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Exploring the consequences of female genital schistosomiasis among women in endemic districts in Southern Ghana: a phenomenological study using photovoice methodology

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Abstract

Background Female genital schistosomiasis (FGS) is a gynaecological indication of Schistosoma haematobium infection characterized by parasite egg deposition in the genital tracts of girls and women. Despite its health and social consequences, women's lived experiences with FGS remain poorly documented. This study used a photovoice approach to contextualize the experiences of women with female genital schistosomiasis (FGS) in endemic districts in Southern Ghana.

Methods This was a phenomenological research design that applied photovoice to data collection. Eight Photovoice Group Discussions (PGDs) were conducted with 54 women aged 18 years and older, who self-identified as having experienced FGS. Data were collected between June and November 2022. All discussions were audio-recorded, transcribed, and analysed thematically with the aid of NVIVO 12 qualitative data analysis software.

Results The study participants demonstrated a clear understanding of the concept of "photovoice" and used thought-provoking photographs to express their experiences with FGS. Women reported multiple health and social challenges associated with the FGS, including abdominal pain, vaginal odour or itches, reproductive complications such as infertility, as well as social trauma and stigma.

Although some participants recognized contaminated water exposure as a risk factor, misconceptions about the causes of FGS such as witchcraft, infidelity, and Sexually Transmitted Infections (STIs) were common.

Conclusions FGS has substantial health and psychosocial impacts on affected women. Strengthening community education and integrating FGS awareness, diagnosis, and management into reproductive health and schistosomiasis control programmes are critical to improving early detection and reducing stigma in endemic communities.

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Photovoice offers a valuable participatory approach for documenting women's experiences and informing community-responsive health interventions.

Keywords Photovoice, Schistosomiasis, Female genital schistosomiasis, Ghana

Introduction

Schistosomiasis, also known as bilharzia, is a chronic and acute neglected tropical disease (NTD) caused by parasitic flatworms of the genus *Schistosoma*. According to WHO estimates, at least 251.4 million individuals needed preventative treatment for schistosomiasis in 2021. Transmission of schistosomiasis has been documented in 78 countries, most of which are in Africa [1]. Women and children between the ages of 10 to 19 years have been identified as high risk of schistosomiasis infection because women use water on a daily basis for chores, and children who often play in water [2].

Schistosomiasis is prevalent in tropical and subtropical regions, particularly in impoverished communities that lack access to safe water and adequate sanitation. At least 90% of people in need of schistosomiasis preventive chemotherapy live in Africa [1, 3].

Female genital schistosomiasis (FGS) is a gynaecological complication of *Schistosoma haematobium* infection, caused by parasite egg deposits in the female genital tract [4]. *Schistosoma haematobium* is the primary species in the genus that causes urogenital schistosomiasis due to egg migration and deposition in the bladder and urethra, frequently resulting in gross haematuria in those infected [4].

In women and adolescent girls, clinical signs of FGS include atypical vaginal discharge, stomach and pelvic pain, dyspareunia, and post-coital and contact bleeding. Infertility, ectopic pregnancies, abortion, early birth, and low birth weight have all been linked to chronic FGS [5]. Evidence suggests that FGS increases the chance of contracting the human immunodeficiency virus (HIV) up to threefold and is associated with increased risk of HPV infection [6, 7].

Over the last decade, research on Female Genital Schistosomiasis (FGS) has increased, although much of the literature still focuses broadly on Schistosomiasis rather than the gender-specific manifestations of the disease. In Ghana, a qualitative study examining healthcare practitioners' knowledge and practices regarding FGS, as well as girls' and women's awareness of the condition, found that FGS was rarely considered in differential diagnosis by medical professionals. The study also reported that adolescents seeking care were frequently stigmatized because FGS symptoms were often misinterpreted as sexually transmitted infections [8].

Similarly, a cross-sectional study conducted in schistosomiasis-endemic communities in Ghana assessed the knowledge and awareness of genital involvement and reproductive health consequences associated with urogenital schistosomiasis. The findings showed that only 18.9% (207/1096) of participants were aware that urogenital schistosomiasis can have reproductive health implications [9]. Several studies have also estimated the prevalence of FGS and examined the parasitological pathology of schistosomiasis among women [6, 10].

Despite these efforts, there remains a paucity of research exploring the lived experiences of women of reproductive age affected by FGS and its symptoms. To address this gap, this study employed photovoice within a qualitative approach to better understand the direct and indirect experiences of women of reproductive age who self-reported schistosomiasis or FGS in endemic communities.

Photovoice is a participatory research technique that allows individuals to express their experiences beyond verbal narratives [11, 12].This is particularly useful for populations with limited verbal expression, language competence, or difficult-to-understand emotional experiences [13, 14]. With this method, participants captured photographs representing their experiences, and subsequently discussed these images through a focus group discussion. In this study, the photovoice approach was used to contextualize the experiences of females experiencing FGS within the North-Tongu and Weija districts in Ghana.

Methods

Qualitative research approach

This study employed a phenomenological research design that utilized photovoice for qualitative data collection. This approach was particularly suitable as it enabled researchers to explore lived experiences related to a specific phenomenon—in this case FGS. Data were collected from June to November 2022. This involved Photovoice Group Discussions (PGDs) with women who have experienced FGS. These discussions provided a platform for participants to share their thoughts and experiences related to FGS through the use of photographs.

This paper is part of a larger study called "FGS Accelerated Scale Together (FAST) Transition to Scale project: Improving Women's Health by Reducing Morbidity from Female Genital Schistosomiasis in Ghana (The FAST Package Project)". The main aim of the FAST Package is to improve adolescent girls' and women's health by reducing morbidity associated with FGS through preventative and curative efforts [15, 16]. This manuscript presentation is guided by the Standards for Reporting Qualitative Research (SRQR) guidelines [17].

