

Community Knowledge, Attitudes and Practices on Schistosomiasis in Western Kenya-The SCORE Project

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Abstract. In an effort to improve intervention strategies, community knowledge, attitudes, and practices on schistosomiasis were evaluated using focus group discussions involving 237 participants, in eight *Schistosoma mansoni* high prevalence districts in rural Nyanza Province, Kenya. The majority of participants reported having heard about schistosomiasis through schools, posters, radio announcements, and community gatherings. Participants had a variety of beliefs about contracting schistosomiasis, including associating it with dirty drinking water and uncooked or contaminated food. Avenues for seeking treatment included health centers, spiritual intervention, herbal treatments, and medicine shops, with health centers receiving the most mention. Barriers to schistosomiasis control included attitudes of community members toward the infection, especially misconceptions that lead to stigma and the perception that diagnosis and treatment are expensive. Schools were the most common avenue for receiving information, suggesting that the existing education infrastructure can be used for health education and improved sensitization about schistosomiasis control programs.

INTRODUCTION

An estimated 207 million people in 74 countries are infected with schistosomiasis (bilharzia),¹ with the bulk of the global prevalence (90%) occurring in sub-Saharan Africa,^{2,3} mostly in rural areas. Of these, 9.1 million Kenyans are infected and schistosomiasis continues to exert significant morbidity despite the availability of an effective and safe drug⁴; although improvements have been made to reduce helminth transmission in many parts of the world,⁴ worm infections remain an issue of major public health and socio-economic concern, indicating the need for enhanced control interventions.

Schistosomiasis can be controlled using approaches that include improved sanitation, health education, and treatment using available and safe drugs. It can also be controlled by targeting vector snails and avoiding contact with contaminated waters.⁵ Regular administration of anthelmintic drugs has been strongly supported by the World Health Organization (WHO) as an effective control strategy. Millions of school-aged children have received anthelmintic treatment (albendazole or mebendazole against soil-transmitted helminthiasis and praziquantel against schistosomiasis) to good effect.^{6–8} In comparison, less emphasis has been placed on improving access to clean water, adequate sanitation, and changing hygiene behavior, although these interventions represent key factors for sustainable control.^{8–10} Health education and promotion campaigns are essential for the acceptance of interventions, especially ones that are newly introduced.¹¹ When working with communities to develop a compelling rationale for their participation, existing knowledge and perceptions must be taken into account.¹² Perceptions and attitudes about parasitic worm infections and their prevention and treatment are important factors.^{13–15} For example, structural and behavioral constraints may influence water contact behavior and influence reinfection rates after drug treatment. Similarly, people may unknowingly contaminate their environ-

ment because of a lack of education. Many researchers in schistosomiasis appreciate the need to incorporate social science research in understanding the disease and designing more effective control interventions, yet only a few have actually incorporated social aspects into their studies.^{11,14,16–19} Societal factors in schistosomiasis transmission are more often inferred than studied.

We have previously carried out research and control activities against schistosomiasis, and soil-transmitted helminthiasis in both rural,^{13,20,21} and urban²² areas of western Kenya. Here, we describe the knowledge, attitudes, and practices (KAP) regarding schistosomiasis and health-seeking behavior of persons in rural communities of western Kenya. This work is a component of studies being conducted in Kenya as part of the Schistosomiasis Consortium for Operational Research and Elimination (SCORE).

MATERIALS AND METHODS

Study area. The study was conducted in eight districts (Bondo, Homa Bay, Rachuonyo North, Kisumu Municipality, Kisumu East, Kisumu West, Nyakach, and Rarieda) in rural Nyanza Province, western Kenya. These districts are populated primarily by members of the Luo ethnic group and were selected on the basis of high prevalence ($\geq 25\%$) for *Schistosoma mansoni* infections (intestinal schistosomiasis). These districts border Lake Victoria, which has been shown to be the main source of *S. mansoni* infection in western Kenya.²⁰ Though there are many development initiatives in these areas, poverty is still a major challenge. More than three-quarters of the population survives on < 1 United States dollar/day, the World Bank's definition of extreme poverty²³; a large proportion of the population lives along the lake in beach communities and one of the main economic activities is fishing. In addition, the lake is used for washing clothing and dishes, bathing, washing cars, harvesting sand, and irrigating farmland. Farming is mostly subsistence-based, with major crops including sorghum, potatoes, cassava, beans, and maize.

