



UNLOCKING
HEALTH AND OPPORTUNITY
FOR WOMEN AND GIRLS
IN AFRICA -

TACKLING A NEGLECTED
REPRODUCTIVE HEALTH CRISIS



Over 50 million women and girls across sub-Saharan Africa are experiencing painful, yet preventable, sexual and reproductive health complications due to FGS (female genital schistosomiasis). This is an indicator of the failure of health systems to respond to the needs and rights of these women and girls. But it doesn't have to be this way. Millions of lives could be improved by providing FGS services through health systems and routine healthcare. Such integrated service delivery offers a crucial opportunity to strengthen systems and ensure progress on reaching health and gender equity goals.



OUR CALL TO ACTION

RAISE AWARENESS ABOUT FGS AMONG DECISION MAKERS AND THE PUBLIC

ADDRESS FGS IN HEALTH AND GENDER POLICIES

INTEGRATE FGS SERVICES IN ALL PARTS OF THE HEALTH SYSTEM, FROM HEALTH SERVICE DELIVERY AND TRAINING TO HEALTH FINANCING

FUND FGS SERVICES AS A PART OF INTEGRATED SEXUAL AND REPRODUCTIVE HEALTH CARE

INCLUDE FGS IN GENDER EQUALITY AND HUMAN RIGHTS ADVOCACY

STRENGTHEN CROSS-SECTOR COORDINATION FOR WOMEN'S HEALTH AND STRONGER HEALTH SYSTEMS

WHAT IS FEMALE GENITAL SCHISTOSOMIASIS (FGS)?



Schistosomiasis, or bilharzia, is a neglected tropical disease (NTD); 90% of people who need treatment are in Africa. It is caused by parasitic worms, transmitted to humans through snails that live in lakes, rivers and ponds where people swim, fish, bathe, wash clothes and collect water.

FGS is a complication of untreated schistosomiasis. It happens when parasite eggs get trapped in body tissues in the genital tract, including organs such as the uterus, vaginal wall, vulva and/or cervix.

Chronic infection can lead to inflammation, lesions and severe complications, particularly in relation to fertility and pregnancy. Other symptoms include significant pelvic pain, bloody vaginal discharge, painful intercourse, post-coital bleeding and genital itching and burning. FGS can also affect the body's immune response to various viruses.



Untreated schistosomiasis is linked to an increased risk of HIV transmission, bladder cancer and cervical cancer.

Often, women and girls affected by FGS are already marginalised. Many lack access to safe, clean water, good hygiene and sanitation facilities and quality, affordable healthcare services.

FGS is treatable and preventable: a short course of medication (praziquantel) kills the adult worms. **The cycle of transmission is broken when all those at risk can access safe water, adequate sanitation and good hygiene.**



THE IMPACT OF FGS



WOMEN'S HEALTH

FGS interacts with, and compounds, the many health issues that particularly or uniquely affect women and girls.

Women and girls with FGS are at high risk of **infertility, spontaneous abortion, ectopic pregnancy, stillbirth**, involuntary urination, menstruation disorders and genital ulcers. These complications, in particular infertility, can lead to social **isolation and stigma**. As a result, women with FGS have a heightened risk of mental health issues, including **depression**.

FGS has been identified as a contributing factor for HIV infection. There is significant geographic overlap in sub-Saharan Africa between communities affected by HIV and communities affected by FGS. Research highlights the increased risk of HIV transmission related to the symptoms of untreated FGS. These include lesions and contact bleeding, changes in immune response to HIV and changes in HIV viral load. A causal relationship between HIV and FGS has not yet been fully identified; additional research is needed.

Data also shows an **association between FGS and HPV**, the virus that causes cervical cancer.

GENDER INEQUALITY

The pain and stigma that women and girls can experience if they have undiagnosed FGS, combined with healthcare costs and other costs associated with it, is compounding and perpetuating gender inequality and poverty.

FGS can affect anyone with female reproductive systems and organs, regardless of their gender identity or sexuality.

In many affected communities, females are more exposed than males to the parasitic worms that cause schistosomiasis. This is because women and girls are largely responsible for tasks that bring them into contact with contaminated water, such as fetching water, bathing children and washing clothes.

As most community members and health workers do not know about FGS, the symptoms are commonly mistaken for a sexually transmitted infection (STI), placing women and girls at risk of stigmatisation. This, together with the difficulties of becoming pregnant and carrying a baby to term for women and girls with FGS, can contribute to **strained relationships, isolation, gender-based violence and social exclusion as well as mental health issues**.

The ill-health caused by undiagnosed FGS has financial, time and opportunity costs for women and girls and their households. The costs of repeat clinic visits and inappropriate medicines contributes further to gender inequalities.

