

Position paper

Female genital schistosomiasis – a neglected reproductive health crisis

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ENDING PARASITIC DISEASE



Key messages

- Female genital schistosomiasis (FGS), a condition caused by the neglected tropical disease schistosomiasis, affects the most marginalised and vulnerable populations who do not have access to safe water supply and sanitation services
- FGS is a significant human rights, development and reproductive health issue
- FGS is underdiagnosed, with serious, long-term implications for women's and adolescent girl's sexual and reproductive health
- The symptoms and complications of FGS can lead to the poor mental health of women and adolescent girls due to associated stigma and social exclusion
- FGS is associated with increased risk of human immunodeficiency virus (HIV) and human papillomavirus (HPV) transmission
- FGS can be prevented through regular treatment with praziquantel, and sustained access to safe water supply and sanitation services
- Multi-sectoral partnerships and integrated programmes are needed in endemic areas to ensure that a holistic approach is used to address FGS



What is FGS?

How the condition occurs

FGS is a complication of chronic *S. haematobium* infection and rarely, by other *Schistosoma* species. Symptoms are caused when the parasite eggs are deposited in the uterus, vaginal wall, vulva or cervix. Chronic infection can lead to inflammation and lesions forming in the reproductive organs (1, 2).

Women and girls in endemic areas become infected following exposure to the parasite in fresh water during their daily activities such as livelihoods (fishing, livestock husbandry, etc), swimming, washing clothes, collecting water and bathing. Communities without access to safe water supplies and adequate sanitation are therefore particularly at risk.

Pathology and complications

Common symptoms of FGS include significant pelvic pain, vaginal (bloody) discharge, painful intercourse (dyspareunia), post coital bleeding, genital itching or burning (1,2). These symptoms are often mistaken for a sexually transmitted infection (STI) and therefore, women may be wrongly accused of sexual promiscuity (3-5). In some communities this can have serious consequences such as gender-based violence and social exclusion.

Complications associated with FGS can include infertility, spontaneous abortion, ectopic pregnancy, involuntary urination, disorders of menstruation and genital ulcers (1, 2). These complications, and in particular infertility, can lead to social isolation and stigma. Women suffering from FGS are therefore more likely to experience mental health consequences including depression (1, 3).



What is schistosomiasis?

Schistosomiasis, also referred to as Bilharzia or Snail Fever, is a disease caused by parasitic flatworms (schistosomes) which can infect both humans and animals. The human form of the disease is widespread in Africa and is transmitted by skin contact with fresh water sources which are infested with the parasite. Schistosomes have a complicated life cycle, involving freshwater snails which act as intermediate hosts, making the disease very difficult to control and eliminate. Several animal and human species of schistosomes exist; the main species of schistosomes which infect humans on the African continent are *Schistosoma haematobium* (causing urogenital symptoms) and *S. mansoni*, (causing intestinal schistosomiasis).

Schistosomiasis is usually associated with young and school-aged children, who can present with symptoms such as anaemia, stunted growth and abdominal cramps.

If the disease is left untreated, it can lead to more serious complications, which are dependent on the species involved. Urogenital morbidities (caused by *S. haematobium*) include bladder pathology and FGS, while intestinal schistosomiasis (caused by *S. mansoni* and all other species) can lead to enlargement of the liver and spleen.

Diagnosis

The method for diagnosing infection with *S. haematobium* is a relatively simple test to detect eggs in a sample of urine, but diagnosis of FGS is more challenging. Not all women who present with eggs in their urine will have FGS and not all sufferers of FGS will have eggs in their urine.

Diagnosis is currently most effectively conducted through visual examination of the cervix and vaginal wall, ideally using a colposcope – a magnifying instrument. However, efforts to diagnose women are often hampered by the lack of expertise or resources to conduct these types of examinations (6). Diagnosis of FGS can also present a challenge due to ethical and cultural barriers associated with invasive diagnostic procedures (7). Current laboratory techniques are also not always appropriate for diagnosing FGS. Biopsy, for example, is invasive and can leave a woman susceptible to infection and /or increased risk of human immunodeficiency virus (HIV) transmission.

