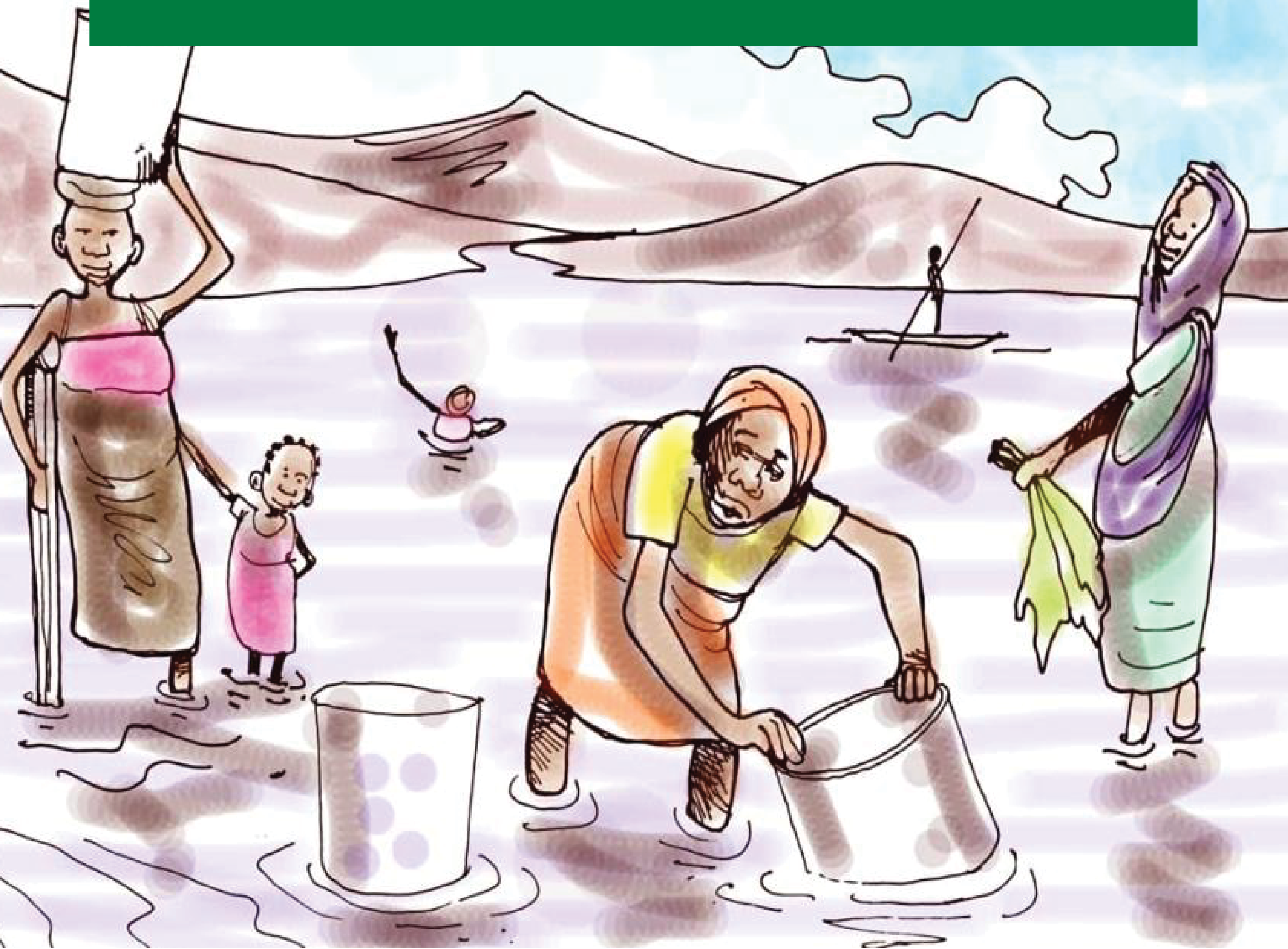
Using Drama to Raise Awareness About Female Genital Schistosomiasis



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A water source in Tanzania

Introduction

Schistosomiasis (also known as Bilharzia) is one of the most prevalent neglected tropical diseases (NTDs) affecting over 240 million people worldwide, and estimated to cause 200,000 deaths annually. It is caused by parasites and transmitted in infested water through tiny snails. Schistosomiasis can infect anyone who comes into contact with infested water. There are different forms of schistosomiasis including intestinal and urogenital. In girls and women, when the disease affects the reproductive system, it is called 'Female Genital Schistosomiasis (FGS)'. FGS affects millions of girls and women who do not have access to clean household water, and who are in contact with natural water sources through washing, bathing and water collection. Contact with water that has the parasite in is the only way to get the infection. The very tiny parasites enter the body via the skin and most people are completely unaware they have been infected.

In many countries there is a lack of awareness and knowledge about FGS, which means that many girls and women go undiagnosed and untreated. Many FGS symptoms are similar to those caused by sexually transmitted infections (STIs), for example vaginal discharge, itchiness, bleeding and abdominal pain. The overlap between FGS symptoms and STI symptoms often causes women with FGS to be afraid to seek treatment due to embarrassment and fear of stigma. The long-term physiological effects of FGS can be irreversible and include infertility, anaemia and menstrual problems. Social consequences can include family rejection, divorce and defamation of character.

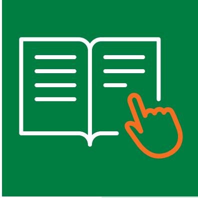
This manual was developed from a research study that was conducted in Zambia, Malawi and Tanzania, where researchers worked with community drama groups and local health providers, to raise awareness and mobilise women to access screening and treatment services for FGS.

Aims of the manual:

To improve the health of women and girls by raising awareness about the impact, diagnosis and treatment of FGS, through community interventions and outreach activities

To share tools for developing community drama and other activities related to addressing FGS

To explore how awareness-raising drama can be embedded in a range of interventions to address the health needs related to women and girls affected by FGS



Who is the manual for?

Anyone working in: sexual and reproductive health; women's and girls' health; water and sanitation projects, and neglected tropical diseases

National organisations including Ministries of Health and Neglected Tropical Diseases control programmes, researchers and programmers working on FGS

Key stakeholders involved in community health – for example district health officials, policy makers, community health workers, drama groups and community leaders

Background to the study

The aim of the study was to see if FGS screening can be successfully promoted through a community-based teaching intervention that addresses socio-structural barriers (including stigma) and links to broader sexual and reproductive health (SRH) prevention services. Study communities were selected based on support from district health authorities and community leadership, relatively high prevalence of schistosomiasis, size and feasibility. Malawi selected five rural villages (Chipoka, Mpalilo, Michesi, Chipala and Mtyala), surrounding Koche Health Centre, in Mangochi District. Tanzania selected three rural villages (Gambasingu, Mitobo, and Budalabujiga) in Itilima district. Zambia selected a peri-urban community (Shikoswe) in Kafue District.

The study initially generated baseline information, using a qualitative Broad Brush Survey (BBS) approach to assess the level of awareness about FGS in communities and amongst health workers, as well as the ability of the health systems to screen and manage FGS cases. BBS focused on documenting women's contact with water sources, household sanitation options and practices, popular knowledge and history of schistosomiasis, stigma linked to symptoms and transmission assumptions, and experiences with screening, diagnosis and care. The BBS was carried out by a social scientist, assisted by a local fieldworker(s) over 10 days in the community in each country. BBS findings were then used to plan and design the intervention.

The intervention used local drama groups to promote FGS awareness and ensured that local health facilities were equipped to screen and treat girls and women. Drama groups and health

workers were taught about FGS since the BBS established that there was limited knowledge. For a period of six weeks to two months, drama performances took place in different settings where girls and women gathered. Performances were coordinated with screening and treatment services. Screening used standard of care urine infiltration analysis and, in Zambia and Tanzania, a novel cervico-vaginal self-swab technique. To evaluate the intervention, an FGS symptom screening questionnaire was used and exit interviews were conducted. In total, 1,598 women were screened, and FGS prevalence varied across the three countries.

A water source in Malawi

SECTION 1 ONE

Key facts about schistosomiasis and Female Genital Schistosomiasis (FGS)

- Schistosomiasis (or Bilharzia) is a water-borne disease caused by infection with schistosome parasites. It can affect all ages and sexes.
- Transmission occurs when urine containing the parasite's eggs gets into fresh water (lakes and rivers). The eggs hatch, releasing larvae in the water, which live and develop inside tiny snails. Later the snails release the parasitic larvae which can swim freely in the water and penetrate the skin of anyone in contact with the water.
- Once inside a human body, the larvae grow into worms in the blood vessels of the urinary and genital tract and release hundreds of eggs each day – some are passed out of the body, but some get trapped in body tissue and cause damage to organs.

The following two diagrams illustrate the transmission cycle of schistosomiasis. The first demonstrates the role of water and snails in the transmission. The second portrays the lifecycle of the schistome parasite outside and within the human body.

SCHISTOSOME LIFE CYCLE

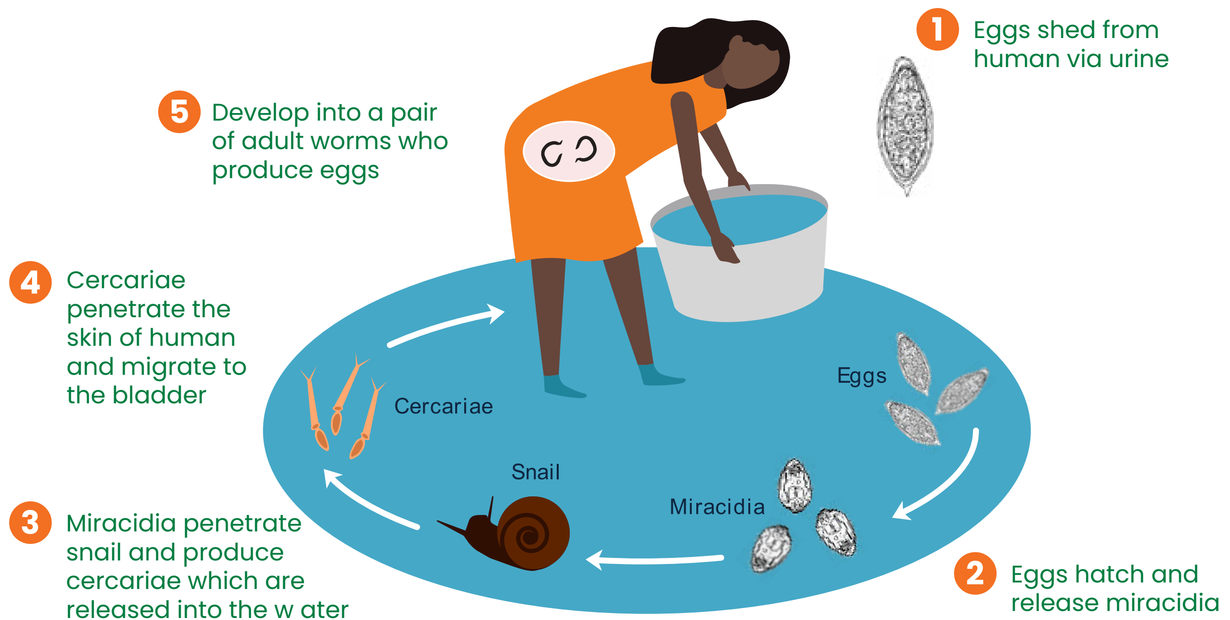


Figure 1: From Countdown Nigeria Manual[1]