Study site

This study was conducted in southern Ghana, specifically in the North Tongu District in the Volta and the Weija District in the Greater Accra Region. The two districts were selected because they have several communities along the Volta Lake (the largest artificial reservoir in the world) and Weija Dam (the second largest water reservoir in the country after the Volta reservoir), where the Ghana Health Service reports that schistosomiasis due to *Schistosoma heamatobium* prevalence is at least 80% in both districts [18].

Sampling strategy

The Photovoice Group Discussion (PGD) process was conducted in multiple stages. Firstly, study participants were identified from FGDs held earlier on schistosomiasis and FGS. Women who reported having experienced FGS were identified during the FGD and their contact information taken. The identified women were then followed up though by phone calls and home visits, during which informed consent was obtained to participate in the photovoice session. During the consent process, the aims and purpose of the study were clearly explained to participants.

In the second stage, the study participants who consented to participate were invited for a first PGD session. In this session, the concept of "Photovoice" was explained in detail to participants as a means to utilise photography to represent and express their experiences of FGS. To facilitate understanding, a hypothetical scenario describing a young lady who has experienced FGS with complications like lower abdominal pain, vaginal discharge, pain during sex, or bleeding after sex, among others was presented (see Supplementary File 1). Participants were then given the opportunity to ask questions about what had been discussed and the session was audio recorded. At the end of the session, participants were asked to reflect on the photovoice concept and tasked with presenting at least two photographs the following day that reflect their personnel experiences with FGS, including how they felt and how they managed the condition. Participants with smartphones were asked to take photographs themselves, while those without smartphones were assisted by a facilitator to capture the images they identified.

In the third stage, the study team and participants reconvened at the same venue the next day for the second PGD session. During this session, each participant presented the photographs they had taken and explained their relevance to their experiences with FGS. The discussion focused on why the photographs were chosen, what made them meaningful to the participant, and how participants felt about each other's pictures. Also discussed were the causes of FGS and strategies to control it in the community.

Sample size

The principle of data saturation was applied in this study to determine the sample size for the study. Data saturation is achieved when no new themes, patterns, or insights emerge from the interviews, indicating that additional data collection would likely yield redundant information. This approach is widely recognized in qualitative research as a means of ensuring that the data collected is sufficiently rich and exhaustive [19–21]. Based on the principles of data saturation and guided by information power [19], a total of 8 PGDs were conducted, with each group consisting of approximately six women. The PGDs were conducted across the two study districts, with 4 PGDs held in North Tongu (2 with younger women and 2 with older women) and 4 in Weija (2 with younger women and 2 with older women). Younger women were defined as those aged 19–29 years, while older women were aged 30–49 years.

The number of PGDs was considered sufficient to generate in-depth insights into women's experiences with FGS while minimizing unnecessary redundancy [19].

Data collection methods

Photovoice Group Discussions (PGDs) were conducted by two experienced qualitative Research Assistants (RAs) in the local languages spoken in the study communities (Ewe and Akan). One RA served as the moderator and the other as a notetaker. Similar to traditional Focus Group Discussion (FGD) [22, 23], a total of eight PGDs were conducted with 54 participants, with each group comprising 6–8 women who discussed their experiences related to FGS.

The PGDs were held within the communities using an interview guide developed specifically for this study with input from subject experts (see Supplementary File 2). Each session lasted approximately 90 min and was audio recorded with participants' consent.

Trustworthiness

Several strategies were employed to ensure the trustworthiness of the study, guided by the principles of credibility, dependability, confirmability, and transferability [24].

Credibility was enhanced by training facilitators on moderating group discussions, managing group dynamics, and encouraging participation from all members. This helped minimize potential power imbalances and fostered an environment that promoted open and open dialogue. The use of participants' photographs during the discussions also facilitated deeper reflections and richer descriptions of their experiences with FGS.

Dependability was ensured by using a semi-structured interview guide developed with input from subject experts, which provided consistency across the PGDs while allowing flexibility for participants to elaborate on their experiences.

Confirmability was strengthened through audio recording of all PGD sessions and detailed note-taking by the research assistants, which allowed the research team to cross-check the data and ensure that interpretations were grounded in participants' accounts.

Transferability was supported by including participants from two different districts and organizing the PGDs into two age groups— younger women (19–29 years) and older women (30–49 years). This diversity of participants enabled the capture of varied perspectives and experiences related to FGS.

Data management and analysis

The PGDs were audio recorded and later translated and transcribed into English. The transcripts were reviewed for accuracy and completeness before being uploaded into NVivo 12 qualitative software to facilitate data management and coding. To enhance the rigor and trustworthiness of the analysis, two researchers independently coded the transcripts. The analysis followed Braun and Clarke's approach to qualitative data analysis [25].

The initial stage involved thoroughly reading through the transcripts to familiarize themselves with the data. Guided by the study objectives, they identified recurring ideas and patterns that emerged from the data. Based on these initial observations, a codebook was developed to outline key themes and subthemes relevant to the research questions. Following the development of the codebook, each researcher conducted independent coding of the transcripts, ensuring an unbiased approach to data interpretation. After completing the coding process, the researchers collaborated to compare their findings, discussing any discrepancies in theme identification and interpretation. Through this iterative process, they refined the themes and reached a consensus on the most accurate representation of the data. A thematic analysis approach was then employed to systematically analyse the data, allowing for the identification of meaningful patterns and insights pertinent to the study's aims. This method enabled researchers to delve deeper into participants' lived experiences about FGS, ensuring that the findings were both representative and reflective of their perspectives.

