing and controlling its spread.

Table 1: Common Terminologies for Trypanosomiasis in Different Provenances with Different Ethnic Groups of People

Tribe	Associated name	Meaning
Chewa	Kawodzera	Trypanosomiasis
Tumbuka	Kaskembe	Tsetse fly /Trypanosomiasis
Sena	Kawojiwoji	Trypanosomiasis

Disease Trends

Trypanosomiasis has been a problem in Malawi for quite a long period of time now. WHO statistics for the period 1976 -1983, estimated that out of a population of 6.4 million people present in Malawi then, 1 million, 2 hundred thousand people were at risk of *T. b. rhodesiense* infection (Delbaere & Matengele, 1991). In 1973, Nkhotakota reported 2 cases and a case each were reported in 1979 and 1980. However, increased trends were reported in 1989 and the following years. In 1989 for instance 21 cases were reported, 209 cases for 1990 and 64 cases for the first two months of 1991 (Nkhotakota District Hospital statistics) (Delbaere & Matengele, 1991). Data from two different sources indicated increases of Trypanosomiasis cases in Malawi from 1973-1984 (Figure 2). Although the r-squared value of .4

indicates moderate correlation of Trypanosomiasis cases within this given period of time, the burden was still high (Figure 2). In case of Nkhotakota, reports suggest that since the beginning of 1991 more than 1 patient suffering from trypanosomiasis were admitted each day. Patients were either in early or late stages of Trypanosomiasis (Delbaere & Matengele, 1991). The "early" stage is where the disease has not affected the central nervous system (CNS), whereas the "late" stage is when CNS spread has occurred. A lumber puncture is done to "confirm" the presence or absence of trypanosomes in the CNS. The pain experienced in this process deters access to diagnosis and medication as people tend to shun away from hospital (Barasa, 2012; Mpanya *et al*., 2012; Mpanya *et al*., 2015; Mulenga *et al*., 2019; Neema *et al*., 2020).

The mortality rate of trypanosomiasis is 100% in untreated patients (Odiit, 1997; Munthali *et al*., 2023). In the advanced late stage of the disease the prognosis is poor though treatment is not hopeless. In 1990 trypanosomiasis accounted for 11 % of all hospital deaths. Researchers have reported that many deaths would continue to occur in tsetse infested areas due to many intertwined factors (Table 2) (Delbaere & Matengele, 1991). Today the extent of the disease in the communities surrounding the wildlife reserves is not known. This is due to the fact that there is no organized active case detection established within the tsetse infested areas. This is a true reflection of Trypanosomiasis being a neglected disease. Basically, the hospital figures represent the tip of the iceberg (Delbaere & Matengele, 1991; Nambala *et al*., 2022).

Trypanosomiasis is associated with a great deal of suffering and misery. The spread of trypanosomiasis depends on the host-vector-parasite relationship. In an endemic situation "game-fly-man" cycle predominates whilst in an epidemic situation (as seen in Nkhotakota) "man-fly-man" and "domestic animal-fly-man" cycles predominate. The complexity posed by these different interplays makes it hard to deal with Trypanosomiasis (PIIVC, 2020; Franco *et al*., 2022; Barrett *et al*., 2024). Domestic animals that serve as reservoir hosts include cattle, sheep, goats, cats and dogs. The game hosts that have been identified as reservoirs are the bushbuck, (which is perhaps the most important host), waterbuck, hippopotamus, warthog, hyena and hartebeest (Delbaere & Matengele, 1991, Nayupe *et al*., 2019). Knowledge of this information would be of paramount importance in prevention and control of Trypanosomiasis disease. Another aspect that is of importance to make people aware of is about the vector of Trypanosomes, the causative agent of Trypanosomiasis disease. The Tsetse fly species *Glossina morsitans* and *Glossina pallidipes,* whose reproduction conditions require warm, shady and humid soils, feed preferentially on a wide range of aforementioned games (Nayupe *et al*, 2019). This poses high-risk to a wide range of groups of people including hunters, poachers, firewood collectors, women collecting water and farmers. Trypanosomiasis is also difficult to eradicate, due to the fact that, it is not possible to make a diagnosis on clinical manifestations alone (Nambala *et al*., 2022). It is through parasitological examination that one can confirm the diagnosis. There are certain symptoms which suggest diagnosis only when they occur in combination. More importantly, wild animals are also host to human parasites hence it is very hard to deal with them in the prevention and control avenues (Kamoto *et al*., 2021; Munthali *et al*., 2023; Nayupe *et al*., 2019). A study by Nambala and others reported a majority of HAT cases in men (70.2%), and the average age being 29.9 ± 15.3 with all fatalities resulting from stage 2 of HAT disease. The study further suggested that rHAT clinical phenotypes in Malawi are focus-dependent and that there has been a steady increase in rHAT cases compared to all countries with incidences of rHAT (Nambala *et al*., 2022). This, therefore, highlights the need to intensify the prevention and control initiatives in the prone areas.

