

Effectiveness of schistosomiasis control programmes and assessing factors contributing to re-infections in risk populations in Uganda: A grounded theory and qualitative study

ABSTRACT

Objective: This study's aim was to document risk population's, including school children's perspectives regarding risk behaviours and effectiveness of therapeutic modes in management of schistosomiasis.

Methods: A grounded theory and qualitative approach was employed in two risk districts in Uganda. Methods including interviews were conducted with selected school children, 21 fishermen and 17 sandminers. Key informants were 2 District Health Officers, 15 head-teachers, 4 Village Health teams, 8 science teachers, 4 professional health workers, 2 officials from the Ministry of Health /Vector Control Division (MOH/VCD). In addition data was collected through 6 Focus (group) discussions with parents, guardians, school children. Observation was done by three researchers and research assistant in each selected school and surrounding communities and fishing villages. The team also observed risk behaviors for schistosomiasis and practices around lake Victoria in Wakiso district and river Pager in Kitgum district.

Results: One hundred purposively selected school children participated in focus group discussions and in-depth interview. We observed risk practices around the lake and river shores- and then discussed with fishermen(n=21) and sand miners(n=17) their perspectives about schistosomiasis control and treatment. Challenges in the chemotherapeutic approach include irregular supply of Praziquantel(PZQ), drug fatigue, side effects of PraziquantelPZQ, poor sanitation and treated people depended on infected waters for their livelihood. Respondents recommended repairing boreholes, immunizing/vaccinating against bilharzia, sensitizing people at risk about the importance of taking Praziquantel-PZQ regardless of the side-effects.

Conclusions: Schistosomiasis still remains one of the endemic neglected diseases in Uganda. There are both river and lake variants of *S. mansoni*. The persistence of bilharzia could be attributed to challenges in the chemotherapeutic approach, re-infection and new infections upon exposure to infected waters.

Keywords: Schistosomiasis; risk groups; school children; fishermen; Praziquantel; Uganda

1. INTRODUCTION

Schistosomiasis is a parasitic chronic disease that affects more than 200 million people, mostly in developing countries ^{1, 2, 3}. In Uganda, schistosomiasis is endemic along lakes and rivers and over 4 million people are affected. Human behavior and practices affect schistosomiasis transmission through contact with infected water bodies and a prevalence of 20.4% has been reported in some schools and communities across Uganda ^{2, 3}.

In Ugandan endemic areas, this parasitic illness thrives in a triad of poor sanitation, presence of infected snails which are its primary vectors and contact by people with infected water. Eggs are eliminated with feces or urine. The eggs are moved progressively toward the lumen of the intestine (*S. mansoni* and *S. intercalatum*) and of the bladder and ureters (*S. haematobium*), and are eliminated with feces or urine, respectively.

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In essence, effective control of schistosomiasis must include chemotherapy, vector control and a public health approach to promote awareness to the people at risk about preventive measures against *Schistosoma mansoni* and *Schistosoma haematobium*. Uganda's Ministry of Health(MOH) launched a Schistosomiasis Control Programme in 2003 focusing on a therapeutic approach in control through regular provision of PraziquantelPZQ to people living in high-risk communities [4].

Although the MOH chemotherapeutic approach in schistosomiasis control targets primarily children aged between 5-15 years living in high-risk areas through administeringPraziquantelPZQ[3, 5]; studies show that children below five years are also affected [5, 6].

The highest prevalence of schistosomiasis has been found in individuals aged 5-15 years [7]. For example, Savioli et al. [8] found out that the presence of blood in urine is an indicator of infection and that *S.haematobium* is the commonest cause of haematuria in children in areas where infection is endemic. Further, Ansell et al. [7] reported a prevalence of schistosomiasis through conducting interviews in 15 schools in Tanzania and findings correlated strongly with the prevalence of infection determined through microscopy with a range of 22 – 93%. It is argued that these children are exposed to schistosomiasis as they engage in risky behaviours such as washing and bathing in contaminated water. This study's main aim was to examine the extent to which the chemotherapeutic approach is effective through finding out key informants and school children's perspectives about risk behaviours and practices which expose them to infections by bilharzia causing parasites. In separate arm of this study we carried out a prevalence study for *S. mansoni* and *S. haematobium*. Results of the prevalence study will be reported in another article.