Table 1 Socio-demographic characteristics of the study participants

Characteristics	Frequency($n = 54$)	Percentage (%)
Age		
19–29	26	48.15
30–49	28	51.85
Educational Status		
No education	26	48.15
Primary	16	29.63
Junior High School	12	22.22
Marital Status		
Not Married	36	66.67
Married	18	33.33

Consent to participate

Written informed consent was obtained from all participants after providing detailed information about the study and addressing any questions they had. Participation was entirely voluntary, and participants were informed of their right to withdraw from the study at any time without any consequences. Participants were also assured of the anonymity and confidentiality of the photographs they produced. To further protect privacy, photographs featuring identifiable individuals were excluded from the manuscript.

Results

A total of 54 community members in 8 groups participated in the PGDs exercise. There was an average of 6 participants per session. The majority (51.85%) fell within the 30–49 year age group. A higher proportion of the participants have no formal education (48.15%) and 66.67% were not married (Table 1).

Themes and sub-themes

The themes and sub-themes that guided the presentation of the results are outlined in Supplementary File 3. Six main themes emerged from the analysis: (1) participants' experiences with the photovoice process, (2) participants' experiences with Female Genital Schistosomiasis (FGS), (3) community perceptions of the causes of FGS infection, (4) participants' experiences of the consequences of FGS, (5) health-seeking behaviour for FGS, and (6) community suggestions to improve the control and management of FGS.

Across these themes, several sub-themes were identified, including reflections on the photovoice process, personal and community experiences with FGS, perceived causes of infection such as contaminated water, witchcraft, infidelity, and sexually transmitted infections, as well as the health and social consequences of the condition. Additional sub-themes captured participants' treatment-seeking practices—including the use of health facilities, traditional and herbal remedies—and community-level recommendations such as health education, improved access to safe water, and increased awareness of praziquantel.

Overall, participants' accounts across the themes and sub-themes were largely consistent across the two study districts and the different age groups.

Participant's experiences with photovoice

Participants expressed enthusiasm about the photovoice approach and reported that the process enabled them to reflect deeply on the experiences of women affected by Female Genital Schistosomiasis (FGS). Many participants indicated that using photographs helped them articulate and visualize their experiences more effectively. The process encouraged reflection and discussion about everyday situations that symbolized the condition and its effects on women.

Initially, some participants suggested taking photographs of physical symptoms such as vaginal rashes or discharge. However, facilitators discussed the ethical concerns associated with photographing sensitive body areas. Despite this limitation, participants creatively identified alternative images that symbolically represented their experiences with FGS, including environmental objects and everyday community scenes.

One participant explained how the exercise encouraged deeper reflection:

> *"We are very happy about the exercise. At first, I thought it was a difficult thing to do. But when I went home, I thought deep, and the issues started coming. I even have lot of pictures to depict some of the situations, but because you said two pictures, I had to limit the pictures." (Young women, 19–29 years, North Tongu).*

Similarly, another participant highlighted the excitement generated by the process:

> *"This is an exciting thing. I have really enjoyed the process of using pictures to show FGS experiences." (Older women, 30–49 years, Weija).*

Participants' experiences with FGS

All study participants reported to have experienced FGS and were familiar with the common signs and symptoms, which included blood in urine and lower abdominal pain. In addition to their first-hand experience of FGS, some participants also shared insights gained from a close friend/neighbour. These experiences reflected the widespread nature of the disease within the communities.

One participant shared the experience of a family member who suffered severely from the disease:

> *"I know of a family member who had FGS. It was very severe. She died but I don't know whether the death was related to the FGS or not." (Younger women, 19–29 years old, North Tongu).*

Others described their ongoing struggles with the disease:

> *"I experienced FGS myself. It is still an issue in me. I am just managing it." (Older women, 30–49 years, North Tongu).*

Participants also recognized the potential complications associated with untreated infections:

> *"Yes, I know untreated schistosomiasis can lead to severe schistosomiasis and some complications such as infertility and bad vaginal odour." (Older women, 30–49 years, Weija).*

Community perceptions of the causes of FGS infection

Although most study participants correctly associated FGS with contact with contaminated river bodies, other perceived causes were also widely mentioned. These included witchcraft, infidelity or promiscuity, and sexually transmitted infections (STIs). These perceptions were consistent across both study districts and among different age groups.

Some of the study participants belief that FGS is linked to supernatural forces or punishment from ancestral gods, particularly in cases involving perceived moral wrongdoing such as adultery.

> *"The way the sickness (FGS) behaves, some people sometimes believe it is spiritual. So, they seek spiritual healing, and they are sometimes healed." (Older women, 30–49 years, North Tongu).*

Similarly, others explained how the disease is sometimes interpreted as punishment for infidelity:

> *"In this community, if a married woman sleeps with another man aside the husband, the gods punish the woman with sickness which is like FGS." (Younger women, 19–29 years, Weija).*

Participants also mentioned beliefs related to witchcraft:

> *"Some people get FGS through witchcraft. Maybe your rival can bewitch you in the form of FGS."(Older women,30–49 years, North Tongu).*

Another participant linked the condition to sexually transmitted infections:

> *"Some of these FGS are STIs and women need to take good care of themselves." (Young women, 19–29 years old, North Tongu).*

Participants experiences of the consequences of FGS

Participants described several negative consequences of FGS, including infertility, severe abdominal and vaginal pain, Itchy and offensive vagina discharge, ad experiences of social exclusion/ trauma and stigma.

Infertility

Infertility was frequently mentioned as one of the most distressing consequences of FGS. Study participants explained that women who are unable to conceive often face blame and social stigma within the community.