As in many other low and middle income countries, health care delivery in Kenya is based on the Primary Health Care

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concept.²⁴ At least one government-owned hospital is located in each district capital and staffed with one or more qualified medical doctors, nurses, pharmacists, laboratory technicians, auxiliary nurses, and other support personnel. There are few other government dispensaries and private clinics and chemists/pharmacies in the district and sub-district capitals. Treatment of schistosomiasis-related symptoms in these health facilities is mostly based on signs and symptoms (presumptive treatment) and an out-of-pocket system of payment (the patient is required to make full payment for consultation before treatment is provided). Most essential drugs are kept in the health facilities for purchase, but patients have to obtain other drugs from private chemists/pharmacies.

Ethical considerations. The study protocol was reviewed and approved by the Scientific and Ethical Review Committees (ERC) of the Kenya Medical Research Institute (KEMRI, SSC no. 1820). The Institutional Review Board of the Centers for Disease Control and Prevention also reviewed the study and chose to rely on the KEMRI ERC approval. Thereafter, permission was obtained from the Provincial administration and Ministry of Public Health and Sanitation (MOPHS). The purpose of the study and its objectives were explained to local authorities, opinion leaders, village elders, and community members. Informed consent was obtained from the participating respondents. Subjects were assured about confidentiality of information obtained from them and personal identifiers were removed from the data set before analysis.

Study design. This was a cross-sectional qualitative study. Four focus group discussions (FGDs) were conducted in each district. In each district, both youth (between 18–24 years of age and unmarried), and adults (24–60 years of age and married) were represented. The youth FGD were carried out in English and or Swahili, which are the languages children use in the Kenyan school system. The adult FGDs were conducted in *dholuo*. The FGDs were further categorized into gender (male youth and female youth and female adult and male adult). Community health workers, familiar with the villages, helped to mobilize participants for the study. Study participants were randomly selected from pools of individuals that met the inclusion criteria. The youth, whether male or female had to be between 18 and 24 years of age, unmarried, and able to speak either English or Swahili. The adults had to be between 24 and 60 years of age. There was no exclusion in terms of language for this category. Further screening was done on site to make sure that participants met the inclusion criteria before obtaining consent, and that they were fully representative of the different villages (Supplemental File 1). The research team, together with other experts in the field of qualitative research, came up with a semi-structured FGD guide that provided a general overview of the topics (Supplemental File 2). Discussions were steered by a moderator who was part of the field team and had undergone training before the data collection exercise. However, the direction the discussion took depended on the participant’s responses and areas that the moderator felt needed probing. The FGD guide was first pilot tested in an area with similar social-economic characteristics to the study sites. The discussion guide covered: familiarity with the term “bilharzias,” knowledge on signs and symptoms, common terms for these signs and symptoms in the local *dholuo* language, mode of transmission, control interventions, groups most at risk, reactions by others toward an individual with schistosomiasis, rationale for choice

of health facility, avenues for seeking healthcare, at what point do people seek help, perception on cost of treatment, and preferred sources of information on schistosomiasis sensitization. All voice data from the FGDs were tape recorded and later transcribed. The information was used to create a detailed reconstruction of villagers’ KAP pertaining to schistosomiasis.

Data analyses. Analysis of qualitative data placed emphasis on the interpretation, description, and recording/writing of what was actually said. The transcripts were first created in the local language, translated into English, and back-translated into the local language to ensure that the English and local language versions carried the same meanings. The research team went through the transcripts before they were imported into the Atlas ti software. After the research team had gone through the transcripts, suitable codes were collectively identified and assigned relevant themes that emerged from the transcripts. These codes were then uploaded into the coding section in the Atlas ti software. Each individual transcript was then examined to identify texts relevant to the coding system already identified. Outstanding themes were collectively identified with close inspection to related phrases to avoid bias. Quotes were later retrieved from the output monitor and arranged according to themes.