Clinicians and healthcare workers are generally unaware of FGS as it is not included in their training and therefore symptoms are often misdiagnosed, resulting in inappropriate and



ineffective treatment. A frequent reason for FGS misdiagnosis is because its symptoms can mimic those of STIs (3-5). This incorrect diagnosis can lead to stigmatisation amongst women and young girls plus the unnecessary treatment, out of pocket expenditure and clinical investigations that fail to reverse symptoms. Furthermore, this results in multiple visits to healthcare services, thereby increasing the burden on the healthcare system as well as on the individual.

Treatment

Praziquantel (PZQ), which is used to treat schistosomiasis, is not effective at reversing chronic infection related morbidities, including genital lesions once they have formed and currently there are no validated therapeutic options. Genital lesions increase susceptibility to HIV (8). After treatment with PZQ, the adult worms are killed and can no longer produce eggs. Treatment can therefore reduce inflammation of existing lesions and is essential to prevent new lesions from developing (2, 9).

Regular treatment with PZQ from an early age prevents chronic infection and associated pathologies. Furthermore, women treated at least once in their lifetime are 50% less likely to develop FGS (10). Regular treatment as well as prevention of infection are therefore critical to ensure there are no long-term health consequences for women and girls exposed to schistosomiasis.

What is the burden and impact of FGS?

FGS is estimated to affect 56 million women and girls in sub-Saharan Africa but is a neglected sexual and reproductive health and rights (SRHR) issue (11). In the 2019 Global Burden of Disease Study, schistosomiasis was estimated to cause the loss of 1.64 million disability-adjusted life years (12), and estimates show that up to 75% of women infected with *S. haematobium* could suffer from symptoms of FGS (13).

The FGS burden of disease is high amongst young women (18-29 years old); however, it is not possible to determine at what age the onset of genital lesions begin, due to the ethical issues associated with examining girls before they become sexually active (1, 6, 14).



Co-morbidities with HIV & HPV

FGS has been identified as a leading HIV/AIDS cofactor in sub-Saharan Africa as there is significant geographic overlap between HIV/AIDS affected communities and those with a high prevalence of FGS. It is associated with a 3 to 4 times greater risk of HIV acquisition and transmission (3, 15, 16) but a causal relationship between HIV and FGS has not yet been fully identified and so more research is needed. Adolescent and young women are often more vulnerable to new HIV infections, for many reasons including cultural practices, socio-economic status, education, and this is therefore further compounded by their vulnerability to FGS.

Data also shows an association between FGS and HPV, the virus that can cause cervical cancer, as FGS of the cervix can affect the immunological response to HPV infection (17).

Why urgent action is needed

FGS is likely to be one of the most common gynaecological conditions in areas with high schistosomiasis prevalence (3). Despite this, it remains a neglected condition that is not routinely included in medical textbooks or trainings for health professionals, or in resources for the control and elimination of schistosomiasis, including education and sensitisation materials, or policies and guidelines at any level (3-5). This means there is a lack of awareness of FGS at all levels, from the community upwards, which also impacts the health seeking behaviour of the women at-risk. Low awareness of FGS and its consequences exacerbates the social impact of the condition and associated stigmatisation.

There are significant gaps surrounding FGS in terms of data, diagnostics, education, and treatment pathways, as shown in the following Figure 1.