> *"The community has negative perception towards that woman, and it is a form of shame to the woman."(Older women, 30–49 yreas, North Tongu).*

Participants illustrated these experiences using symbolic photographs such as a refuse dump (Fig. 1) to represent the neglect and marginalization experienced by women perceived to be infertile. This makes such as woman miserable like a refuge damp.

> *"In our society it is perceived that women are responsible for keeping the house tidy. When a visitor comes in and the house is dirty women are blamed for that, I compare the stigma women go through due to complications of FGS or schisto in the community such as not being able to conceive just like a refuse damp." (Older women, 30–49 years old North Tongu).*

Severe abdominal and vaginal pain

Severe abdominal and pain during sexual intercourse were commonly reported symptoms of FGS.

Participants used images such as thorny plants (Fig. 2) to represent the sharp and persistent pain associated with the disease.

> *"The picture I took demonstrates how a thorn can prick someone and cause pain. It is similar to the pain when I have blood in urine". (Younger women, 19–29 yreas, North Tongu).*

Itchy and offensive vaginal discharge

Participants in the study also reported persistent itching and foul-smelling vaginal discharge, which is uncomfortable and negatively affects women's self-confidence. A study participant used water plant (Fig. 3) to express to symbolize the source of infection and the irritating nature of the symptoms.

Fig. 1 A refuge damp used to explain the consequences of infidelity

Fig. 2 Water plant to explain itchy vagina due to FGS

Fig. 3 The use of thorny tree to express severe abdominal and vaginal pain due to FGS

> *"This is a picture of a water plant. The water plant grows in the river and produces microorganisms which can cause several diseases when you are exposed to the river. The plant when it comes into contact with the body causes itchiness. It is also like a rope that can entangle a person during swimming and may lead to a person drowning. The plant is a very dangerous one which I don't want to ever come*

> *in contact with. This is compared to an experience a young girl had in my household on Schistosomiasis which made her private part itch continuously." (Older women, 30–49 years, North Tongu).*

Social exclusion, trauma and stigma

Women with FGS are sometimes stigmatized and experience what can be characterized as social trauma. Study participants noted that because of the impact of FGS, including infertility, embarrassment, pain, and foul smell, women experience stigmatization, feel shy around others, and isolate themselves from the community. Social exclusion can contribute to poor health and potentially lower physical activity and result in poor mental health. Study participant used a pit latrine (Fig. 4) to depict the issue of stigma and social trauma due to FGS.

> *"Each household needs a latrine, lack of that in a household brings shame. Because we all eat, and we need a place to free our bowels. Imagine having diarrhoea that causes stomach upset and not having latrine close by, see how uncomfortable you will be. This is just like having FGS and not getting treatment for it. It itches, brings some form of bad odour and you can't even conceive, how can you be among people, it is a great shame in our society." (Older women, 30–49 years, North Tongu).*

Health-seeking behaviour for FGS

Study participants acknowledged that FGS needs to be treated in order to provide respite for the patient. Even though most participants said that going to an orthodox health facility is the preferred place for treatment, however, several other treatment approaches were also mentioned. Some participants reported seeking care from traditional/spiritual healers, or herbal preparations. Most women choose spiritual healing or sorcery because they think that their illnesses are caused by supernatural forces and necessitate spiritual remedies.

Fig. 4 Latrine/toilet to express social exclusion/ trauma and stigma due to FGS

> *"I think the best place to seek care is the hospital. So we try to seek care at the hospital with the condition". (Younger women, 19–29 years, North Tongu).*

Additionally, traditional herbal medicine was mentioned as a way to treat schistosomiasis/FGS which some of the study participants mentioned was sometimes effective.

> *"Some of the FGS cases cannot be treated using only the orthodox method. You need to consult the herbalist for some herbs."(Older women, 30–49 years, Weija).*

Another participant described combining herbal remedies with hospital treatment:

> *"Sometimes the medicines from the hospital alone do not help, so we combine them with herbs. We boil the herbs, pour it in a bucket and sit over the steam. This helps relieve the symptoms."(Younger women,19–29 yreas, Weija).*

Surprisingly, some women think blood in urine (schistosomiasis) is a normal occurrence, given that many people in the community experience it, and therefore it does not require treatment.

> *"Many people in the community have experienced schisto. Therefore getting it is not a big deal. It goes away after some days even without treatment" (Older women,30–49 years, North Tongu).*

Study participants mentioned that there is always great joy when a woman gets appropriate treatment for FGS. A participant used a lotto kiosk to illustrate her experience from the time she had the condition until she got treated (Fig. 5).

> *"I personally had experience of blood in urine for about 10 years and I thought it was normal to see blood in my urine until an announcement was made in the community that if you see blood in your urine you should come for treatment. I also went to the community school park for the drug. After taking it, I felt weak and didn't see blood in my urine anymore, I was so happy about that. My experience with the disease through treatment and healing can be associated with the colours on this lotto kiosk. It*

Fig. 5 Lotto kiosk to depict health-seeking behaviour for FGS

> *has red, yellow and green. To me, the red signifies the pain for blood in urine, the yellow signifies the treatment I had which gave me a bit of ease knowing that I would be cured, and the green indicates when I fully recovered from blood in urine." (Older women, 30–49 years old, North Tongu).*

Community suggestions to improve the control and management of FGS

Participants proposed several strategies to improve the control and management of FGS within their communities.

Community education and awareness

Participants emphasized the need for community education to increase awareness about the causes, symptoms, and treatment of FGS. They therefore suggested involving stakeholders like health workers, community leaders (chiefs), and religious leaders in the awareness campaigns.