https://countdown.lstmed.ac.uk/publications-resources/tools-and-booklets

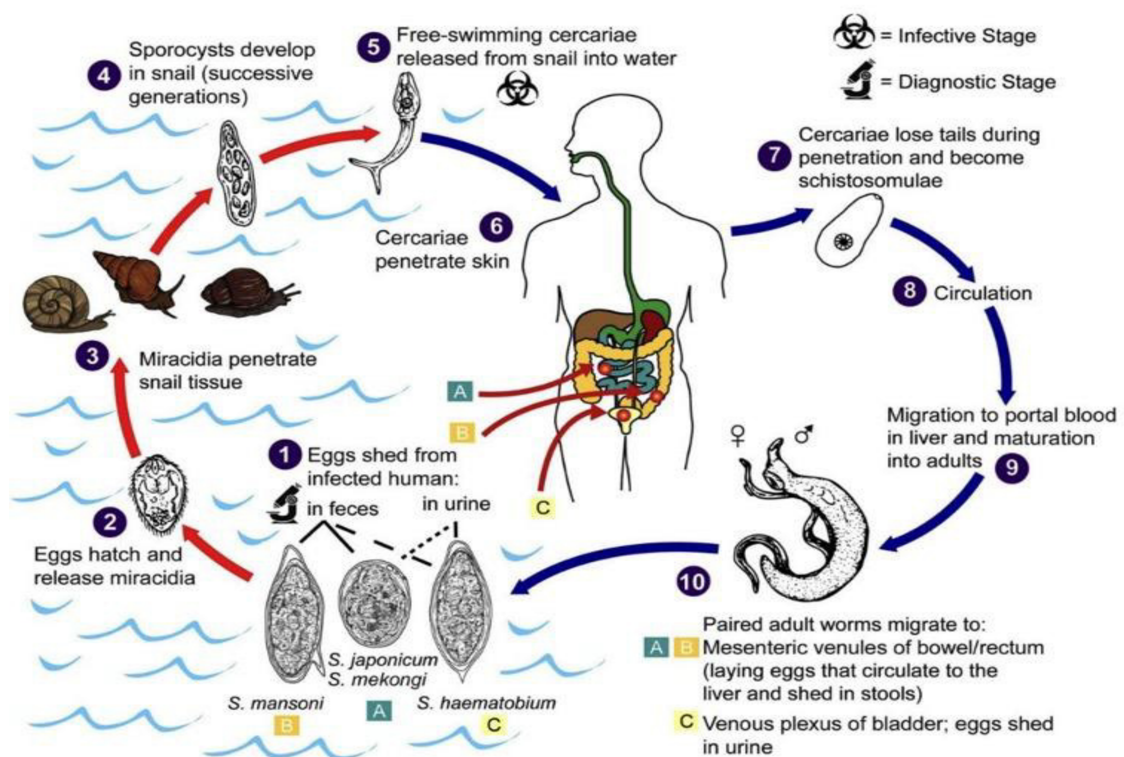


Figure 2: From Centre for Disease Control

https://www.cdc.gov/parasites/schistosomiasis/biology.html

Female Genital Schistosomiasis

FGS is a type of schistosomiasis that affects girls and women because the worm lives in the female reproductive organs.

- In FGS, the eggs migrate and get trapped in organs such as the uterus, fallopian tubes, cervix and vagina.
- Symptoms include vaginal itching, discharge, pain and bleeding. Some women experience pain during sex, or bleeding after sex.
- Untreated FGS can cause infertility, anaemia and menstrual disorders.
- Many of the symptoms are similar to sexually transmitted infections (STIs), but FGS is NOT sexually transmitted - it is NOT an STI.
- Misdiagnosis of FGS as an STI often leads to inappropriate treatment with antibiotics. Antibiotics do not cure FGS.
- Many girls and women experience stigma, or fear of being stigmatised, because of the similarity between FGS symptoms and those of STIs.
- Treatment of FGS is simple - a dose of Praziquantel medicine. Praziquantel is often administered through mass drug administration (MDA) programs in schools and communities to help to treat FGS.

There is more information about FGS in the Post-drama section (Section 10) of this manual, where we have included the Frequently Asked Questions that came from the community.

Schistosomiasis can also affect the genital organs of men, which is called Male Genital Schistosomiasis (MGS). MGS does have different health consequences for men than FGS does for women, and therefore, the focus of this manual is on FGS.

SECTION 2 TWO

Setting up the intervention: The importance of community engagement

We met all chiefs that are in the five villages Chipala, Chipoka, Mpalilo, Mtyala, and Michesi and they were briefed on the research study and for them to be aware that we will be conducting community education in their villages, to encourage women to come forward for screening.
Malawi Study report

Community engagement is the starting point for any community health intervention and is crucial for the success of FGS programmes. Since FGS is a relatively unknown disease, many community members, including traditional/community leaders and health workers, may not have even heard of it and yet they are the ones who face the risks and consequences, so they must be involved in the response.

Include the community from the outset

As programmers and researchers embark on FGS interventions, the first step is to consult the community leaders so that they can be involved from the outset. Those who are identified as community leaders will vary in each site, but may include district health officials, community health workers, religious leaders, chiefs and headmen and headwomen, teachers and political leaders such as village chairpersons and ward councillors. As FGS affects women, it is important to ensure that a number of women are included in the initial stages - the definition of 'community leader' can be flexible if there are not enough women in leadership positions. Since many of the community leaders are men, it is important to address any questions they have about whether men can be affected too.

Broad Brush Survey as the starting point

As a starting point to the FGS studies in Tanzania, Malawi and Zambia, researchers carried out a Broad Brush Survey (BBS) in each of the sites. A BBS is a rapid qualitative assessment methodology with the aim of understanding the key features of a community.

In the FGS studies, the focus of the BBS was:

- to understand community access to water,
- to find out about community experiences of health services,
- to assess knowledge of schistosomiasis and FGS,
- to listen to, and document, any stories about women's and girls' experiences of stigma related to FGS symptoms and transmission.

The BBS methodology involved a mix of qualitative data collection including observations, focus group discussions and in-depth interviews. The starting point is usually a focus group discussion

with community leaders and gatekeepers who help to map out the area and identify key issues that will be important to the study.

The results of the BBS provided key information for planning the intervention in the three countries. As well as providing a picture of knowledge levels and awareness of FGS, the studies helped to identify key partners in the community who could be invited to participate in running the activities, by sharing their local knowledge and networks and thereby building community capacity which would remain long after the studies were completed.

In Zambia, the BBS was also used to help to plan and coordinate the community-based intervention. Established local drama groups were identified during the survey, who would be included in implementation of the program, as well as Neighbourhood Health Committees, who could help to identify sites where girls and women are most at risk of FGS.

Share the results

After the BBS was completed in Zambia, the findings were shared with the district officials, community health workers and health workers, which paved the way for the intervention.

Recommendations for FGS intervention- BBS, Shikoswe, Zambia

More education on FGS causes, symptoms and treatment is needed in the community amongst young people, men and women.

Establish local terminology to speak about FGS during community education platforms.

Provide more training to health workers on FGS.

Address stigma linked to FGS symptoms.

Address links between GBV (gender-based violence) and FGS symptoms.

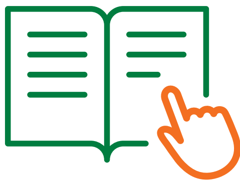
Build on community members' openness to new health initiatives.

Involve established drama groups in the community for community education.

Work closely with the community health workers to increases response from community members.

Include parents and guardians of young women through community programmes in churches, schools and markets.

Other information also emerged in the survey about factors that could increase risks faced by young women; during the focus group discussions several participants mentioned that drug and alcohol use is high amongst some of the youth, and often takes place around the ***pavwas*** (small dams that are used for bathing and drawing water). Some stories about incidents of gender-based violence (GBV) near the dams were also shared. Details such as these can be taken into consideration during the intervention - for example messages about girls' safety were included in some drama performances.



Recommendations for FGS intervention- BBS, Itilima, Tanzania

Community health education should be provided to women and girls on FGS causes, symptoms and treatment.

Educate healthcare workers on FGS in general, and on how to diagnose FGS so they should not mistake it with STIs and cervical cancer.

Use both Swahili and Sukuma languages during the community health education for easy understandings.

Address the link between FGS, stigma and violence during the community health education.

Include local government authorities during the community health education. As people listen to, and respect them, including these leaders will help sensitize women and girls to participate in community health education.

Use local government leaders to reach as many women and girls.

In Tanzania, the BBS took place in 34 closely connected villages in Itilima District, which is a predominantly rice-growing area. The study showed that very few houses had pit latrines let alone running water, and that the only toilets to be found were in schools and health facilities. Most residents collect water from ponds, rivers, shallow wells and canals, and most women use these sources for washing and bathing. An important finding for the intervention was the discovery of two active drama and dance groups who were experienced at working on other health programs such as malaria and TB. These groups would lead the community awareness-raising activities. The importance of the role that the local government played in the district was also acknowledged and the study leaders worked closely with them as they rolled out the intervention.

> The key message that the team shared with the district officials based on BBS data was 'Community members and healthcare workers have a low level of knowledge and awareness about schistosomiasis in general, and FGS'. Therefore, in this phase, we will conduct a targeted intervention aimed at providing advanced schistosomiasis education to the community and schools to raise awareness through the use of arts (drama, songs, music, dancing).
>
> BBS Report, Tanzania

After the BBS was completed in Tanzania, the results were shared with the district officials and local leaders, which paved the way for the intervention.

Community engagement also means taking advice from those on the ground. In Tanzania, the District Executive Director suggested that the Youth Officer, Neglected Tropical Diseases Coordinator, Health Officer, Communications and Information Officer, District Education Officer, Clinic Officer, and District Medical Officer should all be working on the intervention. With so many local bodies involved, the impact of the FGS program would have a lasting effect.

Agenda for Village Meetings in Itilima, Tanzania

- What is the project about and what will the intervention focus on?
- Intervention time frame (includes how many days we will do the intervention, and for how many days in each village and sub-village the intervention will take place)
- Interventions target group (explained in detail that the study will focus on girls and women and why; schistosomiasis and FGS education is for all but we need to sensitize, invite and encourage more women to participate as the main targeted group)
- Venue (place) for screening and FGS education in each village (they recommended the venues based on the geographical context of the respective villages, including clinics, schools, village offices, and other open spaces where village meetings are often held)

- Responsibilities of each team member (we shared our responsibilities as a team, everyone knew what they had to do to accomplish the task that was ahead of us)
- The appropriate time to provide education and screening (we discussed when is the appropriate time to provide education as well as the screening - they suggested that we provide the education in the morning from 9:00 am- because at 9:00 am women will have finished preparing breakfast and the students have gone to school)
- How we will use drama, songs, and music for sensitization and education

Extract from BBS Report, Tanzania

In Malawi, the BBS took place in villages surrounding Koche Health Centre, in Mangochi district close to Lake Malawi, over a 10-day period. The Lake brought extra dimensions for consideration because of the fishing trade and tourism. The fishermen were not necessarily from the local area, but the women who gathered on the lakeshore to carry out daily chores, as well as to buy the fish, were all from the surrounding villages.

'At the lake there would be a space where women would wash clothes and utensils, and men would be in another space mending fish nets and trading fish. It was noted that the women and girls would come from the surrounding communities to wash and bathe, but the men are fishermen from other districts, the Koche area and temporarily staying at the lake'.

