



## Health professionals' knowledge about female genital schistosomiasis. A qualitative investigation in a schistosomiasis endemic area in South Africa



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### ABSTRACT

Female Genital Schistosomiasis (FGS) is a neglected tropical disease that affects the lives of millions of women living in endemic areas. The aim of this study was to identify South African healthcare professionals' perceptions and experiences of Female Genital schistosomiasis. This qualitative study took place in Ugu District, KwaZulu-Natal, South Africa, in one Community Health Centre and two Primary Health Care clinics. The purpose was to explore local healthcare professionals' views and knowledge on FGS in an area endemic for *Schistosoma haematobium*, referred to as bilharzia, or isichenene in isiZulu. The empirical findings collected through interviews and observations are discussed in relation to the well-established research on FGS. This project also took cognizance of the United Nations (UN) sustainability development goals (SDGs) with a focus on gender and sanitation, as well as control programmes to prevent schistosomiasis. The study showed that there was a multi-faceted gap in knowledge between local midwives and professional nurses' work-related knowledge and the medical research team. Among the main causes are skewed power relations, whereby the women affected by FGS often have low socioeconomic status in society while the higher power structures do not prioritize FGS. This leads to health professionals being in a "middle position" where they are responsible for community health but are governed by their training and the guidelines of the institution in which they are a part. Furthermore, the study showed the importance of culture since nurses and midwives consult with patients, as they are part of a framework where their role is constrained due to governmental policies, protocols for patient care and the local culture. To provide adequate health services for FGS patients, this study indicates that policy, female patient management protocols, curricula, post graduate training, clinical practice and schistosomiasis prevention programs should include FGS.

### 1. Introduction

Female Genital Schistosomiasis (FGS) is of serious public health concern but remains a silent and neglected epidemic (Gyapong et al., 2015). The parasite *Schistosoma haematobium* is transmitted by fresh water contaminated by snails. FGS is one of the most serious manifestations of *S. haematobium* in humans and is defined as both an infection and a subsequent disease of the reproductive organs of women and girls

(Kjetland et al., 2012).

Schistosomiasis (also known as *bilharzia*) and known as *isichenene* in the local language, isiZulu, is prevalent in many areas of South Africa, but research shows that the transmission of schistosomiasis may not be well understood by the rural population nor the healthcare professionals (Mazigo et al., 2021). Moreover, FGS is neither included in the training of healthcare professionals nor is it considered in the syndromic management of vaginal discharge, infertility or cervico-vaginal lesions in South

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Africa, and may thus be mistakenly diagnosed as a sexually transmitted disease or cancer (Kjetland et al., 2014; Rafferty et al., 2021). This disease affects females in schistosomiasis endemic areas, where they often live under disadvantaged conditions in the poorest parts of the world, and who then carry the FGS disease associated with increased risk of HIV, cervical cancer, and other reproductive tract disorders (UNAIDS and World Health Organization, 2019). Despite the high prevalence of this disease our study investigated an assumed low level of knowledge regarding FGS among local healthcare professionals who provide the reproductive health services for the communities, to document what is currently known about FGS by healthcare professionals, and identify any knowledge gaps. It is important to explore the knowledge of FGS of the healthcare professionals (midwives and professional nurses) at the primary healthcare (PHC) clinics, and to develop methods for them to diagnose, treat and inform women who seek their help at the clinic (Global Schistosomiasis Alliance, 2019; Mbabazi et al., 2015). Increased knowledge is an important step to prevent increased morbidity among the population in schistosomiasis endemic areas.

### 1.1. Schistosomiasis and female genital schistosomiasis

At least 228 million people require treatment for schistosomiasis and up to 659 million people are at risk (UNAIDS and World Health Organization, 2019). In South Africa, over 25.7 million people are at risk, with an estimated 4.5 million currently infected (Magaisa et al., 2015). In 2013, in KwaZulu-Natal, we found a prevalence of *S. haematobium* of 32% among 10–12 year old girls, including lower genital tract disease (Hegertun et al., 2013). The research by Galappaththi-Arachchige et al. supports this, confirming an “association between self-reported unsafe water contact and urogenital schistosomiasis in adolescent girls and young women” (Galappaththi-Arachchige et al., 2016).

In 1997 the Gender Task Force of the Tropical Disease Research Programme (TDR) of the World Health Organisation (WHO) included FGS on a list of scientific topics that deserve higher research priority (Christinet et al., 2016). Further, the WHO renamed urinary schistosomiasis as “urogenital” schistosomiasis, emphasizing that the parasite can cause pathology in both the urinary and the genital tracts, and

highlighting the overlap in symptoms between FGS and sexually transmitted infections (STIs) (Kjetland et al., 2014). Of the girls infected with *S. haematobium*, 75% appear to live with genital lesions (Christinet et al., 2016; Kjetland et al., 2012).

As shown in Fig. 1, people become infected with schistosomiasis through skin contact with contaminated water infested with the *Schistosoma* parasite (Center for Disease Control and Prevention (CDC), 2014). The disease, schistosomiasis, can cause both acute and chronic problems. *Schistosoma* eggs become trapped within human host tissue, resulting in inflammation and tissue damage (Helling-Giese et al., 1996). While FGS affects the reproductive organs, “eggs can be found throughout the body ... as well as in the genital organs of both genders” (Christinet et al., 2016). The most recognized location is the urinary tract where the most apparent symptoms are haematuria (blood in the urine) and dysuria (painful urination) (Bruun & Aagard-Hansen, 2008). With infection, the eggs may exit the body through urine, faeces, and vaginal discharge. However, trapped *Schistosoma* eggs may cause morbidity such as malodorous vaginal discharge (bad smell from the vagina), discoloured discharge, genital lesions, and contact bleeding. The lesions created in the reproductive tract when left untreated and inflamed, may increase the risk of further super-infections such as HIV and Human papillomavirus (HPV) (Downs et al., 2017; Kjetland et al., 2006; Kleppa et al., 2014).

