

Exploring healthcare professionals' perspectives on neglected tropical diseases in Eastern Uganda: a qualitative study with a focus on schistosomiasis and soil-transmitted helminths

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Background: Neglected tropical diseases (NTDs), including soil-transmitted helminths (STHs) and schistosomiasis, continue to impose a heavy burden, especially in sub-Saharan Africa and Uganda, despite being preventable. Integration of NTD management into primary healthcare has been inadequate. While researchers have explored community perspectives, there is a notable gap in understanding the viewpoints of healthcare workers (HCW), which is crucial for effective NTD control strategies. This study explores HCW' perspectives in Eastern Uganda, highlighting challenges in schistosomiasis and STH prevention and management.

Methods: In this qualitative descriptive study, we conducted semistructured interviews with 10 key informants who were HCW in Eastern Uganda with experience in managing STHs and schistosomiasis. Participants were selected purposively and interviewed through Zoom guided by a comprehensive interview guide. The data were transcribed, coded and analyzed thematically.

Results: We identified five key themes regarding the impact and management of NTDs: (i) the burden of NTDs, where schistosomiasis and STHs were notably prevalent among children and communities adjacent to water bodies; (ii) transmission of NTDs, emphasizing water bodies and poor sanitation as primary routes of disease spread; (iii) clinical manifestations of NTDs, detailing the symptomatic presentations that complicate diagnosis and management; (iv) challenges in managing and diagnosing NTDs, highlighting the shortages of essential medications and diagnostic tools, along with the under-prioritization of NTDs within healthcare systems; and (v) fatalities and complications arising from NTDs, reporting on the severe outcomes and under-reporting of deaths associated with NTDs due to misdiagnosis, delayed treatment and traditional healing preferences.

Conclusion: The interviewed Ugandan HCW demonstrated sufficient knowledge of schistosomiasis and STHs, but faced challenges due to inadequate diagnostic tools and medication shortages. The study underscores the need for NTD prioritization with direct funding and government involvement, alongside strategies that integrate continuous medical training, effective community outreach and an enhanced healthcare system response to reduce the burden of NTDs.

Keywords: neglected tropical diseases (NTDs), healthcare workers, schistosomiasis, soil-transmitted helminths (STHs), eastern uganda, healthcare challenges

Introduction

Neglected tropical diseases (NTDs) present a significant global health challenge, affecting >1 billion people worldwide, with an additional 1 billion at risk.¹⁻⁷ These diseases have profound impacts on health, well-being and the socioeconomic conditions

of individuals, especially in resource-limited settings.^{6,8,9} Sub-Saharan Africa bears a disproportionate burden, accounting for more than two-thirds of the global NTD prevalence, with the highest incidences observed in rural and impoverished communities.^{3,6,10} In Uganda, all five NTDs targeted by the United

© The Author(s) 2024. Published by Oxford University Press on behalf of Royal Society of Tropical Medicine and Hygiene. All rights reserved. For permissions, please e-mail: journals.permissions@oup.com States Agency for International Development (USAID's) Act to End NTDs—soil-transmitted helminths (STHs), schistosomiasis, lymphatic filariasis, trachoma and onchocerciasis—are endemic, contributing significantly to the nation's health burden.¹⁰⁻¹³

Despite their preventability and potential for elimination, NTDs remain a challenge. In its 2013 resolution WHA66.12 on Neglected Tropical Diseases, the WHO aimed for a 90% reduction in the number of people requiring treatment for NTDs by 2030. This resolution also emphasized ensuring universal access to essential NTD interventions, a goal closely aligned with Sustainable Development Goal 3 to promote good health and well-being.³ This ambitious goal involves integrating NTDs into primary healthcare (PHC), ensuring the availability of medical supplies, guidelines and inclusion in public health packages.^{4,14} However, the integration of NTDs into PHC systems in sub-Saharan Africa, including Uganda, has been inadequate. Studies in Nigeria, Tanzania and Burundi indicate low capacity and readiness among healthcare workers (HCW) to diagnose and manage NTDs, attributed to a lack of knowledge and skills.^{3,15,16}

STHs are intestinal parasites, including roundworm, whipworm and hookworm. They are transmitted through contact with contaminated soil or feces, causing anemia, nutritional deficiencies and growth stunting, particularly in children.¹⁷ Schistosomiasis, caused by parasitic flatworms, is transmitted through contact with freshwater infested with snails that carry the parasite. It can lead to chronic health issues affecting the urinary tract or intestines.¹⁸ Both STHs and schistosomiasis are readily treatable with safe, effective medicines.⁴ Schistosomiasis is treated using praziquantel, while STHs are treated using albendazole.¹⁹

In Uganda, among NTDs, schistosomiasis and STHs have the highest prevalence with the burden of these diseases being severe. Schistosomiasis affects 4 million people, with 16.7 million at risk.^{18,20} It is endemic in 96 districts, with communities living on the shores of large water bodies experiencing the highest prevalence.²¹ STHs are also endemic in all districts, with a prevalence of 26.5%.^{18,21,22} Currently, the country's approach to NTD management involves integrated control programs.^{14,21}