BBS Report, Malawi

The BBS uncovered important information about social networks which was essential for informing the design of the intervention. Many women meet daily near their homes at water sources such as standpipes, boreholes and the Lake, and it is here where they not only share local news but often talk about health and social issues together. Further investigation found that although most women would talk openly about many personal issues, most said that sexual and reproductive health (and FGS by implication) was a more personal topic and not to be discussed 'carelessly' in the community. Adolescent girls however were observed to be freer and often held long discussions at school about more personal issues, including sexual and romantic relationships. These findings would help to inform the drama scripts that were played out in different locations, ensuring they were appropriate and relevant to the different groups.

Recommendations for the FGS intervention: Koche, Malawi

Raising awareness of FGS - not many local residents or health workers are aware of the presence of FGS, although they are more aware of schistosomiasis. They are also not sure of the cause, symptoms, treatment and severity of FGS.

Using two local languages - community health education needs to use the two most common languages (Yao and Chichewa) so that everyone will understand the messaging.

Disassociating FGS and STIs - *the* community and health workers need to be educated on FGS, so that FGS is not mistaken for STIs.

Encourage women to talk about their reproductive and sexual health needs; women should be encouraged to open up to health workers, friends and relatives, if they have noticed a health issue linked to their urinary and reproductive health to help them get treated.

Extract from BBS Report, Malawi

Problem-solving with the community

Community Engagement is crucial if the FGS intervention does not go according to plan. In the early days of setting up the drama and screening services in Zambia, the uptake was low and researchers feared that there would be little impact. A meeting with local leaders and organisations was promptly arranged to share concerns and problem-solve together.

The study manager asked all the attendees to help the study team come up with ways and strategies that would help improve the uptake of screening from the women. The suggestions were as follows:

- One of the leaders representing the church suggested that introducing door-to-door sensitizations would help.
- Other women representing the Seventh Day Adventist church added that doing the screening at the outreach activities such as the under-five clinic would help increase the number of women screened.
- The chairpersons for the market asked if we could launch the screening outreach at Shikoswe market.

[All the three suggested strategies were later adopted during the study intervention.]

Extract from Community Meeting Minutes, Shikoswe, Zambia

Checklist For community engagement

Activity	Reason
Make contact with community leaders as early as possible – in the planning stages of the intervention	It is highly recommended to involve the community in the design of the intervention - or before the plans are finalised
Involve a range of leaders - traditional, local government, small businesswomen, teachers, health workers. Ensure there are equal numbers of men and women, or more women	Try to include a diverse group of leaders and because FGS affects women, it is essential women leaders are consulted

Activity	Reason
Even if you are not doing a BBS - type assessment, spend time at the site before implementation to understand the community as much as you can. Walk around / observe / talk to local people / spend time at the clinic to learn as much as you can	This will help to build trust and if you become known amongst key community members, they will feel able to discuss the intervention, and other issues with you freely
Observe the activities at the water sources - times when people are there; who goes there and what they do; any changes on different days?	This will inform your intervention and help you to target the groups most at risk
Don't make assumptions / keep an open mind. Always check out your ideas with those who are affected, or live in the area	Each community is unique - and those who live there have the greatest understanding
Find out how much awareness there is about FGS - among health workers, women's groups, community - based organisations, schools	Knowledge levels will determine how much focus there is on awareness - raising and education
Visit the local health facilities and talk to the staff. Find out how well-resourced they are - space, equipment, personnel	You will need to decide if you can help to build capacity to run local FGS screening and treatment services, or if it will easier to bring in services and staff for the intervention
Be visible and available so that community members can approach you with ideas	Some consultations will happen less formally. You may gather important information from simple chats and unplanned interactions
Identify potential partners - drama groups? Local health workers?	Watch them in action - performing drama, or at the clinic. Discuss FGS and find out who will make the best allies
Discuss where should the intervention be based	Community members will know the best places, times and even seasons for the intervention
Agree on sites for drama performances	Discuss where you reach the most women? Check that you will reach women of different ages/ employment and so on
Ensure opportunities for continued discussions with community leaders after the start of project implementation	Community engagement is a process that continues throughout the project; providing community leaders with structured opportunities to deliver feedback and suggestions may lead to adaptions that will increase the programme's success

SECTION 3 THREE

Developing drama to raise awareness about FGS: Preparation

Working with local drama groups

Once you have identified the site for the FGS intervention, and as you engage with the community members, you can ascertain whether there are any active drama groups in the vicinity who can be incorporated into the program.

Important considerations in choosing your drama groups include:

- Does the group include girls and women? How involved are they? Would they be willing and able to lead the activity? Will the male group members agree?

Watch them perform a drama before you finalise the partnership - let them choose the theme. This will show you how skilful they are, whether they can improvise, how they share out the roles and so on.

- Discuss with the group how they work - does everyone have an equal role? How available are they? Are there any star actors? How do they make decisions?
- Find out if the group has any existing links with other community partners, or health programs (for example, in the Tanzanian study the drama groups had already worked on programs on malaria and TB). Also determine if they have any current commitments to other activities.
- Discuss terms and conditions: this is very important in order to avoid frustration or disappointment. Be clear about how often will the group will need to perform; where and when; how many members will be involved in the play? Will they need any props/ costumes? Do they have access to transport? Discuss the allowances that will paid (according to your budget) and be as transparent as possible from the outset.

A note about costs and allowances

Find out from other NGOs or health officials in the community what the usual allowances for a drama performance are. It is important to set a realistic rate - you do not want to set allowances so high that no other NGOs or groups will be able to match them in the future.

Participatory FGS training for drama groups

Following the principles of respect and open-mindedness that underlie community engagement, the training with the drama group is most effective if it is participatory and experience-based. The drama group are from the community and will have a lot of important local knowledge to contribute to the process - both the researchers and FGS programmers will be learning during the training, as well as the dramatists. A participatory approach will foster an egalitarian environment where all ideas and contributions are welcomed.

Ensure your activists are well - informed

Before developing drama about FGS, it is important to ensure that the drama group members - and anyone else who will be involved in the intervention - are as informed as possible about FGS.

During the three-country study, focused education sessions on FGS were held in each site, run by health workers who are specialised in schistosomiasis. One session was held for the health workers who would be involved in the clinical procedures (screening and treatment) and one with the drama group members. The drama group were required to have a comprehensive understanding of FGS, not only to enable them to develop credible drama scripts, but also so that they would be able to carry out follow-up discussions after the performances.

Drama groups need to be well educated about FGS in order to raise awareness in the community. It is critical to build the capacity of drama group members to understand key facts about FGS.

Training drama groups about FGS facts

The facilitators of the FGS education sessions used a number of resources which the research teams had gathered; they facilitated a participatory training session that covered causes, transmission, symptoms, prevention and treatment of FGS. Diagrams from the Countdown Manuals[1, 3] were used to explain in detail how transmission takes place.

Other options for the basic FGS training include:

- PowerPoint presentation about transmission, symptoms, prevention and treatment, followed by a quiz
- Quiz questions on cards, read out by group members and answered collectively
- Short lecture / presentation followed by small group work where group members practice giving out information on different aspects of FGS

"My status in the community has really improved - I am seen as a very responsible person."

Drama group member

SECTION 4 FOUR

Developing the drama

These are the tools that were used to develop the drama scripts for the FGS intervention. They should be facilitated as participatory exercises, which encourage group members to contribute as much as possible. Remember that the group know their local community well, and understand how to use drama, so learning from them is important. Developing the drama is a collaboration between the facilitators, researchers, programmers and the drama group members.

1. FGS Rotational Cardstorm

Notes about the exercise

This is the first exercise that works well to help the drama group share their knowledge and experiences of FGS. The exercise should be held after the FGS education session has been delivered by the healthcare expert, as it helps to reaffirm what was learnt, and to identify any gaps in the groups' knowledge about FGS. It is important to emphasise to participants that it is not a test - encourage the group members to work together and help each other.

You can also mention that they can use any language, or even pictures to illustrate their points on the cards (they will have a chance to explain their cards during the report back).

Objectives

- to help participants recap on their knowledge of FGS
- to share experiences of FGS
- to identify some of the topics that could be covered in the drama
- to find out if drama group members have any concerns, questions about FGS

Materials and preparation

Cards, markers, sticky stuff (Blutac™)

Write categories on title cards or sheets of A4 and stick them in different spaces around the room:

Categories

- Causes of FGS
- How is FGS transmitted?
- What are the symptoms of FGS?
- What should you do if you think you have FGS?
- Why do some people with FGS get stigmatised?
- What is the treatment for FGS?

Steps

1. **Introduce the exercise:** 'We want you to share everything you know about FGS - the things you have learnt from the education session, any ideas or comments you have heard in the community, even any experiences you - or someone close to you - have had personally. This is not a test - we want you to work together and help each other as much as you can'.

2. **Pairs:** Ask participants to pair up with someone next to them. Give each pair several cards and a marker.

3. **Instructions:**

    - Show the group the different category cards that are posted around the room. Read through each one to ensure that everyone understands the different categories
    - Ask the pairs to each stand next to one of the categories (it doesn't matter if there is more than one pair, as long as there are pairs at each category)
    - Tell the participants that at each category they should discuss answers with their partner

and then write down their ideas on the cards - one idea on each card

- They should stick the cards under the category card
- After a few minutes, there will be a signal - a song or drumbeat for example, to indicate that the pairs move clockwise to the next category
- Continue until everyone has contributed to each category

4. **Gallery Report back:** Walk around the categories with the group and ask a different participant at each station to read through the cards. Ask for any clarifications or comments if something is not clear. Correct any misconceptions gently. Check if anyone has any additions or questions before moving to the next category. If a participant tells a story about FGS, make some notes that you can refer to when developing the drama. Continue until you have reported on all the categories.

5. **Handout:** Give each participant a handout about the basic facts of FGS, and ask them to read through so that they are very familiar with the facts.

