

“Ich-Mupong”, a swollen stomach: An ethnographic study of the daily lived experiences of schoolchildren in schistosomiasis high transmission areas along Lake Albert, Hoima

District: Coding of illustrative quotes.

Major theme: Understanding of illness

Sub-theme: Definitions of bilharzia

Code: water borne disease

P2.docx_ [Interviewer: Is bilharzia comm..]

Codes: [water borne disease]

R: It is a waterborne disease that may not be seen, but it stays in water.

Sub-theme: Ways of contraction

Code: Drinking lake water

P9.docx_[Interviewer: We are going to t..]

Codes: [bathing in lake water] [defecating in the lake] [drinking lake water]

Interviewer: We are going to talk about Bilharzia (use the local name). Let us start by asking in very general terms: What is Bilharzia?

R: All I know is that if you bathe in the lake, the worms get to your body, and then I also know that when you defecate in the lake, the worms enter your body as you defecate.also when you gas in the water, the worms enter your body after you have gassed. Also, if you are bathing in the lake and you accidentally drink the water, you get the disease. Other times, when it rains and the rains carry the stagnant water to the lake, and people fetch the water for cooking, they carry the worms in the water, and yet some of them even drink them.

Sub-theme: Local terminologies

Code: Koko

KII 6.docx [Interviewer: Okay. So ahh in y..]

Codes: [Koko]

Interviewer: Okay. So, in your experience and opinion, what do people think causes bilharzia, as a [identifying information redacted]?

R: Even today, some children told me that somebody had that thing (“Koko” meaning a worm). The stomach started swelling. I said that one has schistosomiasis, and they said no, “Koko.” That worms. And that boy was thinking that if people would come, I would bring him, and they would see him because the boy started by feeling stomach pain like that, and his stomach had swollen

Major theme: Micro-level risk factors for schistosomiasis

Sub-theme: Poor hygiene and sanitation

Code: Bathe in the lake

FDG 10K.docx [Interviewer: Why do some schoo..]

Codes: [bath in the lake] [urinate and defecate in water] [wash clothes]

Interviewer: Why do some schoolchildren in this community get bilharzia while others do not?

P.3: Most children are getting the disease because when they are sent to the lake to wash clothes, they end up bathing in the lake, and while they bathe, some of them urinate and defecate in the water, and that is what makes them get the disease.

Sub-theme: Legitimate beliefs and practices

Code: Fear of falling in the latrine

FDG 10K.docx [Interviewer: what class is mor..]

Codes: [fear of falling in the latrine]

Interviewer: What class is more prone to getting the disease?

P.3: It is mostly the children who are in primary one that tend to get the disease because these children fear that they can fall inside the latrine, so they defecate outside of the latrine while the rest come and urinate on the faeces and others come and step on the faeces sometimes without even knowing. Those who step do not even wash their legs, and that is how they end up getting the disease.

Sub-theme: Choice of water source

Code: water from borehole not sweet

PP 17.docx [Interviewer: Is bilharzia comm..]

Codes: [baya helps] [stomach pain] [water from borehole not sweet]

R: I have a grandchild here with me who came from the lake shores. When this girl started staying with me here, she used to refuse to drink safe water from the borehole, claiming the water from the borehole was not sweet and, therefore, she preferred water collected from River Hoimo. So, she used to drink water from River Hoimo until she started complaining of stomach pain. It is of recent that they tested her at the school for schistosomiasis, and she tested positive. They started her on the schistosomiasis medicine, and immediately, we started seeing some changes.

Sub-theme: Cultural importance of swimming

Code: swimming as a sport

KII 1.docx [Swimming is a habit, it is hab..]

Codes: [swimming as a sport]

R: Swimming is a habit; it is like a sport for children. I would say it, ahh, for them, they take it as a sport. It is part of sports; it's like when people go into the swimming pool to swim, it's like part of the sport. So, these children, they go and take this with this part of the sport not by coincidence, but they love it because every time they are from school, they go swimming.

Code: Bathing {11-0}

PP 17.docx

Codes: [bathing] [swimming]

Interviewer: What about children playing in the water?

R: Children play a lot in that water, most of them spend most of their time playing in that water, and they love playing in the water. When they go to shower, they spend the whole day swimming, and they come back home late

Sub-theme: Gender division of labour - limited livelihood options

Code: Lake is garden

KII 9.docx - [Interviewer: Why? R: If you te..]

Codes: [lake is garden]

Interviewer: Why?

R: If you tell someone not to go to the lake, then the person will ask you, where do you think our garden is? This is our garden. It is where we get money from. If we do not fish or.....go to prepare the net or the boat, where am I going to get the money? And then these young boys go there but for them every day in the lake. They will not go fishing but go there to prepare those things.