Studies in sub-Saharan Africa have examined knowledge, attitudes, practices and barriers to care among affected populations and caregivers. A systematic review demonstrated the significance of comprehensive health education programs in improving knowledge, attitudes and practices regarding schistosomiasis in sub-Saharan Africa.²³ On the other hand, qualitative studies on the healthcare cascade for schistosomiasis and STHs in low-resource settings have largely focused on the perspectives of caregivers and affected communities.^{16,18,19,24} A gualitative study on women in Madagascar who had survived female genital schistosomiasis emphasized the vital need for improved health education and structural changes to effectively address NTDs.²⁴ Additionally, studies have explored community and caregiver perspectives, revealing key insights into exposure routes, the social impacts of STHs and schistosomiasis and barriers to seeking hospital-based care.^{19,25,26}

However, there is a notable lack of research focusing on the perspectives of HCW, who play a critical role in the diagnosis, management and prevention of schistosomiasis and STHs, especially in Uganda. Given the high prevalence of these diseases and the crucial role of HCW, understanding their perspectives is essential for identifying operational challenges and designing effective interventions aimed at achieving the WHO's 2030 elimination targets. In this study, we explored the views of HCW in Kayunga, Serere, Kaliro and Buyende districts in Eastern Uganda, bordering Lake Kyoga, and highlighted operational challenges in the management and prevention of schistosomiasis and STHs.

Methods

Study area and context

The study was conducted from May to July 2023 in health centers across Kayunga, Serere, Buyende and Kaliro districts in Eastern Uganda, bordering Lake Kyoga. This region is highly endemic for STHs and schistosomiasis due to the surrounding water bodies. The population is mainly rural and derives its income from the fishing business, supplemented through subsidiary farming of local foods. Water for cooking, personal hygiene, human consumption and animals is mostly fetched from the lake and surrounding streams. Open defecation and urination are also common in the area due to the dense population compared with toilets and latrines in the households.

Uganda's healthcare system is decentralized. In rural communities affected by NTDs, the initial point of medical contact is often the Village Health Team (VHT). VHTs are comprised of community volunteers who distribute medicines, offer health education and refer patients to formal health facilities. These health centers are organized in a tiered fashion: Health Center IIs provide basic outpatient services and maternal care, led by enrolled nurses. Health Center IIIs offer more comprehensive care, including laboratory diagnostics, and are headed by clinical officers. Lastly, Health Center IVs serve at the county level, offering inpatient services, surgical capabilities and are staffed by medical officers.

Study design and population

This was a qualitative descriptive study, leveraging key informant interviews with 10 HCW who had participated in the management of NTDs. The study specifically focused on HCW in the districts along the borders of Lake Kyoga, including Kayunga, Serere, Buyende and Kaliro. Participants were healthcare providers directly involved in the prevention, diagnosis, treatment or management of NTDs purposively selected with guidance from the District Health Officers (DHOs) and facility in-charges within the districts. Selection was based on their roles and expertise in NTD management and included HCW from Health Centers III and IV. The study adhered to rigorous qualitative research standards and was reported in line with the Consolidated Criteria for Reporting Qualitative Research checklist.²⁷

Data collection

Interviews were conducted by members of the research team trained in qualitative data collection methods (RBK, CM). Each interview was conducted by one member with the other taking memos. Interviews were conducted from 15 May to 15 July 2023 and lasted 30–50 min, with an average duration of 35 min. All interviews were conducted on Zoom. All interviews were conducted in the English language given that HCW are taught in

English. Interviews were audio-recorded and transcribed by two independent members of the research team.

The interview guide was generated through reading literature relevant to NTDs in sub-Saharan Africa in consultation with a trained microbiologist, who was part of the research team. The guide included questions focusing on the burden of common NTDs like STHs and schistosomiasis, their causes, transmission modes, management practices and community impacts to understand the perspectives of the HCW. Additional inquiries focused on challenges faced in NTD management, such as health system issues, diagnostic test availability, drug resistance and case reporting. The guide also sought suggestions for overcoming these challenges and any additional insights from the interviewees. These were used as probing points to guide the interviews.

Data analysis

The transcription process was overseen by CM to identify and rectify any inconsistencies, with RBK conducting a final proofreading. At this stage, all personal identification information was removed to ensure confidentiality. To validate the accuracy of the transcriptions, two approved versions of the interviews were sent back to the respective participants for confirmation. The analysis, which was conducted concurrently with data collection, utilized thematic analysis²⁸ to delve into the complexities of NTDs in the districts of Kayunga, Buyende, Kaliro and Serere.

The thematic analysis was structured around six distinct steps: (i) becoming thoroughly acquainted with the data; (ii) creating initial codes; (iii) identifying potential themes; (iv) refining these themes; (v) finalizing and labeling the themes; and (vi) compiling the final report. A codebook was developed using ATLAS Ti software (https://atlasti.com) after reviewing three transcripts each representing different stakeholder groups, to facilitate the analysis of subsequent interviews via relational content analysis. The research team, comprising RBK, LA, CM, AMK, TK and JB, engaged in weekly discussions to align on the themes identified and to share interpretations of the data. To ensure the validity of the findings, member checking was performed postanalysis.^{29,30}

Ethics

The study was ethically approved by the Mbarara University of Science and Technology Research Ethics Committee (MUST REC) (2023–01–17). Permission for participant engagement was obtained from the DHOs and the facility in-charges. Participants were initially contacted via E-mail, receiving an informed consent form and a link to a detailed Google Form for consent and interview scheduling. Zoom interviews were recorded with explicit participant consent.