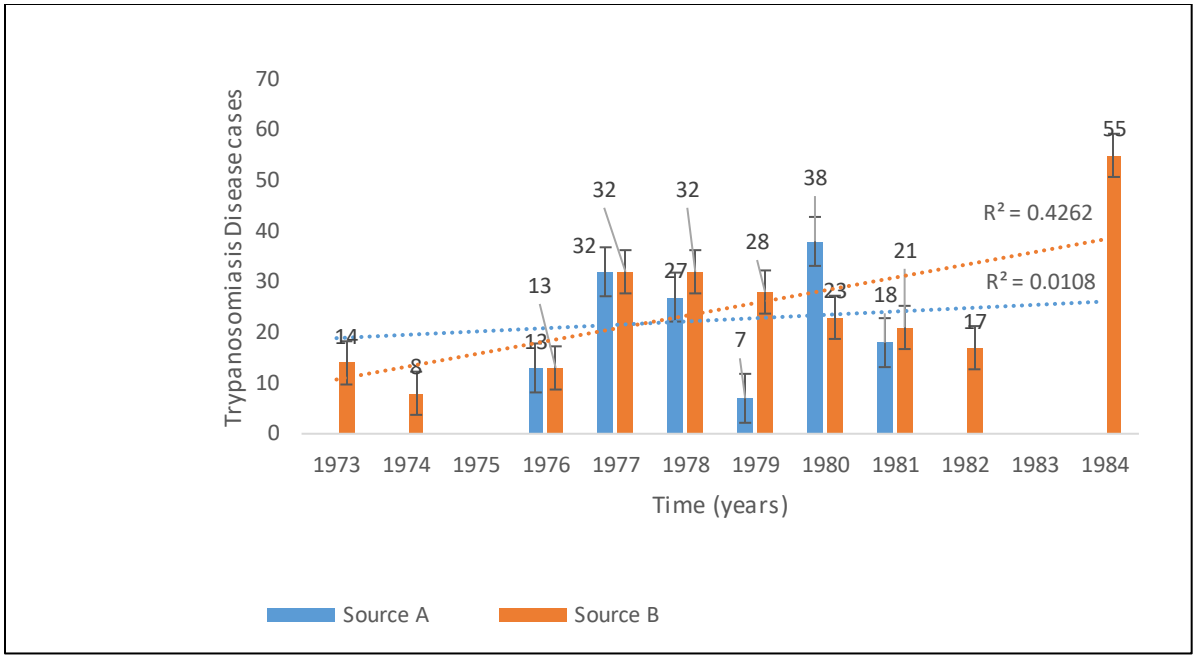

Figure 2: Trypanosomiasis Trends in Malawi from Two Different Sources

Number of rhodesiense sleeping sickness cases in Malawi from 1990–2015 have been fluctuating. Among the challenges facing the r-HAT response is the failure of early case detection resulting in high case fatality rates. Lack of cross-border joint interventions, re-allocation of HAT trained staff, lack of research but also funding for equipment such as utility vehicles hamper disease prevention and control programs (WHO, 2017). From 2011 up to 2020 the trend reveals continued disease burden (Figure 3). For instance, a total of 315 r-HAT cases were reported in three endemic r-HAT districts of Malawi, namely, Nkhotakota, Kasungu, and Rumphi, from January 2012 to August 2020 with an annual mean of 35 ± 25 HAT cases (Nambala *et al*., 2022). No r-HAT case was reported outside of the three endemic districts as per national trend (Figure 3) most of the cases reported were in stage 2. All r-HAT cases were treated for stage 1 when Trypanosome parasites were identified in bloodstream only or for stage 2 when parasites were identified in both blood and cerebral spinal fluid (CSF) regardless of white blood cells (WBC) count. Rumphi district had the highest number of r-HAT cases (80.3%) followed by Nkhotakota (19.4%) and Kasungu (0.32%) districts (Nambala *et al*., 2022). From 2019 to 2020, Rumphi and Nkhotakota districts have had a surge in r-HAT (157 total cases) which represented 49.5% of all cases reported from 2012 to 2020. Rumphi had a total of 108 (34.3%) r-HAT cases and Nkhotakota had 48 (15.2%) cases within 2 years (Nambala *et al*., 2022; Munthali *et al*., 2023). Most of the r-HAT cases were identified through passive r-HAT surveillance at district hospitals revealing the crucial importance and need for active surveillance in disease prevention and control endeavors (Madanitsa *et al*., 2009). From the year 2012 to 2020, Nkhotakota district showed a significant increase in r-HAT cases in comparison to the national total rHAT cases ($p < 0.01$), whereas Rumphi district had a decrease in the percentage of HAT cases though not statistically significant ($p < 0.5$) (Nambala *et al*., 2022). This might be attributed to initiative that started in 2013, where though limited because of distance (more than 60 km away from the reserve) diagnosis of rHAT in the region was available at the Rumphi District Hospital. This was done by Malawi's Ministry of Health in the project initiated to enhance the detection of rHAT in five health facilities around Vwaza Marsh by upgrading laboratories and training technicians (Lemerani *et al*., 2020).