RESULTS

Socio-demographic information/characteristics of the study population. A total of 237 individuals participated in the 32 FGDs held in the eight districts. However, seven participants were excluded from the analysis because of missing socio-demographic details. Table 1 shows the socio-demographic characteristics of the 230 participants in the study. There was equal representation from both male and female participants; most were between 20 and 29 years of age. Only 0.4% of the participants reported to have no education at all, whereas more than half had secondary education. The majority

TABLE 1
Socio-demographic characteristics of the study participants

Description	Frequency (N = 230)	Percentage (%)
1. Sex		
Female	115	50
Male	115	50
2. Age in years		
15–19	17	7.4
20–24	71	30.9
25–29	37	16.1
30–34	30	13.0
35–39	31	13.5
40–44	17	7.4
45–49	11	4.8
≥ 50	16	7.0
3. Educational level		
Primary education*	64	27.8
Secondary education*	120	52.2
Post-secondary education	45	19.6
None	1	0.4
4. Marital status		
Divorced	1	0.4
Married	120	52.2
Single (never married)	85	37.0
Widowed	14	6.1
Undisclosed status	6	2.6

*Includes people who received some education but may not have completed this level.

(52.2%) of the participants were married compared with 37% who had never married.

Assessment of knowledge and awareness. *Avenues of information.* The FGDs with community members revealed that the majority of the participants had heard about schistosomiasis before. The sources of information included schools, posters, radio and community gatherings (*baraza*), with the school receiving the most mention. A 35-year-old housewife from Homa Bay reported, “I heard of the bilharzia topic over the radio, it was somebody from KEMRI who came (spoke) about with the issue of bilharzia. It was just a vernacular station that is where I heard about it.” A 35-year-old male jua kali worker (informal employment) from Kisumu West said, “I heard about it through my children... So some people came to school and gave them some forms. When they brought them home, they told me to go through them as parent so that after signing them then they could be allowed to participate into the research.”

Local names for schistosomiasis signs and symptoms. Participants were able to identify some of the local names in the community that were associated with symptoms of schistosomiasis. A 21-year-old female youth student from Kisumu municipality said: “I hear people call it ‘Aremo’ because of the water.” A male youth in Homa Bay said: “‘*tuo layo remo*’ or ‘*pielo remo*’... ‘Aremo’ is the disease of urinating blood or defecating blood respectively.” And an 18-year-old male youth in Rarieda said: “it is because if you are urinating and when you have finished, you see drops of blood are the ones you are now urinating there, that is what has brought the name ‘aremo.’” “Aremo” was perceived to have several symptoms, including ones with no biochemical relationship to schistosomiasis, as illustrated in Table 2.

Knowledge about schistosomiasis. Our study revealed that the majority of the participants felt they did not have adequate information about schistosomiasis. A 58-year-old male farmer from Rarieda said: “I don’t think we are well informed since it is called ‘aremo’ and we only believe that ‘aremo’ only attacks cows when they take (drink) dirty water, so I don’t think if we are well informed about the bilharzias.” A 19-year-old female business owner from Kisumu West said: “Some are informed while others are not, depending on the literacy level. If you didn’t go to school then you can’t be informed about it.” A 43-year-old male from Homa Bay said: “I just want to add... like in my village three-quarters of the people are illiterate and are not informed of the disease and the few who went to school only have a brief information about it.” A 20-year-old

male youth in Homa Bay said: “Me personally, I don’t think if I am well informed about it, because I only know that it is being caused by snails in the infested areas but what about the symptoms and the medications? I don’t know.”

Lack of adequate information on schistosomiasis was exemplified by the suggested intervention measures that were not linked to schistosomiasis. For example, a 27-year-old adult female from Kisumu West said: “I think by cooking. You leave the food to boil properly [to prevent infection]. Even if its meat because you can get it from the cow.” A male youth from Kisumu West said: “For example, if I wash my clothes with contaminated water then if someone puts on the same clothes, then he or she is likely to get bilharzia as it can get to him through the air cornices (pores on the skin). In short, washing your clothes with contaminated water you can get bilharzia.”