Results

We interviewed a total of 10 HCW strategically selected from four Eastern Ugandan districts: two from Kayunga, three from Buyende, three from Kaliro and two from Serere. The group included seven males and three females, with a median age of 42.5 y, ranging from 31 to 54 y, and a median combined experience of 11 y with a range of 8 to 25 y in their respective fields. Participants held diverse healthcare roles, including Senior Nursing Officers, Senior Clinical Officers, a Medical Laboratory Technician, a Vector Control Officer, an NTD Focal Person, an Assistant Nursing Officer, a Senior Medical Clinical Officer and Clinical Officers. Five major themes emerged from the data analysis: (i) the burden of NTDs; (ii) transmission of NTDs; (iii) clinical manifestations of NTDs; (iv) challenges in managing and diagnosing NTDs; and (v) fatalities and complications arising from NTDs.

Burden of NTDs

Participants noted a varied occurrence of different NTDs across communities, with those near lake shores particularly affected. They identified schistosomiasis (bilharzia) as the most common NTD, reporting frequent cases in these areas. STHs were also frequently reported, especially among children. Participants stated that they observed up to 10 cases of STHs per month, primarily in children aged <5 y, and 10-15 cases of schistosomiasis per month. Other NTDs, such as elephantiasis, and infectious diseases like trachoma, tungiasis (jiggers) and leprosy, were reported to be less frequent. Participants estimated that elephantiasis cases occurred at least once every 3 mo. Trachoma, although not widespread, was perceived as a periodic concern. Significantly, participants described instances where almost every child in a household had jiggers, highlighting localized outbreaks. They also observed leprosy cases, although these were less common. Participants emphasized the vital role of interventions initiated by the Ministry and other health agencies in controlling the spread and severity of these diseases. They also believed that community response to sensitization programs and the adoption of better hygiene practices were crucial factors in reducing NTD cases:

Then the for the helminths, that one is very common among children and I have found out that from our records...from last year up to almost every month you get around 10 to 15 cases especially in children under five who have helminthic infections (Participant 006).

Commonest actually we have bilharzia, yeah we have bilharzia more common with our people (Participant 003).

Transmission of schistosomiasis and STHs

Water bodies were perceived as primary transmission sources by the majority of participants, particularly lakes, swamps and other water-filled areas that become breeding grounds for diseasecausing organisms, especially during the rainy season. Activities like swimming and fishing in these areas, especially at lakeshores and landing sites, were frequently associated with higher risks of contracting NTDs. These locations were especially notable for their higher number of cases among residents, such as fishermen, who are in constant contact with water:

Of course, the lake, people go there to swim, and there are also some other swamps, big swamps, during the rainy seasons, those swamps also flood with water, and when people go there of course that is where they harbor the organisms (Participant 001).

Where we border the lake shores and the majority of patients that we get here are people who are fishermen, so we get them, they have a lot of access to water...we realize that they are fishermen and their lifestyle has been full of fishing and contact with water (Participant 006).

Fecal-oral transmission, closely connected to the lack of proper sanitation and hygiene practices, was identified as another significant pathway for disease spread. Cultural beliefs against using latrines, coupled with the absence of handwashing facilities in toilets, exacerbated the situation. The study highlighted instances of consuming food without prior handwashing, particularly during fruit seasons, as a common practice that contributed to disease spread. Additionally, the habit of eating raw foods directly from the fields without handwashing was a concern for disease transmission. Additionally, participants pointed out that the lack of footwear, especially among children and adults in rural areas, increased the risk of STH infections:

Here are a lot of tribes with a lot of beliefs whereby even some other people don't believe in using latrines especially at the landing corner, yeah so majorly transmission is drinking unsafe water and poor hygiene it is where it is rotating from (Participant 003).

Things of washing hands, they don't wash hands as long as food is there, they eat especially now this season of mangoes, you go to the mango tree and chew directly without washing hands...you buy maize on the road, you just eat without washing the hand (Participant 010).

The participants perceived that the coronavirus disease 2019 (COVID-19) pandemic had a temporarily positive impact on NTD transmission due to improved handwashing and hygiene practices. However, a postpandemic decline in these practices was associated with a resurgence in NTD cases, underscoring the importance of sustained hygiene interventions:

Also, the wash activities, people used to, in the era of COVID 19, the people were seriously and actively handwashing but right now it has declined a bit (Participant 007).

Interviewees also stated that economic factors and environmental conditions further complicated the transmission dynamics. Poverty was seen as a significant factor in NTD exposure, with many children going to school without shoes, increasing their vulnerability to helminth infections. Environmental factors like seasonal flooding disrupted sanitation facilities and heightened the risk of water-washed and waterborne diseases. The presence of snails in water bodies, a crucial factor in the transmission of diseases like bilharzia, was also highlighted.

What I am saying that the economic status of our people, because they normally affect the poor. Majorly the poor. So, [the] majority of these people like the school-going children first of all, as per now, 90% to school without shoes (Participant 007).

Clinical manifestations of NTDs

Schistosomiasis was reported to present with hematuria (blood in urine) and abdominal distension. In children, this condition frequently led to noticeable abdominal swelling, stunted growth and malnutrition, often accompanied by reddened eyes, particularly at the mucosa. In more advanced stages, patients displayed pronounced abdominal extension, severe pallor due to anemia and rough skin texture. The severity of these symptoms was particularly evident in cases where patients experienced a considerable loss of appetite and general bodily weakening:

Bilharzia sometimes when it is [at an] early stage, you may not easily detect but when symptoms and signs [are] worse, you realize there is that extension of the abdomen, these people will complain of bloody urine, they will complain of loss of appetite (Participant 009).

