Fall 2019

Bridging the gap on schistosomiasis: A cross-sectional study examining the knowledge gap and common attitudes and practices regarding S. mansoni infections among varying education levels in Luanda K'Otieno, western Kenya

Kathy Zhang
SIT Study Abroad

Bridging the gap on schistosomiasis: A cross-sectional study examining the knowledge gap and common attitudes and practices regarding *S. mansoni* infections among varying education levels in Luanda K'Otieno, western Kenya

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An independent study project conducted under the School for International Training
Kenya: Global Health and Human Rights
Fall 2019

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Acknowledgements

I would like to extend my gratitude to the entire Neglected Tropical Disease team at the Kenya Medical Research Institute in Kisian, Kenya. In particular, I would like to thank **John Oguso** who introduced me to the site Luanda K'Otieno and provided me with informative feedback and suggestions. Thank you for serving as my translator during the interviews and teaching me the Kato-Katz technique, as well. I would not have been able complete this project without your help. I would also like to thank **Dr. Eric Muok** for guiding me towards the direction I wanted to take in my research project and for helping me with your feedback. To **Churchill**, thank you for helping me collect and organize stool samples from the participants. To **Harrison**, thank you for helping me prepare the stool samples for *Schistosoma* egg examination. To the rest of the NTD staff and field team, thank you for all your time and efforts in helping me make this project possible.

To **Dr. Steve Wandiga**, thank you for your endless support and for your assistance in making this project possible. To **Anne**, thank you for helping me translate the written consent form to Kiswahili. To the rest of the School for International Training Kenya staff – **Miltone, Christine, Walter, Cecilia, Joseph, and Moses** – thank you for allowing me to have an incredible experience studying abroad in Kisumu, Kenya.

Lastly, to the **residents of Luanda K'Otieno**, I am incredibly grateful to you all for welcoming me into your homes, giving me your time, and sharing your stories with me. You have brought the severity of schistosomiasis in communities like yours to my attention.

This paper is dedicated to those who have suffered or have loved ones who have suffered from this terrible disease. To the participant whose brother died recently from schistosomiasis, I am truly sorry, and I hope that one day, we can prevent future loss of life from preventable and curable diseases like schistosomiasis.

Abstract

Background

Schistosomiasis is considered one of the most prevalent neglected tropical diseases in the world. According to the World Health Organization (WHO), the most effective strategy for schistosomiasis control is through preventive chemotherapy with praziquantel (PZQ). In order to successfully control morbidity rates, the WHO recommends mass treatment targeting high risk groups, such as school-age children and adults considered to be at risk.

Methods

This cross-sectional study examined the effects of the National School-Based Deworming Programme (NSBDP) on knowledge of schistosomiasis and subsequent prevalence rates and intensity. A total of 43 residents in Luanda K'Otieno were interviewed, and 34 of those participants provided stool samples for schistosomiasis diagnosis. *Schistosoma mansoni* eggs in the stool samples were evaluated using the Kato-Katz technique.

Results and Conclusions

Of the 34 participants who provided stool samples for diagnosis, 13 were positive for *S. mansoni* infection. The results did not reveal any correlation between the prevalence or intensity of infection and the level of education completed, extent of knowledge on the disease, or occupational risk. The study did determine that the higher of education achieved, the greater the knowledge on schistosomiasis; however, school education was not the primary means of knowledge acquisition. 45.2% of the knowledgeable participants were educated through participation in previous KEMRI studies, and 22.6% were educated through others who were involved in those studies. There were also significant problems discovered based on participants' personal accounts in particular regarding the unreliability of organizations such as KEMRI.

Keywords

Kenya Medical Research Institute (KEMRI), Mass drug administration (MDA), National School-Based Deworming Programme (NSBDP), Neglected tropical disease (NTD), Praziquantel (PZQ), Schistosomiasis Consortium for Operational Research and Evaluation (SCORE), School-aged children (SAC), World Health Organization (WHO)

Introduction

Overview of schistosomiasis

Neglected tropical diseases (NTDs), according to the World Health Organization (WHO), are a group of communicable diseases that prevail in tropical and subtropical conditions, greatly affecting populations living in poverty, without adequate sanitation and in close contact with infectious vectors, domestic animals, and livestock. The presence of NTDs pose a great threat to global health improvement as well as socioeconomic development. There are approximately 20 diseases classified as NTDs under the WHO and Centers for Disease Control and Prevention (CDC), one of which is schistosomiasis, also known as bilharzia. There are over 20 known species within the genus *Schistosoma*, but there are only three that generally infect humans: *Schistosoma haematobium*, *S. japonicum*, and *S. mansoni*. Humans are infected with schistosomiasis when larval forms of the parasite, which are released by freshwater snails, penetrate the skin when people come into contact with contaminated water. Transmission of schistosomiasis then occurs when infected people contaminate freshwater sources with their excreta containing schistosome eggs. Around 240 million individuals worldwide are infected with schistosomiasis, and at least 90% of those individuals reside in Africa where the disease results in more than 200,000 mortalities per year. Schistosomiasis is especially prevalent among poor communities with limited access to clean water and adequate sanitation. As seen in Figure 1, schistosomiasis is concentrated in tropical and subtropical regions of Africa, South America, and Asia; however, there is much higher prevalence for both intestinal and urinary schistosomiasis in sub-Saharan Africa compared to the rest of the world.

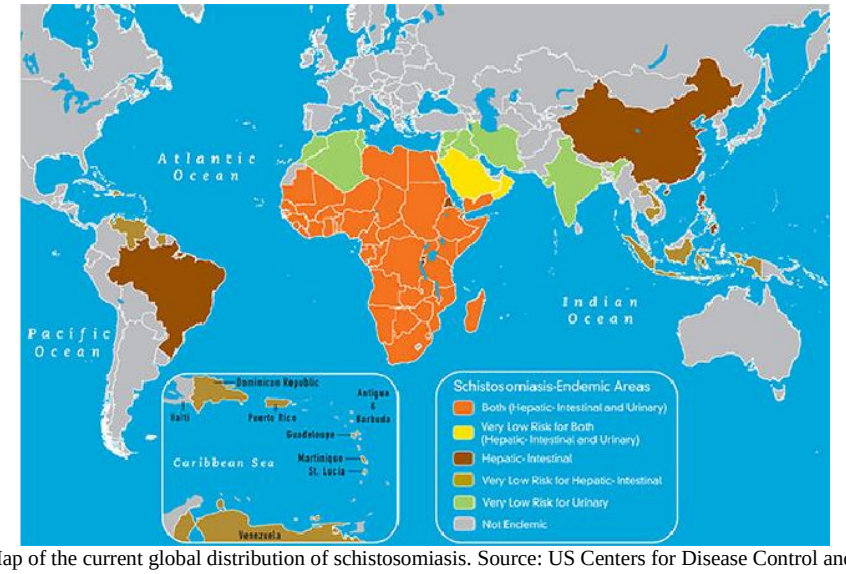

*Figure 1. Map of the current global distribution of schistosomiasis. Source: US Centers for Disease Control and Prevention.

The two forms of schistosomiasis – intestinal and urogenital – result from different *Schistosoma* species. Intestinal schistosomiasis is primarily attributed to *S. japonicum* and *S. mansoni* infection, the most common form of the disease in Kenya. Urogenital schistosomiasis is caused by the species *S. haematobium* and if left untreated, is considered a risk factor for human immunodeficiency virus (HIV) infection among women. Female genital schistosomiasis (FGS), a chronic gynecological condition characterized by the presence of schistosome eggs, or worms, in the genital tract, is a manifestation of *S. haematobium* infection. Unfortunately, there is a significant lack of knowledge of FGS, and consequently, FGS is under-diagnosed as health workers will oftentimes misdiagnose the symptoms as a sexually transmitted infection or menstrual bleeding. FGS occurs when the damage of the schistosome eggs occurs in a part of the female reproductive system, forming fibrotic nodules, commonly referred to as "sandy patches."

Life cycle of Schistosoma eggs

After *Schistosoma* eggs are released in the feces or urine of an infected human, they hatch and release miracidia, the free-swimming larval stage of the parasite, into the water. The miracidia then swim and penetrate the tissue of the snail intermediate hosts. Two generations of sporocysts develop in the snail, and eventually, they mature into cercariae. The free-swimming cercariae are released from the snail into the water, swimming in search of a human host. Once the cercariae penetrate human skin, they lose their tails, becoming schistosomulae. The schistosomulae enter the blood stream, migrating to the lungs, then to the heart, and finally to the liver where they mature into adults. Adults worms of the opposite sex couple, and they migrate to mesenteric venules where they reside. The location where they reside depends on the infecting species. For instance, *S. mansoni* and *S. japonicum* typically migrate to mesenteric venules of the bowel or rectum, laying eggs that circulate to the liver and shed in stools. *S. haematobium*, on the other hand, usually migrates to the venous plexus of the bladder and release eggs in the urine.