Due to limited resources and infrastructure, as it requires expensive equipment (colposcope) and well-trained healthcare professionals, it is difficult to diagnose FGS, which unfortunately causes it to remain undiagnosed in endemic regions (Søfteland et al., 2021). For prevention of chronic morbidity, the WHO recommends anti-schistosomal (Praziquantel) treatment in school aged children (WHO, 2011). Amongst those children exposed to infested water or living in endemic areas, repeated treatment should be given. Hatz et al. reported a study where children's urinary tract lesions resolved within 2–6 months post-treatment (Hatz et al., 1992). Praziquantel may kill the worms in children before they have managed to create the lesions observed in many adult patients (WHO, 2011). Whereas, untreated FGS can cause irreversible damage to the genitals resulting in lifelong health problems (Kjetland et al., 2012).

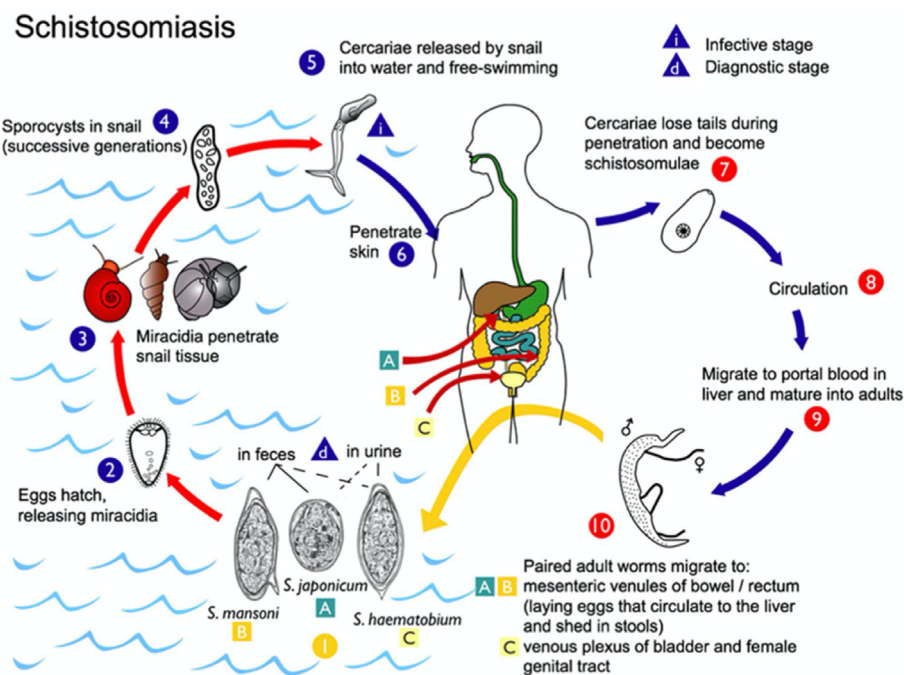


Fig. 1. Schistosomiasis life cycle.

## 1.2. Female morbidity

Schistosomiasis has received insufficient attention as a genital disease (Bustinduy et al., 2022; Nemungadi et al., 2022). However, left untreated, FGS is associated with an increased risk of HIV infection. Similar to many STIs, “FGS causes lesions in the cervix and vaginal mucosa in young women, creating ideal conditions for HIV transmission” (Kjetland et al., 2006; Kleppa et al., 2014).

Healthcare professionals at Primary Health Care Clinics (PHC) and Community Health Centres (CHC) may misdiagnose FGS because the signs and symptoms are associated with STIs. The problem arises when the patient receives treatment for STIs instead of receiving praziquantel, which is the treatment for FGS, because it has little to no effect. (Kukula et al., 2018). It is important to note, that in addition to the physical morbidities, FGS may include consequences such as miscarriage and infertility that may put a strain on women's mental health as well as social status (Lothe et al., 2018). Such consequences may result in stigma and social exclusion, which in turn places a heavy burden on the woman herself as well as her family. Moreover, “misdiagnosis can lead to multiple visits to healthcare professionals, with an increased burden on the patient and the healthcare system” (Kukula et al., 2018).

## 1.3. Water contact as the main risk factor in schistosomiasis endemic areas

Growing up in endemic areas, water connects people and their communities as it is a natural part of the environment and people's daily activities (Kvalsvig & Schutte, 1986; Ndhlovu et al., 1992). Water related activities include domestic tasks (personal hygiene, household chores, collecting water, laundry, washing blankets, bathing), professional activities (fishing, cultural or religious cleansing rituals), and recreational purposes (playing/swimming) or crossing rivers for lack of alternative access routes. Another risk factor for females is managing menstruation, which increases their need for water and sanitation and therefore may increase their risk of infection (Stothard et al., 2020). The sixth Sustainable Development Goal (SDG 6: clean water and sanitation) by the United Nations supports this by recognizing the “unique needs of girls and women for sanitation” (Stothard et al., 2020; United Nations, 2015). FGS thus exemplifies how marginalised women and girls cope with intersecting challenges concerning health, sociocultural, environmental, and economic issues (Moss, 2002). The aim of this study was to identify South African healthcare professionals' perceptions and experiences concerning FGS and reproductive health issues. The research seeks to elucidate the potential gap between the healthcare professionals' work-knowledge and the established research on FGS.

## 1.4. Research questions

- o What roles do behavioural patterns and culture play in patient care, medical treatment and preventive measures regarding FGS?
- o Which barriers do healthcare professionals potentially face in attaining knowledge around FGS?

## 2. Methods

### 2.1. Study area

The study was conducted in Ugu district, KwaZulu-Natal (KZN) province, South Africa, in 2019, selected because of the high prevalence of schistosomiasis in the area, as reported by another study on FGS (Galappaththi-Arachchige et al., 2018). Ugu District covers 5866 km<sup>2</sup> and in 2016, KwaZulu-Natal was populated by 11.1 million people (Lothe et al., 2018). Over 80% of the population are of isiZulu ethnicity, 51% are under 20 years of age, and 55% are female (Hegertun et al., 2013).