For patients suffering from STHs, common symptoms included abdominal discomfort, diarrhea and blood in the stool. Children were particularly affected, presenting with visible abdominal distention, loss of appetite and varying degrees of anemia. In some cases, the worms were visibly present in the stool. An intriguing observation was noted in older patients, where infections by *Strongyloides stercoralis* often mimicked ulcer symptoms, leading to initial misdiagnoses:

Worms are majorly in children, children majorly they come still with loss of appetite, then some mild signs of anemia uh depending on the severity some come with some kind of occult stool or some stool stained with or black stool (Participant 003).

Challenges in managing and diagnosing NTDs

The interviewees indicated substantial logistical challenges, primarily the frequent unavailability of key NTD medications like praziquantel and ivermectin, which led to considerable interruptions in treatment. Similarly, a notable deficiency in essential diagnostic tools and basic equipment, such as stool and urine containers, was observed, often culminating in patients departing healthcare facilities without the required treatment. From a systemic viewpoint, the study revealed a consistent underprioritization of NTDs in terms of funding and support, as reflected in their limited budget allocations and the overshadowing of NTD initiatives by other health programs, particularly immunization campaigns. Furthermore, a general lack of motivation among HCW to engage with NTD cases was reported, resulting in overlooked diagnoses and further impeding the efforts to eradicate these diseases:

Also, stock out of some of these tablets like the mebendazole, you tell someone to go and buy and they are coming from poor families, of course they if don't buy, now another time he may come and it happens that you are still having maybe stock out, so that is, then next time he may not be coming again (Participant 008).

Uh NTDs given less priority in terms of funding in the first instance, it is given less priority even when you are like budgeting even on approval of funds given the PHA budget line, it is given less priority (Participant 003).

Having that attitude of going to the facility and gets diagnosed and treated is also actively low, people stay there and they don't seek for treatment, people even when they are given these deworming tablets sometimes they tend not to take and some areas in the community have those old myths of saying they are bewitching me or they are bewitching us (Participant 003).

Furthermore, it was reported that there was a significant knowledge gap in the community as well as among HCW on NTDs. Clinicians often misdiagnosed NTDs as common conditions like malaria or ulcers, owing to difficulties in suspecting and correctly identifying these diseases. This issue was compounded by the limited familiarity of laboratory personnel with NTD indicators, such as identifying schistosoma eggs in samples:

The challenge is that most of the clinicians are not really suspecting, they are just looking at these other signs of malaria and maybe someone is complaining of abdominal pain and whatever and they could say that's ulcers so when you look at our identification rate is very low (Participant 004).

Even the lab people not knowing how schistosoma eggs look like (Participant 007).

On the other hand, some participants noted that the community attributed NTD symptoms to non-medical causes like familial issues or witchcraft, leading to a preference for traditional healers, particularly in schistosomiasis cases. Medical care was sought only after traditional remedies failed, typically at an advanced disease stage, exacerbating the severity and complicating treatment. Although recognizable symptoms like worms in stools prompted quicker healthcare visits, a reluctance to seek treatment or follow medical advice, including taking prescribed deworming tablets, was observed:

Then these other diseases, really the moment they see the worms, they hurry more to come to our, to our health facilities for deworming because they always know those are worms actually, because when they come, even they come with a sample in the tin when the child has defecated those worms (Participant 002).

Those with enlarged stomach they always have a myth that they are always bewitched so they always try traditional healers and only present to us in late stages (Participant 005).

Myths and misconceptions, such as associating an enlarged stomach with bewitchment rather than a medical condition, significantly influenced this behavior. Concurrently, the HCW noted a shortfall in engagement and awareness efforts. Persistent myths led to delayed medical help-seeking, and the absence of sustained sensitization initiatives, like radio shows or informational campaigns, hindered efforts to dispel these myths and promote timely intervention. Furthermore, while some communityscreening activities were conducted, limitations in resources and facilitation often impeded their effectiveness, highlighting the need for targeted, clear messaging in community sensitization to enhance the impact of screening initiatives:

With limited knowledge, community sensitization is at a low level, there is no continuous...like having radio talk shows, some information to go on concurrent, ongoing, or updating our VHT's. It is not there (Participant 007).

There is a very big gap in community screening and sensitization. You find that the person supposed to do it also may need to know which key messages to give in the community, the screening maybe done but because of limited facilitation the entomologist may not be in position to move around sample water bodies and comes back to some clinical examination occasionally has been doing stool analysis for which worms (Participant 007).

Avoiding these students who swim in waters in where water is, we can prevent without even using funds, we can do it locally by preventing it by giving the right information to the targeted people (Participant 010).

Fatalities and complications arising from NTDs

HCW reported a number of deaths attributed to NTDs in recent years but expressed concern about significant under-reporting in the community. This was often due to delayed diagnoses, refusal of medical treatment, or the preference for religious and traditional healing methods, with symptoms frequently misattributed to non-medical causes like witchcraft. The recorded fatalities generally resulted from severe NTD complications, including distended abdomen with ascites, significant weight loss, severe illness, anemia, liver failure, kidney damage, portal hypertension and lower esophageal varices. Chronic conditions like filariasisinduced hydroceles, which worsened over time, were also noted. Particularly in diseases like bilharzia, complications were often severe, leading to advanced stages of liver failure that were not immediately recognized as NTD-related:

Put her on praziquantel, and when she went she didn't take the medicines by the way, they thought it is not a medical condition, they took her to church somewhere, that's where she died...they might be so many other cases that don't appear at the facility and they do die in the community without our knowledge (Participant 001).