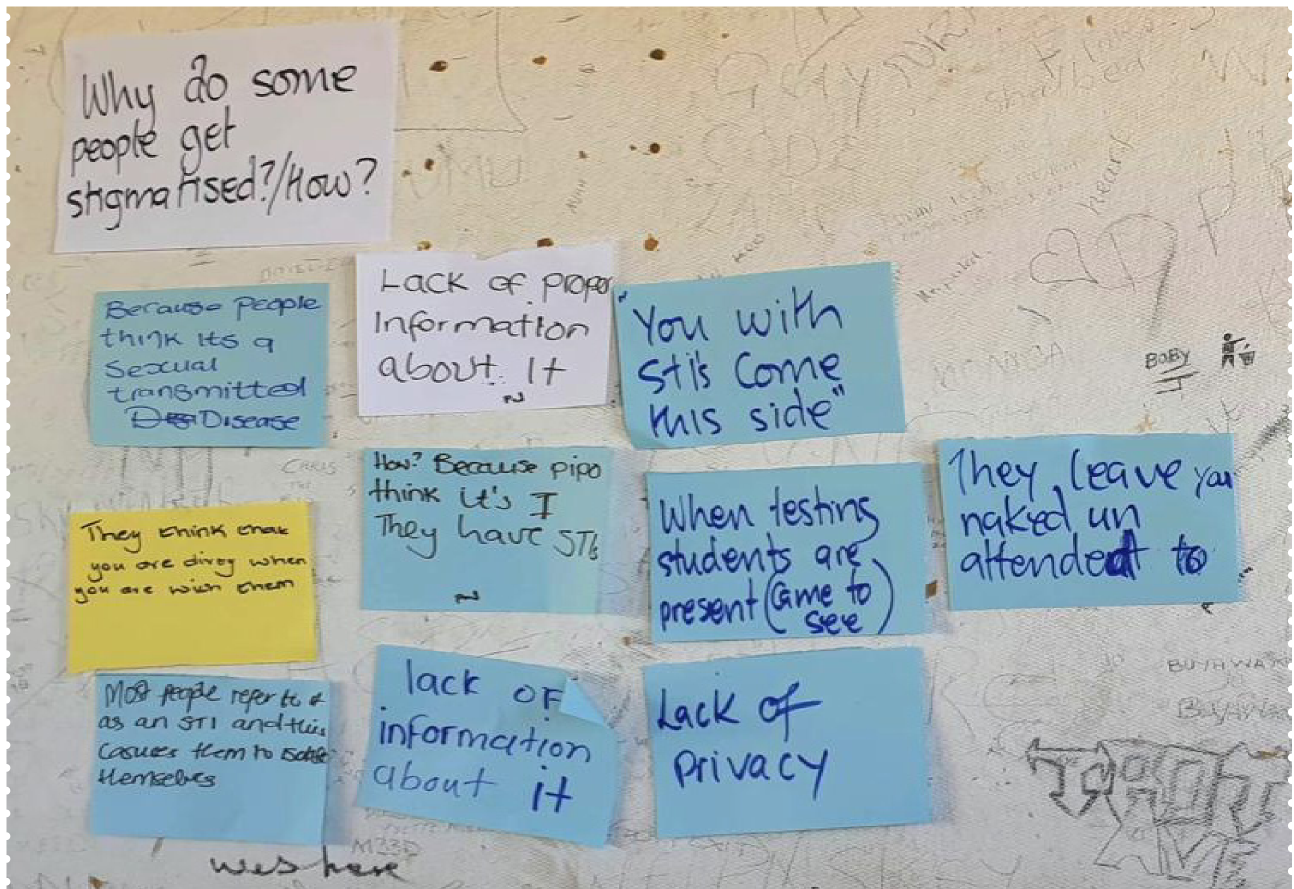


Figure 3: FGS training in Zambia

Sample answers from Zambia training

Causes of FGS

Worm from the snail-chikanono

How is it transmitted?

In activities done in any kind of water as long as the virus is present

Swimming or playing in dirty water

Using water which is stagnant and has snails with bilharzia eggs

Swimming in the chipavwa

Drinking dirty water

Being exposed in dirty water

What can you do if you think you have FGS?

Consult friends or health worker

Visit clinic for a test

Go to nearest hospital

What are the symptoms?

Urinating blood

Pain during sex

Pain when peeing

Yellowish discharge

Abdominal pain

Abnormal discharge from private parts

Muscle aches

Joint pains

Infertility

Complications with your periods

What are the symptoms?

Urinating blood

Pain during sex

Pain when peeing

Yellowish discharge

Abdominal pain

Abnormal discharge from private parts

Muscle aches

Joint pains

Infertility

Complications with your periods

What is the treatment?

Praziquantel

Why do some people get stigmatised? How?

Lack of information about it

Most people refer to it as an STI - this causes people to isolate themselves

They think you are dirty and don't want to mix with you

They just think you have an STI

One young womans story (told during the cardstorm)

My name is Chikondi. I am 16 years old. I want to tell you about my experience because I realise now that I had FGS and it was a difficult time.

I had been having stomach pains and a strange discharge from my private parts. My P's (periods) had stopped coming regularly. I went to the clinic with a friend. I was scared.

At the clinic, they treated me badly. They said it was an STI, but I knew I didn't have a boyfriend, and that I had never had sex. They made me feel ashamed. I tried to tell them it can't be an STI but they didn't believe me. They wanted to do some tests and asked me to undress. At one point they left me naked on the couch, unattended. And then the worst thing was they even brought in students to look at me; there was no privacy, I felt that I had no rights. I even started crying.

Once I got dressed and went outside, I heard someone say "You with STIs, come over here!"

I think we need to educate much more about FGS

2. Using Stop-Start drama to develop FGS story scripts

Notes about the exercise

Stop-Start drama is a great technique to use with a drama group to develop a new play. It is a structured way of trying out a new story with new characters, which involves the whole group even if they are not acting in the drama, by getting feedback and ideas as the drama develops. The idea is to discuss the initial story with the group, agree on the key characters and then play a short scene. At some point the facilitator shouts STOP! And the players 'freeze' (as if you have pressed the pause button). The group can then give feedback and share ideas for what happens next.

Objectives

- To develop a range of stories around the possible transmission and treatment of FGS
- To identify and discuss the characters to be involved in the plays
- To test out the plays and develop scripts for the drama intervention
- To help apply context to the stories/scripts

Description of the technique

Stop-Start drama follows a series of structured steps to enable the facilitators to involve the whole drama group (and others if relevant) in developing the stories that will be used in the community. It is important to follow the steps as you begin, and then as the drama develops, you can become more flexible in terms of when and how much you stop for feedback and changes. It works best if you try out short scenes and then put it all together at the end, so that you keep the attention of the group. Allow the actors to relate the stories to what happens in their community. This helps to bring out the actual contexts and sometimes experience to the stories.

Explain the technique briefly before you start, emphasising that you will be stopping the play at different points, and the actors will be changing in order to try out different roles and actions.

Steps	Example (from group members)
Ask the group to describe the setting - a water source where women and girls gather for washing / drawing water etc.	A settlement nearby a small dam (big pond/ small lake). It is a very hot day
Ask group who should be in the play	Two girls and a mother three friends at the dam
Decide ages/ names/ characteristics	One girl is about 17 years old - what is she called? OK Mwape is good. The other is 14 – what could be her name? Bwalya? Tell us about the girls: Mwape is a bit playful she wants to go and meet her friends by the dam. Bwalya is quieter and usually obeys her mother

Steps	Example (from group members)
Discuss the activity	The Mother tells the girls to go and fetch water for bathing
Ask for volunteers to be in the scene	Who wants to try being the mother? Who can be the daughters? The friends?
Agree key action points (that could lead to FGS transmission)	When they get to the dam, some other girls are in the water swimming. Mwape wants to join them
Play out a scene	Actors play out the scene - once they get up to where the girls are drawing water or playing in the water, shout STOP! Actors 'freeze' in their roles (as if you have pressed pause)
Stop and get feedback	What do you think - is this realistic? Could this happen at the dam? Does anyone want to have a go at being one of the characters?
Change players	Thank /applaud the actors who are leaving. Ask the new actors to take their roles. Decide as a group if you want to replay the scene or move to the next scene with the new players
Play out	Play out the scene. Facilitators take notes of any important lines or events that can be included in the final script
Stop and get feedback	Check back with the group how they think the scene was. Does anything need changing? Agree what happens next
Final run through	Once you have agreed and practiced the different scenes, do a final run through of the whole drama

What happened in Zambia

Scene 1

Three characters chosen to start: a mother and two daughters (Christine and Wamui). The mother is from fetching water and rushes to the market stand, she calls out for her daughters and ask them to clean the vegetables with the water she is from fetching. The daughters ask the mother where she fetched the water from, she says she fetched the water from the stream. The daughters are worried if the water is clean for use, but the mothers insists that the water is clean. One of the daughters also says she will go and fetch some more water for her to bath since there is no water coming out from the tap.

Another family; a mother and her daughter. A mother calls out for her daughter (Precious), she tells Precious that she is hungry and there was no food in the house, they need to go to the market and buy some vegetables. The daughter is worried that there is a lot of water outside since it was from raining. The mother insists that they pass through the rainy water. She tells her daughter to just fold her jeans and they leave for the market.

At the market, Precious and her mother arrive at the market stand for Christine and Wamui's mother. They greet each other, Precious mother wants to buy the vegetables but she is worried about the water that is being used to wash the vegetables, she asks if the water is clean. Christine, Wamui and their mother get argue at Precious and her mother for questioning their source of water. They think Precious and her mother are being boastful. They buy the vegetables anyway.

Scene 2 (a few weeks later)

Precious' mother calls for her daughter, the daughter comes while looking ill. The mother asks what could be wrong. Precious explains about the stomach and abdominal pain she has been feeling of late. The mother is worried and accuses Precious of playing around with boys. Their neighbour comes through and asks why Precious was being scolded at. Precious' mother tells her neighbour about the pain the daughter has been feeling and the neighbours assume Precious is pregnant. Precious denies being pregnant because she has not been with any man. They insist that precious is taken to the clinic to get checked for pregnancy. Precious's mother calls her neighbour on the side to complain about the pain she has been feeling of late. She explains about the itchiness on her vagina and how she sometimes experiences discharge and that she is ashamed that it might be an STI. Her neighbour advises her to go to the clinic. They call for Precious and rush to the clinic to get checked.

Scene 3

At the clinic Precious and her mother find a kind nurse who takes all their details. She refers them to the FGS information desk where a health worker tells them all about FGS. She emphasises to Precious' mother that FGS is not sexually transmitted. Precious and her mother agree to test for FGS. When they learn there is a simple treatment, she prays to God to thank him!

Scene 4

Precious's mother and her neighbour go to the market to inform Christine and Wamui's mother about FGS. They encourage them to go and get screened as well. She shows them the treatment that she was given.

3. Small group work to develop further stories

a. **Identify settings:** Once you have used the Stop-Start drama technique with the drama group, discuss and identify with them different locations and settings in the community, where they can perform FGS drama and reach out to girls and women.

b. **Small group work:** Split the group into smaller groups (4-6 participants) and give each group a different setting. They should develop a story about FGS to suit the audience in that setting (if you have enough facilitators, each group can work with a facilitator, if not circulate around the groups to check how they are doing). Allow at least 30 minutes for this activity.

c. **Watch and feedback:** Ask each group to perform their drama to the others. Ask for feedback from the group and try out changes if any are suggested. Facilitators should record the performances or take notes so that draft scripts can be written up and shared between the drama groups.

SECTION 5 FIVE

Adapting the drama for different contexts

The following drama scenarios were developed by the groups in Malawi, Tanzania and Zambia.

1. Married couple Scenario

What happened in Malawi

The scenario was a married woman explaining that she has the signs and symptoms of FGS to her husband and he did not believe her. The husband thought the wife had been unfaithful and, in the process, she had contracted an STI. As a result, it caused some tension between them and they decided to go to the hospital to find out the truth after sitting down with all the family elders at home. When they saw the doctor, she told them that it was schistosomiasis (likodzo).

The husband apologises to his wife.

Scene 1

A middle-aged woman talks to her close female friend about the problems she is having with her husband, especially linked to their sexual relationship. She has been experiencing pain during sex and has also noticed there is sometimes blood in her urine when she pees. She feels worried and embarrassed, and doesn't know what to do. Her friend listens carefully, and gently persuades her to talk to her husband so that she can get help.

Scene 2

The woman decides to talk to her husband about her worries. At first, he is upset and doesn't understand what is happening. He is convinced she has been unfaithful and she has contracted an STI in the process. There is some tension between them and he starts to accuse her of being unfaithful and bringing disease. They call some family member to help resolve their issues. An aunty suggests that they go to the clinic.