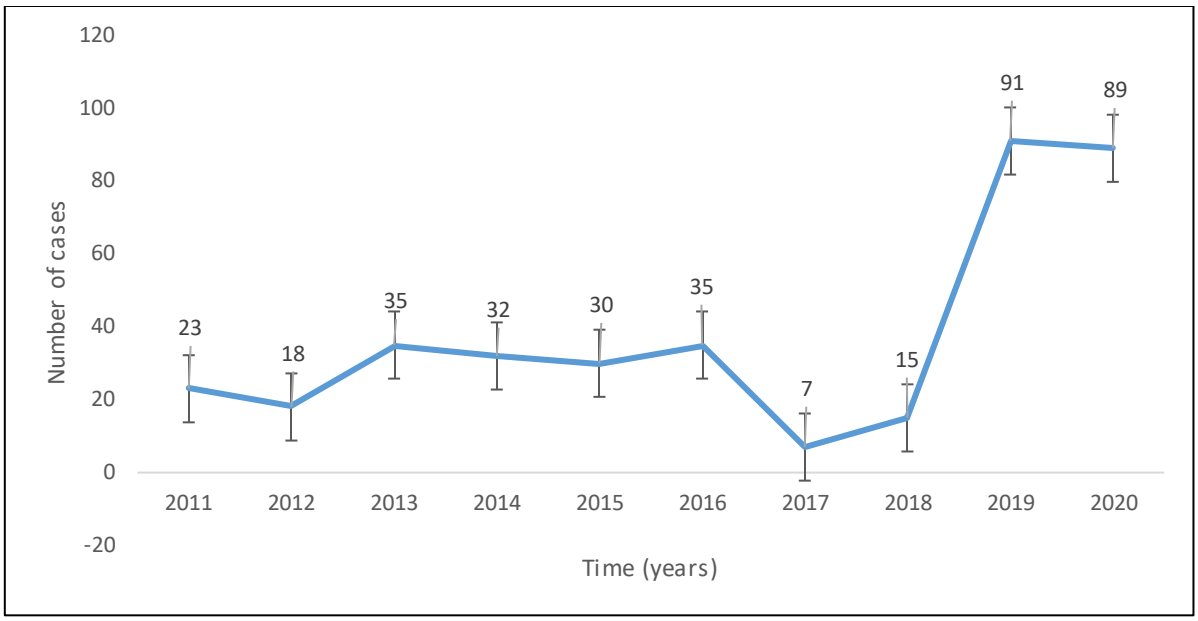

Figure 3: Trend in Number of r-HAT Cases in Malawi

Mindset Change Principle and Alternative Ways of the Disease Redress

Making informed decisions based on available data is one of the principles of One Health. Studies have revealed that health personnel in Malawi were in the past able to manipulate the treatment protocols and develop an enhanced protocol. Through experience in treating trypanosomiasis, and after consulting all available literature on the subject of treatment protocols, a modified treatment protocol was proposed and is now in use. Classical treatment schemes for Trypanosomiasis have been bypassed due to their ineffectiveness. For instance, 1 series (3 days) of Melarsoprol (at full dosage) after Suramin treatment in "early stage" of trypanosomiasis is administered in the modern protocol to address the problem of late giving of medicines to patients, addressing the claim that the Trypanosomes are already present in the central nervous system (CNS) even without changes in cerebral spinal fluid (CSF) which cannot be observed at early stage of the disease (Delbaere & Matengele, 1991). Adoption of this treatment policy has been recommended and is considered reasonable in setting since *T. b. rhodesiense* invades the CNS relatively early. Further arguments in support of this approach are the difficulty in following up patients (theoretically it should be at 3, 6, 12 and 24 months after treatment), and the fact that laboratory detection methods for CSF changes are not that reliable (Delbaere & Matengele, 1991).

It is believed that several patients with early central nervous system involvement are missed. These patients may then die in the village. It has also been reported that 4 doses of Suramin before giving Melarsoprol in late-stage disease is too much. In Kenya and Zambia, 3 doses are given, and in Tanzania and in Uganda only 2 doses are given. Studies have suggested that the interval before Melarsoprol should only be 1 day instead of 1 week. These modifications are deemed reasonable and cost effective in that they would save drugs, shorten the hospital stay, which is one of the barriers to accessing treatment against trypanosomiasis, and do not appear to affect outcome (Delbaere & Matengele, 1991). In Malawi Melarsoprol has been administered in a dextrose solution, but in other countries it is given as Melarsoprol IV STAT for effective outcome. This discovery informed health personnel in Malawi, to start giving Melarsoprol IV STAT (Delbaere & Matengele, 1991). Studies have reported the threat that requires a shift in the current disease control strategies in most developing nations due to inter-species transmission. For instance, multi-drug cross-resistance against the only accessible trypanocides and lack of estimation of mean prevalence in, both large and small domestic animals, in Sub-Saharan countries justify the need to revise the policy in developing countries to promote control of African trypanosomiasis (Okello *et al.*, 2022; Kasozi *et al.*, 2023). This data entails the importance of

globalization and data sharing at international and regional levels. And it augments the one health principle of information dissemination and utilization for one health and globe health achievement.