Sub-theme: Gender division of labour - lakeshore activities

Code: Enter water

KII 5.docx - [Interviewer: Okay. Does that b..]

Codes: [enter water] [swimming]

Interviewer: Okay. Does that bring them into contact with the lake, or is the boat pulled outside?

R: The boat is pulled outside; they even enter the lake, which brings them into contact with the lake. When the workers come, when they reach the lake shore, they remove their luggage and leave the boat when it is still in the water but not very far, a place where someone can move and get that boat. So those children go and begin pushing the boats to bring it outside, so they enter into the water and not only that one maybe you find that some other bosses, let me call them bosses they give them the engine, and they tie it on the boat and move with that boat in the lake and go and leave the boats there. So, when they are coming back, they come back when they are swimming when they put on the life jacket.

Code: washing fish

PP 15.docx - [Interviewer: what else makes y..]

Codes: [fishing] [washing fish]

Interviewer: What else makes you say those next to the shores are more prone to getting the disease

R: It is because so many things happen on the shores; they wash fish from that same water that people step in as they go fishing.

Code: washing motorcycle

FGD 2B.docx - [P.5: Bilharzia is common becau..]

Codes: [washing motorcycle]

P.5: Schistosomiasis is common because you find rivers like Hoimo people washing their motorcycles in it and also drinking it.

Major theme: Macro-level risk factors for schistosomiasis

Sub-theme: Poor WASH infrastructure

Code: No alternative source

P18.docx - [Interviewer: Specifically, for..]

Codes: [bath and drink hoimo] [no alternative source]

Interviewer: Specifically, why do you think you got infected with bilharzia?

R: It is because I bathe and drink water from river Hoimo, given the fact that that's the only water we have, although sometimes I fetch the water and bring it home to first boil it before using it.

Code: long distance {7-0}

P11.docx - [Interviewer: you talked about ..]

Code: [long distance]

Interviewer: You talked about "us as [identifying feature redacted]" We drink water from the river; why do you drink water from the river?

R: One may want to collect safe water for drinking, but when they imagine the distance, they immediately give up and decide to go and collect water from the river; after all, that is also water

Code: toilet full

P8.docx [Interviewer: What other things..]

Codes: [toilet full]

Interviewer: What other things help in the spread of bilharzia

R: Children also bathing in the lake can spread schistosomiasis because they bathe in the lake water. Some of them drink dirty water. Then, some other people in this community put pipes in their toilets to let out faeces when their latrines get full, and all these faeces end up going into the lake, and some children drink that lake water.

Sub-theme: Settlement pattern

Code: Settlement pattern

KII 1.docx

Codes: [settlement pattern]

R: And of course, in terms of settlement, you realise, ahh, why the toilets are located up, it is because those soils up are better. Of course, we recommend it, but some issues need enforcement. The distance from the lake, together with the settlement of the people, the recommended distance is supposed to be around 400 meters, but you find people are just very near. This one actually creates a very big challenge because most of those families which are very close to the water source, mostly they are the ones who misuse that water source. So, you realise sanitation are still a very big challenge because you said you saw three public toilets.

Major theme: Experience of Schistosomiasis

Sub-theme: Definition based on signs and symptoms

Code: swollen stomach

P8.docx [Interviewer: Let us start by a..]

Codes: [diarrhea] [stomach burn] [swollen stomach]

Interviewer: Let us start by asking in very general terms - What is bilharzia?

R: What I know about schistosomiasis is that they start as worms, and these worms burn your stomach and cause diarrhoea. The worms also make your stomach swell. So, if someone portrays the signs that I have told you, that means that the person is suffering from schistosomiasis.

Sub-theme: other symptoms

Code: Loss of appetite

P4.docx - [Interviewer: What else? how we..]

Code: [loss of appetite]

Interviewer: What else? How did you feel when you contracted bilharzia?

R: I feel my stomach is paining, and I feel like I want to sleep, then I sleep, but when I wake up, I feel like not eating that is all.

Code: terrible headache

P18.docx - [Interviewer: Have you ever got..]

Codes: [stomach pain] [terrible headache] [vomit]

Interviewer: Have you ever gotten Bilharzia? If yes, how did you feel?

R: I had terrible headaches, and I also suffered from stomach pain; I would also vomit and feel a lot of pain.

Sub-theme: widely reported signs and symptoms

Code: bathing in lake

P5.docx

Codes: [bathing in lake]

Interviewer: That is good. Are there many people with bilharzia in this community?

Child: yes they are many

Interviewer: oooh, they are many?