Scene 3

The couple go to the clinic together. They talk to a doctor who suspects the woman may have FGS, since she often collects water from the Lake. The doctor does some tests, confirms that indeed this is FGS and not an STI, and reassures the couple that it is easy to treat. She then prescribes Praziquantel tablets for the woman to take. The couple are relieved, and the husband apologises to his wife for blaming her.

2. Drama for a church setting

A similar scenario to the one above, was used in Zambia and adapted for a church audience. The husband was a pastor and the couple were concerned about infertility since they had been trying to have children for the last few years. The wife has experienced some stigma in the form of gossip because they have no children. They eventually go to the clinic to seek help and find out about FGS.

3. Drama for a rural community

1 **Paddy Fields** (Based on Tanzania Script)

Scene 1

It is October and Neema tells her two daughters Jessie and Nia that they will go to plant rice in the family paddy fields. The paddies are full of mud and freshwater, and the family plants rice for about 4 hours. They return home and eat lunch.

Scene 2

Jessie and Nia must go and collect water from a nearby pond. It has been raining and Jessie comments about the bad smell coming from the pond. They even spot a man defecating in the bush and make sure they make a lot of noise so that he runs away. At the pond, the girls find their two friends Zubeda and Salma playing and swimming. They greet and once they have filled their buckets, they join the others and swim. As they all swim, Zubeda admits she has pee-ed in the pond. They all laugh. After a while they return home.

Scene 3 (two months later)

Nia tells her mother that she is getting some pain when she pees, her urine looks strange and she has some discharge. Neema takes her to the clinic where there is a friendly doctor who tells them about FGS and does a urine test on Nia. He also suggests Neema takes a test when she tells him she is a rice farmer, and that she brings her other daughter Jessie. The doctor tells Nia and Neema that they have both tested positive for FGS, and gives them treatment to take later when they eat.

Last scene - a village meeting

The drama ends with Neema giving a plea to all the people at the meeting. She talks about the symptoms and modes of transmission, and treatment of FGS. She insists that all women and girls have to test for FGS. She thanks them. The drama ends.

2 Growing Vegetables (Based on Zambian Script)

Scene 1

Two women neighbours meet down by the stream, where they have gone to water their vegetable gardens. One is complaining about abdominal pains, and that her periods are no longer regular. She is worried about getting help because she feels embarrassed.

Scene 2

A young woman joins the two women - she is the daughter of the neighbour and has overheard a bit of their conversation. She apologises saying she should not have been listening, but she wants to help. The young woman tells her mother about a drama that she saw at school recently, that was all about FGS. She explains what she remembers about FGS and says they should all go to the clinic where they can test for it.

Scene 3

The three women go to the clinic and are directed to the FGS helpdesk, where they meet a nurse who explains how FGS is transmitted and treated. She takes their details and asks if they would like to do a test. The women are relieved.

4. Drama in the market scenario

Scene 1

Two women are selling vegetables at a stall in the market. One serves a customer buying some tomatoes. Two young women (from the drama group) come to talk to three women about 'bilharzia for women' i.e.– FGS. They ask if the women often go down to the nearby stream. One of the women says that is where she grows her vegetables and she has to water them every day. The other woman says they draw water every day from the stream for washing and cooking. The young women tell them about the risks of getting FGS from the water. They explain about how it is transmitted. When one of the young women mentions some of the symptoms, the woman with the garden remembers her daughter complaining of the same kind of abdominal pain and blood in her urine.

Scene 2

The mother from the market is taking her daughter to the clinic to get tested for FGS. Her daughter is a teenager and is worried what the health workers at the clinic will say. Some neighbours see them heading towards the clinic and make some stigmatising comments about the daughter ('She is too playful'; 'We have seen how she is with the boys'). The mother calls to them and says 'Have you heard about FGS? We all need to get tested'.

Scene 3

At the clinic, they first see a nurse. The mother explains some of the symptoms that her daughter has, and tells the nurse that she thinks it may be FGS. The nurse talks to her about FGS and they both decide to get checked. They are prescribed Praziquantel and are happy that it is so easy to treat.

5. Drama for a School Setting

What happened in Tanzania

Boarding School

Scene 1

It is Friday and the headmistress addresses all the students. She has been attending a seminar and has learned that FGS is endemic in their district. She is aware that students are fond of swimming in the pond close to the school. She asks the pupils to stop swimming there. There will be a security officer stationed at the pond to make sure. The students start murmuring their disappointment.

Scene 2

Three female students - Justa, Annet, and Zubeda - are talking to each other. They are discussing how they can continue swimming in the pond. Zubeda is worried about the security officer. Justa suggests they swim the whole day on weekends. They all laugh and agree.

Scene 3

It is Saturday. Justa, Annet, and Zubeda wake up, get the breakfast and clean their rooms. “What next?” Asks Zubeda. They all laugh. “Swim like fish, all day” Annet replies. They all pick their swimming costumes and go to the pond for swimming.

Scene 4

It is Sunday and the girls are going swimming again. On their way, Annet tells her friends that she smells faeces. Justa even points at the faeces she can see. Annet says, “Let’s not think about that because we won’t swim.” They go to the pond and start swimming. After 4 hours, they are all exhausted and decided to return to the hostel for resting.

Scene 5

Three months later, Justa tells Annet that she has seen blood in her urine and she doesn’t know why. Zubeda tells Justa and Annet that she also has blood in her urine and she has bad abdominal pain. They are all confused and don’t know what to do.

Scene 6

In the next few days, Justa tells her other friend and classmate Juliana about the blood in her urine. Juliana suggests that Justa goes to see the school nurse to get medical advice. Justa hesitates because the nurse might think she aborted. Meanwhile Juliana meets some classmates and tells them about Justa. They start debating what could such a symptom mean. Some say she is bewitched. Others say she might have an STI. Some say Justa must be sleeping with boys and is a prostitute.

Scene 7

The next day, the Schistosomiasis Control Program team visits the school. They teach about the symptoms, modes of transmission and treatment during the school assembly. Zubeda, Justa and Annet are surprised to hear that blood in urine and abdominal pain are symptoms of FGS. They are also surprised that swimming in (infested) freshwater transmits FGS. The Schistosomiasis Control Program team conducts urine tests. Zubeda, Justa and Annet, and many form-three female students get tested. Treatment is given to all students regardless of their positive or negative test.

Scene 8

The next day Zubeda, Justa and Annet meet for a chat. Everyone reveals that they had a positive test. Zubeda tells the others that she has heard a rumor that Juliana and most students in Form Three also had a positive test. They all laugh. Juliana goes to Justa and asks for forgiveness for circulating the rumors. Justa forgives her and they shake hands.

SECTION 6 SIX

Portraying FGS-related stigma in drama

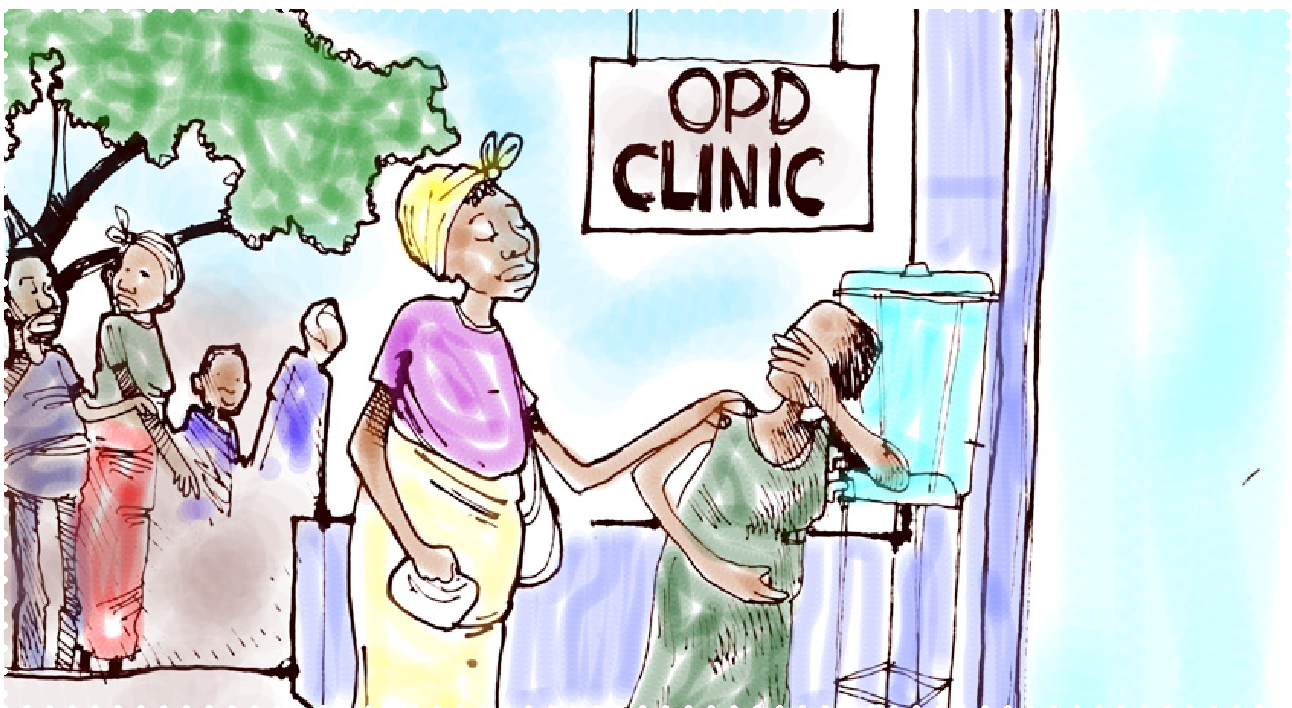
"What I do know is that in our society, people will think she is a prostitute."
(Adult woman, North-Western Tanzania)

"It is very difficult to talk to even your loved ones because you are afraid that they may spread rumours to others that you are suffering from a sexual disease and then others will start isolating you and calling you bad names like prostitute, or having sex with many men."

(Teenage girl, North-western Tanzania)

FGS is classed as a 'neglected tropical disease' and because it has been so neglected, there is a lack of information and awareness about what it is, what causes it, how it is transmitted, how do you diagnose or treat it. This exists not only in the community, but among healthcare workers too. This lack of knowledge can lead to many problems, but among the biggest challenges is the stigma that girls and women face - either because the symptoms are often misdiagnosed as an STI, or because the fear of being stigmatized is a barrier to seeking help.

The impact of FGS stigma is far-reaching. It can lead to FGS being untreated, which in turn, results in menstrual problems, anaemia, infertility and low birth weight of babies. Stigma can also reduce the quality of care that a patient receives if they are brave enough to go for testing. Un-informed health workers may provide less conscientious services, or in the worst-case scenario, blame and shame clients. The psychological impact of stigma can lead to mental illness, suicide and depression.



There are existing resources on how to recognise and combat FGS stigma and it is important to address this issue with all the partners involved in the intervention [1,3,4]. This section focuses on how to portray FGS-related stigma in the awareness-raising drama- without reinforcing it. The trick is to show the stigma and then 'unpack' it - who is stigmatising, why are they stigmatising and how can we change this?

There have been many studies about stigma, particularly in the last twenty years because of HIV and the minefield that is HIV-related stigma.

Most researchers agree on the underlying drivers of stigma and these are equally applicable to FGS, as to HIV (and mental health, gender and sexual diversity, epilepsy etc.).