Trypanosomiasis disease control cannot be dealt with in isolation of any of the one health triad (Wood *et al*., 2024). Considering rapid population growth, land which was previously allocated as "Reserves" (close to the boundary of the Game Reserve) has now been released for settlement and agricultural use. However, public concern is now to avoid or even abandon this tsetse fly infested areas. Advising villagers to abandon their villages is not a solution since acquisition of alternative land is not feasible and survival depends on having sufficient land for food production. Vector control is possible with the use of odor baited insecticide impregnated targets. In Zimbabwe trials have shown that placing targets at a density of 4 per square km achieved more than 95% reduction of tsetse flies (Nambala *et al*., 2022). In the control of this disease, baseline data on the tsetse fly population and their behavior but also human behavior, is necessary to draw up a strategy for vector control. Nethertheless, medical surveillance of the human population having the disease and prone to disease infection is virtually non-existent. There is an observed disjointedness in tackling the disease by the responsible stakeholders hence need for their collaboration (Grant *et al*., 2015; Nambala *et al*., 2022). Previously much emphasis has been towards control of the disease in domestic and game animals, and vector control which has been worse still done in isolation by the concerned players (Nambala *et al*., 2022). Studies suggest the need to extend these programs towards control of the disease in the human population but also having an enhanced collaboration among all the concerned stakeholders (Wood, 2023). Regular medical surveillance of the population at risk and mass treatment for those infected (coupled with vector control) seems to be the only hope for controlling the disease in Trypanosomiasis prone areas in Malawi and elsewhere (Madanitsa *et al*., 2009; Nambala *et al*., 2022). Unless there is a combined response from the medical surveillance and vector control sectors, hospital treatment can never yield intended results in this fight against trypanosomiasis (Wood, 2023). A comprehensive situation analysis is required as observed in protocol manipulation to develop more pertinent strategies for disease control (Nambala *et al*., 2022). Information is needed on the prevalence and spread of trypanosomiasis; demographic data on the population at risk; information on the vegetation of the area with emphasis on demand for land and food because these are some of the notable drivers to Trypanosomiasis increased prevalence. Prevention can be achieved by a combination of various strategies. First the identification of carriers /cases (both active and passive) and treatment of all patients infected is needed to break the transmission cycle (man-fly-man). This will require a sufficient stock of drugs; hence donor aid as stipulated in one health principle should be embraced and encouraged to assist those countries lacking in their efforts against this transboundary problem. Community awareness can be increased through health education. Primary health care-based programs should involve villagers and follow up of treated patients (NTD, 2014). All these require financial support hence political will is an engine in steering the initiatives targeting Trypanosomiasis control.