> *"If you like using the river and you start urinating blood you should know that it is schistosomiasis. But some of our young girls do not know that. They need education from the health workers." (Older women, 30–49 years old, Weija).*

Improved access to safe water

Study participants mentioned that lack of pipe born water is the main reason they visit the rivers to get water for the households and the risk of contracting schistosomiasis. They therefore recommended the provision of boreholes or other safe water sources for the communities.

> *"Sometimes, it is not our fault. We do not have borehole close by, so we do not have option but to use the river water for our activities. We will be grateful if they provide us boreholes in the community." (Older women, 30–49 years, North Tongu).*

Increased knowledge about praziquantel

There was limited knowledge about the use of praziquantel to treat FGS. Study participants mentioned that some women in the community do not know that there is medicine (praziquantel) that can effectively treat FGS. As a result, they waste time seeking herbal treatment instead of visiting the health facilities. It was therefore suggested that community education on simple treatment with praziquantel should be promoted at the community level.

> *"I know women who do not know that blood in urine can be treated effectively in the hospital with just a simple medication." (Younger women, 19–29 years, North Tongu).*

In addition, participants further emphasized the need to address stigma associated with the disease to encourage women to seek treatment without fear of embarrassment.

> *"Some women who have blood in urine shy because of stigma. So, they manage it their own ways without going to the hospital. Education to make people know that blood in urine is because of the river but not because of anything." (Older women, 30–49 years, North Tongu).*

Discussion

This study used a photovoice approach to explore women's experiences with Female Genital Schistosomiasis (FGS), community perceptions of its causes and consequences, and health-seeking behaviours in two endemic districts in Ghana. The findings highlight the usefulness of participatory visual methods in capturing lived experiences of FGS and reveal important gaps in knowledge, persistent misconceptions about the disease, and structural barriers affecting prevention and treatment.

Photovoice as a tool for understanding lived experiences of FGS

The findings demonstrated the feasibility and value of photovoice as a participatory research method for documenting lived experiences of FGS in rural settings. Participants expressed enthusiasm about the photovoice approach and reported that it enabled them to reflect deeply on their experiences with FGS. Photovoice approach has previously been used among women in rural areas in Kenya to explore water, sanitation, and hygiene (WASH) behaviours [26], highlighting its effectiveness in facilitating community engagement and reflection on health-related practices. However, its application to understanding the lived experiences and social implications of FGS has been limited. In this study, participants were able to grasp the photovoice concept and were able to produce compelling images to describe their own FGS experiences as well as those in their household and community. This participatory process encouraged critical reflection and dialogue around FGS, thereby empowering participants to articulate issues that may otherwise remain hidden in conventional research approaches.

Experiences and burden of FGS among women

Participants in this study reported personal and community experiences with FGS, indicating that the condition remains a significant health problem in endemic communities. Women described symptoms such as blood in urine, abdominal pain, vaginal itching and discharge, which align with clinical descriptions of urogenital schistosomiasis and FGS [4, 27–29]. Some participants also reported long-term complications such as infertility, consistent with evidence that genital schistosomiasis can impair fertility and reproductive health [4, 27–29]. In many Ghanaian communities, childbearing is highly valued, and infertility can lead to social tension within families as well as marginalization [30]. Previous research has similarly documented how reproductive health conditions, including FGS, can exacerbate gendered stigma and social vulnerability [31]. The findings highlight how the burden of FGS extends beyond physical symptoms to include psychological and social consequences.

Community perceptions and misconceptions about the causes of FGS

Although most participants correctly associated FGS with contact with contaminated water, several misconceptions about the disease were also identified. Participants attributed the condition to witchcraft, spiritual punishment for infidelity, or sexually transmitted infections. These perceptions are consistent with previous studies in schistosomiasis-endemic settings where adolescent girls and women presenting with schistosomiasis or FGS-related symptoms were often assumed to have STI or to be sexually promiscuous [10, 31–33]. Such misconceptions are not unique to FGS, but reflect broader patterns in many low- and middle- income countries, including Ghana, where illness causation is frequently linked to supernatural or spiritual forces [34, 35].

Misconceptions about disease causation can influence treatment-seeking behaviour and delay access to appropriate care. For example, beliefs that FGS may be caused by supernatural forces may encourage women to seek spiritual or traditional healing rather than biomedical treatment. Similar findings have been reported in other schistosomiasis-endemic settings where cultural interpretations of illness shape health behaviours and health service utilization [33, 36, 37]. Addressing these misconceptions requires culturally sensitive health education strategies that acknowledge existing belief systems while promoting accurate biomedical understanding. Engaging traditional and spiritual healers in awareness and referral systems may also help bridge gaps between community beliefs and formal health services. In addition, since some participants reported perceived benefits of herbal remedies, further research is warranted to examine the potential efficacy of such treatments and explore whether safe and evidence-based integration into broader treatment strategies may be feasible.

Health-seeking behaviour and barriers to treatment

The study found that women use a variety of treatment pathways when experiencing symptoms of FGS. Although many participants identified health facilities as the preferred place for treatment, traditional and herbal remedies were also commonly used. Some participants reported combining hospital treatment with herbal therapies, while others relied solely on traditional healers. Similar findings have been reported in other endemic settings where pupils were referred to traditional healers and herbalists by parents or elderly relatives for the treatment of schistosomiasis [33].

In addition, some women considered blood in urine to be a normal condition because it is common within the community, which may reduce the perceived need for treatment and contribute to delayed care-seeking. Similar perceptions have been noted in other endemic areas, where schistosomiasis symptoms are normalized due to high prevalence [32].