Some have come with portal hypertension, and they come with chronic liver disease, portal hypertension, some have been coming when they are having lower esophageal varices (Participant 006).

It was diagnosed at a later hour when the client was urinating blood, blood was falling just at the later hour though the owners attached it to witchcraft you know our local people but for us medically we realized what caused the death (Participant 003).

Discussion

NTDS were common in the study area, Lake Kyoga, as has been reported in previous studies that saw a high prevalence in wetlands and lake shores.^{17,18,22,31} The HCW described schistosomiasis as the most common NTD in the area, similar to the findings of previous studies in Uganda.^{17,18,22} NTDs were reported to be more common among children, particularly the STHs, which is consistent with previous studies.^{32,33} The high number of cases in this age group could be due to the habit of children often moving barefooted³⁴ and also playing in mud that is contaminated with helminths.³² A study conducted in three Ugandan regions near the Nile River (West Nile and Jinja) and rivers in South Western Uganda revealed that children related to fishermen, and those who interact with water bodies through swimming and drinking the water, are at a higher risk of NTDs.^{18,35} Participants also reported NTDs to be common among fishermen who were in consistent contact with water. This could be due to ingestion of contaminated water, as reported by similar studies in Uganda.³⁵

Sociocultural practices such as poor sanitation, poor hygiene and poor wasted disposal were mentioned as key players in the transmission of NTDs. This is similar to studies done in Ethiopia and Bangladesh that found poor sanitation and unhygienic practices as predictors for NTD infections.^{18,36-39} This was mainly through habits such as open defecation, which is one of the major factors that contaminate common areas and facilitate fecal-oral transmission, and is linked to traditional beliefs in that some elders do not believe in using latrines, which strongly suggests a community belief in a similar vein.^{18,40,41} Moreover, it was observed that, during the COVID-19 pandemic, there was a decrease in number of cases of NTDs due to imposed hygienic practices such as handwashing, a trend also seen in Ethiopia.⁴² Although previous studies have emphasized the importance of water, sanitation and hygiene (WASH) activities in the control of schistosomiasis and STHs,²⁵ disadvantaged communities experiencing poverty, like those in this study area, are still affected because of poor access to clean and safe water, which

exacerbates the transmission of NTDs.³⁴ Poverty within the community also predisposed children and some adults to infection due to a lack of necessary items such as footwear for going to school, predisposing them to walking barefoot on contaminated soil; there was also inadequate waste disposal.^{36–39}

The HCW expressed good knowledge of the symptoms of schistosomiasis and STHs. Participants reported that schistosomiasis was among the most common NTDs, manifesting with hematuria and abdominal distention, as was also observed in previous studies.⁴³ Children, who were mostly affected by STHs. frequently presented with abdominal swelling, stunted growth, malnutrition, anemia and reddened eyes. This is similar to other studies that reported ascaris as the main cause of malnutrition among NTDs in children,⁴⁴ as well as hookworms as the main cause of anemia.⁴⁵ Despite the good knowledge of symptoms, there were several challenges in management of these diseases that the HCW highlighted. These challenges included cases of misdiagnosis, and alternative treatment for these diseases because of the wide range of symptoms that could easily be mistaken for other diseases like malaria, due to the low suspicion of NTDs at these facilities,⁶ which led to late management after other treatments had failed. This was also coupled with the inability of some laboratory technicians being unable to identify the eggs and larvae of schistosoma or STHs in the stool and blood samples due to unfamiliarity or improper training on these species, which also hindered proper diagnosis and management. Another challenge noted in management was the frequent unavailability of common medications, which prevents proper treatment and also discourages the community from seeking help within the facilities. Shortage of medications is a common problem within lower income countries, and is often affected by funding and government prioritization of needs.⁴⁶

Additionally, the participants reported a significant logistical gap and a systemic neglect of NTDs, evident in the lower prioritization of funding, as also observed in other low- and middleincome countries,^{12,47} and this could have been exacerbated by the COVID-19 pandemic.⁴⁸ They noted that the logistical gap manifested through drug stock-outs, as well as a failure to perform outreaches in the community on NTDs.^{11,12,45,48} This could be due to the costs associated with the prevention, diagnosis and treatment of NTDs not being economically viable for governments.⁴³ Furthermore, the under-reporting of cases and unrecorded fatalities could also have contributed to the misdistribution of resources in the fight against NTDs. In view of the limited funds, participants recognized support from non-governmental organizations and donor funds that support the management of NTDs, as also seen in other sub-Saharan countries such as Ghana.⁴⁹ Donor funds have largely supplemented the budget of the Ministry of Health of Uganda, and with NTDs being one of the underfunded areas, they are useful in the fight to eradicate them. However, given the implications of relying on external funding,^{11,50} there is a need to determine the economic impact of NTDs on the country's economy, which can be the basis to lobby for more funds from the government to facilitate diagnosis and management of NTDs. The funds lobbied should also be invested in equipping HCW to properly manage NTDs; a study in Ethiopia showed that supportive supervision coupled with continuous education and an improved supply of medical tools led to improved diagnosis, management and reporting of NTDs.⁵¹