These drivers are:

- Lack of knowledge and information
- Moral judgements about behaviour (e.g. linking/ assuming FGS is an STI and making moralistic judgements about how someone acquired it)
- Lack of awareness of stigma and its damaging effects (not realising actions are stigmatising and not understanding the harm that stigma causes)
- Fear (of 'contagion'/ association)

It is useful to understand these drivers so that when stigma is portrayed in the community drama, it can also be challenged in an appropriate way.

How to portray combatting stigma

There are many ways to portray challenging stigma in drama. It may be done with a direct challenge - 'I don't think stigmatising someone will solve the problem of FGS' or 'Do you realise how hurtful those words are?' or the challenge can be more subtle - for example by showing behaviour opposite to that of the stigmatiser.

> **Example:**
> *A young woman has just been scolded by her mother who suspects she has an STI. When she arrives at the clinic, she is warmly greeted by a kind nurse, who offers reassurance and acceptance.*

Hence modelling behaviour that directly contrasts with the stigma, can also be a good way to challenge it.

Other modes of stigma-free behaviour include showing respect, treating someone with dignity, offering help and hope if someone is feeling low, ensuring confidentiality (especially health

workers), checking for consent for testing and treatment and keeping an open mind.

Non-verbal gestures and body language can also be used to show both stigma (disapproving looks, finger-pointing, turning your back) and approval and acceptance (open arms, smiles, eye contact).

The table below lists some suggestions that can be incorporated into the FGS drama scripts. Have a discussion with your drama group about stigma - many of the young women will have experienced, or witnessed, different kinds of stigma in their own lives. They will probably have some ideas of their own to add to the list!

Portraying stigma in FGS drama

Form of stigma	Example of how to portray stigma	Example of how to portray challenging the stigma	Stigma reduction strategy explained
Judgements about sexual activity	Neighbours gossiping about the one who is sick, pointing fingers	Another neighbour joins them and talks about FGS, asking if they know that you can get tested for it at the clinic. She emphasises FGS is not sexually transmitted	This strategy helps to break down the 'us' and 'them' attitude. By asking her neighbours if they have thought of testing for FGS, she is showing them that anyone can be affected, so there is no need to point fingers
Assumptions about multiple sexual partners	Someone at the clinic (staff or another patient) makes a comment about a young woman in waiting room, ***'looking like she sleeps with a lot of men'***	Nurse calls them to one side and asks if they know how much they are stigmatising and how this can make someone feel	Sometimes we do not realise we are stigmatising, or we do not think about the impact that stigma has on others. Here, the nurse helps the stigmatiser to reflect on their actions
Linking FGS to STIs	Young woman tells parent about FGS symptoms (discharge/ itchiness). Parent scolds her assuming it is an STI	Parent finds out from friend or clinic staff that FGS is not sexually transmitted. She apologises to daughter for the stigmatising	Some stigma happens because of misinformation, or a lack of knowledge. This strategy shows that attitudes change when someone has all the information they need

Form of stigma	Example of how to portray stigma	Example of how to portray challenging the stigma	Stigma reduction strategy explained
Judgements about infertility	Husband accuses wife of not being able to produce children	Couple go to clinic and learn about FGS - husband acknowledges it is not his wife's fault	See above
Anticipated stigma	Two women talking about FGS symptoms, scared to go to the clinic because of what nurse might say	The women find out about FGS from a sensitisation and go to get tested together. Nurse welcomes them	Information and solidarity - the friends get informed and realise they could both be at risk. The mutual support helps to break down their fear of stigma
Clinic stigma comments	Nurse gossips to colleague about the possible sexual activities of a young woman who has come for FGS tests	Colleague corrects the nurse, telling her about the FGS screening and how the symptoms often get mistaken for STIs. She also warns against gossiping	FGS is often as an STI - so giving the correct information can change the stigmatising attitudes. Warning against gossiping is reminding the colleagues about the importance of being professional
Lack of privacy	Nurse discusses female client loudly with receptionist, telling her she has to do ***'so many tests on her'***	Sister in charge overhears and challenges the nurse and receptionist - reminds them about confidentiality and apologises to the client	Reminding staff of professionalism and codes of conduct can help to reduce stigma - and the apology shows solidarity with the client, rather than colluding with the stigmatiser
Suspecting witchcraft	School friends whispering about classmate who says she has urine in her blood. One suggests she could be bewitched	One of the other school friends challenges her and thinks they should support the friend who is sick to go to the clinic	Showing solidarity by challenging and suggesting support. Hopefully the group of school friends will learn more at the clinic to change their ideas about witchcraft

SECTION 7 SEVEN

A note about, FGS, gender-based violence (GBV) and drama

Gender-based violence (GBV) is violence directed against a person because of their gender. Women and men experience GBV but the majority of victims are women and girls. It is estimated that one in three women and girls will experience GBV in their lifetime. GBV can severely affect mental wellbeing.

GBV may be evident in connection with FGS, for example, a woman attending a consultation in the clinic or being screened may reveal signs of sexual and GBV. Fear of stigma and violence may also be a barrier to some girls and women coming forward for FGS screening.

Women who have been subjected to violence often feel ashamed or embarrassed to talk about it openly because it carries fear and stigma. This is why mentioning it and providing opportunities to discuss it can help to break down the taboos and encourage more openness to challenge the violence, and the damage that it causes to individuals, families and society. It is therefore important to ensure that FGS intervention staff have some training about GBV and are aware of local relevant referral agencies if women ask for help or if staff fear a client is in danger.

Training on GBV might include:

There is a lot of information about training on gender-based violence (see Resource List). Here we include a brief outline of topics you may include for health workers

How to talk about GBV during FGS screening, diagnosis and treatment

Many women may be fearful or reluctant to talk about their experiences of violence, so it is important to be sensitive and gentle when asking about abuse. Avoid direct questions and emphasise confidentiality and the benefits of asking for support. Health workers with training in counselling skills will especially understand the importance of not forcing a client to open up until she is ready, but also to keep offering opportunities to talk as trust is built with the staff.

Useful questions to ask, if you are worried about a client's safety, include:

- Have you ever been injured in a conflict at home?
- Does anyone shout or insult you at home?
- Can you tell me what you are afraid of, about coming to the clinic?

- Do you know that there are organisations that help women who are in trouble in their relationship?

How GBV affects mental well-being

GBV has a huge impact on mental wellbeing, and one of the first steps in helping a woman who has experienced GBV is to enable her to express her feelings, and start to acknowledge how she has been affected by GBV. Ideally agencies who specialise in supporting people who have experienced GBV will be able to provide counselling; however, it will benefit health workers to have an understanding of the impact of GBV:

- Many women will have feelings of shame and embarrassment, as if the violence is somehow their fault. This can lead to self-blame and feelings of guilt.
- Fear of speaking out is often linked to fear of recurrent or further abuse, especially if the violence has been coercive and emotional, including receiving threats if the violent incidents are shared with anyone else.
- Many women will fear judgement or ridicule by others, from within the family or wider community, if it becomes known that she has been abused.
- Some women may fear accusations or blame from her family (or her husbands' family) about having failed as a wife and having brought the violence on herself. Women need reassurance that they hold no blame. Many women will still fear for their physical safety, even if the perpetrator is removed.
- Anxieties about economic considerations, especially if there are children involved, may become a barrier to a woman feeling able to take action against a violent partner.

Knowing where, when and how to refer women to for help

During the community consultation before the FGS intervention is set up, implementers can find out about community understanding of and attitudes to GBV. They can also identify any local agencies or NGOs who provide support services to women who have experienced GBV. Building links with these agencies and developing a list of possible referral services will enable health

workers to feel confident about supporting women clients to open up about abuse. Programs should have some clear guidelines for health workers about safeguarding issues and these would cover what health workers should do if they are concerned about the safety of a client in the context of GBV. However, wherever possible, clients should be enabled to make their own decisions about when they ask for help and should not be pressured into leaving home or a relationship by anyone. It is important that they feel in control and that health workers support their decisions. It may take time and a lot of courage for many women to take action to protect themselves.

Once a woman has decided that she wants further help, programme staff or health workers may offer to accompany her to the referral agency, at least for her first visit. Some women may fear what will happen to them, or will worry about questions or assessments. They may want support to tell their story and to take the next steps towards escaping the violence.

Drama and GBV

We would not recommend actually portraying GBV in the drama, but if it feels appropriate, it can be mentioned during the plays.

Examples of ways to illustrate/ mention GBV in drama scripts:

- A mother warns her daughters about the dangers of going to bathe at the dam after dark.
- A sister talks about the importance of sticking together as they walk to draw water, because of the risk of attack.
- An older schoolgirl talks to her friend about feeling scared of her boyfriend's temper if she refuses to have sex, even when it hurts to have sex.
- A wife talks about how her husband beat her when she was bleeding after sexual intercourse because he suspected the blood was caused by an STI and accused her of cheating on him.
- A student who tells the women about the FGS service might mention that they can offer support about other health issues and problems at home like GBV or other forms of abuse.

SECTION 8 EIGHT

A note about gender: Girls, women, FGS and drama groups

One consideration for FGS programmers is whether to include men and women in the forefront of the intervention, or to work with a model that is led by girls and women. During the study in Zambia, it was decided to involve only the female members of the drama groups, to develop and perform the plays in the different settings as a way of empowering them to lead the initiative. In Tanzania and Malawi, it was seen to be more appropriate to involve male drama group members, so that men would hear the messages and share information about FGS with their families. During the planning stages of the intervention, this is an important consideration to discuss with the community.

There is no 'right' answer but feedback from the three studies included the following observations from drama group members and community leaders:

It is more culturally appropriate for us (women) to be involved - men can't discuss such things.

It is a taboo topic for men - it would be seen as disrespectful if men started talking about women's bodies like that.

We even sing a song about the FGS symptoms! Men can't sing it...

It has been empowering for us - usually the men take the leading roles, but this time we were leading the drama.

It was important to involve the men - they were like positive role models, seen to be supporting their women.

Men and boys need to understand about FGS because they are also involved in prevention and transmission.

Having men in the drama meant that we also had boys and men watching and learning too. They can spread the message to their families.

SECTION 9 NINE

Preparing to perform the drama

Linking the drama to FGS screening services

Before planning the drama performances, ensure that the FGS testing, screening and treatment services are set up in conjunction with local health facilities. Raising awareness about FGS through drama is crucial, but once the community is aware, they need to know what they can do about it. For more clinical information about setting up FGS screening see Countdown Nigeria.

In our study, each country used a different model in providing the clinical services for screening and treating FGS. Malawi engaged a health facility (Koche Health Centre) that is primarily run by a Christian Health Organization, though the Ministry of Health partly supports it. Tests were conducted at Maldeco Clinic, which is next to Koche, and had the required equipment. Tanzania had mobile clinics run by the study team, linking to local government dispensaries. Zambia worked with the local government health facility, including running some outreach clinics with the facility to bring services closer to women and improve uptake.

