[FIG] TOGETHER TO END FEMALE GENITAL SCHISTOSOMIASIS

FEMALE GENITAL SCHISTOSOMIASIS
FREQUENTLY ASKED QUESTIONS (FAQS)

What is FGS?

Female Genital Schistosomiasis (FGS) is an acute and chronic condition caused by an inflammatory reaction to the eggs of parasitic worms (schistosomes) when they become trapped in body tissues of the female genital tract. Schistosomiasis is also known as bilharzia.

How is FGS acquired?

FGS is caused by the parasitic disease known as schistosomiasis. Schistosomiasis occurs when parasite eggs are deposited in freshwater bodies through the faeces or urine of infected individuals, hatching in the water and replicating as parasite larvae in water-based snails. The larvae exit the snail and penetrate the skin of individuals coming into contact with water for daily activities such as bathing, laundry or swimming. Once inside the human body, schistosome larvae develop into adult worms and lay eggs which can become trapped in the body's tissues.

Can FGS be transmitted from person to person?

FGS, and schistosomiasis, cannot be transmitted directly from person to person and is not transmitted sexually.

How prevalent is FGS?

The precise burden of FGS is not yet known; however the World Health Organization estimates that as many as 56 million women and girls may be affected, predominantly on the African continent.

Who does FGS affect?

FGS primarily affects women and girls who lack access to safe, clean water, and sanitation facilities, and therefore are to some extent already marginalised and vulnerable.

What are the physical symptoms of FGS?

Symptoms can be similar to those of sexually-transmitted infections (STIs) and include significant pelvic pain, bloody vaginal discharge, painful intercourse, bleeding after intercourse, and genital itching and burning. However, for some infected individuals the symptoms may be mild or hidden and so more likely to be ignored, allowing the disease to progress.

If left untreated FGS leads to chronic inflammation, open lesions/tissue damage, and scarring throughout the female genital tract and results in severe reproductive health complications including infertility, subfertility, ectopic pregnancy, miscarriage, complications during and after pregnancy and poor birth outcomes.

FGS has also been associated with an increased vulnerability to Human Immunodeficiency Virus (HIV) and Human Papillomavirus (HPV) infection, and cervical cancer due to the physical and immunological changes caused by schistosomiasis.

What are the psychosocial impacts of FGS?

- Mental health: as FGS is little known, it is often misdiagnosed as a STI, which can lead to mental health issues for women suffering with FGS. Advanced FGS leading to infertility and failed pregnancies causes much suffering. Repeated health-seeking behaviour without resolution adds to the distress of affected patients. This can result in depression and isolation.
- Stigmatisation: FGS is not included in medical training in most affected countries and clinical awareness among health care workers is low. Symptoms are non-specific (vaginal discharge, pain, bleeding, and infertility) and diagnosis is complex leading to frequent misdiagnosis with sexually transmitted infections (STIs) or cervical cancer. Misdiagnosis as an STI and infertility can lead to stigmatisation of patients and affect uptake of health services.
- Violence: Due to the overlap with STI symptoms, FGS is often misdiagnosed as a STI, which can lead to gender-based violence.

How can FGS be prevented?

FGS is treatable and preventable. Primary prevention relies on avoiding contact with water inhabited by snail hosts and preventing faeces or urine of infected individuals from entering water bodies. Water contact can occur during work in agricultural fields, washing clothes, fetching water, swimming, fishing and bathing among other tasks. Access to safe and reliable water supply and sanitation services is therefore vital to ending FGS.

Once infection has occurred, a single dose of treatment with the drug praziquantel kills the worms and prevents eggs from entering body tissues.

Can FGS be treated and cured?

Once FGS has developed, the parasite can be killed with the drug praziquantel, stopping any more eggs and new damage developing, and some of the symptoms may be alleviated or reduced. However, advanced lesions (tissue damage) caused by the parasite eggs cannot be completely cured once they have developed. There is ongoing research to find treatments that can reverse lesions, manage symptoms and improve health outcomes for affected individuals.

