**Focus Group Discussion Guide with the Community members**

**‘AN ANTHROPOLOGICAL STUDY ON THE PERCEPTIONS OF PRAZIQUANTEL TREATMENT AND ADHERENCE TO MASS DRUG ADMINISTRATION IN PERSISTENT SCHISTOSOMIASIS MORBIDITY HOTSPORTS ALONG LAKE ALBERT, HOIMA DISTRICT WESTERN UGANDA**

**A Form for social and demographic characteristics of FGD participants**

|  |  |
| --- | --- |
| **FGD\_NO** | **Social category: (e.g. An FGD community members** |

|  |  |  |  |
| --- | --- | --- | --- |
| **DATE** |  | **DISTRICT** |  |

|  |  |
| --- | --- |
| **Place of discussion** | (e.g. subcounty.Village/school nearby) |

|  |  |
| --- | --- |
| **Moderator**  **Recorder/notetaker** | **Name or Code** |
|  |
|  |

|  |  |
| --- | --- |
| **Recording system (to be linked to audio file)** | (e.g. digital recording +notes taking) |

|  |  |  |  |
| --- | --- | --- | --- |
| **Time** | **Start:** | **Finish:** | **Duration:** |

Participant identifier

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **S/No** | **Participants number** | **Sex** | **Age** | **Education** | **Occupation** | **Marital status** | **Religion** | **Ethnic group** | **Ever had Bilharzia/or child/member of HH** |
| **1.** | (e.g. 01) | M/F |  |  |  |  |  |  |  |
| **2.** |  |  |  |  |  |  |  |  |  |
| **3.** |  |  |  |  |  |  |  |  |  |
| **4.** |  |  |  |  |  |  |  |  |  |
| **5.** |  |  |  |  |  |  |  |  |  |
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| **8.** |  |  |  |  |  |  |  |  |  |
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| **10.** |  |  |  |  |  |  |  |  |  |
| **11.** |  |  |  |  |  |  |  |  |  |

**Purpose:**

* To understand community perceptions, knowledge and practice related to Bilharzia and Praziquantel drugs
* To ascertain the inhibiting and facilitating factors in the uptake Prazinquantel treatment
* To establish the inhibiting and facilitating factors in the adherence to Mass Drug Administration

**Key Domains and questions**

**a) Understandings of illness:**

We are interested to learn how people in this area understand illness in general - and Bilharzia (use local name) in particular.

(1) Let us start by asking in very general terms – in you view where does illness come from - what are the main sources of illness that can make a person unwell in this community

(1.1) Probe: from the environment – from other people – inherited – failure to look after oneself - from supernatural/magic/spiritual sources? Etc.

(2) What do you think are the causes of Bilharzia? What are local terminologies uses t describe bilrazia? Why those terms

**b) The experience of illness**

(3) Is Bilarzia common in this place?

(4) Is Bilharzia common in some groups than others?

(5) When a person has bilharzia what does he/she feel? What are the symptoms?

(5.1) Probe: are these serious symptoms or something one just lives with?

(5.2) Probe: How do these symptoms affect everyday life?

(5.3) Probe: do these symptoms ever persist or return – and how does that make a person feel – what does it make them do?

(6) Is there any stigma associated with these particular symptoms/bilharzia?

(6.1) Probe: If there is stigma - Why are these symptoms stigmatised?

(6.2) Probe: If there is stigma - How is stigma expressed?

(6.3) Probe: If there is Stigma - How is it experienced by a person with the symptoms – and how does it affect what they do about their symptoms?

(6.4) Probe: Are things the same or different for different groups (men/women, adults/children/elders, poor/wealthy)

**c) Pathways to care**

We are interested to learn what people do when they become ill with Bilharzia.

(7) When people in this community get bilharzia what do they do?

(7.1) Where do they get treatment?

(7.2) Which treatment?

(8) When they fail to get better what else do they do?