Screening for FGS

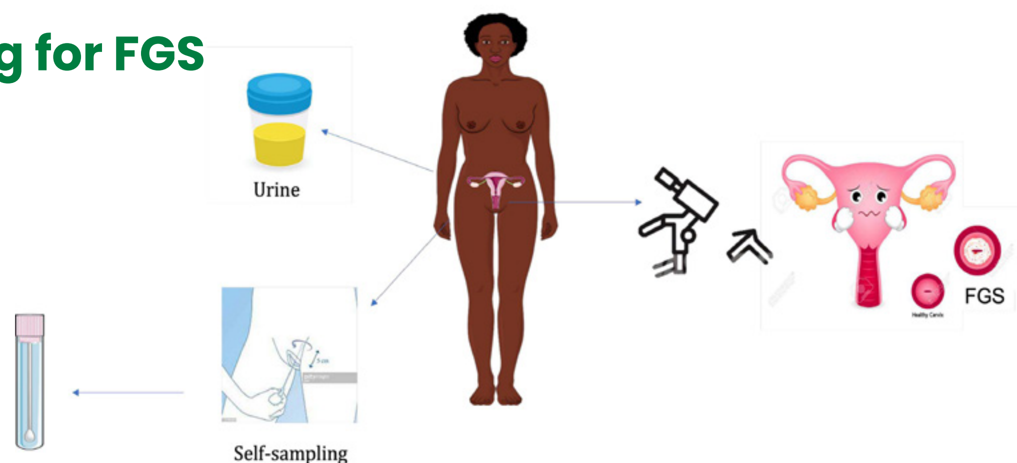


Figure 4: Suggested screening procedures in women for the detection of FGS:

(1) Urine test for parasite detection; (2) Self-sampling for parasite detection; (3) Clinic visit to see if FGS can be visualized in the cervix

Planning where and when to perform:

Consult the community leaders, health workers, drama group members on the best places and times to perform the drama. These can vary so that you reach different groups of women at different times.

Timing

Be aware of other activities that the audience is involved in, for example, if you are performing in a market, consult the stall holders when the best time would be. If you are hoping they will come for screening following the drama - agree with them when they are most likely to be available. If you are performing during a church meeting, find out if there are other activities on the agenda, or agree to be the last item so that you can lead women to the screening services afterwards. If you are planning to perform at a communal water point, consider the time that women are found there, morning and evening, and the need to adjust scripts because most women would be rushing back to their homes to do house chores or to cook. Similarly in schools, plan with the teachers the best time to reach the optimum number of girls and plan screening times to fit their timetable.

- In Malawi, there was intensive coverage when the drama was performed in different neighbouring villages every day for four days.
- In Zambia, performances were linked to the outreach clinics held in local churches and community halls, so that the audience could access screening immediately after watching the drama.
- In Tanzania, a choir and dance group performed before the drama in order to attract crowds to the performances, after rice-planting.

Getting permission

Remember - always get permission to perform the drama in different venues - even if you are in an open outdoor space- check with local councils, leaders and shop keepers.

Plan and Practice!

Discuss with the drama groups when they are going to plan and practice the drama. They must be sure to decide on the drama script that fits the likely audience - and practice beforehand. This includes:

- Deciding which story script they are working with
- Agreeing who is playing which roles
- Choosing any songs that will be used
- Practicing audibility and clarity
- Discussing stage presence- where each person stands/ any props that are needed/ what the rest of the group will do when they are not on stage

Mobilisation

In all three countries during the study, mobilising enthusiasm for the drama in the community, and among the players, was an important component.

> ***"I was a very shy person now I can stand in front of people and Communicate"***
> Drama group member

Providing T-shirts and chitenges for drama group members (and health workers) meant that they could be easily identified when they were out and about. The FGS logo also helped to raise the profile of the disease and many people were prompted to ask what it is.

A megaphone or PA system is useful to announce the beginning of the activities and to call people to the drama. In Tanzania, a Master of Ceremonies drummed up support and attracted the crowds, and a choir sang a specially written 'Schistosomiasis song'. Dancing is also a popular spectacle, particularly if the audience is encouraged to join in.

Posters and leaflets can be posted around the community in strategic places to advertise the drama and the times and location of the screening facilities.

Incentives

Programmers may decide to include incentives to encourage girls and women to attend the drama performances or go for the FGS screening services. Bars of soap were used in one site in the study, given to each woman who screened for FGS. In Malawi, transport refunds were given to support women who came for testing.

SECTION 10 TEN

Post drama activities

One of the important things about using drama in the community to raise awareness is what happens afterwards. Although the drama can convey strong messages, it is important that the audience have a chance to process what they have seen, have an opportunity to ask questions and find out more, especially if they have been moved by the drama and feel it is relevant to them.

These follow-up activities can take different forms:

- One to one discussion among the audience. After one market place drama, members of the drama group moved around the market stands, talking to the women and answering any questions, and also informing the stall holders where the outreach screening clinic was being held.
- Distribution of a Fact Sheet among the audience, which contains basic information about FGS, and the times and location of the screening clinics.
- A facilitated group discussion with members of the audience, for example after a school or church group performance, sit with the audience and ask some open questions: 'What did you think about the drama? Have you heard of FGS before? Do you know that you can get tested for FGS at the local clinic? Who knows what the treatment is for FGS?' Ensure that everyone can hear, and offer one to one discussion if anyone has more personal questions.
- Snowballing: Ask the audience to tell family and friends about the drama, FGS and screening facilities, especially if men are part of the audience. Give out extra Information, Education and Communication (IEC) materials that they can share with others. Inform them about the next performance / outreach clinic and ask them to come with friends.

What the community asked...

These were the most common questions about FGS that were asked by the community members in Zambia, Malawi and Tanzania, following a drama performance or education discussion about FGS.

Question	Answer
Is FGS sexually transmitted?	**NO!!** - the parasite **cannot** be transmitted through sexual contact, only through contact with contaminated water.
Can you catch FGS from drinking contaminated water?	No - it is **not** transmitted through drinking. The parasite penetrates the skin in water (e.g. when someone is bathing or washing or drawing water).
Is FGS transmitted from person-to-person contact?	No - there is no transmission from person to person- it takes place in contaminated water.
Does FGS put you at risk from other diseases, including HIV and cervical cancer?	Yes - girls and women with FGS are three times more vulnerable to catching HIV and two times more at risk of HPV, if they are sexually active.
Is the treatment safe to take if you are pregnant?	Yes - Praziquantel is safe to take during pregnancy.
If you boil contaminated water does it reduce the risk of FGS if used for bathing?	Yes boiling water reduces the risk of FGS you can also add chlorine.
If you have FGS can you have problems getting pregnant?	Yes you may - if FGS is not treated it can lead to infertility or problems during pregnancy, like ectopic pregnancy (when the foetus is outside the uterus).

Question	Answer
Can FGS affect children?	Yes - it can affect children, girls and boys get infected when they go into the water or use contaminated water. It can give them problems from early childhood. These can include growth retardation and anaemia. Early FGS can go unnoticed for years from a young age.
Does FGS affect men too?	Men can be infected with bilharzia but FGS is specific to women. In men, they can have changes in their sperm and genitals.
What happens if you are not treated?	The long-term effects of FGS include infertility, painful sex, bleeding with sex and in between cycles, menstrual issues, abdominal pain.
Why does screening only start at 17 years old and not for younger girls?	In many countries 17 years old is the age when someone can give consent for screening. If there is concern about a younger girl, her parents can take her to the clinic for advice/ screening.
Is the treatment free?	Yes - from the health facility. There is also community treatment through mass drug administration for the control of bilharzia.
How can we protect ourselves from FGS during the growing season?	Praziquantel can be taken preemptively (as a prevention) in endemic areas. Of course the best solution would be safe uncontaminated water for everyone, but until then FGS will be there. Other precautions to reduce risks include wearing boots and gloves during growing seasons.
Is there a difference between FGS and UTIs?	Yes - FGS is caused by worms (parasites), whereas UTI is a bacterial infection. FGS is found in stagnant water, and its infection depends on the presence of specific snails.

SECTION 11 ELEVEN

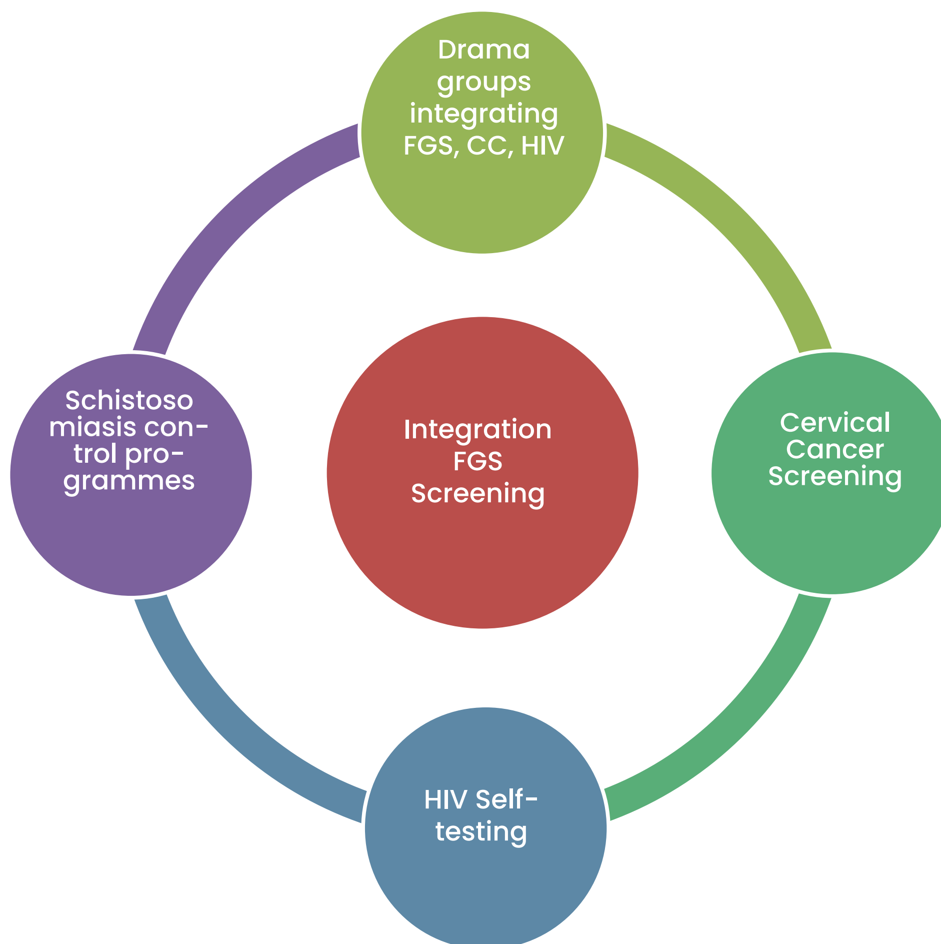
Embedding drama in wider interventions

This section outlines how using drama to raise awareness about FGS can be integrated into a wider context of interventions, in order to achieve maximum impact on the disease.

Cervical Cancer screening programmes

FGS is a disease that affects the female reproductive tract where other diseases can happen at the same time. An important one is Cervical Cancer (CC); a disease that also affects a women's genital tract, and like FGS, it is treatable.

There are CC screening programmes in Zambia, Tanzania and Malawi (and many other countries) conducted by nurses. These practitioners can easily be taught to diagnose FGS lesions and also encourage self-sampling. If both diseases are diagnosed and treated jointly, there are better chances for the women to live free of these disabling conditions.



HIV testing

There are HIV testing programmes in Zambia, Tanzania and Malawi and some of these programmes also encourage self-testing for HIV. This increases the chances of detecting HIV in the community. As women with FGS have increased chances of acquiring HIV, it is important that FGS screening is also integrated in HIV screening programmes in areas where there is schistosomiasis present.