## 2.2. Ethical considerations

The study received ethical clearance from the Norwegian Centre for Research Data (NSD 78009), Biomedical Research Ethics Committee of the University of Natal in South Africa (BF029/07), and from the KZN Department of Health and Ugu District Health Department. Every clinic leader gave permission, and all the individual healthcare professionals signed an informed consent form. All forms and original audio recordings are stored at the OneDrive of the University of Agder. However, one informant (a professional nurse lecturer in nursing at the training college), chose to share information about her own medical condition, concerning infertility and recently detected FGS. She wanted to use her condition as a motivator to further develop the field of knowledge related to lower reproductive health and FGS in nursing education.

## 2.3. Selection of clinics

In a schistosomiasis endemic area, two Primary Healthcare Clinics and one Community Health Centre were purposely selected because of the known high prevalence of schistosomiasis in those areas (Livingston et al., 2021) and were conveniently selected for the study, as those three facilities were easily accessible to the researcher. This made it possible to visit them several times to establish trust.

The clinics are referred to as Clinic 1, 2, and 3. Clinic 1 is a Community Health Centre which functions as a referral site for nine local Primary Healthcare Clinics, providing health services 24 h a day, for 33 000 people. The selected informants at Clinic 1 were midwives. Primary Healthcare Clinic 2 is run by nurses and midwives, from 8 a.m. to 8 p.m. Clinic 3 provides 24-h health services, and offers support groups in psychiatry, diabetes, and asthma.

## 2.4. Study design

Interviews with clinical staff and observations were done at the clinics between October and December 2019. The empirical findings were considered in relation to secondary data from observation, interviews and focus group discussions (FGDs) to explore the perceptions and practices of healthcare professionals at PHC clinics concerning FGS. Their recollection of texts (procedures and regulations) in the healthcare sector were thus observed as items governing their choices and actions. The researcher observed how healthcare professionals interacted, if they considered schistosomiasis, and how they met with patients and otherwise organized their workday by documentation, procedures, and institutional work-knowledge (Smith, 2005). The informants explained their activities and conversations, and there were also opportunities for the researcher to ask questions.

## 2.5. Choosing the study sample

Three separate meetings were held with key academic informants in nursing, midwifery, public health, and infectious diseases at the University of KwaZulu-Natal and Durban University of Technology. The aim was to improve the researcher's understanding before meeting the healthcare professionals working in the schistosomiasis endemic areas. The academic informants comprised a public health specialist for information on the health system, a specialist in infectious diseases to discuss training on schistosomiasis, and a lecturer in nursing, to provide information about healthcare professionals' training. Thereafter, data collection took place in the three local primary healthcare clinics in Ugu district.

The study sample was obtained using purposive sampling, “a technique in which the researcher initially samples a small group of people relevant to the research questions, and these sampled participants

propose other participants” (Bryman, 2016). The Clinic Operational Nurse suggested suitable informants, based on the requested criteria which were: healthcare professionals experienced in treating lower reproductive tract problems and/or schistosomiasis (see Table 1 and 2).

Through regular visits the researcher learnt how the clinics organise and administer their routines, the services provided for the patients, and the diseases and challenges they face. Through visits and conversations, the researcher spoke to healthcare professionals about schistosomiasis, as well as how to diagnose and treat this infection. When referring to the respective informants, the researcher distinguishes between “professional nurses” and the “midwives”, who work exclusively with reproductive health. All professional nurses had four years of education. They work in shifts and from those at work on that particular day, the researcher selected those who had the time in their schedule to meet with her.

Although two and a half months are not enough to get an appropriate understanding of the context and FGS, the researcher gained an understanding that could not have been acquired through reading or other resources. As an outsider looking in, the researcher could get some insight into how people interact in South Africa as a multicultural, post-apartheid society. The researcher was able to observe and better understand some of the many challenges that needed to be considered or implemented, such as e.g. the queuing culture that patients follow in the clinics, how some do not have birth certificates, some are not registered citizens, coping with family problems as single parents, large numbers of patients with infectious diseases such as HIV and TB, older patients with chronic diseases, environmental challenges (rain, heat, cold), and governmental challenges (new rules and regulations, shortage of water and electricity). The study enabled the researcher to learn from her respondents and through her observations and analysis, provide a better understanding of the current situation of the local responses to women that may or may not seek help, in an endemic schistosomiasis area. As described in Thurka Sangaramoorthy and Karen Kroeger's ‘Rapid Ethnographic Assessments: A Practical Approach and Toolkit for Collaborative Community Research’, this brief study in a public health setting provided an opportunity to better understand the local concerns, and to offer suggestions for strategies to improve the experiences of women seeking help for FGS (Sangaramoorthy and Kroeger, 2020).

## 2.6. Collecting the data

The researcher visited and observed Clinic 2 five times, in addition to the days when personal interviews were conducted. The researcher met the Operational Nurse [the clinic head] twice, to gain insight into how the government regulations are adhered to and how the clinics work on a structural level. A semi-participative observation was done by sitting with Interviewee 4 three times after the initial interview – both to get an insight in the midwives’ routines, but also to see if schistosomiasis was considered when investigating reproductive problems in pregnant women.

One spontaneous [informal] meeting was held with Interviewee 6 after the initial interview, where a young female patient was discussed [presenting symptoms of STIs although the patient said that she had not

**Table 1**  
Informants’ professions.

	Female	Male	Total
Community health worker (CHW) - lay person	1		1
Professional nurses (PN) - includes specialities in midwifery, psychiatry, and public health and general nursing	17	3	20
Teacher in nursing/Professional nurse	1		1
Medical Doctor (FGS expert)	1		1
Academics in nursing, public health medicine and Infectious diseases	3		3
Total	23	3	26

yet become sexually active]. The researcher also joined an outreach visit [a mobile clinic] with a “Ward Nurse” [Interviewee 12, who was a professional nurse who had specialized in psychiatry] together with a “Community Health Worker” [Interviewee 13, a trained lay person]. “Ward” in this context refers to the geographic area served, so the researcher joined them on their scheduled visits to four households. Thereafter, both were interviewed together.