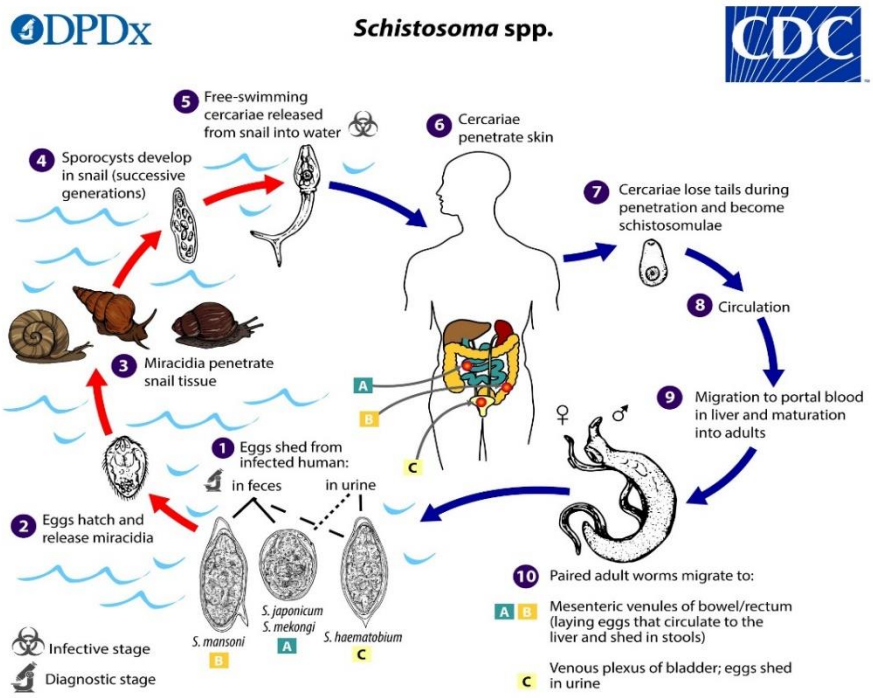

*Figure 2. Life cycle of *Schistosoma* eggs. Source: Centers for Disease Control and Prevention.

Schistosomiasis in Kenya

Schistosomiasis remains endemic throughout the entire region of Kenya with approximately 6 million people infected and 15 million at risk of the disease. *S.* haematobium, which is transmitted through *Bulinus* snails, and *S. mansoni*, transmitted through *Biomphalaria* snails, are the two species endemic in Kenya. Due to the proximity of western Kenya to Lake Victoria. *S. mansoni* infection is particularly common in areas along the shores of the lake.

In 2009, the Government of Kenya launched the National School-Based Deworming Programme (NSBDP) due to the significant threat of worm infection on children's health and education. The Kenya Medical Research Institute (KEMRI) was a critical partner of the NSBDP, monitoring and evaluating sub-counties in targeted regions. The aim of the program was to eradicate parasitic worms, including soil-transmitted helminths (STH) and schistosomes, as a public health problem in Kenya. In order to do so, the program aimed to treat at least five million Kenya children each year for at least five years in all primary schools in endemic areas for parasitic worms. Beginning in 2012, the program included praziquantel (PZQ) administration in addition to albendazole, and by 2013, approximately 3.6 million school-aged children (SAC) were treated. However, because the mass drug administrations (MDAs) focused on targeting SAC in schools, children not

enrolled in school, women of childbearing age, and adults at occupational risk were left out. The MDAs initially targeted four regions endemic for both STH and schistosome infections: Western, Nyanza, Rift Valley, and Coast. Programme coverage then expanded the following year to include the Eastern, Central, and North Eastern regions.

Site Information

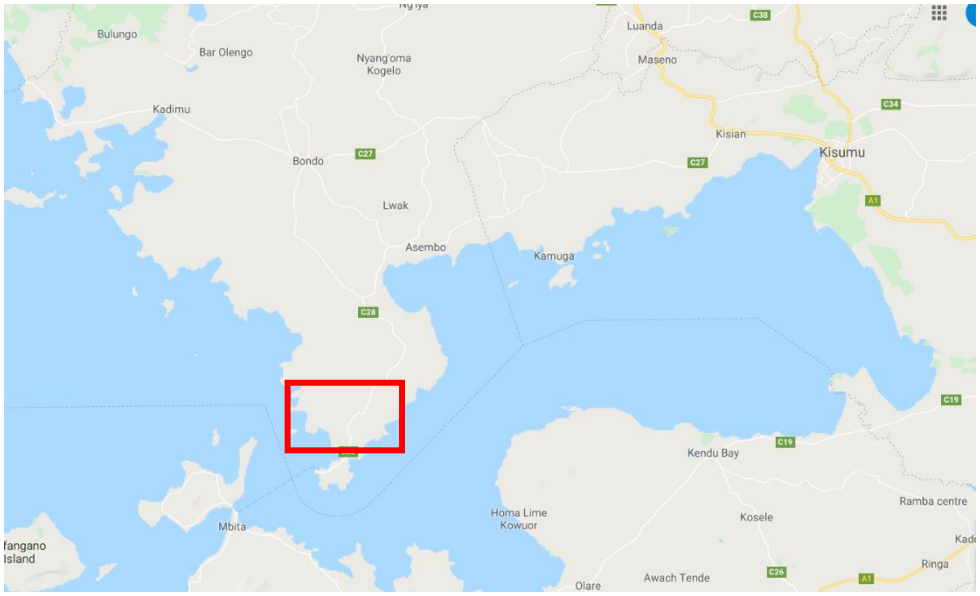

*Figure 3. The location of Luanda K'Otieno in western Kenya as indicated by the red outline. Source: Author.

As seen in Figure 3 above, Luanda K'Otieno lies on the shores of Lake Victoria in Siaya County, which is part of the former Nyanza Province. Known for its pier where ferry boats coming to and from Mbita regularly dock, the site is approximately 95 kilometers from Kisumu and 11.4 kilometers from Mbita. Luanda K'Otieno Beach is home to a large fishing community; however, due to the occupational risk of schistosomiasis and proximity to Lake Victoria in general, Luanda K'Otieno is a schistosomiasis hotspot.

A majority of the local people in Luanda K'Otieno identify as Luo, and almost all of them only speak the Luo dialect, Dholuo. The Luo tribe is the fourth largest community in Kenya after the Kikuyu, Luhya, and Kalenjin, making up 10.1% of the population. They mainly practice fishing or agriculture as their main economic activity, and explicably so, most of them reside in western Kenya near the eastern shore of Lake Victoria. Polygamy was also a common practice of the Luo

and remains an accepted customary practice to this day. For instance, one of the participants had four wives, all of them living within the same homestead.

A typical household of a lower socioeconomic status family in Luanda K'Otieno is a hut with mud walls and a thatched or tin roof. On the contrary, households of a higher socioeconomic status family are built from concrete or brick, usually with a gated front door. There is no electricity nor running water in any of the homes, but some were solar powered. For household chores, such as washing clothing and dishes, and bathing, the local people source their water from the lake out of convenience, and a majority of the households did not have a toilet indoors, only a pit latrine outside.

Statement of the Problem and Justification

While MDAs with PZQ have successfully reduced prevalence and morbidity levels of *S. mansoni* infection among schoolchildren, there are at-risk groups who have been left behind by these programs. For instance, even though Luanda K'Otieno is a site previously frequented by KEMRI researchers in their studies on schistosomiasis, there are still many community members with no knowledge on the disease at all. Those who are occupationally at risk, fishermen in particular, are also the most vulnerable to the disease because they have no means of protecting themselves, and they are also harder to reach by MDAs.

By 2020, the WHO aims to control morbidity for *S. mansoni* in particular, and by 2025, to eliminate schistosomiasis as a public health problem in certain regions. A 2018 update found that the current guidelines set by WHO – coverage of at least 40% among adults and coverage of at least 85% of SAC – are likely to achieve these goals in low-prevalence regions, but for moderate and high-prevalence regions, these goals may be achieved within a longer time span, or possibly not at all. In order to achieve these goals in all regions and, more importantly, to address the high prevalence of infection and transmission, there is a need to re-examine the guidelines set by WHO and to gain a deeper understanding of possible reasons as to why communities continue to suffer from a preventive and curative disease.

Objectives

The aim of this study was to examine the knowledge gap on schistosomiasis and common attitudes and practices regarding schistosomiasis in the Luanda K'Otieno village of Siaya County, Kenya.

1) To examine the relationship between level of education and knowledge on schistosomiasis, the researcher determined:

- If there is a correlation between knowledge on schistosomiasis or level of education and disease prevalence or intensity
- If there is a strong correlation between occupation and disease prevalence or intensity
- The most frequent means by which local residents acquire their knowledge on the disease

2) To examine the improvements in education on schistosomiasis in an at-risk community following the implementation of NSBDP

3) To evaluate the attitudes and opinions of the local residents regarding ongoing schistosomiasis prevention and treatment methods

- To uncover their perspectives on the work of KEMRI researchers previously conducted in their community

Literature Review

Existing literature on the prevalence of schistosomiasis in sub-Saharan Africa countries stresses the significant risk for people living or working near Lake Victoria in Kenya. The following section summarizes relevant findings of studies conducted by the Schistosomiasis Consortium for Operational Research and Evaluation (SCORE). In general, results showed that public health interventions, in particular MDAs, have been successful for the most part in lowering prevalence and intensity rates of schistosomiasis as well as increasing knowledge on the disease, as well.