Furthermore, the participants noted that there was a lack of community awareness and engagement, coupled with misconceptions and myths. The HCW noted that community members attributed the contraction of NTDs to witchcraft and sought help from traditional healers and places of worship first. This is coanizant with the findings in a narrative article on experiences on NTDs in Liberia where citizens sought help from traditional and faith healers to cure sickness.⁵² This led to a worsening of mental health and the need to hide their sickness form. NTDs. Participants reported inadequate community sensitization regarding preventative measures. These practices include wearing shoes, avoiding infested waters and raising awareness about common NTDs through community outreach services. A similar study in Brazil found that community sensitization and health education improved treatment outcomes and preventive measures.²⁵ However, these efforts should be integrated with poverty-reduction initiatives, as earlier studies in Uganda and Brazil have linked poverty to the spread of NTDs.¹² This lack of awareness and community engagement contributed to delays in seeking medical help and sometimes the failure of patients to take the prescribed medications, hence increasing the prevalence of NTDrelated morbidity and mortality.^{6,53}

Community engagement has been key in the fight against NTDs in other settings and should be adopted in this setting. In Ethiopia, it led to an increase in the reported number of NTD cases, while it also led to improved health efficiency and service delivery in rural Tanzania care.⁵⁴ Additionally, community engagement led to sustainable NTD control and prevention programs in both Tanzania and Nigeria.^{55,56} Community intervention is needed, particularly at drug-distribution points, to educate about NTD prevention and treatment.⁵⁷

Limitations

This qualitative study relied on participants' perceptions and experiences. While this approach offers valuable insights, it does not provide quantifiable data on NTD prevalence. We mitigated this limitation by utilizing rigorous qualitative reporting standards and detailed thematic analysis to enhance validity. Additionally, while purposively selecting participants enhanced the depth of insights, this methodology introduces potential selection bias. We addressed this by working closely with the DHOs and facility incharges to ensure the inclusion of diverse HCW with extensive NTD management experience. Our interviews were conducted via Zoom. The use of Zoom interviews presented both advantages and potential limitations.^{58,59} While there is debate about the impact of Zoom on qualitative interviews, with some studies suggesting potential limitations in capturing non-verbal cues or building rapport, others find it can yield similarly rich data as face-to-face methods.^{58,59} Zoom may offer enhanced participant comfort due to the convenience of interviewing from their own environment.^{58,59} In our study, we found Zoom to be a flexible data-collection method and rigorously adhered to ethical standards to ensure confidentiality and consent. Finally, our focus on health centers in specific Eastern Ugandan districts may not fully reflect NTD management practices elsewhere in Uganda or sub-Saharan Africa. However, our findings offer valuable guidance for

tailoring interventions and policies to improve NTD management in similar contexts across wider regions.

Conclusion and recommendation

The current study demonstrates that, despite there being good knowledge regarding the signs, symptoms, diagnostics and management of schistosomiasis and STHs, the interviewed HCW reported challenges in their diagnosis and management because of inadequate diagnostic tools, a shortage of medications and perceived limited community engagement. These challenges can be solved through increased prioritization of NTDs through direct funding and government involvement in management of these NTDs. There is also a need to increase community awareness and involvement in campaigns, as well as efforts to combat NTDs to tackle the myths and misconceptions exacerbating their spread. A combined approach of continuous training of HCW, effective community outreach and an improved healthcare system response is essential to effectively address these challenges.

Authors' contributions: Conception and design of the study: RBK, TMK and JB. Data collection: CM and RBK, and its coordination by RBK. Supervision: JB. Formal analysis and data cleaning: RBK, LA, CM, AMK, TMK and JB. Transcription was overseen by CM and final proofreading by RBK. Initial draft: RBK and LA. Review of the manuscript: RBK, LA, CM, AMK, TMK and JB. Final editing: RBK. All the authors approved the final version of the manuscript.

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Data availability: The datasets and transcripts used during the current study are available on request.

References

- 1 World Health Organisation. Implementation tools package of essential non-communicable disease interventions. 2013; 210.
- 2 Ortu G, Williams O. Neglected tropical diseases: exploring long term practical approaches to achieve sustainable disease elimination and beyond. Infect Dis Poverty. 2017;6(1):1–12.
- 3 Emeto DC, Salawu AT, Salawu MM, et al. Recognition and reporting of neglected tropical diseases by primary health care workers in Ibadan, Nigeria. Pan Afr Med J. 2021;38:224.