Notably, Nkhotakota is one of the districts witnessing a resurgence of Tsetse flies responsible for the transmission of trypanosomiasis. The expanding population and increased demand for agricultural land has made this devastating disease a major communicable disease in this district (NTD, 2014). A combined approach of active medical surveillance to detect trypanosomiasis cases, treatment and education of those infected and vector control with "targets" have been suggested as the only hope of reducing the spread of this major communicable disease. Sound planning, organisation collaboration, and provision of financial resources are crucial in this endeavor (NTD, 2014). Nevertheless, the cuts in international funding for health programs could slow down or even reverse the gains and lead to re-emergence of the disease due to lack of post-validation surveillance to detect any resurgence early (Panday, 2025). Community involvement is recognized as a crucial pillar for the success of disease control and elimination. In most developing countries, disease prevalence and incidence are heightened because of the interplay of economic, social, and biological factors (Lubanga *et al*., 2024). While most health programs focus on dealing with the biological component of the disease, the social and economic aspects also remain crucial toward mitigating the impact of most NTDs. Controlling any endemic diseases at the community level requires well-implemented and relevant sensitization and education of community members and implementation of strategies that integrate and involve the communities

affected by the disease. Community engagement activities have largely been utilized in controlling infectious diseases particularly in low-and middle-income countries (Lubanga *et al*., 2024). This includes a range of approaches to involve communities in the improvement of their health and wellbeing. The high burden of Trypanosomiasis and other NTDs reflects the neglect of the community in planning and execution of disease control programs by the responsible stakeholders. An effective elimination strategy for Trypanosomiasis needs to be comprehensive and directly feature the affected community members in planning and implementation of control measures. In Malawi, the "top-down" strategies to control Trypanosomiasis have largely been faulted. These are developed based on evidence acquired from research and are thus imposed on the communities (Lubanga *et al*., 2024). This reduces community ownership and sustainability of the programs. The (Neglected Tropical Disease) NTD report of a situation analysis conducted between February and April 2017, in Nigeria under the NTD COUNTDOWN project also highlighted that involving the community as primary stakeholders in NTD control programs implementation can help attain and sustain wider treatment coverage (WHO, 2017; Lubanga *et al*., 2024). A study conducted in Kenya investigating the capacity of local communities to address the burden of NTDs revealed firstly, the need for inter-sectoral collaboration between governments and affected populations for inclusive and sustainable NTD solutions (Lubanga *et al*., 2024; Wood *et al*., 2024). Secondly, the study recommended the need for a "bottom-up" approach that enhances capacity building, sensitization, and behavior change for improved uptake of NTD interventions. Study reports suggest that most NTDs have available interventions that work (WHO, 2017). The most significant challenge remaining however is to deliver interventions to affected populations in areas experiencing weak health systems such as weak surveillance (Madanitsa *et al*., 2009). For countries such as Malawi, where various health disparities exist when it comes to access to universal health coverage, the communities members need to be actively involved in designing most health interventions. The need to engage the community in planning disease control and mitigation measures is becoming more evident now than before. Malawi needs community engagement since despite all other initiatives surges in r-HAT continue to exist (Figure 3). Eliminating high endemic diseases and more importantly NTD requires joint efforts from health program implementers and the community (NTD, 2014). A study in Sub-Saharan Africa (SSA) indicated that most health programs that run with little community involvement result in marginal success (Lubanga *et al*., 2024).