Prevalence and intensity rates of schistosomiasis

Lake Victoria, the largest lake in Africa, is a hyper-endemic area for schistosomiasis, and consequently, communities living in close proximity to the lake suffer severe health implications from the contaminated water. A study conducted in the Mbita region found that *S. mansoni* prevalence was 2-fold higher and the intensity of infection 54% higher on the Lake Victoria islands compared to the mainland (Odiere 2012). The study also discovered that prevalence increased from 31.4% among children aged 5-7 years to peak at 61.8% among children aged 11-16 years before declining among children aged 17-19. A different cross-sectional study conducted in Homabay County, as well, determined the prevalence and intensity of single and mixed schistosomiasis infection among schoolchildren attending six different primary schools. Results from this study showed *S. haematobium* prevalence to be 37.6% and *S. mansoni* prevalence to be 12.2%, and unprecedentedly, a mixed infection of *S. haematobium* and *S. mansoni* was observed with a prevalence of 2.3% (Amollo 2013). Compared to rates of regions such as Kwale, a coastal province in Kenya, the mean school prevalence rate of both infections was slightly lower, most likely due to the closer proximity of school in those regions to Lake Victoria. Both studies concluded that proximity to contaminated water directly correlates to higher prevalence rates of schistosomiasis.

Of the schoolchildren surveyed in the latter study, as a result of the significant burden of schistosomiasis in the area, 100% of the schools required mass treatment for schistosomiasis, and 100% of the schoolchildren would benefit from mass treatment, as well. Fortunately, the high morbidity and prevalence rates in this schistosomiasis endemic region decreased greatly after the implementation of MDAs with PZQ. However, hard-to-reach areas with high levels of

prevalence and intensity remain because they have not received much attention from MDA programs. MDAs are successful in terms of curative care; however, they must be complimented with other preventive measures such as improvement of access to clean water and proper sanitation as well as vector control to prevent disease transmission.

People occupationally at risk of schistosomiasis acquisition suffer high prevalence rates, as well. The *S. mansoni* infection prevalence rate was found to be significantly higher among fishermen (44.7%) compared to the lowest prevalence rate among schoolteachers (6.1%). There were no significant intensity differences among different occupational groups, though. Groups whose occupations revolved around contact with infested water – fishermen, farmers, irrigation workers, car washers – are highly at risk of disease acquisition.

Awareness and knowledge of community members regarding schistosomiasis

Based on a review synthesizing 27 studies from Kenya, Uganda, Nigeria, Mozambique, Ghana, Tanzania, Malawi, South Africa, and Swaziland, there is a lack of comprehensive knowledge on the signs and symptoms, transmission, prevention, and treatment of schistosomiasis (Saccolo 2018). 60% of the studies found that participants oftentimes misidentified the prevention and transmission of schistosomiasis with that of soil-transmitted helminths; however, after the implementation of MDA programs, there was an increase in participants' knowledge, attitudes, and practices regarding schistosomiasis. Studies conducted in Kenya found that some participants believed schistosomiasis to be caused by HIV. Regarding treatment methods, participants mistook PZQ for family planning tablets used by MDA programs to prevent them from having an excessive number of children.

There is a major gap in the prevention and treatment of FGS in particular, mainly due to the lack of knowledge surrounding the disease. A general misconception that many assume – FGS is not a tropical disease, but rather a sexually transmitted infection (STI) – has inhibited progress on addressing the disease. Oftentimes, health workers will misdiagnose the symptoms of FGS as an STI or menstrual bleeding. There was an instance of a 25-year-old woman who reported that the "nurses are very rude to us young women" and recalled an incident her friend endured with the nurse telling her to "change her bad ways else she will one day get AIDS if she keeps sleeping

around" (Kukula 2018). The stigma behind STIs hinders people's willingness to seek care at formal health clinics, causing more severe health consequences later on. As government-run institutions expanded MDAs across communities and schools targeting *Schistosoma* infections, FGS has been nearly forgotten, leaving millions of girls and women suffering from the disease.

SCORE

Established in 2008, SCORE aimed to address the issue of schistosomiasis control. SCORE organized field studies, with a five-year time span, across Africa with the objective to fully understand all preventive chemotherapy approaches, involving but not limited to, community-wide treatment and school-based treatment. In areas along the shores of Lake Victoria with greater than 25% prevalence of schistosomiasis, SCORE also provides communitywide treatment through community health workers (CHW).

A study conducted in 75 villages of western Kenya examined the opinions of CHWs regarding MDAs with PZQ. All of the CHWs distributed the drug house-to-house rather than mobilizing community members in central places for treatment. One of the CHWs reported that "there were some people that refused the medication completely because there were others that we gave the medication, then after some hours, some really vomited…" (Omedo 2015). Other CHWs disclosed that others refused to take the drug due to their religious affiliation, suspicion that the drugs were anti-retroviral drugs, or their belief the MDA was a government conspiracy to decimate ethnic communities. Given the lack of knowledge coupled with heightened conspiracy theories, organizations responsible for MDAs have a responsibility to comprehensively educate community members on the disease.

A 2016 study conducted in a schistosomiasis endemic area of Dar es Salaam, Tanzania revealed that a larger majority of parents or guardians possessed extensive knowledge on urinary schistosomiasis disease with 83.6% accurately identifying transmission, symptoms, availability of modern treatment and preventive measures. The high awareness can be attributed to the school-based preventive chemotherapy campaigns initiated by the government through the Ministry of Health a year prior to the study. Health communication interventions are especially effective in overcoming misconceptions about public health interventions, referring to MDAs in

particular (Omedo 2014). The mass media campaign process integrated various communication mediums, for instance radio call-in sessions, allowing people living in hard-to-reach areas to access important health information. Improved awareness on the disease itself and its control methods led to better treatment compliance as people were not as fearful of the drug or the intentions of the organization in charge.

In a mid-term analysis of a five-year study in western Kenya, researchers found that *S. mansoni* infection prevalence and intensity levels lowered significantly following two rounds of community-wide treatment (CWT) and school-based treatment (SBT). In half of the communities included in this study, CHWs distributed PZQ by going house-to-house each year, and in the other half, health teachers delivered PZQ to children twice a year, attempting to include children who were not enrolled in school in the MDA, as well. From 2011 (year 1) to 2013 (year 3), the prevalence rate among 9-12-year-old children in both the CWT and SBT groups decreased significantly, from 60% to 48% and 63% to 34%, respectively. In terms of prevalence, there is no observable difference in the effectiveness of the two different treatment approaches; however, in regards to reductions in intensity levels, SBT proved to be the more effective approach. The desired effects of MDAs are evident based on the results of this study, but there is still a need to amplify the reach of these programs across more community members aside from school-going children.

Interestingly enough, a final study, measuring the effect of MDA regimens on morbidity among schoolchildren over a five-year period, contradicts the findings from the previous study. Researchers compared morbidity markets between two groups of schoolchildren in Siaya and Kisumu counties with greater than or equal to 25% infection prevalence among 9-12-year-old children. At year 5, findings indicated that neither prevalence nor intensity was significantly reduced compared with baseline numbers, regardless of which tactic, CWT or SBT, was employed. However, there are outside variables that may have affected the results of this study, including but not limited to, large variability in baseline numbers and insufficient sample size. The results of this study may not accurately portray the true beneficial impact of public health interventions on at risk communities, as further research is required to achieve representative data.

Methodology

Interviews

Throughout a one-week period, 43 interviews were conducted at the village and beach of Luanda K'Otieno. A majority of the interviews took place in participants' households in order to better visualize the socioeconomic status of the participants. There were a few interviews that were conducted at workplaces, though, because the participants were unable to leave work during that time. Interviews were usually conducted in the local Luo language with the exception of one, which was conducted in English. The interviews were arranged through a community health worker who guided the researchers to the households.

Stool Sample Collections

In order to measure the prevalence and intensity of *S. mansoni* in Luanda K'Otieno, stool samples from the participants were collected. Participants were provided with a stool cup, toilet paper, and a wooden applicator stick, and those who were able to provide a sample immediately following the interview were provided with antibacterial soap to wash their hands. Most participants were unable to provide a stool sample the same day, though, so the stool cups were labeled with their unique study identifying code and collected the following day. The stool samples were stored in cool box throughout the day, then transferred to a refrigerator. There were nine participants who did not provide samples.

Kato-Katz Technique

The stool samples collected from the participants were tested for schistosomiasis prevalence and intensity using the Kato-Katz Technique. Two microscopic slides were prepared for each sample in order to ensure the diagnosis accuracy. Luanda K'Otieno is considered a schistosomiasis hotspot, and the WHO recommends the Kato-Katz method in areas of moderate to high infection intensity due to its ability to provide both prevalence and intensity data for larger samples. The procedure of the technique is as follows (extracted from the World Health Organization SOP #3001-SCH-012):

Preparation of the fecal material

1. Place the fecal material in the stool cup on a piece of paper and press a piece of nylon screen on top in order to sieve some of the feces through the screen.

2. Scrap a flat-sided spatula across the upper surface of the nylon screen to collect the sieved feces.

3. Place the template on the center of the microscope slide and add feces collected from the spatula so that the hole is completely filled.