- 4 World Health Organization (WHO). Integrating neglected tropical diseases into global health and development: fourth WHO report on neglected tropical diseases. World Health Organization. 2017;270.
- 5 World Health Organization (WHO). Investing to overcome the global impact of neglected tropical diseases. 2015.
- 6 Ochola EA, Karanja DMS, Elliott SJ. The impact of neglected tropical diseases (NTDs) on health and wellbeing in sub-Saharan Africa (SSA): a case study of Kenya. PLoS Negl Trop Dis. 2021;15(2):e0009131.
- 7 World Health Organisation. Essential medicines donated to control, eliminate and eradicate neglected tropical diseases. 2016;1997–9.
- 8 Lenk EJ, Redekop WK, Luyendijk M, et al. Productivity loss related to neglected tropical diseases eligible for preventive chemotherapy: a systematic literature review. PLoS Negl Trop Dis. 2016;10(2): e0004397.
- 9 Stolk WA, Kulik MC, le Rutte EA, et al. Between-country inequalities in the neglected tropical disease burden in 1990 and 2010, with projections for 2020. PLoS Negl Trop Dis. 2016;10(5):e0004560.
- 10 Uniting to Combart Neglected Tropical Diseases. Uganda and neglected tropical diseases. 2016.
- 11 Kolaczinski JH, Onapa AW, Ndyomugyenyi R, et al. Neglected tropical diseases and their control in Uganda: situation analysis and needs assessment. 2006.
- 12 Kolaczinski JH, Kabatereine NB, Onapa AW, et al. Neglected tropical diseases in Uganda: the prospect and challenge of integrated control. 2007;23(10):485–93.
- 13 Act to end ntds east. Uganda | Act to End NTDs [Internet]. 2022. Available from: https://www.acteast.org/where-we-work/uganda [accessed April 20, 2022].
- 14 Marchal B, Van Dormael M, Pirard M, et al. Neglected tropical disease (NTD) control in health systems: the interface between programmes and general health services. Acta Trop. 2011;120(Suppl 1):S177–185.
- 15 Bizimana P, Polman K, Van Geertruyden JP, et al. Capacity gaps in health facilities for case management of intestinal schistosomiasis and soil-transmitted helminthiasis in Burundi. Infect Dis Poverty. 2018;7(1):1–9.
- 16 Mazigo HD, Uisso C, Kazyoba P, et al. Primary health care facilities capacity gaps regarding diagnosis, treatment and knowledge of schistosomiasis among healthcare workers in north-western Tanzania: a call to strengthen the horizontal system. BMC Health Serv Res. 2021;21(1):1–9.
- 17 Ojja S, Kisaka S, Ediau M, et al. Prevalence, intensity and factors associated with soil-transmitted helminths infections among preschoolage children in Hoima district, rural western Uganda. BMC Infect Dis. 2018;18(1):1–12.
- 18 Exum NG, Kibira SPS, Ssenyonga R, et al. The prevalence of schistosomiasis in Uganda: a nationally representative population estimate to inform control programs and water and sanitation interventions. PLoS Negl Trop Dis. 2019;13(8):e0007617.
- 19 Kibira SPS, Ssempebwa JC, Ssenyonga R, et al. Schistosomiasis infection in pre-school aged children in Uganda: a qualitative descriptive study to identify routes of exposure. BMC Infect Dis. 2019;19(1):165.
- 20 Mujumbusi L, Nalwadda E, Ssali A, et al. Understanding perceptions of schistosomiasis and its control among highly endemic lakeshore communities in Mayuge, Uganda. PLoS Negl Trop Dis. 2023;17(1):e0010687.
- 21 Republic of Uganda Ministry of Health. Uganda neglected tropical diseases Master Plan 2023-2027. 2023.
- 22 Ministry of health Uganda. Sustainability Plan for neglected tropical diseases Control Program. 2020.

- 23 Sacolo H, Chimbari M, Kalinda C. Knowledge, attitudes and practices on schistosomiasis in sub-Saharan Africa: a systematic review. BMC Infect Dis. 2018;18(1):46.
- 24 Schuster A, Randrianasolo BS, Rabozakandraina OO, et al. Knowledge, experiences, and practices of women affected by female genital schistosomiasis in rural Madagascar: a qualitative study on disease perception, health impairment and social impact. PLoS Negl Trop Dis. 2022;16(11):1-25.
- 25 Lesshafft H, Schuster A, Reichert F, et al. Knowledge, attitudes, perceptions, and practices regarding cutaneous larva migrans in deprived communities in Manaus, Brazil. J Infect Dev Ctries. 2012;6(05):422–9.
- 26 Anyolitho MK, Nyakato VN, Huyse T, et al. Health-seeking behaviour regarding schistosomiasis treatment in the absence of a mass drug administration (MDA) program: the case of endemic communities along Lake Albert in Western Uganda. BMC Public Health. 2023;23(1):1–15.
- 27 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
- 28 Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.
- 29 Lietz CA, Langer CL, Furman R. Establishing trustworthiness in qualitative research in social work: implications from a study regarding spirituality. Qual Soc Work. 2006;5(4):441–58.
- 30 Terry G, Hayfield N, Clarke V, et al. Thematic analysis. In: the SAGE Handbook of Qualitative Research in Psychology [Internet]. SAGE Publications Ltd. 2017;17–36.
- 31 Nyandwi E. Understanding wetlands reclamation and soil-transmitted helminths and schistosomiasis incidence patterns in Rwanda (2001-2012). 2017 [cited 2024 Jan 26]; Available from: https:// research.utwente.nl/en/publications/understanding-wetlandsreclamation-and-soil-transmitted-helminths.
- 32 Genet A, Motbainor A, Samuel T, et al. Prevalence and associated factors of soil transmitted helminthiasis among school-age children in wetland and non-wetland areas of Blue Nile Basins, northwest Ethiopia: a community-based comparative study. SAGE Open Med. 2021;9:205031212110633.
- 33 Soil-transmitted helminth infections [Internet]. 2022 [cited 2024 Jan 18]. Available from: https://www.who.int/news-room/fact-sheets/ detail/soil-transmitted-helminth-infections.
- 34 Magalhães AR, Codeço CT, Svenning JC, et al. Neglected tropical diseases risk correlates with poverty and early ecosystem destruction. Infect Dis Poverty. 2023;12(1):32.
- 35 Kibira SPS, Ssempebwa JC, Ssenyonga R, et al. Schistosomiasis infection in pre-school aged children in Uganda: a qualitative descriptive study to identify routes of exposure. BMC Infect Dis. 2019;19(1): 1–10.
- 36 Hotez PJ, Bundy DAP, Beegle K, et al. Helminth infections: soiltransmitted Helminth infections and schistosomiasis. In: Jamison DT, Breman JG, Measham AR, Alleyne G, Claeson M. Evans DB, et al., editors. Disease Control Priorities in Developing Countries [Internet]. 2nd ed. Washington (DC): The International Bank for Reconstruction and Development /The World Bank; 2006 [cited 2024 Jan 26]. Available from: http://www.ncbi.nlm.nih.gov/books/NBK11748 /.
- 37 Alemu A, Atnafu A, Addis Z, et al. Soil Transmitted Helminths and Schistosoma Mansoni Infections among School Children in Zarima Town, Northwest Ethiopia. 2011;189.
- 38 Alelign T, Degarege A, Erko B. Soil-transmitted helminth infections and associated risk factors among school-children in Durbete Town, Northwestern Ethiopia. J Parasitol Res. 2015;2015:641602.