Limited awareness of praziquantel as an effective treatment for schistosomiasis was also reported. Although praziquantel is widely recommended for schistosomiasis control [38], knowledge about its availability and effectiveness remains limited in some endemic communities. In Ghana and many other endemic countries, praziquantel is often available primarily during mass drug administration (MDA) campaigns, with limited availability at health facilities afterward. Therefore, it is essential to ensure that praziquantel is consistently available through the essential drugs available at health facilities, especially in communities where schistosomiasis is endemic.

Structural determinants and community-level solutions

Participants emphasized the role of environmental and structural factors in sustaining transmission of schistosomiasis and FGS. The lack of safe water sources forced many households to rely on rivers for domestic activities, increasing exposure to contaminated water and perpetuating parasite transmission. This echoes broader evidence that inadequate water, sanitation, and hygiene (WASH) infrastructure is a key driver of schistosomiasis transmission [39, 40].

To curtail the effects of FGS, study participants proposed several community-driven solutions- including community education, improved access to safe water, and increased awareness about praziquantel. These suggestions align with global recommendations that emphasize integrated control approaches combining preventive chemotherapy, health education, improved water and sanitation infrastructure, and community engagement [1, 41]. Improved access to safe water and sanitation infrastructure is particularly critical for preventing schistosomiasis transmission. However, access to these services remains uneven in many parts of Ghana. According to a UNICEF report, even though access to water in Ghana has considerably increased, one out of every ten people must travel more than 30 min to reach a better source of drinking water. Another 11% of the population continues to drink from contaminated surface and underground water sources [42]. The study communities are situated along the Volta River and the Weija Dam, which serve as key sources of treated water for Ghanaian communities. Regardless of their proximity to these water sources, the communities have limited access to potable water. In addition, there are sanitation challenges, such as limited toilet facilities in the communities, and community members defecate along the riverside, which is a source of schistosomiasis transmission. In general, open defecation is a challenge in Ghana, particularly in rural areas and it is reported that the proportion of households with no toilet facility is 29% in rural areas [43, 44]. These factors (untreated and limited water and sanitation) place community members at risk of schistosomiasis. Therefore, there is a pressing need to improve access to affordable potable water to reduce community contact with river water and improve access to affordable toilet facilities to reduce open defecations.

Importantly, participants also highlighted the need to address stigma associated with FGS. Stigma can discourage women from seeking treatment and may exacerbate the psychological burden of the disease. Community-level education and dialogue are necessary not only to improve knowledge about FGS but also to reduce stigma and encourage supportive social environments for affected women.

Implications for policy and practice

The findings of this study have important implications for schistosomiasis control and reproductive health programmes in endemic settings. First, there is a need to integrate FGS awareness into existing schistosomiasis control initiatives and sexual and reproductive health programmes. Second, community education campaigns should address both biomedical and cultural understandings of the disease to correct misconceptions and promote appropriate health-seeking behaviour. Third, improving access to safe water sources remains a critical structural intervention for reducing exposure to schistosomiasis.

Participatory approaches such as photovoice may also serve as effective tools for community engagement and health promotion. By enabling community members to document and share their experiences, photovoice can support advocacy efforts and inform locally relevant interventions for the prevention and management of FGS.

Strengths and limitations of the study

A key strength of this study is the use of photovoice, a participatory visual method that enabled participants to express their experiences in creative and meaningful ways. The method facilitated deeper reflection and generated rich qualitative data about the lived experiences of women affected by FGS. The inclusion of participants from two districts and different age groups also allowed for the exploration of diverse perspectives.

However, several limitations should be acknowledged. The nature of FGS is often sensitive, and sharing personal experiences through photographs can raise privacy issues. Participants may be hesitant to depict their realities due to fear of stigma or social repercussions. However, since participants were instructed to present only images that do not include themselves or other individuals, the potential privacy concerns were minimized and unlikely to impact the study's findings.

The photovoice process requires considerable time and resources, including multiple visits, explanations of concepts, and ongoing support for participants. Nevertheless, due to careful planning, these challenges were effectively managed, ensuring that they did not compromise the study's results.

In the study areas, discussions around reproductive health issues like FGS may be considered taboo, potentially limiting participants' willingness to engage openly. However, the strong rapport developed between the study team and participants facilitated more honest expression, helping to mitigate this cultural barrier and minimizing its impact on the findings.

Despite these limitations, the study provides important insights into the social and health experiences of women affected by FGS and highlights key areas for intervention.

Conclusion

This study used a photovoice approach to explore women's experiences with Female Genital Schistosomiasis (FGS) in two endemic districts in Ghana. While many participants recognized contact with contaminated water as a key cause of FGS, misconceptions—such as beliefs related to witchcraft, spiritual punishment, and sexually transmitted infections—persisted and influenced treatment-seeking behaviours. Women also reported significant physical and psychosocial consequences of FGS, including infertility, chronic pain, stigma, and social exclusion.

Participants highlighted the need for improved community education, better access to safe water sources, and increased awareness of effective treatment with praziquantel. These findings underscore the importance of integrating FGS awareness into schistosomiasis control programmes, strengthening access to treatment within routine health services, and improving water and sanitation infrastructure. Addressing FGS therefore requires integrated strategies that combine biomedical interventions with community engagement and broader investments in water, sanitation, and reproductive health services.

Abbreviations

FAST	FGS accelerated scale together
FGD	Focus group discussion
FGS	Female genital schistosomiasis
IDI	In-depth interviews
MDA	Mass drug administration
NTD	Neglected tropical disease
PGD	Photovoice group discussions
RA	Research assistant
STI	Sexually transmitted infection
WASH	Water, sanitation, and hygiene

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12905-026-04485-0.

Supplementary Material 1.