4. Pushing down, pass over the template using the side of spatula to remove excess feces from the edge of the hole.

5. Remove the template carefully so that the cylinder of feces is left on the slide.

6. Cover the fecal material with presoaked cellophane strip.

7. Invert the microscope slide and press the fecal sample firmly against the cellophane strip on a smooth hard surface.

8. The fecal material should be spread evenly between the microscope slide and the cellophane strip.

9. Carefully remove the slide by sliding sideways to avoid separating or lifting off the cellophane strip.

10. Place the slide on the bench with the cellophane facing upwards.

11. Keep the slide for at least one or more hours at room temperature in order to clear the fecal material prior to examination for schistosomiasis.

Examination of the fecal smear

1. The fecal smear should be examined in a systematic manner and the number of eggs of each species reported.

2. The number is then multiplied by 24 if using the 41.7 mg template in order to obtain the number of eggs per gram of feces (epg).

3. The epg gives an estimation of the worm burden and allows the identification of individuals likely to suffer from schistosomiasis.

Disposal of the fecal samples

1. The fecal samples and all the disposable materials used in the procedure are placed in a waste polythene bag placed in a pail, closed, and taken to the incinerator for disposal.

Ethical Considerations

Efforts were taken to protect the participants' anonymity and privacy as any identifying information and medical information were kept confidential. Only the researcher, translator, and community health worker have access to the names of those who tested positive for schistosomiasis in order to properly treat them. The consent form was verbally explained to the participants in the local Luo language, and if the participants agreed to take part in the research study, a signed consent form was obtained. Participants were informed of their right to withdraw from the study at any point during the interview or stool sample collection if they chose to do so. For those who were diagnosed positive for *S. mansoni* infections, treatment with PZQ was provided to them the following week.

Approval to interview and collect stool samples for schistosomiasis diagnoses from the local residents of Luanda K'Otieno was previously reviewed and confirmed by the Scientific and Ethical Review Committees of the Kenya Medical Research Institute and the Institutional Review Board of the Centers for Disease Control and Prevention. Permission to conduct field study in Kisumu County was given by Dr. Onyango D., the County Director of Health. The research proposal was approved and conducted according to the Local Review Board guidelines of the School for International Training.

Data Analysis and Results

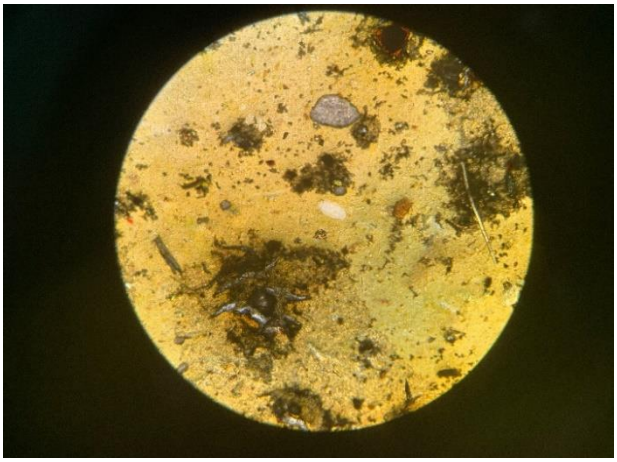

*Figure 4. An illustration of a *Schistosoma* egg. Extracted from a microscopic image of SITL06 sample Slide A.

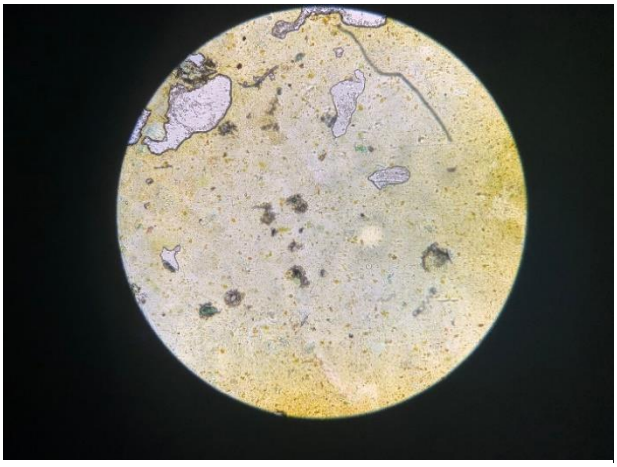

*Figure 5. An illustration of a clear stool sample negative for *S. mansoni* infection.

Using Table 1 below, the prevalence and intensity of *S. mansoni* infection were determined. The average epg of the two slides prepared for each stool sample was calculated in order to measure the intensity of infection. The slides were also examined for starch granules, which are an indication of malabsorption.

Eggs per gram of feces (epg)	**Intensity of infection**
1-99	Light
100-399	Moderate
>=400	Heavy

*Table 1. Epg criteria for determining the intensity of *S. mansoni* infection.

Prevalence and intensity of S. mansoni infection

	Intensity Level of Infection				
Level of Education	None	Low	Moderate	Heavy	Total
More highly educated	13	5	3	1	22
Less highly educated	17	4	0	0	21
Total	30	9	3	1	43

*Table 2. Intensity level of *S. mansoni* infection categorized by the level of education completed.

*More highly educated is classified as having at least finished primary school. Less highly educated is classified as not having finished primary school or not having attended school at all.

	Intensity Level of Infection			
Extent of knowledge on schistosomiasis	Low	Moderate	Heavy	Total
Minimal	3	0	0	3
Somewhat	2	0	1	3
Extensive	4	3	0	7
Total	9	3	1	13

*Table 3. Intensity level of *S. mansoni* infection categorized by the extent of knowledge on schistosomiasis.

*Extensive knowledge is classified as accurately identifying the source of *S. mansoni* infection, mode of transmission, and method of treatment. Somewhat knowledge is classified as accurately identifying only one or two of the following: source of infection, mode of transmission, and method of treatment. Minimal knowledge is classified as having only heard of the disease name at most.

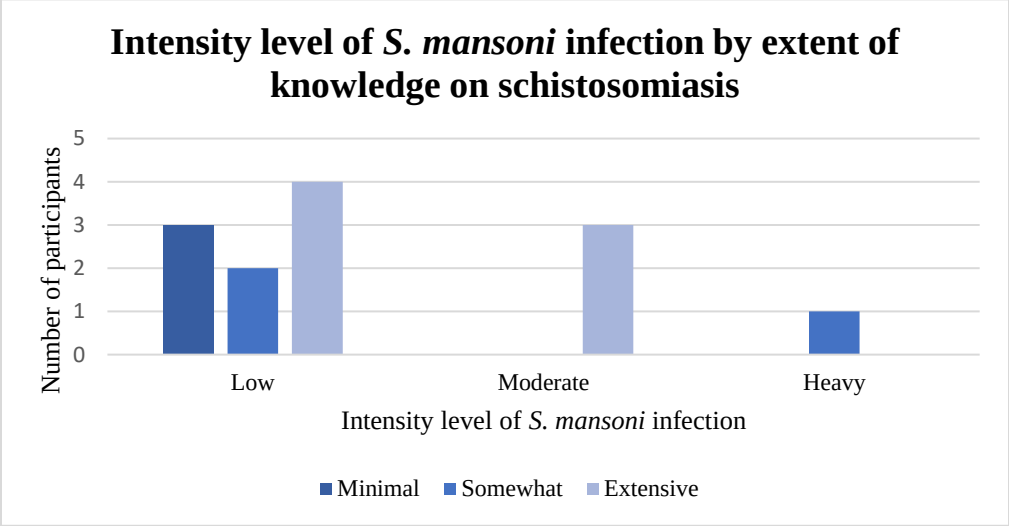

*Figure 6. A graph representation of Table 3. Source: Author.

Out of the 34 participants who provided a stool sample for diagnosis, 13 were diagnosed positive for *S. mansoni* infection (38.2%) with nine low infections, three moderate infections, and one heavy infection. From Figure 6, the results fail to show a relationshp between the level of education completed and intensity of *S. mansoni* infection. Participants' extent of knowledge on schistosomiasis also did not seem to have any impact on disease prevalence nor intensity. Regardless of participants' comprehensive understanding of the source of *S. mansoni* infection, mode of transmission, and course of treatment, they were equally as susceptible, or arguably even more susceptible, to disease acquisition compared to those with minimal knowledge on the disease.

	Intensity Level of Infection			
Occupationally at risk?	Low	Moderate	Heavy	Total
Yes	3	1	0	4
No	6	2	1	9
Total	9	3	1	13

*Table 4. Intensity level of *S. mansoni* infection categorized by whether participants are occupationally at risk.

*Occupationally at risk is defined as those who are exposed to the water from Lake Victoria as part of their work, such as fishermen, fishmongers, water vendors, etc.

From the 13 participants who tested positive for *S. mansoni* infection, four of them were occupationally at risk (30.8%). These results fail to show any association between occupational hazard and prevalence or intensity, suggesting that all community members are equally at risk of disease acquisition. All of the participants stated that they heavily rely on the water from Lake Victoria for household chores and drinking. For drinking purposes, most of the participants either boil the water or treat the contaminated water with a water guard disinfectant. However, for washing clothes and dishes and bathing, they all reported to use untreated water from the lake. No one is exempt from the risk of *S. mansoni* infection, yet, most of them have no means of protection and no alternatives to contaminated water.