(8.1) Probes: alternative care or traditional care (herbal etc.)?

(8.2) When do they do that and why?

(9) Kindly tell us more about situations when people go to the clinic/hospital? When do they do that and why?

(10) Please us about any situations when people access private clinics rather than government ones – who does that – when and why?

**d) Contexts for decision making**

(11) When someone is thinking about seeking treatment or accessing care – what are the things they need to think about?

(11.1) Probe: Does it depend on the person (e.g. man/women, old/young, family responsibilities… etc)

(11.2) Probe: Is money, time, type of illness What problems or barriers do people face when trying to get care/treatment/medicine/advice – for bilharzia?

**e) Risk factors for Bilharzia**

(12) Several things can help the spread of Bilharzia. Please explain what you think they are in this community?

(13) Why do some people in this community get bilharzia while other do not get it? What are those factors that make some people prone to getting bilharzia.

(13.1) Probe for Gender, age, ethnic differences

(14) What are the effects of Bilharzia: probe at individual, household, community.

**f) Inhibiting and facilitating factors in the uptake Prazinquantel treatment**

(15) People suffering from Bilharzia are given medicine called Praziquantel. Tell me about it. What do people who have taken it say about it?

* 1. What do they like about the medicine? Why do they want to continue taking the drug? (motivating factors)
  2. Why do some people don’t want to take the medicine? What don’t they like about the medicine? Probe for the barriers- taste etc

(16) What do you think should be done to improve the uptake of the medicine?

**g) Inhibiting and facilitating factors in the adherence to Mass Drug Administration**

The bilharzia medicine (Praziquantel) is distributed to people including children during the mass drug administration (MDA).we want to know why some like to participate while other so not.

(17) Why do people want to participate in MDA in this community? Who are those who usually participate?

(18) Why do some people **not** want to participate in MDA in this community? Who are those who usually don’t want to participate?

(19) What should be done to improve adherence to MDAs? Who should do it?

***We are coming to the end of our discussion. Is there anything else you would want to share with us about what we have been discussing?***

***Do you have any questions you would like to ask us – we will do our best to answer them***

***Thank you so much for your time and insights.***

**In-depth Interviews (community level)**

*Target: those who have ever been affected by Bilharzia or their family member*

*Aim: to understand the lived experiences of having bilharzia and the pathways to care*

***Socio-demographic characteristics***

1. Gender

2. Age

*3*. Marital status

4. Highest level of education?

5. Occupation-What kind of work do you do on a daily basis?

8. Ever had Bilharzia? Family member ever had bilharzia

**Key Domains and questions**

**A) Understandings of illness:**

We are going to talk about Bilharzia (use local name).

1. Let us start by asking in very general terms – in you experience and opinion, what do think causes bilharzia?
2. Is Bilharzia common in this community?
3. Is Bilharzia common in some groups than others? Please explain
4. When you get Bilharzia? How did you feel?
5. How do you think you contracted it?
6. What were the symptoms that affected you most?
7. Did people stigmatize you? Explain
8. How did you deal with the stigma?

**B) Pathways to care**

(9) When you got Bilharzia what did you do?

(9.1) Where did you go for treatment? Which treatment did you get?

(10) When you failed to get better what else do they do?

(10.1) Probes: alternative care or traditional care (herbal etc.)? why?

**C) Risk factors for Bilharzia**

(11) Several things can help the spread of Bilharzia. Please explain what you think they are in this community?

(12) Why do some people in this community get bilharzia while other do not get it?

(13) Specifically for you, why do you think you got infected with bilharzia?

(14) What are those factors that make some people prone to getting bilharzia. Probe for Gender, age, ethnic differences

(15) What are the effects of Bilharzia: probe at individual, household, community,

**D) Inhibiting and facilitating factors in the uptake Prazinquantel treatment**

People suffering from Bilharzia are given a medicine called Praziquantel.

(16) Were you given this medicine?

(17) Tell me more about the medicine?