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Authors' contributions

MAD, AK, AKM, MI, KA, JJ and MG, contributed to the conception, design, and interpretation of the data. The data collection was done by MAD, ESV and EEM. All authors contributed to the writing of the manuscript. MG acted as guarantor of this work.

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Data availability

The datasets used and/or analysed are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethical clearance for this study was obtained from the Ghana Health Service Ethics Review Committee (GHS-ERC 003/04/21). Written consent was obtained from all study participants. All study procedures were conducted in accordance with relevant ethical guidelines and regulations, including the Declaration of Helsinki.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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References

1. WHO. Schistosomiasis and soil-transmitted helminthiases: progress report. 2022. 2022. https://www.who.int/publications-detail-redirect/who-wer9851-667-676. (Accessed 23 Apr 2024).
2. Aula OP, McManus DP, Jones MK, et al. Schistosomiasis with a Focus on Africa. Trop Med Infect Disease. 2021;6:109. https://doi.org/10.3390/tropicalmed6030109.
3. Ndassi VD, Anchang-Kimbi JK, Sumbele IUN, et al. The epidemiological status of urogenital schistosomiasis among reproductive aged individuals in the Tiko Health Area- a semi-urban setting in the Mount Cameroon area. PLoS Negl Trop Dis. 2021;15. https://doi.org/10.1371/journal.pntd.0008978.
4. Orish VN, Morhe EKS, Azanu W, et al. The parasitology of female genital schistosomiasis. Curr Res Parasitol Vector Borne Dis. 2022;2:100093. https://doi.org/10.1016/j.crpvbd.2022.100093.
5. Anchang-Kimbi JK, Ndassi VD, Wepnje GB, et al. Diagnosis of female genital schistosomiasis and pre-emptive treatment with praziquantel: a community-based pilot intervention study in Tiko, Cameroon. Reprod Health. 2026;23:39. https://doi.org/10.1186/s12978-025-02240-6.
6. Mazigo HD, Samson A, Lambert VJ, et al. Female genital schistosomiasis is a sexually transmitted disease: Gaps in healthcare workers' knowledge about female genital schistosomiasis in Tanzania. PLOS Global Public Health. 2022;2:e0000059.
7. Lamberti O, Bozzani F, Kiyoshi K, et al. Time to bring female genital schistosomiasis out of neglect. Br Med Bull. 2024;149:45–59. https://doi.org/10.1093/bmb/ldad034.
8. Kukula VA, MacPherson EE, Tsey IH, et al. 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 Negl Trop Dis. 2018;13:1–14. https://doi.org/10.1371/journal.pntd.0007207.
9. Yirenya-tawiah DR, Ackumey MM, Bosompem KM. Knowledge and awareness of genital involvement and reproductive health consequences of urogenital schistosomiasis in endemic communities in Ghana: a cross- sectional study. Reproductive Health. 2016;1–9. https://doi.org/10.1186/s12978-016-0238-5.
10. Kukula VA, MacPherson EE, Tsey IH, et al. 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 Negl Trop Dis. 2019;13:e0007207. https://doi.org/10.1371/journal.pntd.0007207.