The Ministry of Health's (MOH) chemotherapeutic approach is however expensive and ineffective since people still get infected and re-infected. Moreover, if a multipronged approach in control of schistosomiasis is implemented focusing on the vector and the health risk behaviors practiced by children, it could be possible to minimize infection and re-infection by *S.mansoni* and *S.haematobium*. There are some awareness activities which have been implemented in endemic areas like Bugungu and Wang-kado fishing villages in Wakiso and Nebbi districts, but these targeted mainly fishermen who are adults and are always away from their communities[4-9]. Therefore a need arises to qualitatively assess risk populations' viewpoints about chemotherapeutic approaches in schistosomiasis control and factors contributing to re-infections.

2. METHODOLOGY

2.1. Study design: This was a grounded theory and qualitative study.

2.2. Study area: We focused on two purposively selected high risk districts for schistosomiasis, namely Kitgum and Wakiso. In Kitgum, we focused on schools and villages within a 5 Km radius from river Pager and in Wakiso we examined Lake Victoria fishing villages and primary schools within a 5 Km radius from the lake.

2.3. Sampling procedure: We did purposive sampling for all study respondents. People deemed to be particularly at risk of infections and re-infection with schistosome parasites and have experience with taking Praziquantel frequently distributed to risk populations were selected for interview[10]. Adults including 21 fishermen and 17 sand miners in the selected high risk areas for schistosomiasis were approached by researchers and requested to participate both in interviews and focus group discussions.

2.4. Study methods

Qualitative techniques were employed in this study. High quality data collection techniques have been recommended by Delmar [11-12] for qualitative studies. Interviews were conducted with purposively selected school children and key informants including 2 District

Health Officers, 15 head-teachers, 4 Village Health teams, 8 science teachers, 4 professional health workers, 21 fishermen, 17 sand miners, 2 officials from the Ministry of Health /Vector Control Division (MOH/VCD); 6 Focus (group) discussions, 4 with parents, guardians and 2 focus group discussions with school children. Observation was done by three researchers and research assistant in each selected school and surrounding communities and fishing villages. The team also observed risk behaviors and practices around lake Victoria and river Pager.

2.5.Data management and analysis

Qualitative data was recorded, transcribed and recurrent themes reported verbatim. Manually coding data and compiling recurrent themes for subsequent analysis is consistent with the grounded theory analysis of research findings. Although we are cognizant of the quality of our findings, we are also aware of limitations due to employing only qualitative data collection and analysis techniques [17-see 12/1].

2.6. Ethical considerations

- The study was presented to and approved by the Institutional Review Board in Gulu University and at the Uganda National Council of Science and Technology (ID Number SS 2807).
- School children of ages eight to sixteen assented to their participation and their parents/ guardians gave verbal consent or written informed consent.
- Permission was sought from headteachers, class teachers, District Health Office, District Health Inspector and village-leaders.

Inclusion criteria:

- Key informants included teachers of primary science who also teach about bilharzia. They were based in Kitgum and Wakiso districts for at least three years. They must have also consented to the study. Fishermen, drug shop owners, local leaders, village health team and sand miners who have ever been taught about bilharzia and ever treated with PraziquantelPZQ.
- Children interviewed were those who attended selected schools in Wakiso and Kitgum districts. In addition, the school children's parents and caretakers granted written permission for them to participate. The children were also those who had learnt about bilharzia, had been repeatedly treated with PraziquantelPZQ.

Exclusion criteria

- Children and adolescents, parents, teachers and caregivers who did not consent to the study
- Adolescents not in selected primary schools and science teachers who do not teach about bilharzia in primary schools. Fishermen and sandminers who have never participated in schistosomiasis training programs and never treated with PraziquantelPZQ.
- School children whose parents did not consent to the study were not interviewed – even when they give their assent. This is because parents' decision did override that of the child.

3. RESULTS AND DISCUSSION

All key informants including school teachers, fishermen, school children, village health team drug shop owners, local leaders in Wakiso fishing villages and Kitgum whom we interviewed knew about bilharzia. They knew risk practices which could expose them to infections. They were however grappling with how to implement this knowledge. For example, (10 of 21) fishermen inquired loudly during in-depth interviews, "how can we minimize exposure to infections when our very livelihood exposes us to infections".