Preferred sources of information. With regard to spreading information about schistosomiasis, participants mentioned a few sensitization methods that they felt would work best in their community: a 40-year-old female farmer from Kisumu West said: “Door to door is best because the village elders know each and every one of their village and they can do it easily...” A female adult from Nyakach said: “Moving to the shopping centers is best because there will be many people around as opposed to the barazas that others might feel guilty to attend.” A 19-year-old male youth in Homa Bay said: “... theater will be the best when you want to reach a larger population within a short time.” A 35-year-old male farmer in Rarieda said: “I wish they can use billboards up to those rural areas it is the best one because you see as you walk.”

Participants admitted to feeling at risk of contracting schistosomiasis. The reasons given though were not related to the disease, further confirming the lack of knowledge about the infection. A male youth in Kisumu East said: “Yes I can get it through drinking water, by seeing that the water we drink is clean but clean water is not pure and safe water for drinking.” A 35-year-old adult female in Homa Bay said: “Yes I can get it because it depends with what I do. Maybe I move from my home to somewhere else. Maybe I go visit my relatives and maybe they don’t have latrines and clean water. Ok I will have bilharzia because I will drink the same water that they are drinking.”

At risk groups. It was the general view of participants that there is no particular gender or age that is more at risk compared with others. They attributed this to modernization where both women and men do more or less the same tasks and have the same levels of exposure as explained by a 45-year-old female farmer in Bondo “I think both male and female. Because nowadays, people believe that it is gender equality. What men can do, ladies also try.” This was echoed by a 47-year-old fisherman in Bondo, “As for me, I think anybody can get infected by this disease (bilharzia), whether it’s a child or an adult and especially those people whose his main work constantly involves water.” A few however, bearing in mind gender roles, felt that a particular gender was more at risk “For me, if I may reflect back on how we grew up, men... male children were the people who were really affected by bilharzia; I didn’t know any girl suffering from bilharzia; I can’t tell whether they were infected since I did not observe it—perhaps they hid it as girls. So it is us men who would realize that we were passing out blood or victims of bilharzia. The reason why we are mostly affected is that we expose

TABLE 2
Beliefs about schistosomiasis

Accurate information
Abdominal pain (2)
Body weakness (5)
Weight loss (2)
Swollen stomach (3)
Skin rash (4)
Blood in urine and stool (19)
Beliefs
Foul smell (2)
Pain while urinating (7)
Red lips (1)
Sores in genitals (2)
Swellings on the whole body (3)
Facial rash (3)

ourselves in areas having water when we go to graze animals or when we are playing while girls are always at home.” said a 34-year-old farmer from Kisumu West.

Assessment of attitudes. One of the factors that the participants mentioned and that could pose as a barrier in schistosomiasis control is the attitude of community members toward those infected with the disease. A 32-year-old male unskilled laborer in Kisumu East said: “They can judge you and mistake it for other diseases like syphilis.” A 47-year-old female in Homa Bay put it succinctly: “harlot, because it affects your private parts. They will say you have many partners and they will look down upon you.” A female youth in Homa Bay said: “I think they will be discriminated [against]; they will be viewed as dirty people that is why they are contaminated with the disease.” An adult male from Kisumu West said, “Suppose I’m infected with the disease . . . there are some things which when you become a victim then you cannot share it with your wife since she will rebel. She would not accept that it is bilharzia-she would say it is HIV.”

Susceptibility and severity. More than half of the participants were of the opinion that schistosomiasis is a serious disease, and that their activities exposed them to infection. These sentiments were reflected by a 20-year-old female youth in Homa Bay “Where I come from it is a problem because, next to our home we have a river. People swim there. I have heard that somebody ana layo remo (is suffering from schistosomiasis) but it is there it is affecting the community. . . .” A 40-year-old female from Nyakach went on to elaborate “Bilharzia is not a joke, reason being that it also brings with it headache, diarrhea of bloody stool, and as you urinate blood you end up losing a lot of blood. So it comes along with many infections to your body. You are always weak even standing up to walk becomes a problem.” Similar thoughts were echoed by a 23-year-old male student in Kisumu West. “It’s very serious because any disease can kill if not treated in time, so according to me bilharzia can kill and therefore it’s a very serious disease.”