The interviews were a platform for the respondents to express their thoughts and experiences regarding the research topic. All study subjects spoke English fluently. Semi- and unstructured interviews were conducted in English as part of the exploratory research (Appendix 1). The interviews were a platform for the respondents to express their thoughts and experiences regarding the research topic, and allowed the respondents to talk about personal/controversial issues in a more confidential manner.

Three FGDs complemented the findings of the individual interviews using an interview guide for the FGDs (Appendix 1) (Bryman, 2016). The focus group discussions were carried out with healthcare professionals. They were selected based on their availability at the suggested time. They were experienced healthcare professionals between 30 and 55 years of age, who had worked in rural clinics most of their professional lives. The FGD participants were all women, selected for their availability at the time of the FGD. Three were held to achieve data saturation. The number of participants varied between two and seven healthcare professionals. The FGDs resulted in a sharing of experiences and differing perspectives relating to their professional roles, and were continued until no new information was obtained. The FGDs explored whether the healthcare professionals have any professional knowledge of FGS and whether they can diagnose the problem and differentiate FGS from STIs.

The researcher was not guided by one theory when collecting data, but inspired by Institutional Ethnography and rather tried to extract relevant content from people's work knowledge (O'Reilly, 2012). This included how their work was interconnected with other people's work, as well as texts and discourses.

## 2.7. Data analysis

The data from this study were analysed using an iterative inductive approach, and in accordance with O'Reilly's approach: ‘read-then-do-then-write’ (O'Reilly, 2012). Thus, gathering data, analysing, and writing were linked during the research with constant evaluation of the process. All data were gathered face-to-face, which allowed non-verbal cues as well as verbal communication. The data were reread multiple times and other researchers' views were obtained in order to ensure a deeper understanding. The data were analysed according to Bryman and O'Reilly, with thematic analysis and coding (Bryman, 2016; O'Reilly, 2012; Walliman, 2011). The data were broken down into different themes, by manually sorting all data into categories (thematically and descriptive topics), for example, “schistosomiasis risk water activity” and “patient care”. The analysis also required weaving together the secondary data used in the literature review, the data gathered from the field research and the interpretation of this, enhancing the trustworthiness and dependability (Bryman, 2016). The researcher was able to check the information received from one informant in subsequent interviews, thus confirming the findings.

## 2.8. Reflexivity

Some informants related to the researcher as a nurse rather than as a social science student. The researcher emphasised that she was there to learn from the respondents and hoped it would not prevent respondents from holding back information. Therefore, the researcher assured the participants that her role was as a student, not as a nurse, to avoid confusion.



**Table 2**  
Recall of initial awareness of schistosomiasis.

interviewee number	Female	Male	Profession	Knows schistosomiasis <sup>a</sup>	Site <sup>b</sup>
Focus group discussion	2		Midwife	Unaware	Clinic 1
Interviewee 3	1		Midwife	Aware	Clinic 1
Interviewee 14	1		Midwife	Recalled from childhood, neglected disease today	Clinic 1
Interviewee 4	1		Midwife	Recalled from childhood	Clinic 2
Interviewee 5	1		Professional Nurse	Only through profession	Clinic 2
Interviewee 6		1	Professional Nurse – reproductive health	Infected as a child	Clinic 2
Interviewee 7	1		Professional Nurse	Only through profession	Clinic 2
Interviewees 12 + 13	1	1	Ward nurse, Community Health Worker	Both was aware, referred it to “isichenene” in isiZulu	Clinic 2
Focus group discussion	7	1	Professional Nurses	Mix	Clinic 2
Interviewee 8	1		Professional Nurse – reproductive health	Through profession	Clinic 3
Interviewee 9	1		Professional Nurse	Through profession	Clinic 3
Interviewee 10	1		Enrolled Nurse + Professional Nurse	Through profession	Clinic 3
Expert informant 11	1		Doctor	Recalled from childhood, expert in FGS	Academic <sup>c</sup>
Interviewee 15	1		Professional Nurse + teacher in training	FGS infected	Academic

<sup>a</sup> Question: “Have you heard about schistosomiasis”.

<sup>b</sup> Clinics were in semi-rural area, the interview conducted in the labour ward. Clinic 2 and 3 were in rural areas.

<sup>c</sup> BRIGHT Academy (a research station), Ugu District.

### 3. Results

In the schistosomiasis endemic area of Ugu District, healthcare professionals lacked knowledge of FGS. These healthcare professionals at the clinics were aware of schistosomiasis, but their information was somewhat limited, and schistosomiasis was not linked with the management of e.g. vaginal discharge or infertility.

Although female genital schistosomiasis was unknown to 13 out of 15 informants, schistosomiasis/bilharzia was known as an infection in the urinary system, presenting with blood in the urine, whereas nine interviewees claimed that boys were more likely to have schistosomiasis than girls. This was because schistosomiasis was said to be caused by ‘dirty water’ and boys were more likely to play in the rivers than girls. Interviewee 12 explained that because of the high crime rate: “Mostly boys play in the water, and not girls, because the girls must be protected”. Only one participant said that girls would be most likely, and this interviewee (interviewee 7) herself had been a urinary schistosomiasis patient as a child.

Interviewee 15 described the nurses' role and responsibility at a PHC governmental clinic:

“At the clinics, the nurses function independently [in their role at the PHC clinics]. They see sick acute and chronic patients, conduct deliveries on pregnant women unless there are complications (...) if there is no advanced midwife in that clinic, they refer to hospital where there is a doctor, otherwise nurses here are trained to everything, including dispensing medication according to the patient's problem.”

Thus, it is important that the healthcare professionals have a good professional knowledge of FGS and are able to diagnose the problem and differentiate FGS from other STIs.

#### 3.1. Perceptions about schistosomiasis

The views of the healthcare professionals interviewed appeared to differ as some considered that access to clean water in Ugu had reduced the prevalence of schistosomiasis:

Interviewee 1: “Yes ... Maybe in deep rural areas where they still use water from the river, because here we have tap water.”