Drivers of Disease Trends

Studies have reported different changes in disease trends in different Trypanosomiasis fields. The factors influencing these changes are not yet known, although other factors such as the training of clinicians on r-HAT, increased r-HAT surveillance, community engagement, improved access to diagnostic and control strategies but also environmental factors might have played a role in the observed trend differences (Kivali *et al*., 2020), nonetheless, the contribution of such factors entails further investigation in future studies (Lemelani *et al*., 2020). Rumphi district recorded a higher number of cases with stage 2 disease (84.6%), whereas in Nkhotakota, most of the reported cases (82.0%) were early stage 1 diseases. This increased case in Rumphi might be attributed to the fact that people in this area harbor the idea of Trypanosomiasis being caused by witchcraft (Table 2) (Munthali *et al*., 2023), which might lender them seeking medical help late after the disease has advanced to the second crucial stage. The prevalence of a disease in a community may be influenced by several factors such as gender, age, and ethnicity (Nambala *et al*., 2022). These factors could also have a reciprocal impact, for example, on the risks of exposure to Tsetse fly bites infected with human infective trypanosomes in the case of r-HAT. The World Health Organization (WHO) aimed to achieve control and elimination of Trypanosomiasis as a public health problem and move towards interruption of its transmission by the year 2020 (Nambala *et al*., 2022). This aim has not been achieved by Malawi due to the fact that, living in an endemic country, coupled with lack of knowledge of the disease, increased the population's vulnerability to infection. This is supported by reports of studies in which it was found that people believed that Trypanosomiasis was caused by witchcraft and this affected treatment seeking practices of human beings (Mpanya *et al*., 2012; Bukachi *et al*., 2018; Mulenga *et al* 2019; Neema *et al*., 2020; Munthali *et al*., 2023). Other than this reason, the disease has been misdiagnosed as malaria, poverty, fear of undergoing the painful diagnostic lumbar puncture (Barasa, 2012; Mpanya *et al*., 2012; Mpanya

et al., 2015; Mulenga *et al*., 2019; Neema *et al* 2020), belief that HIV test was part of r-HAT diagnostic procedure (Gibson, 2004; Barasa, 2012), and the transfer of the well trained health personnel due to shortage of stuff (MoH, 2017) has highly impacted the capacity of patients seeking to access treatment against Trypanosomiasis. *Rhodesiense* human African trypanosomiasis (r-HAT) remains a public health problem in Malawi, with the country reporting the highest number of cases of this acute form of sleeping sickness in the East African endemic region in 2019 and 2020 (Munthali *et al*., 2023). This may be due to weak surveillance and unimproved case detection and management processes (Madanitsa *et al* 2009; Kwedi Nolna *et al*., 2020). Since r-HAT has similar signs and symptoms to malaria, patients either self-medicate or are prescribed antimalarial treatment, delaying the initiation of r-HAT treatment (Nambala *et al*., 2022). While diagnosis of r-HAT can be done at health centre level, treatment requires hospitalization at the district hospital situated far away (Munthali *et al*., 2023). Due to high levels of poverty, patients struggle to afford transport to district hospitals, and their upkeep during hospitalization. In addition, patients fear undergoing very painful diagnostic lumbar puncture. Belief that r-HAT is caused by witchcraft still prevails, which also delays initiation of treatment. Misconceptions pose a big barrier in treatment seeking practices for many diseases in malawi and its neighbouring countries (Liheluka *et al*., 2023). The delivery of r-HAT services is also affected by the transfer of trained health workers to other locations. Access to r-HAT services, including treatment, could improve if community members were sensitized by involving them in in-service programmes or training about the causes, signs and symptoms of the disease, and the fact that the disease can only be treated at hospital and not by traditional healers (Munthali *et al*., 2023, Chiumia *et al*., 2023). Improving health infrastructure and providing treatment for r-HAT by health facilities around the communities of the victims would eliminate transport costs for patients and their guardians. Wild animals being the main reservoirs of r-HAT facilitate parasites transmission to human beings by Tsetse fly bites (Nambala *et al*., 2022). Research is therefore needed to look at animal movement and disease transmission dynamics.