(17.1) Any side effects?

(18) What did you like about the medicine?

(19) Why did you continue taking the drug? (motivating factors)

(20) Why do some people not want to take the medicine?

(21) Did you at any time think of not taking the medicine?

(22) What don’t you like about the medicine? Probe for the barriers- taste etc

(23) What can prevent you from taking the medicine

(24) In your opinion what do you think should be done to improve the uptake of the medicine?

**E) Inhibiting and facilitating factors in the adherence to Mass Drug Administration**

The bilharzia medicine (Praziquantel) is distributed to people including children during the mass drug administration (MDA). We want to know why some like to participate while other so not.

(25) Why do people want to participate in MDA in this community? Who are those who usually participate?

1. Why do some people **not** want to participate in MDA in this community?
2. Who are those who usually don’t want to participate?
3. Did you participate in MDA?
4. What should be done to improve adherence to MDAs? Who should do it?
5. What final suggestion do you have eliminate Bilharzia in your community?

***We are coming to the end of our discussion. Is there anything else you would want to share with us about what we have been discussing?***

**Key Informant Interview Guide**

**Background information**

**Date of interview:..............................**

**Level District, subcounty, community, school) .......................................**

**Type of organization working for (e.g. government, private, church, other)...............................................**

**Sex of informant:...............................**

**Informant’s highest level of education (e.g. Certificate, diploma, degree, post graduate degree)................................**

**Informant’s designation (e.g. Medical Officer, Clinical officer etc.)............................................................**

**Interviewer’s code:..........................**

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**Key Domains and questions**

**A) Understandings of illness:**

We are interested to learn how people in this area understand illness in general - and Bilharzia (use local name) in particular.

1. Let us start by asking in very general terms – in you experience and opinion, what do people think causes bilharzia?
2. Is Bilharzia common in this community/district/subcounty?
3. Is Bilharzia common in some groups than others? Please explain
4. Is there any stigma associated with particular symptoms/bilharzia?
   * + - 1. (4.1) Why are these symptoms stigmatised?
   1. (4.2) How is stigma expressed?
   2. (4.3) How do patients deal with the stigma?

**B) Pathways to care**

(5) In your experience and opinion when people in this community get bilharzia what do they do?

(6) Where do they get treatment? Which treatment?

(7) When they fail to get better what else do they do?

(7.1) Probes: alternative care or traditional care (herbal etc.)? When do they do that and why?

**C) Risk factors for Bilharzia**

(8) Several things can help the spread of Bilharzia. Please explain what you think they are in this community?

(9) Why do some people in this community get bilharzia while other do not get it?

(10) What are those factors that make some people prone to getting bilharzia. Probe for Gender, age, ethnic differences

**D) Inhibiting and facilitating factors in the uptake Praziquantel treatment**

(11) People suffering from Bilharzia are given medicine called Praziquantel. What do people who have taken it say about it?

(17.1) Any side effects?

(12) What do they like about the medicine?

(13) Why do they want to continue taking the drug? (motivating factors)

(14) Why do some people don’t want to take the medicine?

(15) What don’t they like about the medicine? Probe for the barriers- taste etc

(16) What are the effects of Bilharzia: probe at individual, household, community,

(17) In your opinion what do you think should be done to improve the uptake of the medicine?

**E) Inhibiting and facilitating factors in the adherence to Mass Drug Administration**

The bilharzia medicine (Praziquantel) is distributed to people including children during the mass drug administration (MDA).we want to know why some like to participate while other so not.

1. Why do people want to participate in MDA in this community? Who are those who usually participate?
2. Why do some people **not** want to participate in MDA in this community?
3. Who are those who usually don’t want to participate?
4. What should be done to improve adherence to MDAs? Who should do it?
5. As a key stakeholder, what final suggestion do you have eliminate Bilharzia in your district/community?

***We are coming to the end of our discussion. Is there anything else you would want to share with us about what we have been discussing?***