Whilst others, such as Interviewee 8, reported that Bilharzia remained a problem, with the river nearby, but was not taken seriously by the local community.

Interviewee 8: “Yes, it is serious, but I don't think, because they are still coming with Bilharzia. You can treat them today and tomorrow, and they are still coming. These children, they are still swimming. ....

They (community) don't take that thing serious, yeah, because sometimes you tell them to bring the child. You'll treat the child today, they will never come back. It is not (seen as) a serious issue, Bilharzia.”

Researcher: “Would women still wash clothes in the river?”

Interviewee 8: “Yes, they do.”

Researcher: “Who will be using the river, here in this community?”

Interviewee 8: “Everyone is using the river.”

Researcher: “Why do you think only the boys who are 12–14 years old will only have Bilharzia, and not the other ones who are using the river?”

Interviewee 8: “Most of them swimming. There is a big river that side.”

Researcher: “So, you won't be affected if you just use water to wash hands and things?”

Interviewee 8: “No, you won't be affected.”

Researcher: “How do you think ... how will the Bilharzia enter your body while swimming?”

Interviewee 8: “When you are swimming you are naked, right? They can enter through the penis, or the vagina if you are female”.

#### 3.2. Perceptions about FGS

The majority of the interviewees did not recognize schistosomiasis as a disease affecting the genitals:

Interviewee 3: “No, it is not one of the sexual transmitted diseases. It is usual, if you are not pregnant, even the children; if they swim in the river, they use to contract Bilharzia ... Because Bilharzia is a normal condition. Yes. It is not like HIV or sexual transmitted diseases. They don't feel ashamed because it's not sexual something.”

#### 3.3. Awareness of prevalence of schistosomiasis

Many informants claimed that schistosomiasis is a rare disease nowadays. As indicated below:

Interviewee 6: “It's not very common nowadays. Even though it comes, it comes very rare. It's something that's, hm, that's really really, really rare ... I mean, you should see, even the treatment for

Bilharzia that we have stays very long ... I mean, the package, the one we have, it is not very quick to run out. I mean, one pack stays the whole year to get finished.”

At Clinic 1, the midwives said that they had not seen schistosomiasis in their female patients and did not understand why the researcher would ask about it.

Interviewee 1: “It is rare to see a patient with Bilharzia, but if ... there is Bilharzia in the urine, they will order praziquantel (the treatment for schistosomiasis) and it is given according to the weight of the patient.”

Common knowledge was that schistosomiasis is prevalent amongst young boys swimming in the rivers and dams, and that the symptom is blood in the urine. Several of the interviewees also mentioned that schistosomiasis was a common disease when they were young. However, Interviewee 4 said there was a lot of (urinary) schistosomiasis while she was growing up, but it was not until she went to nursing college that she understood that schistosomiasis needs medical attention. Interviewee 8 said that they sometimes find blood in urine these days, although it is rare in females. She had given a patient schistosomiasis treatment three months previously, then it had been more than 2–3 years since she had last prescribed it. This was supported by Interviewee 6 who said that 6 tablets anti-schistosomal medication praziquantel (Biltricide®), could last up to a year at Clinic 2, revealing an extremely limited focus on schistosomiasis in this schistosomiasis endemic area.

### 3.4. Healthcare professionals' knowledge on the causes of schistosomiasis

Every informant was aware that the disease is spread through contaminated water, usually through recreational water contact, such as playing and swimming. Many interviewees explained as reported below that:

Interviewee 1: “Bilharzia was common in young boys who used to swim in the river.”

Several informants said that if one is naked the schistosomiasis parasite can swim through the orifice of the urethra (urinary tract opening) and some said that drinking it could irritate the bladder. Only one informant was aware that skin contact with infected water would suffice for schistosomiasis infection. Most informants answered that the majority of people have tap water installed in their houses nowadays for household chores.

Interviewee 1. “Yes ... Maybe in deep rural areas where they still use water from the river, because here we have tap water.”

However, water outages are common in this district, affecting the lower socioeconomic classes, especially. When tap water is not available, people must collect water from other sources, such as rivers and dams. Interviewee 12 clarified that they boil the water or add a teaspoon of chlorine before using it because most people are aware that their river water is contaminated. He stated that schistosomiasis is not contagious unless one is fully naked under water but did not know how the parasite enters the body. Almost all informants shared the same understanding as Interviewee 12 below.

### 3.5. Knowledge about symptoms of schistosomiasis

All of the informants knew that haematuria (bloody urine) is a common symptom of schistosomiasis. Interviewee 12 explained:

“Once they have seen the signs. I think that the most obvious sign is, whenever one is urinating, is that the urine is bloody. It becomes very, very red. And then one having this problem, will come to the clinic. And then, they will treat that Bilharzia.”

However, there was a lack of knowledge about FGS, and confusion with STI symptoms, as explained:

Interviewee 12. “There is no connection ... you say there are symptoms of STI. You would think of “maybe there is some sort of a cancer”. But there no connection between these two; urinal and genital issues.”

During an interview, Expert Informant 11 [doctor in infectious diseases, female] clarified this by explaining how bloody urine often disappears without treatment, because the worms inside the body move to other organs, die, or eggs are trapped inside hardened lesions.

### 3.6. Diagnosis, prevention and treatment of FGS

FGS may cause morbidity in the lower reproductive tracts (and other organs) at an early age (Kjetland et al., 2012; Magaisa et al., 2015). Hence young girls may experience problems similar to sexually transmitted diseases, even before they are sexually active. In children, one cannot easily perform an intravaginal examination, using ordinary adult-size speculums. Furthermore, young girls may be embarrassed to report this:

Interviewee 4: “Some girls, they would feel as they are reporting lower reproductive health problems, we will assume that they are sexually active. So maybe they will under-report, feeling that we will be thinking that they are sexually active, just because they are reporting lower reproductive health problems. So that is an obstacle.”