Between 2011 and 2014, Uganda reported the highest number of cases of r-HAT in Eastern and Southern Africa. However, since 2015 with an exception of 2017, Malawi has been reporting the highest numbers r-HAT (Franco *et al*., 2022). This has caused increased social-economic burden in remote rural communities. Significant progress has been made in reducing reported HAT cases in some countries, for instance Kenya has recently been reported as 10th African nation to eliminate sleeping sickness (Panday, 2025). Lessons might be learnt from these countries on how their efforts have managed to achieve the reported gains. More importantly, area-specific updated epidemiological and clinical data may facilitate understanding the progress of efforts toward Trypanosomiasis. This coupled with development of new area-specific intervention strategies would help minimize the surges of sleeping sickness and reduce the social economic burden in Malawi.

Table 2: Barriers to Seeking Treatment for Rhodesiense-Human African Trypanosomiasis

Notable Barriers to Seeking Treatment For r-HAT	Consequences
The disease is misdiagnosed as malaria	Administration of wrong medication
Beliefs in witchcraft	Late visit to the hospital
High levels of poverty	No medical assistance given
Fear of undergoing the very painful diagnostic lumbar puncture	Late or no medical assistance given
Transfer of well-trained health workers away from the area	No professional assistance
Fear of knowing their HIV health status	Late or no visit to the hospital
Poor attitude and practices of health workers	Discourages patients visit to the hospitals

Conclusion

Despite the long history and initiatives to curb Trypanosomiasis in Malawi, there is still a high burden of the disease. Effective interventions, however, such community-based interventions fail to achieve optimal coverage and implementation due to a remarkable lack of community engagement. This is due to poor awareness of the disease in communities and lack of effective coordination of the health programs. Therefore, it is imperative to conduct comprehensive community education campaigns as well as define specific responsibilities of all relevant stakeholders as they work in coherence in order to ensure effective implementation of Trypanosomiasis control and prevention programs.

Recommendations

Community engagement and participation are essential for reducing the burden of NTDs like Trypanosomiasis. Studies show that community involvement improves program effectiveness, ownership, and long-term sustainability. Therefore, all NTD prevention and control efforts should build strong community participation.

For effective engagement, communities need sufficient knowledge about Trypanosomiasis and other NTDs—its burden, transmission cycle, and how their actions influence transmission and prevention. This can be achieved through comprehensive education using mass media, health-facility education, and house-to-house campaigns. Clear explanations of ongoing health programs and community roles are also important.

A bottom-up approach is necessary, involving communities at every stage of Trypanosomiasis control—from design to implementation, monitoring, and evaluation—to ensure context-specific, culturally acceptable programs. Such openness fosters ownership, collective action, and commitment, resulting in sustainable and effective outcomes.

Using existing community leadership structures further strengthens engagement. Traditional leaders, religious leaders, and school teachers can be trained as agents of change to promote Trypanosomiasis prevention. Additionally, decentralizing control programs to district level enables District Health Management Teams to coordinate with all stakeholders and target high-burden areas. This improves coordination, coverage, and the successful implementation of Trypanosomiasis prevention and control activities.

Conflict of Interest

The author(s) declare that there is no conflict of interest regarding the publication of this article.

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