Table 1: Summary of qualitative findings regarding respondents' perspectives about schistosomiasis

Category	Response
Some(8/21) fishermen had experienced bilharzia and many local leaders, primary school children and school teachers disclosed that they had seen or know of close kin who had ever had bilharzia.	 My father went to hospital in Entebbe last year when he had rashes on his skin, big stomach and was thin. He was told he had bilharzia (Interview, 10 year old boy, Namugala P/S).
Fishermen described <u>Praziquantel</u> as <u>PZQ</u> or <u>Ekkerendaeddene</u> or <u>Agakerenda</u> (big tablets) or medicine which causes diarrhea and vomiting and never to be taken again.	Those tablets! you can keep distributing them to us, but for me, I can never swallow them. (FGD, Fisherman in Bugiri landing site)
To the question, what else can be done in prevention of bilharzia? Six of 21fisherman responded by inquiring if it was possible to immunize people against bilharzia?	Each time we take these medicines they always cause severe diarrhea and vomiting. During those days we cannot go and work (fish) (FGD, fishermen in Bussi island).Is it possible to immunise people against bilharzia, so that we deal with the problem once and for all?
What are effective ways to control bilharzia	"Maybe you will tell us to stop fishing. But what will I eat, how will I support my family?" (In-depth interview with one fisherman in Namugala)
	"Sensitise people about the disease. People know it only affects fishermen"...
	"Sensitise children about it. When we teach, they think information is only for passing exams. They just go and do the same bad habits life easing themselves in lake". School teacher, in Namugala primary school during interview. "Teach people about how to avoid bilharzia". Interview with Interview with VCD in Kitgum district. "I must confess, we at the VCD have failed to control schistosomiasis. Perhaps the solution is now with you Social Scientists. For over 15 years of doing the same thing, and mass drug administration, there is no significant change in the high risk communities". Interview with one VCD officer.
	"Perhaps you will also give fishermen motorboats with toilets. They have a saying <i>Enyanjatenogga</i> , meaning, "many wastes can be directed to the lake, and there will be

	no variation in it afterwards" - but they didn't know that they are infecting the water with bilharzia Headmaster, (Namugala PS during indepth interview)
	"Maybe you can give all the school children shoes. Most of them do not have shoes /(15 year old child in Bussi PS). "Repair all damaged boreholes. People use lake water for home use (A motorbike rider in Bussi Island in Wakiso district
Side effects of PraziquantelPZQ and community response	"It was really a bad experience. Some children started mourning, and others vomiting while touching their stomachs as if they were in pain. That was two years ago. These days, when VCD people come here, I welcome them, but I just store these medicines" (Headteacher Kasanje)
	"The hospital and clinics in Kitgum are full of children whom you gave PraziquantelPZQ. Some are vomiting, others are crying of pain in the stomach and are admitted. Some parents are looking for the officers who distributed the medicines so that they can arrest them" (District inspector of schools in Kitgum during interview)

During an interview with a purposively selected drug-shop owner in Bugiri trading centre in Wakiso district about commonness of bilharzia, he excused himself to go and summon one fisherman whom he said frequented his shop for PraziquantelPZQ. When the fisherman came in, he complained of foot itch and sometimes diarrhea, which he attributed to the fact that *his* bilharzia was difficult to cure, because although he regularly bought medicines for bilharzia, symptoms recurred after a few weeks.

3.1. Chemotherapeutic approach

In Wakiso and Kitgum, respondents knew about PZQPraziquantel. In Bussi Church of Uganda primary, we found a team from USAID had just delivered tins of PraziquantelPZQ. USAID worked in partnership with the district VCD in both Wakiso and Kitgum.

In Namugala, Kasanje, Kigungu and Bussi primary schools, perhaps due to regular administration of PraziquantelPZQ, school children renamed the medicines *Aggawogo*(big chunks of cassava), or *Muwogoomukalu*(dry cassava). Although the senior women teacher discouraged them from doing so, many children insisted on renaming the medicines and discussed during interviews how the medicines are too big and difficult to swallow. The school senior woman teacher argued that School children have to be given the so-called *aggawogo* to swallow each school term, because they do not practice preventive measures. Many children were exposed to infections especially during end-of-semester activities like swimming, fishing, fetching water from lake Victoria and they did not have sanitary facilities at home.

3.2. Observation data

High risk activities observed include fishing, fetching water for home use, swimming, bathing children, washing clothes, sand mining, washing cars in infested waters.

Some adolescent children who could not get stool samples but wanted to donate samples easily picked stool from surrounding bushes - suggesting poor sanitation and disposal of human waste in these area.