Interviewee 5: “Hm (thinking), because I don't remember any STI/sexual transmitted diseases in which the patient presents with blood in urine. They only present with just a discharge or ulcers or warts.”

### 3.7. Questioning the development of FGS

Researcher: “The worms would go to the urinary or genital tracts – because the worms favour those parts of the body, right? But would the worms, after some time, spread to other organs as well?”

Expert Informant 11: “We do not know when the worms move around, some research in this area indicates that parasite eggs are in the genital organs already in childhood. You may have noticed that you had red bloody urine when you were a child but when you are an adult, you don't notice that anymore. And there is a lot of reasons for that, I won't delve into it. They might get stuck in the kidney region, blocking off the drainage. And if they are here, they are silent; you don't feel them.”

Researcher: “So, when they [the worms] are finished in one place, they move to another place?”

Expert Informant 11: “That could be a way, or they could go and block fallopian tubes and make you infertile, or if they are sitting on the surface [of the vaginal tract], they can create a bloody surface for the women. In men, they can go into the prostate.”

However, interviewees 3, 4, and 6 explicitly said that red urine disappeared after growing up, although they did not receive medical treatment.

### 3.8. Knowledge about syndromic management of disease

Expert Informant 11, who has handled many women with both FGS and STIs issues, explained that it is impossible to draw a conclusion based on symptoms:

“Well, I do not know if she has FGS: if a patient reports smelly discharge, it could be sexually transmitted disease or cancer; a burning sensation in the genitals; bloody discharge could be cancer;

pain during sex could be psychological, you know – perhaps a problem with husband/partner or endometriosis, - it could be STIs, it could be cancer.”

Expert Informant 11, who knows the complexity of FGS, says “contact bleeding” is an issue related to FGS:

“(…) sometimes it bleeds as I open the speculum [device to inspect the vagina]. I am very gentle when I work, gentler than a sexual intercourse. And these women must be bleeding after every sexual intercourse; some of them are so damaged.”

Interviewee 4 confirmed this as she said she is not comfortable with using a speculum due to “contact bleeding”. However, she seemed to consider “contact bleeding” in pregnant women to be normal (which is incorrect, per personal communication with Gynaecologist Obstetrician Tarek Meguid). She did not want to inspect as it could lead to anxiety for the patient and herself.

### 3.9. Knowledge about the diagnosis

During the FGD, participants were shown the “WHO Pocket Atlas for Female Genital Schistosomiasis” which portrays images of different types of morbidity caused by *S. haematobium* on the surface of the cervix or in the genitals (Mbabazi et al., 2015). Participants recognized some of the clinical cases that they had seen in real life, one informant said the pictures in the pocket atlas shows eroded cervixes can be seen in prolapse [a condition when the organ is out of place or sunken]. Two participants said they would suspect that the patients had cancer and they would refer her to the hospital. Another participant said a picture (page 25), resembles menstrual blood.

### 3.10. Lack of FGS in nurses' and midwives' curriculum

Interviewee 6 had not heard of FGS, but he said that urinary schistosomiasis was included in the curriculum during his nursing education, as confirmed by interviewee 15, who is a lecturer in nursing. Interviewee 15 informed the researchers on the curriculum:

“The curriculum is developed by the different nursing education institutions and it is approved by the South African Nursing Council. I would like to believe that they just forgot to include FGS in the curriculum maybe because the majority of the curriculum development team are not affected by it or they are from the big cities, so they are not so sure that it has affected a lot of people.”

Interviewee 15 said she remembered being sick as a child, although she did not get medical treatment. She was recently diagnosed with infertility due to FGS. She explained how her understanding of schistosomiasis and FGS changed only because of her own medical condition.

Interviewee 15: As a professional registered nurse, and a lecturer ... I was clueless. I do have information, but it was so limited, until I went into depth researching about it, for my own personal use ... it is not there, in the curriculum.

An informal informant working within Public Health explained that FGS is neglected because the country has such a big burden of other infectious diseases, such as TB, HIV, and malaria.

### 3.11. Cultural consequences of genital problems in young girls

According to several informants, in the isiZulu culture it is traditional that the husband-to-be will pay ‘lobola’ (bride-price) to his future wife’s family. Currently, this is the value of 12 cows (approximately US\$ 4739) and the final amount is the topic of serious negotiation between the two families. If the bride-to-be is not a virgin the price may be reduced. Although virginity testing is illegal in South Africa it occurs in traditional

communities and a study has shown that the majority of school-going young women are prepared to be tested (Taylor et al., 2007). Interviewee 4 explained that if a girl’s child presents with signs and symptoms of STIs:

“We just refer her to hospital because it is beyond us. Because we cannot pass a Cusco [do a speculum investigation]. If we do that, we have to pay the cow [laughing]. It will be like, deflowering, breaking the hymen, and traditionally that is done by the husband when the girl is married and he paid a cow for her ... I can’t pay a cow ... how many cows am I going to pay? [laughing]. So, we mostly send them to hospital. And mostly, their parents don’t consent the Cusco being passed, until the girl is no longer virgin.”

Several informants told the researcher that they have seen young female patients who said that they are virgins, but who complain of symptoms resembling STIs. In such cases it is appropriate to consider FGS as a cause. Nevertheless, there were several healthcare professionals who would find it difficult to provide adequate healthcare, as it is not “logical” that a young child before sexual debut should show symptoms which appear to be STIs.

Interviewee 14 was experienced with “virginity testing” as a ritual to reveal if young girls are “pure” or not engaging in sex before marriage. She explained that girls often lie about having sex because they do not want to lose their value and honour due to a broken hymen. The hymen is an accurate pointer to a woman’s sexual status:

Interviewee 14: Firstly, it is a pride of the family. Having a hymen is a pride. It is something precious. So, losing it, it must be known. “How did you lose it? You have to explain to the parents.”

Researcher: Ah, what’s it called ... like a bride price ... what do you call it?

Interviewee 14: The “Mqhoyiso” [chuckle laugh].