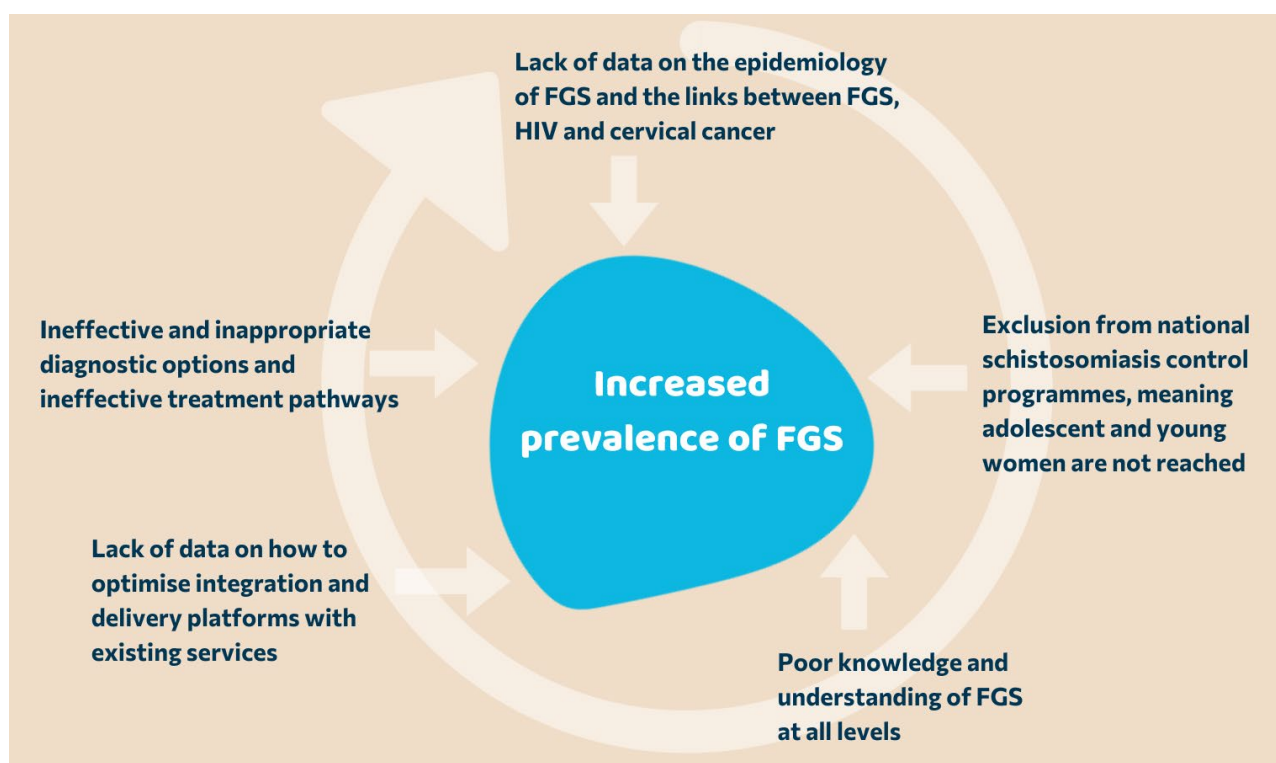


Figure 1: Factors influencing the increase in prevalence of FGS.

In recent years, the global community has started addressing the neglect of FGS. At the end of 2019, global events including a dedicated [meeting](#) on research into FGS, and publications (3, 11) brought attention to the need to integrate services for FGS with existing sexual and reproductive health interventions (18). This is particularly important to allow for a more holistic people-centred design which takes into consideration the multiple needs of the patient (19). Research is also beginning to take place to understand community perspectives and pilot strategies for integration. As the many gaps in evidence start to be filled, it is essential that efforts are made to ensure a coordinated approach which is evidence based.

Action needed to address the burden of FGS

Actions required to tackle the burden and consequences of FGS are set out in three key areas below. These will need to be supported by policy decisions at the global level, including the improvement of global access to PZQ for management of all at-risk groups, as well as a



comprehensive, integrated approach to public health programming for women and girls; including sexual health, HIV, mother and child health (MCH), cervical cancer screening and family planning.