Two of the participants, both fishmongers, reported that they do not wear any protective clothing when handling water from the lake. Participant SITI02, a fishmonger as well, stated that in order to protect herself from *S. mansoni* infection, she wears "normal flat shoes while standing in the water." Despite her efforts to protect herself against larval penetration in the water by covering exposed skin, the participant fails to recognize the concept that the contaminated water seeps through her shoes, coming in contact with her skin and putting her at risk of infection.

Another participant revealed that even though she was aware of the serious health risks associated with schistosomiasis, she continued to bathe in the lake and collect water for household chores because there were no alternatives to using the contaminated water.

> *"Bilharzia kills. If there is a way for people to protect themselves from the disease, then it can be okay. Collecting water instead of standing or swimming in the lake can be of help to them as a way of preventing the disease, but there is really no alternative to using water from the lake.*" (Participant SITL14)

Unfortunately, due to the lack of accessibility to clean water and adequate sanitation, residents of communities like Luanda K'Otieno have no choice but to use contaminated waters. Even though Luanda K'Otieno was a site targeted by KEMRI during MDAs a few years ago, there continues to be a relatively high schistosomiasis prevalence rate, which can most likely be attributed to the lack of access to clean water. Without a means to eliminate any potential risk of *Schistosoma* infection, there is a likely chance of recurrence of the initial infection.

Improvements in education on schistosomiasis post-NSBDP

	Extent of knowledge on schistosomiasis			
Level of education	Minimal	Somewhat	Extensive	Total
More highly educated	2	10	10	22
Less highly educated	10	4	7	21
Total	12	14	17	43

*Table 4. Extent of knowledge on schistosomiasis categorized by the participant's level of education completed.

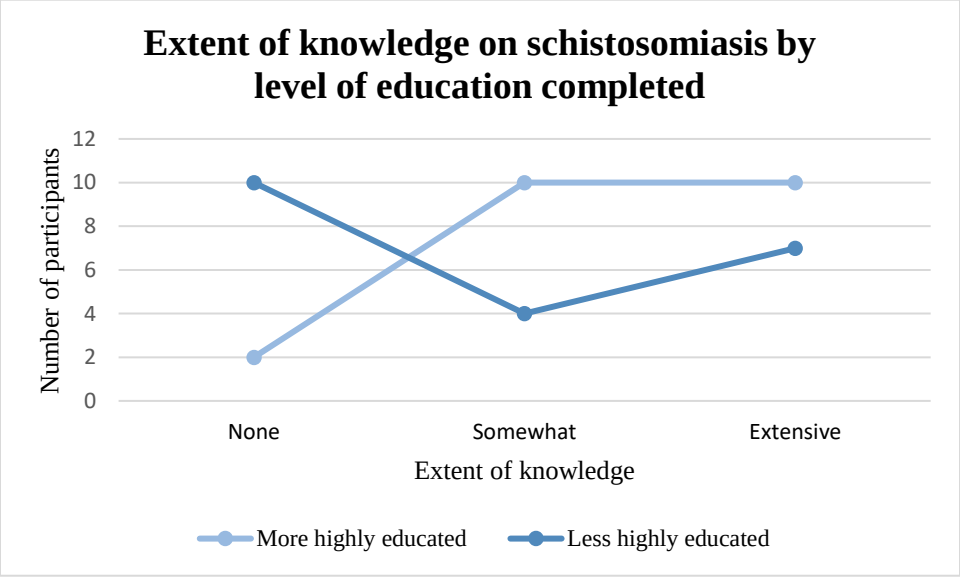

*Figure 7. A graph representation of Table 4. Source: Author.

There is a significant positive correlation between a participant's level of education achieved and the extent of his or her knowledge on schistosomiasis ($\chi^2 = 9.21$, $P < 0.02$, $df = 2$). A majority of those with less education – those who have not completed primary school or have not attended school at all – acquire information on the disease through KEMRI researchers who previously visited their households.

When asked if they knew what schistosomiasis is, 27.9% of the participants responded negatively. Those participants were asked a follow-up question about whether they had at least heard of the disease name before, and some did. 23.3% of those who had minimal knowledge on schistosomiasis were identified as the less highly educated, while only 4.7% of those with more education held minimal knowledge on the disease.

Participants provided their opinions on the accessibility of information on schistosomiasis and, if applicable, their means of knowledge acquisition:

> *"I know about bilharzia from my primary school education and from KEMRI. Education on the disease [schistosomiasis] is only accessible to people who attend school." (Participant SITL02)*

> *"Very few people have access to education on bilharzia because majority living in the village are fishermen. For them to access knowledge on bilharzia can be difficult because most of the time, they are at the lake so they cannot meet with the KEMRI researchers who go around households." (Participant SITL12)*

> *"It is not easy to get information on bilharzia unless you are a participant of a KEMRI study." (Participant SITI18)*

One participant recalled a hospital visit when she was diagnosed with schistosomiasis:

> *"I heard about bilharzia in the hospital when the doctors diagnosed me with the disease. I had abdominal pain, blisters in my mouth, and loose stool. I initially thought that I had malaria. The doctors asked me whether I bathed in the lake, and that was when I learned the source of infection of bilharzia. The doctor also told me that some insect in the lake causes the disease." (Participant SITL18)*

Based on her symptoms, the participant's initial suspicion was malaria. However, according to Mayo Clinic, the symptoms of malaria are generally characterized as follows: fever, chills, headache, nausea and vomiting, and muscle pain and fatigue. Although the participant resides in a schistosomiasis endemic area, she had never heard of the disease prior to her visit to the hospital. Evidenced by this example, there is a lack of schistosomiasis awareness in Luanda K'Otieno despite the implementation of MDAs in the area, and unfortunately, there is also limited access to education on the disease, which is further illustrated below.

	Level of education		
Means of knowledge acquisition	More highly educated	Less highly educated	Total
Directly through KEMRI researchers	10	4	14
Indirectly through KEMRI researchers	5	2	7
Community Health Worker	0	2	2
School education	6	0	6
Health facility	3	0	3
Other	1	3	4
Total	25	11	36

*Table 5. The means by which participants with moderate or extensive knowledge on schistosomiasis acquired their knowledge. Mutually inclusive.

*Indirect knowledge acquisition through KEMRI researchers is defined as learning from schoolchildren or community members who were educated by KEMRI researchers during MDAs. Other includes learning from church, group meetings, etc.

	Level of education		
Means of knowledge acquisition	More highly educated	Less highly educated	Total
Directly through KEMRI researchers	10	4	14
Indirectly through KEMRI researchers	5	2	7
Community Health Worker	0	2	2
School education	1	0	1
Health facility	3	0	3
Other	1	3	4
Total	20	11	31

*Table 6. The mutually exclusive version of Table 3. Categories were determined based on the medium from which the participant learned a bulk of his or her knowledge on schistosomiasis.

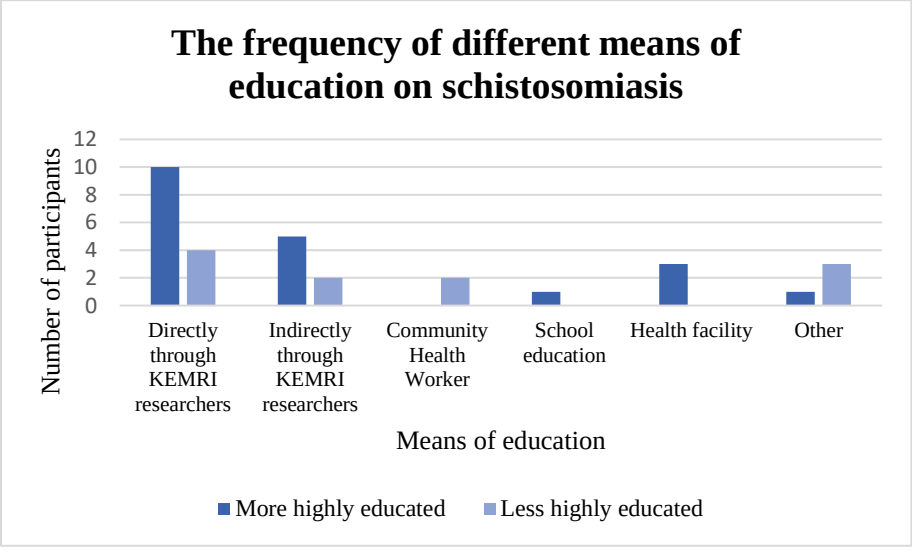

*Figure 8. A graph representation of Table 6. Source: Author.

When asked how they learned about schistosomiasis, many participants responded with more than one answer. However, as statistical significance can only be determined using mutually exclusive data, participants were accounted for under one category, which was decided based on the means through which they learned the bulk of their knowledge. The number of participants who acquired their knowledge on schistosomiasis through KEMRI researchers, either directly or indirectly, is significantly greater than any other means of knowledge acquisition, as shown in Figure 8 ($\chi^2 > 15.09$, $P < 0.0006$, $df = 5$). 45.2% of the 31 knowledgeable participants were educated through participation in previous KEMRI studies, and 22.6% were educated through schoolchildren or community members who were participants of previous KEMRI studies.