- **39** Roy E, Hasan KZ, Haque R, et al. Patterns and risk factors for helminthiasis in rural children aged under 2 in Bangladesh. South Afr J Child Health. 2011;5(3):78–84.
- 40 Boisson S, Engels D, Gordon BA, et al. Water, sanitation and hygiene for accelerating and sustaining progress on neglected tropical diseases: a new Global Strategy 2015-20. Int Health. 2016 Mar;8(suppl 1):i19–21.
- 41 World Health Organization. Health worker density and distribution and health worker labour motility. 2018;14.
- 42 Ali AS, Yohannes MW, Tesfahun T. Hygiene behavior and COVID-19 pandemic: opportunities of COVID-19-imposed changes in hygiene behavior. Inq J Med Care Organ Provis Financ. 2023;60: 00469580231218421.
- 43 Ajibola O, Gulumbe B, Eze A, et al. Tools for detection of schistosomiasis in resource limited settings. Med Sci. 2018;6(2):39.
- 44 Parija S, Chidambaram M, Mandal J. Epidemiology and clinical features of soil-transmitted helminths. Trop Parasitol. 2017;7(2):81–5.
- 45 Arney JK, Headland MK, Bertone AM, et al. Synthesis of findings from the literature and a qualitative research study on the impacts of gender, disability, and ethnicity in Neglected Tropical Diseases programs. PLoS Negl Trop Dis. 2023;17(12):e0011782.
- 46 Marchal, B, Van Dormael M, Pirard M, et al. Neglected tropical disease (NTD) control in health systems: the interface between programmes and general health services. Acta Trop. 2011;120(Suppl. 1).
- 47 Gyapong JO, Gyapong M, Yellu N, et al. Integration of control of neglected tropical diseases into health-care systems: challenges and opportunities. Lancet. 2010;375(9709):160–5.
- 48 Forbes K, Basáñez MG, Hollingsworth TD, et al. Introduction to the special issue: challenges and opportunities in the fight against neglected tropical diseases: a decade from the London Declaration on NTDs. Philos Trans R Soc B Biol Sci. 2023;378(1887):20220272.
- 49 Otoo DD, Appiah-Agyekum NN, Adzei FA. Perceived determinants of implementation success of the neglected tropical diseases programme in Ghana: a qualitative study among programme officers. BMC Public Health. 2021;21(1):2074.
- 50 Agaba E. Funding the promise: monitoring Uganda's health sector financing from an HIV/AIDS perspective. Afr Health Sci. 2009;9(Suppl 2):S81–85.
- 51 Donovan L, Habte T, Batisso E, et al. Improving neglected tropical disease services and integration into primary healthcare in Southern Nations, Nationalities and People's Region (SNNPR), Ethiopia: results from a mixed methods intervention evaluation [Internet]. Health Systems and Quality Improvement. 2023. Available from: http://medrxiv.org/lookup/doi/10.1101/2023.10.11.23296918.
- 52 Zaizay EG, Joefay F, Dennis D. Creating a network of people affected by neglected tropical diseases in Liberia: the same secret we were keeping, they are keeping it, too. Int Health. 2023;15(Supplement_3): iii10–1.
- 53 Hofstraat K, van Brakel WH. Social stigma towards neglected tropical diseases: a systematic review. Int Health. 2016;8(suppl 1):i53–70.
- 54 Davis A, Virhia J, Bunga C, et al. "Using the same hand": the complex local perceptions of integrated one health based interventions in East Africa. PLoS Negl Trop Dis. 2022;16(4):e0010298.
- 55 Madon S, Malecela MN, Mashoto K, et al. The role of community participation for sustainable integrated neglected tropical diseases and water, sanitation and hygiene intervention programs: a pilot project in Tanzania. Soc Sci Med. 2018;202:28–37.
- 56 Lar LA, Dean L, Adekeye T, et al. Lessons from participatory community mapping to inform neglected tropical disease programmes in Nigeria. Int Health. 2023 Apr 1;15(Supplement_1):i6–17.

- 57 Forson AO, Awuah RB, Mohammed AR, et al. Perceptions of the roles, impact, challenges and needs of community drug distributors in the control and elimination of neglected tropical diseases in difficult-toaccess communities in Ghana. BMC Infect Dis. 2023 Jul 10;23(1): 460.
- 58 Oliffe J, Kelly M, Gonzalez Montaner G, et al. Zoom interviews: benefits and concessions. Int J Qual Methods. 2021;0:160940692110535.
- 59 Lindsay S. A comparative analysis of data quality in online zoom versus phone interviews: an example of youth with and without disabilities. Sage Open. 2022;12(4):21582440221140098.

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