Assessment of practice. Most participants agreed that schistosomiasis is curable. Various avenues for seeking treatment were pointed out, including prayers, traditional healers/herbalists, hospitals, and chemists. As expressed by a 30-year-old female adult, who is a dressmaker in Homa Bay, “In terms of prayers, it is your faith which will help you . . . if you have strong faith the disease will just go, yeah it is according to your faith.” A 24-year-old male youth in Rarieda also elaborated that “It is about your belief and your faith some believe that they have strong faith that they don’t take any medicine and they get cured . . . so it is about somebody’s faith and belief.” With regard to traditional healers/herbalists, a female youth in Homa Bay said, “Ok I don’t want to bring many stories but they have cured me of a disease, so me I think when you go to a witch doctor and explain yourself that you have bilharzia even if they don’t understand English, you can say layo remo they will understand if they know the leaves or whatever they are using they will just cure you but that is the best thing you use when the hospital is very far away.” Hospitals and chemists were also mentioned as important points for seeking healthcare as illustrated by a 20-year-old female youth in Bondo who said, “[Go] to the nearest hospital so that you can be treated where they can give a medicine or if they cannot help you, they will transfer you to a place where they can help you.” With regard to the chemist, a male in Homa Bay also indi-

cated that “I may take some oral medicine at home by buying some medicine over the counter.”

The majority of the participants thought that treating schistosomiasis at a hospital is very expensive and cited this as a reason for seeking alternative treatment. A male youth in Kisumu West stated, “To get a tablet that treats bilharzia it can cost about Ksh500 [\$5.89] but it might not be easy for someone to get this amount.” A 30-year-old female dress maker in Homa Bay said, “The reason why I was saying that is like three hundred [\$3.53] because now days we have retired doctors and they have their chemists so you know a lot of people don’t go for the treatment in the hospitals they go to the chemist. Why? Because it is expensive there (hospital).” A 39-year-old male business owner in Rarieda said, “We cannot use three hundred or one thousand two hundred [\$14.14]! That is the least amount you can pay now days even if you go for a malarial treatment my friend you will even pay five hundred shillings, so for bilharzia you go for so many tests then you are being prescribed for drugs. Then I think you can reach five.”

Other reasons cited by participants for seeking alternative treatment (other than at the hospital) included: distance from

Box 1

Distance from health facility

A 20-year-old male farmer said, “In rural areas sometimes the health facility is very far so reaching there may be a problem, that is why they go to the herbalist.”
 “Even me, I can’t go all the way. That place (hospital) is too far. Then maybe you are weak and you can’t walk all the distance, and maybe you don’t have money for a bus. You will end up going to a herbalist.” expressed a 24-year-old female youth from Rachuonyo.

Beliefs

A 48-year-old male farmer said “We have people who think about drinking twenty-four hours. . . When they do feel sick after coming from fishing the only thing they think about is chang’aa (alcoholic beverages) and bhang (marijuana) to cheer them up. When they are drunk they believe they are resistant to pain; they don’t feel any pain thereby assuming they are now well; meanwhile the disease is developing.”
 “Luos believe that if they see something strange especially that of urinating blood then they would take it that her/his child has been bewitched. . . and therefore he has to go to the witchdoctor for consultation on that particular issue. So this issue of witchcraft is one of the barriers that hinder people from going to the hospital for appropriate treatment of bilharzia.” reported a 35-year-old adult female from Nyakach.

Lack of drugs

A male student in Kisumu West who is 23 years old said “If you go to the hospital and find there are no drugs, after second trials then the third one you will not go because you will suspect that there’s no drugs.”