Whilst the delivery platforms to reach women at-risk remain sub-optimal, this poses a challenge to reaching the 2030 universal health coverage goals set by the World Health Organization (WHO), which needs to be addressed (20).

1) Integration within the health system:

Integration within the national health system of *S. haematobium* endemic countries is essential to fully address FGS as a health problem. The following two approaches should be taken:

- a. **Prevention:** The development of FGS can be prevented through treatment with PZQ. Identification of the optimal delivery platforms to reach the women and girls at-risk should be done with consideration of the increasing evidence linking FGS with HIV and cervical cancer. As such, delivery platforms may include services such as HPV immunisation programmes or HIV screening and prevention programmes (Figure 2). Optimisation of existing platforms should also be considered, for example utilising praziquantel deworming programmes by including FGS messages in training and sensitisation materials and examining the possibility of expanding the target population to include women of child-bearing age, although this will be dependent on the availability of drug donations or ability to procure PZQ.
- b. **Diagnosis and treatment:** Diagnostic techniques appropriate to low resource settings are urgently needed. Resources such as the [Female Genital Schistosomiasis Pocket Atlas](#) are valuable tools to aid diagnosis, but they rely on the resources and expertise necessary for visual inspection, ideally with a colposcope (21). A validated and effective symptomatic algorithm could greatly improve diagnostic capabilities in low resource settings and even enable the involvement of community health workers. Furthermore, strengthened capacity for diagnosis is needed to differentially screen for FGS, cancers (vulva, vagina, cervix, endometrium), STIs and urogenital tuberculosis. This is essential in order to provide a comprehensive package of reproductive health services for women and girls.



In most cases, pre-emptive treatment is appropriate and syndromic diagnosis of FGS can be based on the following criteria:

✓ Water contact at any time in their lifetime in an endemic area

And one or more of the below:

✓ Abnormal discharge

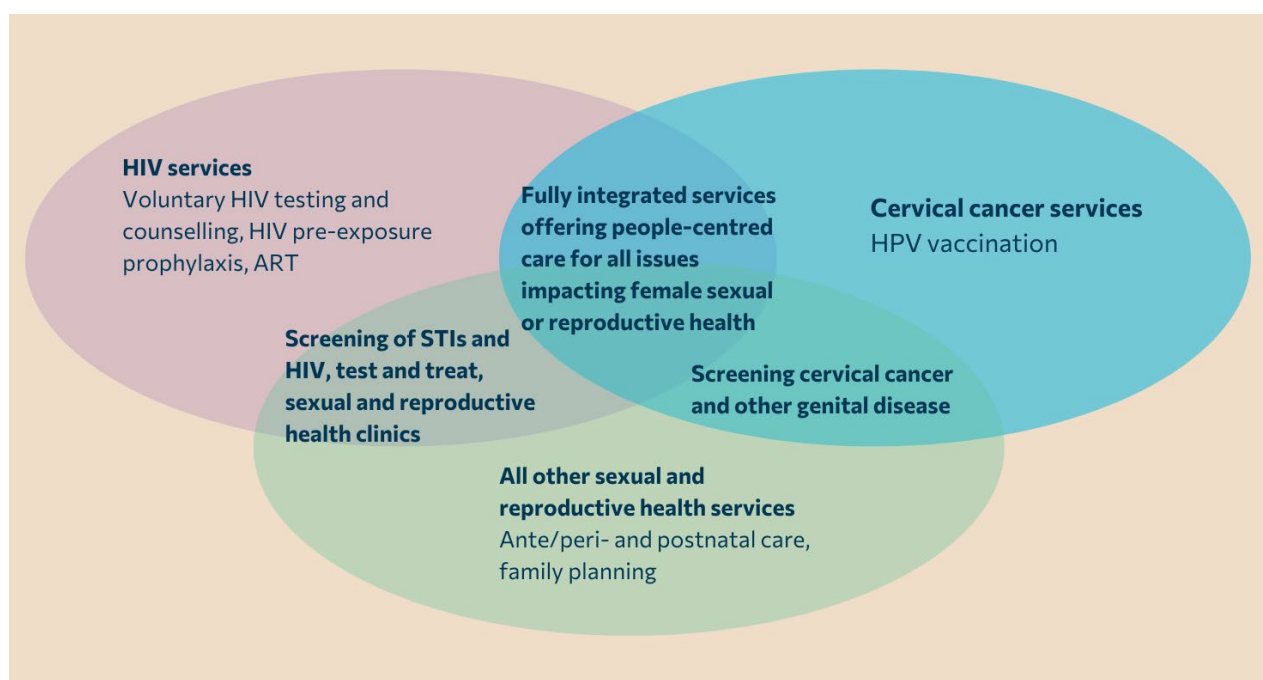
✓ Bloody discharge

✓ Secondary infertility

✓ Burning sensation in genitals

There must also be clear guidance on how to effectively treat and care for women who have already developed genital lesions. More research is needed to explore whether a treatment regimen with PZQ which is different to the standard dose recommended by the WHO is effective and if the inclusion of additional symptom management is necessary (22).

More detail on the key services that could provide platforms to reach women and girls at-risk of FGS with prevention and treatment services is provided in Figure 2.



Community outreach and mobilisation:

- Age-appropriate school/university health or sexual education programmes
- Behaviour change programmes for HIV, STIs or water, sanitation and hygiene (WASH)
- Migrant or vulnerable population outreach programmes
- Community health worker programmes for health or education
- Menstrual health or education services
- Reproductive health community engagement through mechanisms such as women's groups, maternal and child health clinics and village health clinics

Other health services:

- Mother and child health days, including immunisation clinics and campaigns
- School/university health programmes
- Praziquantel deworming programmes
- WASH interventions

Figure 2: Conceptual framework identifying key health and education services for the integration of FGS prevention and control measures.

ART: antiretroviral therapy; HIV: human immunodeficiency virus; HPV: human papilloma virus; STIs: sexually transmitted infections. Adapted from: UNAIDS, 2019 (11) and Engels et al, 2020 (18)

Integration will require training and capacity-building of community and health-care professionals, with the support of evidence-based resources and tools.



2) Developing a holistic approach:

An integrated, holistic global schistosomiasis control and elimination approach should include:

- Collaboration with water and sanitation authorities to ensure provision of safe services in endemic areas, to interrupt the cycle of transmission and infection
- Female sexual or reproductive health services which provide integrated, people-centred care and the health system strengthening measures required to support sustained and equitable service provision
- Expansion of praziquantel deworming programmes to groups other than those commonly targeted, including pre-school aged children and women of reproductive age
- Increased advocacy, promotion and communication around FGS and its links to cervical cancer and HIV at all levels from the community upwards; this should capitalise on existing platforms to improve reach
- Stigma-reduction programmes, which can be combined with existing programmes for health education or behaviour change communication, to enable health seeking behaviour and avoid any negative impacts and social exclusion women may suffer as a result of developing FGS
- Socially inclusive, gender- and youth-friendly approaches to ensure all those in need are represented and have access to appropriate and affordable services
- Collaboration across all partners to ensure a coordinated and evidence-based approach.

3) Addressing research gaps:

The key research gaps can be summarised into the following categories: 1) Identification of the characteristics and risk factors of at-risk women and the location of high-burden areas; 2) Identification of more appropriate delivery platforms for at-risk women, including integrating with HIV/AIDS and sexual reproductive health services; 3) Development of treatment pathways and diagnostic techniques which are appropriate for low resource settings, including validating new techniques such as symptomatic algorithms or genital self-sampling (23); 4) Improvement of strategies to raise awareness and reduce stigmatisation of FGS at all



levels from the community upwards; and 5) Evaluation of the impacts and financial implications of integrating services (this list has been adapted from Engels et al. (18)).

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