11. Anderson K, Elder-Robinson E, Howard K, et al. A Systematic Methods Review of Photovoice Research with Indigenous Young People. *International Journal of Qualitative Methods*. Published Online First: 5 June. 2023. https://doi.org/10.1177/16094069231172076.
12. Smith J, Nels A, Emery L, et al. Exploring the Use of Photovoice in Understanding the Lived Experience of Neurological Conditions: A Scoping Review and Reflexive Thematic Analysis. Int J Qualitative Methods. 2023;22:160940692311563. https://doi.org/10.1177/16094069231156344.
13. Lindhout P, Teunissen T, Reniers G. What about Using Photovoice for Health and Safety? Int J Environ Res Public Health. 2021;18:11985. https://doi.org/10.3390/ijerph182211985.
14. Earnshaw VA, Cox J, Wong PL, et al. Acceptability and Feasibility of Online, Asynchronous Photovoice with Key Populations and People Living with HIV. AIDS Behav. 2022;1–15. https://doi.org/10.1007/s10461-022-03938-5.
15. Krentel A, Arogundade K, Raharinivo M, et al. Sustainable integration of FGS into the health system: Findings and lessons learned from the FAST package project in Ghana and Madagascar. Front Trop Dis. 2024;5. https://doi.org/10.3389/fitd.2024.1395467.
16. Gyapong M, Dalaba MA, Immurana M, et al. Breaking the silence of female genital schistosomiasis in Ghana's health system: A case of health workers within the FAST project. PLoS Negl Trop Dis. 2024;18:e0012443. https://doi.org/10.1371/journal.pntd.0012443.
17. O'Brien BC, Harris IB, Beckman TJ, et al. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. Acad Med. 2014;89:1245. https://doi.org/10.1097/ACM.0000000000000388.
18. Ghana Health Service. Master plan for neglected tropical diseases programme, Ghana (2016–2020). 2020.
19. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Soc Sci Med. 2022;292:114523. https://doi.org/10.1016/j.socscimed.2021.114523.
20. Hennink MM, Kaiser BN, Weber MB. What Influences Saturation? Estimating Sample Sizes in Focus Group Research. Qual Health Res. 2019;29:1483. https://doi.org/10.1177/1049732318821692.
21. Creswell JW. Research design: Qualitative, quantitative, and mixed methods approaches. Third: SAGE; 2009.
22. O.Nyumba T, Wilson K, Derrick CJ, et al. The use of focus group discussion methodology: Insights from two decades of application in conservation. Methods Ecol Evol. 2018;9:20–32. https://doi.org/10.1111/2041-210X.12860.
23. Wolff B, Aborigo RA, Dalaba M et al. Community Barriers, Enablers, and Normative Embedding of Second Year of Life Vaccination in Ghana: A Qualitative Study. Global Health: Science and Practice. Published Online First: 20 June 2023. https://doi.org/10.9745/GHSP-D-22-00496.
24. Ahmed SK. The pillars of trustworthiness in qualitative research. J Med Surg Public Health. 2024;2:100051. https://doi.org/10.1016/j.glmedi.2024.100051.
25. Braun V. Using thematic analysis in psychology. Qualitative Res Psychol. 2006;3:77–101. https://doi.org/10.1191/1478088706qp063oa.
26. Bisung E, Elliott SJ, Abudho B, et al. Using Photovoice as a Community Based Participatory Research Tool for Changing Water, Sanitation, and Hygiene Behaviours in Usoma, Kenya. Biomed Res Int. 2015;2015:903025. https://doi.org/10.1155/2015/903025.
27. WHO. New WHO guidelines for schistosomiasis | Pediatric Praziquantel Consortium. 2022. https://www.pediatricpraziquantelconsortium.org/what-we-do/new-who-guidelines-schistosomiasis. (Accessed 13 Jun 2024).
28. Yirenya-Tawiah DR, Ackumey MM, Bosompem KM. Knowledge and awareness of genital involvement and reproductive health consequences of urogenital schistosomiasis in endemic communities in Ghana: a cross-sectional study. Reproductive Health. 2016;13:117. https://doi.org/10.1186/s12978-016-0238-5.
29. Tonga C, Ngo Bayoi C, Tchanga FC, et al. Schistosomiasis among pregnant women in Njombe-Penja health district, Cameroon. J Infect Dev Ctries. 2019;13:1150–8. https://doi.org/10.3855/jidc.11767.
30. Ofosu-Budu D, Hanninen V. Living as an infertile woman: the case of southern and northern Ghana. Reproductive Health. 2020;17:69. https://doi.org/10.1186/s12978-020-00920-z.
31. Schuster A, Randrianasolo BS, Rabozakandraina OO, et al. Knowledge, experiences, and practices of women affected by female genital schistosomiasis in rural Madagascar: A qualitative study on disease perception, health impairment and social impact. PLoS Negl Trop Dis. 2022;16:e0010901. https://doi.org/10.1371/journal.pntd.0010901.
32. Mazigo HD, Samson A, Lambert VJ, et al. We know about schistosomiasis but we know nothing about FGS: A qualitative assessment of knowledge gaps about female genital schistosomiasis among communities living in Schistosoma haematobium endemic districts of Zanzibar and Northwestern Tanzania. PLoS Negl Trop Dis. 2021;15:e0009789. https://doi.org/10.1371/journal.pntd.0009789.
33. Lothe A, Zulu N, Øyhus AO, et al. Treating schistosomiasis among South African high school pupils in an endemic area, a qualitative study. BMC Infect Dis. 2018;18:239. https://doi.org/10.1186/s12879-018-3102-0.
34. Badasu DM, Abuosi AA, Adzei FA, et al. Educational status and beliefs regarding non-communicable diseases among children in Ghana. BMC Public Health. 2018;18:313. https://doi.org/10.1186/s12889-018-5211-5.
35. Nketia A, Nakua E, Tetteh AW, et al. Herbal medicine practice in Ghana: A cross-sectional study to understand the factors influencing patient utilization of herbal medicine services. IRJPEH. 2022;9. https://doi.org/10.15739/irjpeh.22.003.
36. Angelo T, Kinung'hi SM, Buza J, et al. Community knowledge, perceptions and water contact practices associated with transmission of urinary schistosomiasis in an endemic region: a qualitative cross-sectional study. BMC Public Health. 2019;19:703. https://doi.org/10.1186/s12889-019-7041-5.
37. Sacolo H, Chimbari M, Kalinda C. Knowledge, attitudes and practices on Schistosomiasis in sub-Saharan Africa: a systematic review. BMC Infect Dis. 2018;18:46. https://doi.org/10.1186/s12879-017-2923-6.
38. Darko SN, Hanson H, Twumasi-Ankrah S, et al. Three monthly doses of 60 mg/kg praziquantel for Schistosoma haematobium infection is a safe and effective treatment regimen. BMC Infect Dis. 2020;20:323. https://doi.org/10.1186/s12879-020-05053-z.
39. Ntajal J, Evers M, Kistemann T, et al. Influence of human–surface water interactions on the transmission of urinary schistosomiasis in the Lower Densu River basin, Ghana. Soc Sci Med. 2021;288:113546. https://doi.org/10.1016/j.socscimed.2020.113546.
40. Campbell SJ, Biritwum N-K, Woods G, et al. Tailoring Water, Sanitation, and Hygiene (WASH) Targets for Soil-Transmitted Helminthiasis and Schistosomiasis Control. Trends Parasitol. 2018;34:53–63. https://doi.org/10.1016/j.pt.2017.09.004.
41. WHO. WHO | Launch of new guideline for the control and elimination of human schistosomiasis. GSA. https://www.eliminateschisto.org/news-events/news/who-launch-of-new-guideline-for-the-control-and-elimination-of-human. (Accessed 13 Jun 2024).
42. UNICEF. Water situation in Ghana. 2021. https://www.unicef.org/ghana/water. (Accessed 4 May 2022).
43. Adzawla W, Alhassan H, Jongare AI. Explaining the Effects of Socioeconomic and Housing Characteristics on the Choice of Toilet Facilities among Ghanaian Households. J Environ Public Health. 2020;2020:4036045. https://doi.org/10.1155/2020/4036045.
44. Ghana Statistical Service. Ghana Living Standard Survey (GLSS7) main report. 2019.

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