Long queues

A 34-year-old male farmer, “What do happen that can make people to give up is that you may find, for example, you go to a particular hospital in the community and find a long queue. When it reaches lunch hour, then nurses will leave and . . . this makes people to give up.”
 “If you go to the hospital perhaps you have accompanied a sick person to the hospital in the morning. . . , you find that nurses are reluctant to attend to the patient fast. You find that the patient is on the waiting bench but if you talk to the nurses., they do not act immediately. This drives people away from the hospital saying that if you go to such and such hospital, then nurses are relaxed just telling stories. People are not happy with that hospital when such things do happen. . . . So this makes people to give up on a health facility.” said a 35-year-old male business owner from Bondo.

the health facility, long queues in the facility, and rumors promulgated by some members of the community. Text Box 1 shows some of the participants' views related to treatment.

DISCUSSION

The objective of this study was to deepen our understanding on the local KAP about schistosomiasis and health-seeking behavior in eight endemic districts in rural western Kenya before mass treatment campaigns in this area. Research has shown that health promotion interventions may fail if they are designed without understanding the health behavior of the target population.²⁵ In appreciation of this, the current study was premised on the fact that to design and implement optimal prevention and control strategies against schistosomiasis to complement chemotherapy, an in-depth understanding of the knowledge and practices of the target population is essential. In our study, we defined "knowledge" as awareness of, familiarity with, or understanding about schistosomiasis. We sought to find out whether "bilharzia" or "schistosomiasis" meant anything to the participants and also what it meant. "Attitude" was interpreted as the manner in which participants view schistosomiasis and how this affects the way they might view the need for an intervention program. "Practice" was the customary and habitual way of the participants' response to schistosomiasis. The majority of the participants reported to have previously heard about schistosomiasis from several sources including school, posters, radio, and community gatherings called by government leaders (chief's *baraza*). Despite this, erroneous beliefs on the mode of transmission prevailed with participants associating it with promiscuity, dirty drinking water, uncooked and contaminated food, and washing clothes in dirty water. As seen in a previous study in this region,²⁶ there was also some confusion between the disease in humans and cattle. It also emerged that community members' attitudes toward individuals infected with schistosomiasis could create social stigma and hamper control efforts. Health centers, prayers, witch doctors, and medicine shops were cited as avenues for seeking treatment. Participants felt that diagnosis and treatment of schistosomiasis in hospitals was expensive, which often led them to seek alternative treatments.

Similar to our observations, previous studies in other schistosomiasis-endemic areas found a high level of awareness of schistosomiasis. For instance, Ndamba and others²⁷ reported that 80% of villagers in Zimbabwe were aware of schistosomiasis. Similarly, studies in Brazil¹⁵ and Egypt²⁸ revealed that people were fairly familiar with schistosomiasis. From our study, information on schistosomiasis seems to have been readily available. However, it is conceivable that little attention was paid to the details, perhaps in some cases there was misinformation about the disease, or recognition of schistosomiasis as a major health problem was still limited in these communities. It is possible that some of the beliefs on the mode of schistosomiasis transmission may emanate from a lack of interest in seeking to understand the disease. This is especially true in a setting where schistosomiasis competes with other diseases perceived to be more life-threatening, such as malaria and HIV. The desire for an in-depth understanding of schistosomiasis and its mode of transmission may require the demonstration of more adverse effects associated with the disease, similar to the scenario when people consider

the symptoms a health threat before seeking health care.²⁹ It is clear that hearing about the disease is simply not enough, a proper understanding of the disease and its causes/mode of transmission is what is required to augment prevention and control efforts. Perceived symptoms and causes of schistosomiasis that are incongruous with the biomedical perspective have also been reported in other studies.^{14,30}

It is noteworthy that schools, radio, and community gatherings (*barazas*) were mentioned as sources of information on schistosomiasis, further indicating the need to strengthen the role of teachers in health education and the importance of community social organizations as an intermediary to deliver health education messages. However, a study in Senegal³¹ showed low awareness of intestinal schistosomiasis among the population despite several years of health education, using a diversity of communicational outlets including radio, television, and posters, among others. It has been suggested that both the school and community structures should be integrated in health education programs, so that school children can act as agents for the diffusion of health education messages¹¹; the importance of schools as a key source of information for schistosomiasis has been shown in studies from Brazil.¹⁵