Integrating resources

To integrate FGS screening in ongoing programmes, there are several elements that need to be included (see Figure 5) Some of these are:

- Training of community workers
- Liaising with schistosomiasis control programmes from the national Ministries of Health to map the high-risk areas - this will help target resources efficiently
- Integrating FGS into ONGOING programmes of CC and HIV screening to maximise interventions
- Drama groups can also integrate FGS, CC and HIV as a comprehensive approach to women's sexual and reproductive health

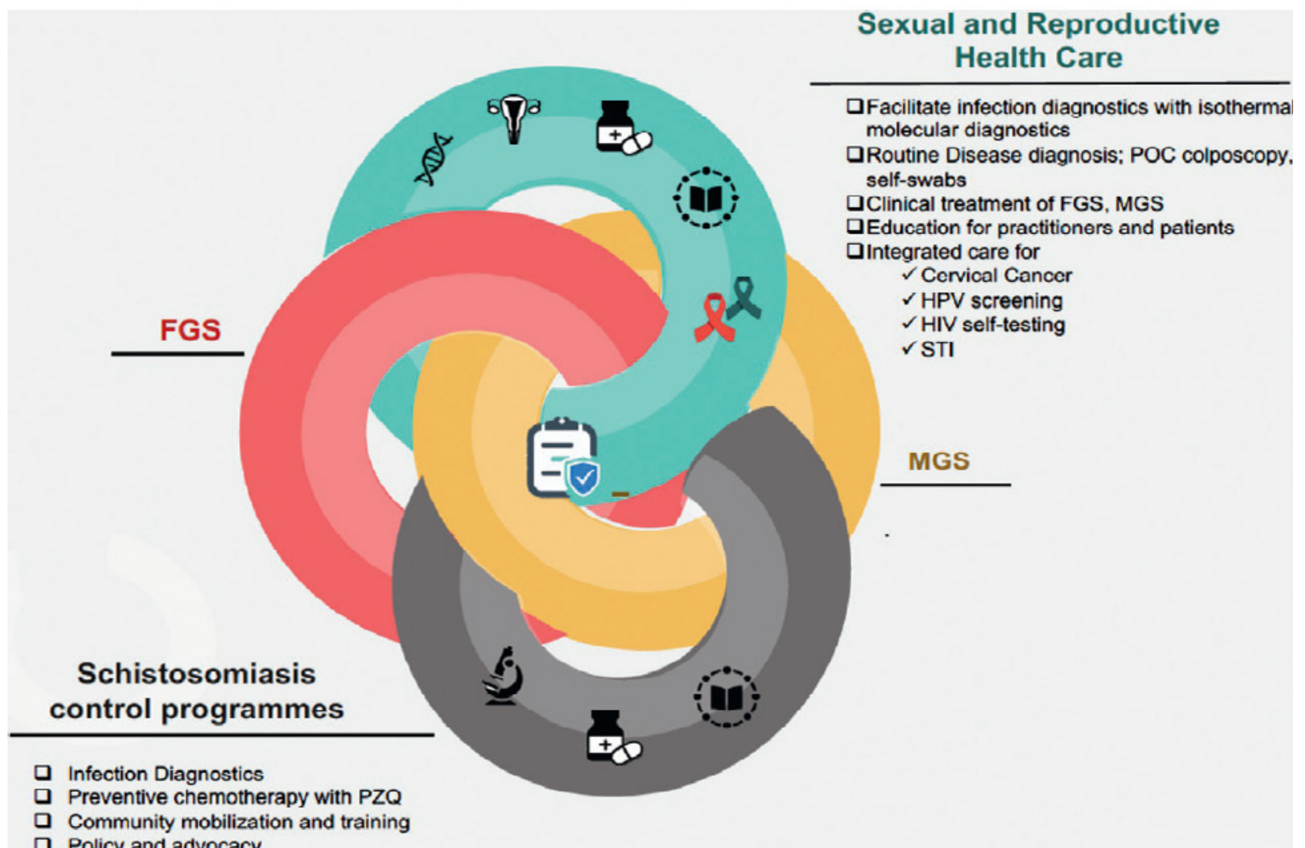


Figure 5: Integration of FGS screening with SRH services; from review of FGS and MGS[5]

https://www.sciencedirect.com/science/article/abs/pii/S0065308X21000592

GIRLS
AND
WOMEN
GET SCREENED
FOR
FGS

Appendix 1

FGS Fact Sheet

Schistosomiasis (also known as Bilharzia) is one of the most prevalent neglected tropical diseases (NTD) affecting over 240 million people worldwide, and estimated to cause 200,000 deaths annually. It is caused by parasites and transmitted in infested water through tiny snails. Schistosomiasis can infect anyone who comes into contact with infested water. There are different forms of schistosomiasis including intestinal and urogenital. In girls and women, when the disease affects the reproductive system, it is called 'Female Genital Schistosomiasis (FGS)'.

Transmission (How you can catch FGS)

FGS affects millions of girls and women who do not have access to clean household water, and who are in skin contact with natural water sources, through washing, bathing and water collection.

In FGS, the eggs migrate and get trapped in organs such as the uterus, fallopian tubes, cervix and vagina.

Symptoms of FGS (How you know you might have FGS)

Vaginal itching, discharge, ulcers and bleeding. Some women experience pain during sex, or bleeding after sex.

Long-term effects of FGS (What happens if you do not treat FGS)

If it is not treated, FGS can cause infertility, anaemia and menstrual disorders.

Treatment of FGS (How to cure FGS)

Treatment of FGS is simple - a dose of Praziquantel medicine. Praziquantel is often administered through Mass Drug Administration programs in schools and communities to help to treat FGS.

Important!!! FGS is NOT sexually transmitted

Many of the symptoms of FGS are similar to sexually transmitted infections (STIs), but it is **NOT an STI**

Sometimes health workers mistake FGS for an STI

Sometimes girls and women are scared they will get stigmatised if they go for testing, because they may be suspected of having an STI

The more information we have about FGS, the better we can recognise it and treat it

Appendix 2

FGS Resource List

1. Countdown (2021) Health Worker Training Guide for Female Genital Schistosomiasis (FGS) in Primary Health Care. Liverpool School of Tropical Medicine, UK https://countdown.lstmed.ac.uk/publications-resources/tools-and-booklets

2. Bond V, Ngwenya F, Murray E, Ngwenya N, Viljoen L, Gumede D, et al. (2019) Value and Limitations of Broad Brush Surveys Used in Community-Randomized Trials in Southern Africa. Qualitative Health Research. 29(5):700-718

3. Countdown (2021) Female Genital Schistosomiasis (FGS) Intervention Manual. Liverpool School of Tropical Medicine, UK https://countdown.lstmed.ac.uk/publications-resources/tools-and-booklets

4. Countdown (2021) Learning Pack: Female Genital Schistosomiasis - A guide to inform equitable schistosomiasis control efforts in Ghana. Liverpool School of Tropical Medicine, UK https://countdown.lstmed.ac.uk/publications-resources/tools-and-booklets

5. Bustinduy AL, Randriansolo B, Sturt AS, Kayuni SA, Leustcher PDC, Webster BL, et al. (2022) Chapter One - An update on female and male genital schistosomiasis and a call to integrate efforts to escalate diagnosis, treatment and awareness in endemic and non-endemic settings: The time is now. Advances Parasitology. 115: 1-44

6. Engels D, Hotez PJ, Ducker C, Gyapong M, Bustinduy AL, Secor WE, et al. (2020) Integration of prevention and control measures for female genital schistosomiasis, HIV and cervical cancer. Bulletin of the World Health Organization. 98(9): 615–624

7. FAST Package (2021) Questions and Answers for Workshop Female Genital Schistosomiasis. https://fastpackage.org/

8. Kukula VA, MacPherson EE, Tsey IH, Stothard JR, Theobald S, Gyapong M, et al. (2019) A major hurdle in the elimination of urogenital schistosomiasis revealed: Identifying key gaps in knowledge and understanding of female genital schistosomiasis within communities and local health workers. PLoS Neglected Tropical Diseases. 21;13(3):e0007207

9. Person B, Ali SM, A'Kadir FM, Ali JN, Mohammed UA, Mohammed KA, Rollinson D, Knopp S (2016) Community Knowledge, Perceptions, and Practices Associated with Urogenital Schistosomiasis among School-Aged Children in Zanzibar, United Republic of Tanzania. PLoS Neglected Tropical Diseases. 11;10(7):e0004814

10. UNAIDS (2019) No more neglect: Female Genital Schistosomiasis and HIV. https://www.unaids.org/sites/default/files/media_asset/female_genital_schistosomiasis_and_hiv_en.pdf

11. UNTC: Policy Briefing: Female Genital Schistosomiasis. Uniting to combat neglected tropical diseases. https://unitingtocombatntds.org/wp-content/uploads/2019/05/UNTC_policy_FGS.pdf

12. WHO (2015) Female Genital Schistosomiasis: A Pocket Atlas for Clinical Healthcare Professionals

13. https://www.who.int/publications/i/item/9789241509299?msclkid=c75ef412b69811ecae68a86a503d83fe

Drama performance in Malawi

FGS screening demonstration in Malawi

Gender inclusivity in Tanzania

Drama performance in Zambia

illustration by Kiss Abraham

illustration by Kiss Abraham

illustration by Kiss Abraham

illustration by Kiss Abraham

illustration by Kiss Abraham

illustration by Kiss Abraham

illustration by Kiss Abraham

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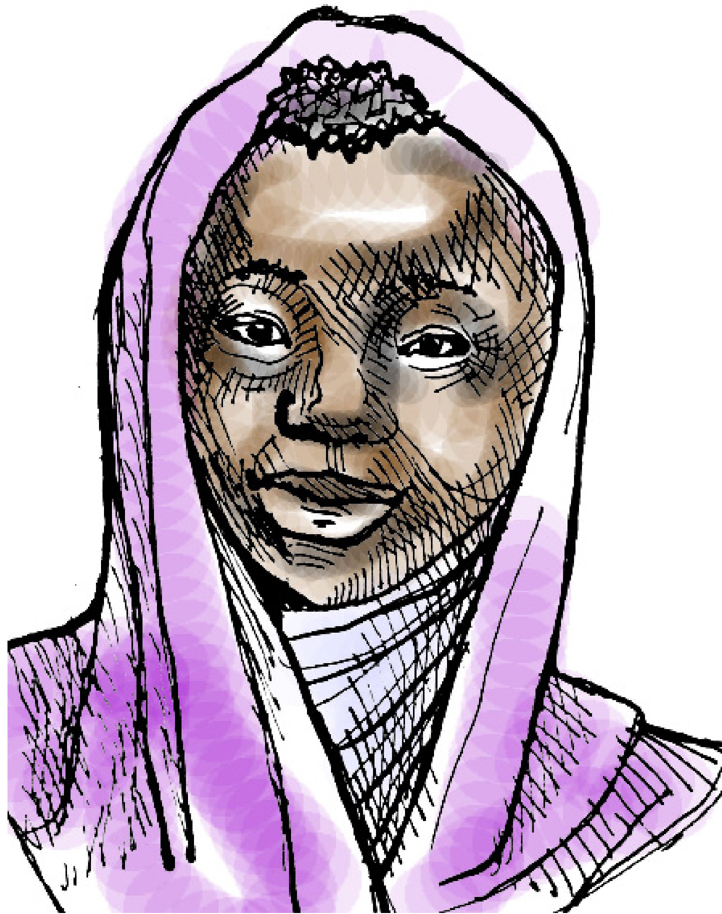

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