R: There are many children suffering from it. There is some boy up there; his stomach is big, and he over bathes in the lake

Sub-theme: stigma associated with schistosomiasis

Code: Isolation

FDG 8K.docx - [P.2: Sometimes they know that ..]

Codes: [isolated]

P2: Sometimes, they know that you have the disease, so they think that when we go and sit with that person, I may get infected; it is better such a person plays alone, and I also play alone with those without the disease.

KII 20.docx - [Did people stigmatize School c..]

Codes: [isolation] [swollen legs] [swollen stomach]

Did people stigmatize schoolchildren when they contracted bilharzia? *Explain*

R: They feel so bad because they see them not feeling well with their swollen stomach and big feet, and these people who are okay always laugh at those who are sick, thereby starting to isolate them when they no longer socialise with themv

Sub-theme: educational effects

Code: effects of bilharzia

FGD 6B.docx [P.3: they feel bad because you..]

Codes: [educational effects of bilharzia]

P.1: I feel bad in that case because I am unable to go to school yet my friends are going to school

Code: School absenteeism

P60: KII 7.docx - [Interviewer: Bilharzia seems t..]

Codes: [interrupts learning] [school absenteeism]

Interviewer: Bilharzia seems to be a common place in this area. What could be some of the effects of Bilharzia may be say at household level, at individual level and at the community?

R: At the individual level, like our children, it affects their learning because if a child is having, maybe is not feeling well, it will make the child be absent. At times, it even leads to school dropout. If the child is not feeling well, the child says, ahh, I have left schooling, so sometimes it leads to school dropout.

Supplementary Table 1: Socio-demographic characteristics of the in-depth interview

Participants (Schoolchildren)

Gender	N (%)
Male	8 (42%)
Female	11 (58%)
Age range	
10-13	12 (63%)
14-17	7 (37%)
Class	
Primary seven	2 (11%)
Primary six	4 (21%)
Primary five	7 (37%)
Primary four	6 (31%)
Ethnicity	
Alur	11 (58%)
Mugungu	3 (16%)
Munyoro	2 (10%)
Others (Lugbara, Jukoth, Congolese)	3 (16%)
School	
Kaiso Primary School	10 (53%)
Buhirigi Primary School	9 (47%)
Heard of Bilharzia	
All	19 (100%)

Supplementary Table 2: Socio-demographic characteristics of the in-depth interview participants (Parents)

Gender	N (%)
Male	7 (37%)
Female	12 (63%)
Age range	
27-37	5 (26%)
38-47	7 (37%)
48-57	5 (26%)
58-67	2 (11%)
Education	
None	2 (11%)
Primary	13 (68%)
Secondary	3 (16%)
Tertiary	1 (5%)
Marital status	
Married	17 (89%)
Widow	2 (11%)
Occupation	
Farmers	7 (37%)
Fishing business	8 (42%)
Fisherman	2 (11%)
Other	2 (10%)
Ethnicity	
Alur	14 (74%)
Others (Munyoro, Mugungu and Japadhola)	5 (26%)
Site	
Kaiso primary school	10 (53%)
Buhirigi primary school	9 (47%)

Supplementary Table 3: Socio-demographic characteristics of the Focus group discussion

participants (schoolchildren)

FGD	School	Number of participants	Age range	class	Gender	Heard of Schistosomiasis
1	Buhirigi	7	14-17	Primary Seven	Male & Female	Yes
2	Buhirigi	7	13-16	Primary Six	Male & Female	Yes
3	Buhirigi	8	12-16	Primary Seven and Six	Male & Female	Yes
4	Buhirigi	7	12-14	Primary Five	Male & Female	Yes
5	Buhirigi	10	12-15	Primary Four	Male & Female	Yes
6	Buhirigi	8	10-15	Primary Five and Four	Male & Female	Yes
7	Kaiso	6	14-16	Primary Seven	Female	Yes
8	Kaiso	6	14-16	Primary Six	Male & Female	Yes
9	Kaiso	6	11-15	Primary Seven and Six	Female	Yes
10	Kaiso	6	12-14	Primary Five	Male & Female	Yes
11	Kaiso	7	11-13	Primary Four	Male & Female	Yes
12	Kaiso	8	10-13	Primary Five and Four	Male & Female	Yes

Supplementary Table 4: Socio-demographic characteristics of the key informants

Gender	N (%)
Male	8 (44%)
Female	10 (56%)
Level	
School	8 (44%)
Community	6 (33%)
Sub-county and District	4 (22%)
Designation	
Health worker	9 (50%)
Educator	6 (33%)
Government	3 (17%)
Education	
Secondary	12 (66%)
Diploma	3 (17%)
Degree	2 (11%)
None	1 (6%)