Researcher: Ok, so it [she] will lose value?

Interviewee 14: Exactly. You lose the value. The bridal price has to be reduced.

Researcher: Would such lead to stigma, you think?

Interviewee 14: Sort of, that is why you have to make sure that you keep it very safe.

This indicates that social and cultural norms and practices lead to guidelines regarding what healthcare professionals can and cannot do in cases where they suspect illness.

Likewise, in discussion with Interviewee 6 he said he had a young female patient with problems in her genitals although she was not yet sexually active. He could not do a vaginal examination on her without her parents’ permission, and he assumed they would refuse for fear of losing their daughter’s value due to lost virginity.

## 4. Development of knowledge about FGS

### 4.1. Training of professional nurses in South Africa

Universities use the strategy of “problem-based learning” (PBL) in training professional nurses. With this strategy, the students learn based on the cases they meet, under supervision, in their clinical practice periods. According to Interviewee 15, Nursing Colleges do not have enough laboratories and computer labs. Therefore, colleges primarily use oral lectures in addition to “in service training”. Interviewee 15 further spoke about a new strategy called “Continued Professional Development” for nurses, which is a pilot project to be rolled out to ensure they stay updated.

#### 4.2. Measures to increase knowledge about FGS

After the interviews interviewees were asked how to develop a higher level of knowledge about schistosomiasis. Interviewee 14 answered:

“Hm, I think, going to the communities but, because the healthcare professionals do not know about it. That’s a first thing; they must help the healthcare professionals know about it and understand. What it [FGS] is, and the affects is. And if they know ... you know, there are community outreach, even in rural areas, they can be included. When the community health workers go for outreach in the rural area, we include the diagnoses. Like, when they do BP checking [blood pressure], checking for diabetes. It must be included, checking for bilharzia [schistosomiasis]”.

During the FGD Interviewee 4 said she wanted to be trained so that she can recognize the FGS disease:

“Because I was going to suggest. Because we are professional (...) If they can make a pamphlet that can be distributed amongst the facilities. Because there are a lot of facilities, if you can imagine KZN as a whole (...) It can even assist us to educate the patients.”

Considering “training of health personnel” as a measure to develop a higher level of knowledge regarding FGS in the community health services, the researcher asked Expert Informant 11 if speculum examination is necessary for training. The answer was following:

“We want to develop a teaching tool that is cell phone based, where they can look at images; be trained and tested, as many people now have a smartphone. For me, it has taken about 6 weeks to train other doctors, and here we have to train nurses to do it because they are in the frontline.”

## 5. Discussion

None of the local healthcare professionals in these schistosomiasis endemic areas had heard about female genital schistosomiasis, except one person who was diagnosed after extensive investigations for infertility. The study found that there was neither health education nor health promotion on female genital schistosomiasis. Further, urinary schistosomiasis was not considered a current health concern despite 20% prevalence, regular tap water outages in the area, and current use of the rivers (Galappaththi-Arachchige et al., 2016; Hegertun et al., 2013; Livingston et al., 2021). According to the study informants, schistosomiasis and the isiZulu and English terms (Isichenene and Bilharzia) refer exclusively to urinary *S. haematobium* infection. Reproductive problems due to the *S. haematobium* are not considered.

To diagnose *S. haematobium*, healthcare professionals use a urine dipstick. If haematuria is found, the next step is to send a urine sample for laboratory testing. If this is positive for urinary schistosomiasis, the patient will receive medication. However, this is rarely done and the anti-schistosomal tablets are “on the shelves” for many months or even years. Moreover, *S. haematobium* may be found in the genitals without involvement of the urinary tract (Kjetland et al., 2005; Poggensee et al., 2001). The urine dipstick is then not adequate. In such cases, it is necessary to do a gynaecological examination (Søfteland et al., 2021).

Syndromic management is an algorithm used by healthcare professionals as a strategy to choose broad-spectrum treatment for e.g., vaginal discharge, which would warrant treatment for three diseases (Chlamydia, gonorrhoea and trichomoniasis) (Kjetland et al., 2014). However, current patient management protocols make no mention of FGS and healthcare professionals are not aware of the symptoms and clinical manifestations of FGS. It follows, that it is easy to misdiagnose FGS.

Research has shown that FGS causes damage in the lower reproductive organs even in childhood and young girls may experience problems

that resemble STIs, even before they are sexually active (Hegertun et al., 2013). Thus, it is important that healthcare professionals understand that girls and women who have been exposed to fresh water may symptoms similar to the STIs but caused by FGS (Kjetland et al., 2012). The World Health Organization renamed urinary schistosomiasis as “urogenital” schistosomiasis recognizing the importance of FGS and the suffering of the many women (World Health Organisation, 2009).

In Ugu District, there is a gap in healthcare professionals’ understanding of the aetiology, transmission and prevention of schistosomiasis, and the diagnosis and sequelae relating to FGS. The situation in Ugu District amongst healthcare professionals is similar to that reported by others who have shown that health care professionals lack knowledge about FGS (Mazigo et al., 2021; Williams et al., 2022). Although FGS was first reported in 1899, it has received limited attention inside the health systems.

Although the prevalence of schistosomiasis was found to be high with almost a third of primary school girls infected (Hegertun et al., 2013), it appears that girls and women in this district have not received information or treatment. However, this study showed that there is a willingness amongst healthcare professionals to improve their knowledge, they wanted to meet their communities’ needs. This underscores the need for health education on FGS and health promotion amongst healthcare professionals.

### 5.1. Knowledge about schistosomiasis

All informants in this study knew that contact with contaminated water causes schistosomiasis, which is consistent with previous research (King & Dangerfield-Cha, 2008). Health professionals in this study claimed that local communities now have a provision of clean water and that this prevents schistosomiasis transmission, but many informants concurred that swimming in the rivers remained a recreational pastime for children. Healthcare professionals were sometimes unaware of the risk of schistosomiasis infection by skin contact with infested water (Musuva et al., 2014). Furthermore, water outages are common in Ugu District and the lack of a daily clean water supply means that many in the community use the river water occasionally or as their only available source (Secor et al., 2003).