What is praziquantel and where is it available?

Praziquantel is the drug of choice for treating schistosomiasis and is usually provided in tablet form. It is generally safe and well-tolerated. A single dose will kill adult worms in humans. Praziquantel tablets should be taken with food to reduce any mild side effects such as nausea. Praziquantel is listed as an essential medicine by the WHO; however, it is often not stocked in local health facilities. In schistosomiasis-endemic areas there may be an active schistosomiasis control programme, run by the ministry of health, that is distributing

praziquantel for free to school-aged children. However, this may miss adolescent girls and women, leaving them at risk of developing FGS.

How is FGS diagnosed?

FGS is best diagnosed through a pelvic examination and colposcopy. Visual tools such as the WHO Atlas on Female Genital Schistosomiasis can be used to help with diagnosis of lesions that affect the lower genital tract. Lesions affecting the upper genital tract leading to infertility will not be seen by examination.

Other diagnostics that are being researched include molecular testing with the aim of developing a point-of-care test, and a screening questionnaire that can be used by healthcare workers.

What are some of the challenges in tackling FGS?

Female Genital Schistosomiasis is treatable and preventable but remains largely undiagnosed and untreated. As signs of FGS are frequently hidden, it has not yet been acknowledged as a specific women's health condition, nor are there global guidelines for genital schistosomiasis.

What can be done to tackle FGS?

1. Make praziquantel, the treatment for schistosomiasis, available to those that need it by including it in:
    - public health campaigns that reach children, adolescents and adults in schistosomiasis-endemic areas.
    - healthcare facilities where people seek healthcare services.
    - reproductive health services as a prevention and treatment measure in endemic areas.
2. Integrate FGS information and testing into the healthcare sector to ensure that:
    - Healthcare workers are trained on how to identify the symptoms of, and risk factors for, FGS, so that they consider it when females, girls and women present with such symptoms.
    - FGS screening is included in other key services such as HIV testing, STI screening and cervical cancer screening.
3. Raise awareness of FGS and its risk factors through community health services, health campaigns and social behaviour change interventions.
4. Call for increased access to high quality, available, accessible, acceptable and affordable water supply and sanitation services to reduce reliance on surface water for basic needs and create a clean and healthy environment.

Are men also affected by genital schistosomiasis?

Men can develop a condition called male genital schistosomiasis (MGS). Similarly, this is caused by schistosomiasis, contracted through contact with contaminated freshwater during swimming, fishing, bathing, and household chores. The parasite's eggs become trapped in the male genital tract. MGS can not be contracted through sexual intercourse. In males, symptoms of MGS include pelvic pain, pain during coitus and/or upon ejaculation, and blood

in semen. If left untreated, MGS may lead to erectile dysfunction, infertility and an increased risk of developing prostate cancer. Similar to FGS, there have been few studies on MGS and the precise burden and morbidity is unknown.

What can I do?

- Call for recognition of FGS as a women's sexual and reproductive health condition and its integration into relevant services.
- Conduct national advocacy with the Ministry of Health to recognise FGS and integrate services, including making praziquantel available.
- Help raise awareness about FGS among peers and allies.
- Call for more research to be undertaken on MGS to better understand what needs to be done to protect boys and men from developing MGS.

The FGS Integration Group (FIG)

The FGS Integration Group FIG is a group of organisations working in a range of sectors (including neglected tropical diseases, HIV, HPV, cervical cancer, Sexual and Reproductive Health and Rights and Water, Sanitation and Hygiene [WASH]) that have come together to mobilise for the sustainable integration of FGS into sexual and reproductive health services - including HIV, Cervical Cancer, STIs - and NTD and WASH programming. By including FGS within sexual and reproductive health, and community health policies, programs, and services, we can strengthen the public health response and universal access to healthcare.

Further information:

Schistosomiasis fact sheet
Female genital schistosomiasis: A pocket atlas for clinical health-care professionals
No more neglect — Female genital schistosomiasis and HIV — Integrating sexual and reproductive health interventions to improve women's lives