3.3. Knowledge about prevention and treatment of bilharzia

Older school children interviewed knew about causes and prevention of bilharzia. They readily pointed at posters on their classroom walls with illustrations of the life cycle of schistosomiasis with captions of men either passing urine or defecating in the lake. They

also discussed risk behaviours like fishing and swimming in the lake. Many of them however mentioned that they engage in these risk factors and also do fetch water, wash from the lake and swim in it during hot and dry weather. In all the schools Wakiso and Kitgum districts, perhaps due to the numeracy of posters depicting the lifecycle of schistosome parasites, there was a stigmatization of persons with itchy feet and when researchers went to disseminate laboratory results for *S. mansoni*, there was an unusual curiosity to find out who had bilharzia. Many children in Wakiso inquisitively looked on and pushed towards the lead researcher and some mentioning “tonsiiga bilharzia woo!”, meaning “do not contaminate me with your bilharzia!”.

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3.4. School children's perspectives regarding bilharzia control

In many instances, one probing question would be asked by respondents, after discussing all the side effects of Praziquantel, “*obulwaddebwa bilharzia, mubugema?*” (is it possible to immunise for bilharzia?). In the respondents' view the best way to control bilharzia was not through regular administration of drugs, but through immunisation. Results are not consistent with the MOH's main approach in control through regular administration of Praziquantel to populations at risk. Although VCD was relatively less active in Kitgum, in Wakiso district lake shores schools received regular supplies of Praziquantel. Our findings justify the search for innovative ways of controlling schistosomiasis like *immunisation*. This could partly be due to the experiences with severe side effects caused by Praziquantel.

4.5. Challenges in the chemotherapeutic approach

One of the key findings in this study is that some places which regularly received Praziquantel/PZQ regimen complained about its severe side effects and some school children had renamed Praziquantel, *agawoogo*(big chunks of cassava) to express their dislike for the regimen and its being difficult to self-administer.

Further, in some parts of Wakiso and Kitgum districts, there was an irregular supply of the medicines. This in effect contributed to a high prevalence of schistosomiasis. Fortunately, after discussion of our findings with the concerned officials, there was an immediate response through mass treatment in the areas where we found high prevalence(46.2% in Kitgum compared to the national prevalence of 20.4% [21]) of bilharzia.

USAID is the key donor of praziquantel and the VCD officials discussed how they had no other sources of funding for Praziquantel/PZQ. The latter scenario leaves a lot to be desired and has implications about future control activities. Additionally Parker and Allen [13] discuss how while some people benefit from the chemotherapeutic approach in schistosomiasis control, it is unrealistic to assume that it would shift such impoverished and politically excluded population out of poverty. It is also mostly neglected people who are infected with neglected diseases - and this fact could not just be wished away.

4. CONCLUSION

Schistosomiasis still remains one of the endemic neglected diseases in Uganda. *S. mansoni* parasites can be found in both lakes and rivers in Uganda. The high prevalence of bilharzia could be attributed to challenges in the chemotherapeutic approach, new infections upon exposure to infected waters and re-infection of treated persons and poor sanitation.

A high proportion of school children in both districts, some teachers and parents in high risk districts did not know about the causes and prevention of infection with bilharzia parasites. We therefore recommend that dissemination of information about various preventive approaches not target only fishermen, but also farmers, sand miners in Kitgum, school children and the entire population which directly interacts with infected waters such as river Pager and Lake Victoria. Data collected suggests that more complex ways need to be designed in control of bilharzia including provision of clean water, improving sanitation at landing sites, fishermen's purchase of motor boats with lavatories, and chemotherapy with smaller pills. Ultimately, —as many respondents frequently inquired, “is it possible to immunize against Schistosomiasis. It's because we are tired of taking the large tablets with many side effects.”

ETHICAL APPROVAL (WHERE EVER APPLICABLE)

This study was approved by the Uganda National Council of Science and Technology (ID Number SS 2807). In addition the research protocol was reviewed and approved by the Gulu University, Faculty of Medicine Institutional Review Committee.

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DEFINITIONS, ACRONYMS, ABBREVIATIONS

FGD: Focus Group Discussion

MOH: Ministry of Health

~~PZQPZQ~~: Praziquantel

USAID: United States ~~Agency for International Development of America International AID~~

VCD: Vector Control Division