With more than 50% of participants having learned about schistosomiasis through KEMRI researchers, directly and indirectly, there is no question that MDAs have been successful in improving the education of the local people. Even though these results illustrate the impressive reach and influence of organizations such as KEMRI on communities like Luanda K'Otieno, there are problems and challenges that have yet to be resolved, as addressed below.

Perspectives and opinions of the community on schistosomiasis

Participants with somewhat or extensive knowledge of schistosomiasis understood the serious health consequences of the disease, and most of them reported that if they suspected themselves of presenting with symptoms corresponding to schistosomiasis, they would immediately report to a hospital. However, as mentioned in previous existing literature, there are people skeptical of the efforts of organizations like KEMRI, especially in regards to treatment with drugs like PZQ.

One participant shared her perspective on this subject:

> *"I would like to be diagnosed, and I am ready for treatment if I need it. However, some people do not want to learn about bilharzia because they fear that there is hidden agenda or other intentions of organizations like KEMRI." (Participant SITI18)*

The mistrust of community members towards institutions such as KEMRI suggest that there is a lack of rapport between researchers from the organizations and residents of the community. A

possible explanation for this mistrust is that there is a lack of clarity and communication between the two groups.

Participant SITI20, who was a participant of a previous KEMRI study, was not pleased when asked to provide a stool sample for schistosomiasis diagnosis. Previously, when she had provided KEMRI researchers with a sample, she never heard back from them with her results. She did not mind taking part in the interview aspect of this study; however, during the stool sample collection stage, she felt ambushed and withdrew from the study as she did not want to a repeat of her previous experience. Another participant, SITI11, shared a similar story. Initially, she expressed hesitation in participating in this study because she did not want to endure a repeat of her past experience: KEMRI researchers had collected a stool sample from her a few years back, but they did not inform her of the results. After ensuring her that she would receive feedback this time around, she agreed to partake in the study; however, she was unable to provide a stool sample when researchers returned to collect her stool sample the following day.

Both participants' experiences illustrate a major issue regarding the reliability of organizations regulating MDAs. Participants are voluntarily participating in these studies under the impression that they will receive feedback and, if needed, treatment. However, in reality, they are not receiving what they were guaranteed. After diagnosis, KEMRI researchers were solely concerned with providing treatment for those who tested positive. They neglected to inform the rest of the participants of their results, causing apprehension about whether they had the disease or not.

Five of the participants reported that they were previously diagnosed and treated for schistosomiasis by KEMRI researchers, but when asked about their knowledge of the disease, two of them had minimal to no knowledge of schistosomiasis. For instance, participant SITL19, who was previously diagnosed positive for *S. mansoni* infection by KEMRI researchers and treated with PZQ tablets as was her child. Yet, she could not identify the source of infection nor the mode of transmission and commented:

"I was diagnosed for bilharzia by KEMRI researchers before and treated. My child was also diagnosed positive and treated. I feel like bilharzia is just like any other normal sickness. It does not kill you."

An essential role of the KEMRI researchers conducting these studies is to educate the community members on schistosomiasis. Despite their success in providing a cure for those in need of treatment, they fail to address the issues causing these high prevalence rates. The key to ending the cycle of disease acquisition is preventive, not curative, measures. As mentioned previously, without access to clean water and adequate sanitation, high prevalence rates of schistosomiasis will remain in the region because people are unable to prevent themselves from recurring infections. Also, if people are not thoroughly educated on the disease, they will not know how to properly protect themselves nor will they know when to seek medical help.

Another pressing concern is the lack of precedence of schistosomiasis for local residents, especially among the fishing community. Participant SITL19 claimed that schistosomiasis is not a fatal disease, which is concerning provided that more than 200,000 deaths per year in sub-Saharan Africa are caused by schistosomiasis.

One participant shared a personal story about the recent death of her brother, further illustrating the severity of this issue:

"My brother died of bilharzia in September this year. He was a fisherman. During his sickness, he was jaundiced and had a distended stomach. He was asked to go to the hospital, but he refused to seek medical attention. The sickness got worse to the extent which he was vomiting blood and was then rushed to the hospital. Unfortunately, he died before doctors could administer the drug."

"People should know that once you see this kind of clinical symptoms, it is better to rush to the hospital. The problem, though, is that the majority of the community is fishermen, and they do not take the disease seriously. They are only concerned about catching fish." (Participant SITI19)

Community members are so accustomed to using contaminated water from Lake Victoria that they are willing to accept the risks and consequences of *S. mansoni* infection. Those working in the fishing industry, especially, have no choice but to put themselves at risk of disease acquisition in order to financially support themselves and their families. Their weekly income

varies drastically, ranging anywhere from Ksh300 to Ksh3000. Because of this constant occupational stress, not knowing whether they will catch or sell enough fish every day, the burden of disease acquisition does not seem significant compared to the more pressing issues they face.

Not only does there need to be increased awareness regarding the serious health implications of schistosomiasis acquisition, but there needs to be increased access to treatment options, as well. Currently, there is limited accessibility to schistosomiasis treatment due to the lack of affordability of PZQ. In a village where the average income reported by participants is approximately Ksh500 a week, people are unlikely to afford the high cost of medication. Their fear of these costs discourages them from visiting health facilities when they become sick, resulting in graver health complications if left untreated.

> *"People are also hesitant to learn about bilharzia because they know PZQ and fear the reaction of the drug. PZQ can cost over Ksh2000, which is too high, and people also fear that health facilities cost a lot of money." (Participant SITL01)*

The participant's estimation of the cost of PZQ may not be entirely accurate, but the general idea behind his statement is valid. A study conducted in Kwale County, Kenya indicated that a single dose of the anti-helminth drug PZQ is "safe, highly efficacious, and cheap," costing less than 0.50 USD, or approximately Ksh50, per dose (Kimani 2018). However, *S. mansoni* infected persons who are not schoolchildren will typically need between three to four doses of PZQ, totaling around Ksh150 to 200. For those facing financial instability, these costs can present a financial burden for them, and consequently, they may choose to not purchase the medication in favor of spending the money on other life necessities.

Relating back to the issue of miscommunication between organizations responsible for MDAs and community members, the discrepancy between the estimated costs of PZQ by Participant SITL01 and the study by Kimani illustrates that there is an inadequate circulation of accurate information among the community. If the local people are led to believe that the cost of the drug is over Ksh2000, they will undoubtedly be hesitant to seek medical help. Addressing issues of miscommunication and misinformation would be incredibly beneficial to establishing more

aware and better educated groups of people, and a chain reaction would then follow, ideally resulting in the elimination of schistosomiasis as an endemic disease in many areas.

Discussion

The 13 participants who were diagnosed as positive for schistosomiasis were treated with PZQ tablets, and the dosage was determined using their respective heights. They were also provided with water and biscuits since there are adverse effects if PZQ is taken on an empty stomach. For those participants who were not present in their homes, the appropriate number of PZQ tablets were left with the CHW to give to them at a later time. While participants positive for *S. mansoni* infection were prioritized in receiving feedback, those who tested negative were a prime concern, as well. Due to a limited time frame, the principal researcher was unable to revisit every household to present the results, so she notified the CHW to inform the remaining participants.

The lack of initiative of organizations like KEMRI in ensuring that participants receive feedback and an adequate understanding of the disease prevalent in the area is unfortunate. Based on participants' recalled experiences with KEMRI studies, there is reason to believe that the knowledge gap on schistosomiasis is partly caused by the organization's disregard of their responsibility to provide comprehensive information to participants. Previous studies have shown that schistosomiasis control programs, such as MDAs with PZQ, have successfully lowered prevalence rates and disease-related morbidity in endemic regions; however, some areas with high prevalence and intensity remain. For instance, Luanda K'Otieno is still considered to be a schistosomiasis hotspot despite the implementation of MDAs by KEMRI in the past. This study revealed that people living in communities with limited to nonexistent access to clean water suffer great health implications from using the only water available to them. Regardless of the implementation of MDAs, schistosomiasis will remain endemic in areas where people have no means of disease prevention because unless preventive methods are established, the disease will recur.

A major limitation of this study was the lack of sufficiency in sample size, reducing the power of statistical results. There were only 43 participants interviewed and 34 stool samples collected for schistosomiasis diagnosis. For results measuring the prevalence rates and intensity levels of *S.*

mansoni infection in the village, they may not accurately represent the entire community. The limited sample size is also a possible explanation for the absence of correlation between extent of knowledge on schistosomiasis and prevalence rates as well as intensity levels. There were not enough participants surveyed to generate a significant conclusion regarding statistical data. Future research is required in order to expand the applicability of these results to the entire village of Luanda K'Otieno as well as other similar schistosomiasis hotspot regions. Due to the insufficient sample size in measuring prevalence and intensity, the focus of this study is on the personal experiences of the participants with MDAs organized by KEMRI and their opinions on issues inhibiting major progress on addressing the schistosomiasis endemic. Their narratives on the hardships and fears they faced as a result of the disease shine a light on a bigger issue at hand: the absence of compassion from both organizations managing MDAs and health facilities. This may partly explain the reluctance of many community members to seek education on the disease or medical help if they become sick.