It was interesting to note that schistosomiasis was perceived to be associated with promiscuity in our study. Elsewhere, a number of respondents found schistosomiasis to be a shameful disease,^{14,32} highlighting the need to consider the impact of social stigma associated with the disease, and how this could impact control efforts caused by fear of disclosure. Social stigma not only increases feelings of fear and shame but can reduce people's capabilities to successfully obtain appropriate treatment.³³

To seek health care, people must consider the symptoms of a health threat and have resources available.²⁹ In terms of avenues for seeking treatment, several routes were mentioned in this study, but the health centers received the most mention. Even so, participants felt that diagnosis and treatment of schistosomiasis in hospitals was expensive and that perception formed the basis for seeking alternative treatment. However, it is widely acknowledged that there is always a delay in seeking treatment, because many people do not seek care for symptoms that they perceive as mild or moderate and wait until they become severe. This is especially detrimental considering that morbidity in schistosomiasis is a function of infection intensity and duration.³⁴ Similar to findings in our study, a lack of money and the perceptions that symptoms were not serious enough were cited in a previous study as reasons for failure to visit a hospital/health center.¹⁶ Participants also mentioned visits to traditional healers, even though there is no known traditional medicine for treating schistosomiasis-related symptoms in the study area. In our study, religious beliefs also influenced health-seeking behavior, with some community members who believed in spiritual healing and would neither go to the hospital nor take medication. The implications of such avenues of seeking treatment is that they are less effective, and symptoms may not be relieved, and risk of late morbidity is not or only partly averted.¹¹ Furthermore, such actions from infected individuals place the entire community at risk of infection because they continually serve as reservoirs of infection and sustain transmission. Other potential determinants on health-seeking behavior that may have influenced our findings include recall bias or social desirability bias.

Social desirability might lead to over-reporting of positive practices such as visits to health facilities. One of the limitations of the current study is that we did not check the hospital records that participants kept in their homes to verify health-seeking data. Future surveys may be enhanced by incorporating these data. In addition, Acka and others¹¹ have suggested that there may be seasonal variation in health-seeking behavior over the year. Other studies found that health-seeking practices are generally much worse in poorer communities.³⁵

In conclusion, our results show that although participants had a fair idea of schistosomiasis, some beliefs on the pathology and mode of transmission were mentioned that could hinder control efforts. The study also supports further socio-cultural research on schistosomiasis to quantify the social burden of the disease. In addition, there is a great need for health education on the signs, symptoms, and risk factors of schistosomiasis to strengthen the impact of control strategies and reduce infection. Currently, treatment of schistosomiasis in sub-Saharan Africa is primarily effected through mass administration of praziquantel and most information is disseminated using this treatment model. However, as prevalence levels drop, it will also be necessary to consider what other messages may be needed to encourage participation in a more targeted treatment approach. Ultimately, it is expected that following a community-based public health education campaign, knowledge of common symptoms and transmission may lead to improved health-seeking behavior and early treatment. Even though the participants in the FGDs were all adults, their recognition of schools as the most popular avenue for receiving information indicates the prominence of schools in these communities and that the education infrastructure already present can be used for sensitization on schistosomiasis. Continued health education is critical in raising awareness in the population about schistosomiasis, and encouraging symptomatic individuals to seek care and treatment with praziquantel, the price of which has fallen enormously.³⁶ Emphasis on treatment in the early stages of infection (perhaps not always perceived as severe) can help to prevent later morbidity. There is a need to upgrade government facilities' diagnostic and treatment capacity with regard to schistosomiasis, reduce/subsidize the cost of diagnosis and treatment, provide alternative water sources, and develop health education programs to be incorporated into the primary school curriculum. Findings from this study will be useful for the design and implementation of control programs alongside preventive chemotherapy. We hope to use the information gained in this study toward future research on which health education strategies are most effective.

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