### 5.2. Prevention of schistosomiasis

In the study clinics, there were posters concerning TB and HIV but no posters about schistosomiasis, possibly indicating low awareness or that this disease is not considered important. Preventive measures include Mass Drug Administration in endemic areas, as recommended by the WHO, which would require access to praziquantel. Although this is included in the School Health Policy, it has yet to be implemented (Livingston et al., 2021; Nemungadi et al., 2022; South African National Department of Health, 2008). Improved water and sanitation would reduce risk factors for schistosomiasis transmission as specified in the sixth UN Sustainable Development Goal, and would improve the lives of the rural communities, and women in particular (United Nations, 2015; WHO, 2011). Further, HIV and FGS are closely linked, and prevention programs are very necessary (Engels et al., 2020). In this study, healthcare professionals, being unaware of FGS, were unaware of these associations.

In the light of Institutional Ethnography, it is noted that the common beliefs about schistosomiasis are out-dated. Urinary schistosomiasis was first reported in South Africa in 1863 (Harley, 1864). Discourses regarding schistosomiasis, as affecting “mostly boys”, and being an exclusively “urinary problem,” are well established in this society and among these healthcare professionals. The literature and research on FGS indicate otherwise, since girls perform, for example, household chores, cross rivers, and perform customary rituals involving river water.



### 5.3. Training of healthcare professionals and their tools

Healthcare professionals are guided by written procedures and routines that must be adhered to, to provide continuity and accountability (National Department of Health, 2020). Many informants were confused by the topic of the unfamiliar manifestation of schistosomiasis, namely FGS. The researcher explained that their current lack of knowledge about FGS was to be expected as FGS is known to be a neglected tropical disease. *S. haematobium* may be part of the urinary tract syllabus for health professionals, but the lack of information on FGS indicates that amendments in the curriculum and in the guidelines are required. In our opinion, each clinic should have more than one skilled nurse on the presentations and diagnosis of FGS. Furthermore, adequate equipment to examine the cervix and vagina is needed (Softeland et al., 2021). The training is required for the healthcare professionals since FGS is a differential diagnosis to STIs and cervical cancer in this FGS high-endemic area (Livingston et al., 2021).

The symptoms of FGS may be similar to those of an STI and such symptoms may “prove” that young women are no longer virgins. In addition, our study indicates that the cultural importance of an intact hymen, is relevant to the clinical investigations for FGS. The importance of virginity may prevent health professionals from undertaking gynaecological investigations as they may be blamed for deflowering young women. This prevents healthcare professionals from undertaking the necessary investigations for FGS. Hence the clinical decision-making power is threatened by external power factors, including cultural factors (Smith, 2005).

The neglect of FGS is not only a local problem in South Africa, but also a global problem affecting 56 million women (Hotez et al., 2009). Since FGS remains undiagnosed, this constitutes a marginalization and discrimination of millions of women who are being exposed to social stigma and negative self-esteem. As explained by the informants, girls may be perceived to be of “less value” if presenting with symptoms of STIs. In other words, such a diagnosis causes external pressure that threatens women's self-agency. The healthcare professional's judgment is important and the impact of not diagnosing FGS may marginalise women in society, as well as confuse healthcare professionals. The training of healthcare professionals thus will require emphasis that FGS is not sexually transmitted. Likewise, it is important that health education on FGS is provided to schools and communities. Barriers could be further reduced by providing adequate diagnostic tools (Holmen et al., 2015; Softeland et al., 2021). This is currently under investigation and shows much promise.

### 5.4. Strengths and limitations of the study

Ideally, interpretivism requires participative observations in the designated research field and context over a long period of time, rather than observations and interviews, over a short period of time (Alvesson & Sköldberg, 2018). We did not include data collection from patients as it was beyond the scope of the study, but it could have improved our understanding about the needs. At Clinics 1, 2 and 3, direct observations were undertaken to perceive the behaviour and care processes within the clinic setting, rather than participatory observation. However, confirmability was maintained since the information and the findings were repeated by several informants and were therefore comparable. The findings indicate a lack of knowledge about FGS and the need to address this by training the healthcare professionals as has been seen for other sub-Saharan countries (Jacobson et al., 2022; Schuster et al., 2022). Further in a recently published paper Nemungadi et al. (2022) suggests the establishment of a Female Genital Schistosomiasis control program in the existing health system (Nemungadi et al., 2022).

## 6. Conclusion

In the District of Ugu, where several studies have found a high prevalence of Female Genital Schistosomiasis, there is a gap between the

biomedical research findings and the healthcare professionals' knowledge about *S. haematobium* (Livingston et al., 2021). Although schistosomiasis is a well-known urinary disease, FGS is not known in primary healthcare clinics. Healthcare professionals should be able to educate, manage and treat patients, but local healthcare professionals should not be blamed for their lack of knowledge (Nemungadi et al., 2022). We recommend that the national and provincial health authorities support the message on FGS to reach people at risk, patients and healthcare professionals alike. The disease should be included in treatment protocols, such as the syndromic management of vaginal discharge, vaginal lesions, and infertility. FGS should be included as a differential diagnosis during any speculum investigation. The education of healthcare professionals, and Continued Professional Development (post-graduate training) should include FGS to sustainably address what seems to be an under-diagnosed disease, with severe impact on primarily rural women, who represent a group already marginalised in society and in their access to healthcare. Further research is needed on diagnostic aids.

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## Intellectual property

We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

## Research ethics

We further confirm that any aspect of the work covered in this manuscript that has involved human patients has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript.

IRB approval was obtained (required for studies and series of 3 or more cases).

## Authorship

All listed authors meet the ICMJE criteria.

We attest that all authors contributed significantly to the creation of this manuscript, each having fulfilled criteria as established by the ICMJE. We confirm that the manuscript has been read and approved by all named authors. We confirm that the order of authors listed in the manuscript has been approved by all named authors.

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## Appendix A. Supplementary data

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