Recommendations

Organizations like KEMRI, conducting studies in at-risk communities need to take more initiative in their communication with the local people. A handful of participants in this study were dubious towards the purpose of this study based on their negative previous experiences. KEMRI has a duty to inform its study participants of their diagnosis and educate them on the disease so that they can hopefully protect themselves from infection. By not doing so, the reputability of KEMRI is at risk as local people will lose their faith in the organization's work and no longer be willing to participate in future studies.

Additional research examining the prevalence rates and intensity levels in areas where MDAs have not been effective would be beneficial in gaining a better understanding as to why schistosomiasis remains endemic in certain regions. This would help alleviate the severe health consequences and risks many people face, and finding answers to this pressing question may also help achieve the goal of WHO to eliminate schistosomiasis as a public health problem, especially in high-prevalence regions.

Appendix

SIT Study Abroad
a program of World Learning

CONSENT FORM

"Bridging the gap on schistosomiasis: A cross-sectional study examining the knowledge gap and disparities in prevalence and intensity of *S. mansoni* infections among varying education levels in Luanda K'Otieno"

What is the purpose of this study?

The purpose of this study is to examine the knowledge gap on schistosomiasis among residents of different education and socioeconomic levels, living or working near Lake Victoria. This study also aims to determine the difference in prevalence and intensity of schistosomiasis among those residents.

What are the procedures of this study?

The researcher will interview households in villages along the shores of Lake Victoria and groups who work there, as well, to learn about their knowledge on the disease. Interviewees will be asked a series of questions regarding their habitual behaviors and what they know about schistosomiasis, lasting about 20 minutes. Stool samples will also be collected at the end to determine the prevalence and intensity of schistosomiasis, and the results will be shared with the participants.

What are the potential risks of this study?

There are no risks to participating in this study. However, if you wish to discontinue participation at any time during the interview or stool collection, you may do so.

What are the potential benefits for participants of this study?

The participants who donate a stool sample for this study will receive a diagnosis for schistosomiasis free of cost. The results will be shared with participants within a few days following collection, and if tested positive for schistosomiasis, participants will also receive treatment free of cost, courtesy of the Kenya Medical Research Institute.

Rights Notice

In an endeavor to uphold the ethical standards of all SIT ISP proposals, this study has been reviewed and approved by a Local Review Board or SIT Institutional Review Board. If at any time, you feel that you are at risk or exposed to unreasonable harm, you may terminate and stop the interview. Please take some time to carefully read the statements provided below.

a. ***Privacy*** - all information you present in this interview may be recorded and safeguarded. If you do not want the information recorded, you need to let the interviewer know.

b. ***Anonymity*** - all names in this study will be kept anonymous unless the participant chooses otherwise.

c. ***Confidentiality*** - all names will remain completely confidential and fully protected by the interviewer. By signing below, you give the interviewer full responsibility to uphold this contract and its contents. The interviewer will also sign a copy of this contract and give it to the participant.

Contact Information

If you have any questions or concerns, please feel free to contact the researcher, Kathy Zhang, at 0741 491 468.

Rights of Research Participant – IRB Contact Information

In an endeavor to uphold the ethical standards of all SIT proposals, this study has been reviewed and approved by an SIT Study Abroad Local Review Board or SIT Institutional Review Board. If you have questions, concerns, or complaints about your rights as a research participant or the research in general and are unable to contact the researcher please contact the Institutional Review Board at:

School for International Training
Institutional Review Board
1 Kipling Road, PO Box 676
Brattleboro, VT 05302-0676 USA
irb@sit.edu
802-258-3132

Statement of Consent

"I have read the above, and the research study has been explained to me verbally. I voluntarily agree to take part in the study."

_____	_____
Participant's name printed	Participant's signature and date
_____	_____
Interviewer's name printed	Interviewer's signature and date
_____	_____
Witness's name printed	Witness's signature and date

SIT Study Abroad
a program of World Learning

FOMU YA IDHINI

"Bridging the gap on schistosomiasis: A cross-sectional study examining the knowledge gap and disparities in prevalence and intensity of *S. mansoni* infections among varying education levels in Luanda K'Otieno"

Lengo la uchunguzi huu ni?

Lengo la uchunguzi huu ni kuchunguza pengo la maarifa kuhusu schistosomiasis kati ya wakazi wa viwango tofauti vya elimu na kiuchumi wanaoishi au kufanya kazi karibu na Ziwa Victoria. Uchunguzi huu pia unalenga kuamua tofauti katika kiwango cha maambukizi na makali ya schistosomiasis kati ya wakazi wale.

Utaratibu wa uchunguzi huu ni gani?

Mtafiti atahoji wakazi vijijini kando ya Ziwa Victoria na vikundi vnavyofanya kazi pale pia ili kujifunza maarifa yao kuhusu ugonjwa huu. Wahojiwa wataulizwa maswali kadhaa kuhusu tabia zao za kila siku na wanachojua kuhusu schistosomiasis kwa dakika ishirini. Sampuli za kinyesi zitakusanywa kuamua kiwango cha maambukizi na makali ya schistosomiasis na matokeo yatatolewa kwa washiriki.

Kuna uwezekano wa hatari kuhusu uchunguzi huu?

Hakuna hatari kwa kushiriki kwenye uchunguzi huu, hata hivyo ikiwa unataka kutoendelea kushiriki wakati wowote ule, wakati wa mahojiano au wakati wa ukusanyaji wa kinyesi unaweza.

Manufaa ya washiriki wa uchunguzi huu ni gani?

Wahusika kwenye ukusanyaji wa sampuli za kinyesi kwa uchunguzi huu, watapata utambuzi wa schistosomiasis bila malipo. Matokeo yatatolewa kwa washiriki baada ya siku chache za ukusanyaji na ikiwa wamepatikana na schistosomiasis, washiriki watatibiwa bila malipo kwa niaba ya KEMRI.

Haki za ilani

Katika juhudi za kutekeleza viwango vya maadili ya mapendekezo lya SIT uchunguzi huu umekaguliwa na kupitishwa na kamati au Taasisi ya uangalizi ya SIT kama kwa wakati wowote ule unahisi kwamba uko hatarini, unaweza kusitiza na kuacha mahojiano haya. Tafadhali chukua wakati wako kwa makini usome maelezo hapo chini.

a. ***Faragha*** – Maelezo yote utakayotoa katika mahojiano haya yanaweza kurekodiwa na kuhifadhiwa. Kama hutaki maeleza haya kurekodiwa unahitaji kumwelezea mwenye kukuhoji.

b. ***Kutojulikan*** – Majina yote katika uchunguzi huu hayatajulikana isipokuwa mhusika aamue.

c. ***Usiri*** – Majina yote yatawekwa kwa siri na kufichwa kabisa na mwenye kukuhoji. Kwa kutia sahihi hapo chini unampa mwenye kukuhoji jukumu kamili la kutekeleza huu mkataba na yaliyomo. Mwenye kuhoji atatia sahihi kwenye hii nakala na kumkabithi mhojiwa.

Maeleza ya mwenye kuhoji

Ikiwa una maswali au chochote kile, tafadhali uko huru kuwasiliana na mtafiti, Kathy Zhang, kwenye hii nambari 0741 491 468.

Haki za wahusika – Maelezo ya mawasiliano

Katika juhudi za kutekeleza viwango vya maadili ya mapendekezo yote ya SIT, uchonguzi hu umekaguliwa na kupasishwa na kamati au taasisi ya uangalizi ya SIT. Ikiwa una maswali, wasiwasi, au malalamiko juu ya haki zako kama mshiriki wa utafiti au utafiti kwa ujumla na hawawezi kuwasiliana na mtafiti tafadhali wasiliana na Bodi ya Ukaguzi wa Taasisi kwa:

School for International Training
Institutional Review Board
1 Kipling Road, PO Box 676
Brattleboro, VT 05302-0676 USA
irb@sit.edu
802-258-3132

Taarifa ya idhini

“Nimesoma kila kit una kuelezewa kuhusu utafiti wa uchunguzi huu kwa maneno. Nimekubali kushiriki kwenye uchunguzi kwa hiari.”

_____	_____
Jina la mhusika	Sahihi ya mhusika na tarehe
_____	_____
Jina la mwenye kuhoji	Sahihi ya mwenye kuhoji na tarehe
_____	_____
Jina la mshahidi	Sahihi ya mshahidi na tarehe

List of participants

Study ID Code	Date	Level of education completed	Occupation	Diagnosis
SITL01	7.11.2019	Secondary school Level II	Fisherman / small-scale fishing business	Negative
SITI01	7.11.2019	Primary school Class VII	Fishmonger	Negative
SITI02	7.11.2019	Primary school Class V	Fishmonger	Negative
SITL02	7.11.2019	Enrolled in college	Student	Low infection
SITI03	7.11.2019	Primary school Class V	Not working	Negative
SITI04	7.11.2019	Primary school Class III	Fishmonger	Inconclusive
SITL03	7.11.2019	Primary school	Not working	Moderate infection
SITL04	7.11.2019	Primary school	Retired fishmonger	Negative
SITL05	7.11.2019	Secondary school Level III	Small-scale food business	Negative
SITI05	7.11.2019	Primary school Class V	Fishmonger	Negative
SITL06	8.11.2019	Primary school	Small-scale food business	Heavy infection
SITL07	8.11.2019	Secondary school Level II	Not working	Negative
SITI06	8.11.2019	Primary school Class III	Making and selling rope	N/A
SITI07	8.11.2019	Primary school Class IV	Retired fishmonger	Low infection
SITI08	8.11.2019	Primary school Class IV	Retired fisherman	Negative
SITL08	8.11.2019	College	Retired fisherman / owned and rented out boats	Negative
SITI09	8.11.2019	N/A	Rents out housing	N/A
SITI10	8.11.2019	Primary school Class V	Preparing and selling food to schools	Negative
SITL09	8.11.2019	Secondary school	Farming and selling produce	Low infection
SITL10	8.11.2019	Primary school	Not working	Low infection
SITL11	11.11.2019	Secondary school Level II	Preparing and selling food to schools	Negative
SITI11	11.11.2019	N/A	Not working	N/A
SITL12	11.11.2019	Secondary school	Fishmonger	Negative
SITL13	11.11.2019	Primary school	Not working	N/A
SITI12	11.11.2019	Primary school Class V	Not working	Negative
SITL14	11.11.2019	Secondary school	Selling clothing at the market	Moderate infection
SITI13	11.11.2019	N/A	Retired fishmonger	Negative
SITI14	11.11.2019	N/A	Fishmonger	Negative
SITI15	11.11.2019	Primary school Class V	Selling firewood	Negative
SITL15	11.11.2019	Primary school	Fishmonger	Moderate infection
SITI16	11.11.2019	Primary school Class VII	Fisherman	Low infection
SITI17	11.11.2019	Primary school Class II	Not working	Low infection
SITL16	11.11.2019	University	Cereal shop owner	N/A

SITL17	12.11.2019	University	Previous kindergarten teacher	Low infection
SITL18	12.11.2019	Primary school	Tailor	Negative
SITI18	12.11.2019	Primary school Class VI	Selling water	Low infection
SITI19	12.11.2019	Primary school Class VI	Cooking and selling porridge	Negative
SITL19	12.11.2019	Primary school	Selling Nile Perch Fingerlings	Low infection
SITL20	12.11.2019	Secondary school Level II	Preparing and selling food	Negative
SITI20	12.11.2019	Primary school Class VII	Not working	N/A
SITI21	12.11.2019	Primary school Class VIII	Not working	N/A
SITL21	12.11.2019	Primary school	Fishmonger	N/A
SITL22	12.11.2019	Secondary school	Selling food	N/A

Sample Interview Guide

Introduction questions

- What is your current occupation?
    - If you have a spouse, what is his or her current occupation?
- How much do you typically make in a week on average?
- What is the highest level of education you have completed?
- Where do you usually source your water for common household tasks such as washing clothes and dishes?
    - What about for drinking water?
- Do you use water from the lake for bathing, or is there running water in the house?
    - If you use water from the lake, do you bathe in the lake or collect water to bathe elsewhere?

Current knowledge on schistosomiasis

- Do you know what bilharzia is?
    - If yes, continue to the following questions.
    - If no, have you ever heard of the disease before?
- Do you know the source of infection?
- Do you know how bilharzia is transmitted?
- Do you know the treatment method for bilharzia?
- Do you take any preventive measures to protect yourself against bilharzia?
- What is your opinion on bilharzia?
    - Do you think the disease is serious and life-threatening?
    - Are you comfortable with the disease, or do you seek medical care immediately?

Actions taken to educate communities on schistosomiasis

- How did you acquire your knowledge on bilharzia? Through doctor visits, school education, etc.?
- Would you say there are easily accessible means of education on bilharzia?
- Would you say treatment is easily accessible and affordable for you?
    - Do you think the government should take more action in educating communities like yours on schistosomiasis?

SIT Study Abroad
a program of World Learning

Statement of Ethics

(adapted from the American Anthropological Association)

In the course of field study, complex relationships, misunderstandings, conflicts, and the need to make choices among apparently incompatible values are constantly generated. The fundamental responsibility of students is to anticipate such difficulties to the best of their ability and to resolve them in ways that are compatible with the principles stated here. If a student feels such resolution is impossible, or is unsure how to proceed, s/he should consult as immediately as possible with the Academic Director (AD) and/or Independent Study Project (ISP) Advisor and discontinue the field study until some resolution has been achieved. Failure to consult in cases which, in the opinion of the AD and ISP Advisor, could clearly have been anticipated, can result in disciplinary action as delineated in the "failure to comply" section of this document.

Students must respect, protect, and promote the rights and the welfare of all those affected by their work. The following general principles and guidelines are fundamental to ethical field study:

I. Responsibility to people whose lives and cultures are studied

Students' first responsibility is to those whose lives and cultures they study. Should conflicts of interest arise, the interests of these people take precedence over other considerations, including the success of the Independent Study Project (ISP) itself. Students must do everything in their power to protect the dignity and privacy of the people with whom they conduct field study.

The rights, interests, safety, and sensitivities of those who entrust information to students must be safeguarded. The right of those providing information to students either to remain anonymous or to receive recognition is to be respected and defended. It is the responsibility of students to make every effort to determine the preferences of those providing information and to comply with their wishes. It should be made clear to anyone providing information that despite the students' best intentions and efforts, anonymity may be compromised or recognition fail to materialize. Students should not reveal the identity of groups or persons whose anonymity is protected through the use of pseudonyms.

Students must be candid from the outset in the communities where they work that they are students. The aims of their Independent Study Projects should be clearly communicated to those among whom they work.

Students must acknowledge the help and services they receive. They must recognize their obligation to reciprocate in appropriate ways.

To the best of their ability, students have an obligation to assess both the positive and negative consequences of their field study. They should inform individuals and groups likely to be affected of any possible consequences relevant to them that they anticipate.

Students must take into account and, where relevant and to the best of their ability, make explicit the extent to which their own personal and cultural values affect their field study.

Students must not represent as their own work, either in speaking or writing, materials or ideas directly taken from other sources. They must give full credit in speaking or writing to all those who have contributed to their work.

II. Responsibilities to Hosts

Students should be honest and candid in all dealings with their own institutions and with host institutions. They should ascertain that they will not be required to compromise either their responsibilities or ethics as a condition of permission to engage in field study. They will return a copy of their study to the institution sponsoring them and to the community that hosted them at the discretion of the institution(s) and/or community involved.

III. Failure to comply

When SIT Study Abroad determines that a student has violated SIT's statement of ethics, the student will be subject to disciplinary action, up to and including dismissal from the program.

I, Kathy Zhang, have read the above Statement of Ethics and agree to make every effort to comply with its provisions.

Date: 4.11.2019

COUNTY GOVERNMENT OF KISUMU

Telegrams: "PRO.(MED)"
Tel: 254-057-2020105
Fax: 254-057-2023176
E-mail: kisumucdh@gmail.com
When replying please quote:
RE:

County Director of Health,
Kisumu.
P. O. Box 721-40100,
KISUMU.

DEPARTMENT OF HEALTH

RE: GN 133 VOL. IX (371) **Date: 23rd September, 2019**

All Medical Superintendents

All SCMOHs

Kisumu County

RE: PERMISSION TO CONDUCT FIELD STUDY IN KISUMU COUNTY

The following students are hereby authorized to conduct their internships and/or independent study projects within the County Government of Kisumu, its health facilities and surrounding communities.

NAME	PASSPORT/ID NUMBER
Kathy Zhang	645672022

Their topics will contribute towards the implementation and review plans for the County as the SIT partners with us under its program. Any assistance you accord them in the process of conducting their field work will go a long way in promoting intercultural learning.

Dr. Onyango D.
County Director of Health
Kisumu County

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Calendar (Oct. / Nov.)

28 Acquire KEMRI badges Introduction to the Neglected Tropical Disease team Tour of the NTD section in the laboratory and the snail and hamster facilities	**29** Create a set of interview questions for field visits and a consent form for the participants	**30** Meet with John Oguso and Dr. Muok to discuss logistics and to seek approval for the study Create a budget breakdown	**31** Observe monitoring of the snail tanks Review the consent form with John	**1** Finish the ISP Application for Human Subjects Review
4 Review the consent forms in English and Kiswahili with John Discuss the logistics for the field visits	**5** Purchase the supplies for the field visits Print consent forms	**6** Field Day #1 Meet with Rosemary, the Community Health Worker, to discuss the project logistics	**7** Field Day #2 Interview participants and collect stool samples	**8** Field Day #3 Interview participants and collect stool samples
11 Field Day #4 Interview participants and collect stool samples	**12** Field Day #5 Interview participants and collect stool samples	**13** Prepare the stool samples collected using the Kato-Katz technique Analyze the microscopic slides for *Schistosoma* eggs	**14** Organize data from the previous week Writing Day #1	**15** Writing Day #2
18 Writing Day #3	**19** Writing Day #4	**20** Purchase the supplies for tomorrow's field visit to treat those who tested positive for *S. mansoni* infection	**21** Field Day #6 Provide PZQ tablets for the participants positive for schistosomiasis	**22** Writing Day #5
25 Writing Day #6	**26** Writing Day #7	**27** Writing Day #8	**28** Writing Day #9	**29** Presentations