ACT ON FGS TO END SCHISTOSOMIASIS, PREVENT HIV, PREVENT CERVICAL CANCER AND IMPROVE REPRODUCTIVE HEALTH.

RAISE AWARENESS ABOUT FGS AMONG DECISION MAKERS AND THE PUBLIC.

Neglecting FGS is a missed opportunity for joined-up action on women's health and gender equality. Aligning action could be transformative for women's health and gender equality.

ADDRESS FGS IN HEALTH AND GENDER POLICIES.

Include FGS as a specific sexual and reproductive health condition which affects women and girls living in schistosomiasis endemic countries, increasing risk for HIV and cervical cancer and impacting on gender equity and economic opportunities for women.

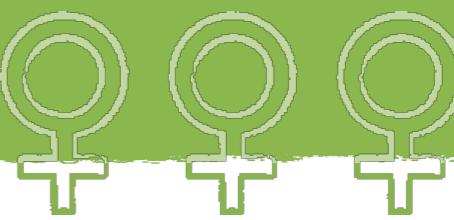
INTEGRATE FGS IN ALL PARTS OF THE HEALTH SYSTEM, including women's sexual and reproductive health services, prevention services, information systems and associated programme guidance and health worker training. This may include providing at-risk individuals with praziquantel during family planning, ante- and postnatal and HIV prevention services, and screening for FGS during cervical cancer screenings.

FUND FGS SERVICES AS A PART OF INTEGRATED SEXUAL AND REPRODUCTIVE HEALTH CARE, including HIV prevention and cervical cancer screening, ensuring it is included in all relevant budgets such as health and education.

INCLUDE FGS IN GENDER EQUALITY AND HUMAN RIGHTS ADVOCACY, to address its link with women and girls' increased social exclusion and experiences of gender-based violence and reduced access to services.

STRENGTHEN CROSS SECTOR COORDINATION FOR WOMEN'S HEALTH AND STRONGER HEALTH SYSTEMS across NTDs, HIV, sexual and reproductive health and education policy and programming. Active coordination across sectors is needed to address FGS as a part of person-centred care and to strengthen health systems for women.
A holistic approach must be taken to preventing and treating FGS, including by collaborating with the water, sanitation and hygiene (WASH) and education sectors.

HEALTH SYSTEMS



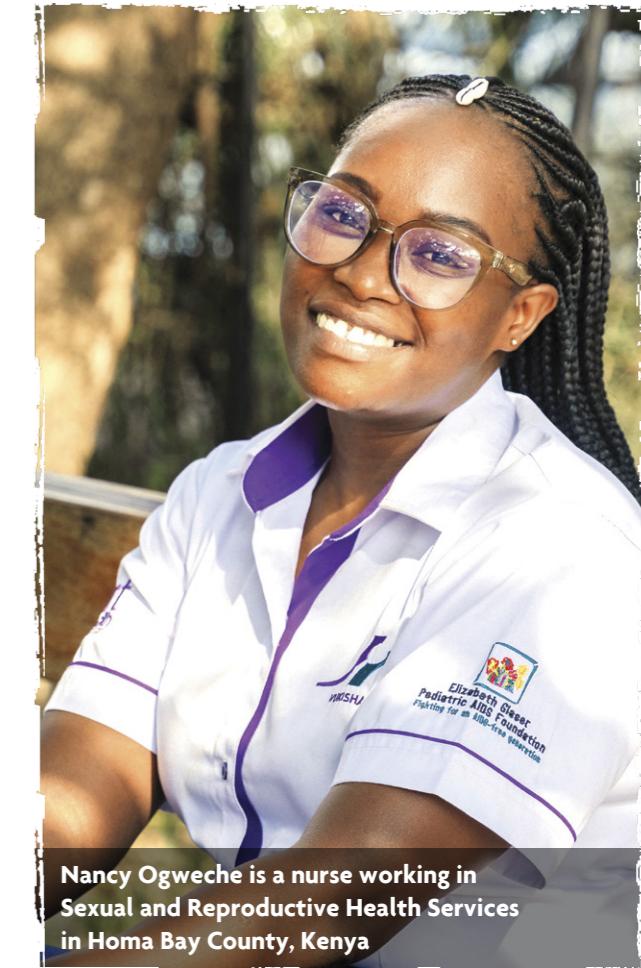
Despite the fact that FGS affects millions of women and girls, it is a neglected condition that is not visible across most parts of the health system.

FGS is not routinely included in medical textbooks or training for health professionals. As a result, most health professionals in schistosomiasis-endemic countries are not aware of FGS and are not able to diagnose it as a reproductive health condition caused by schistosomiasis.

FGS is not included in training and guidance on the control and elimination of schistosomiasis, including health promotion and sensitisation materials for communities and schools

Misdiagnosis of FGS and a lack of awareness contributes to ineffective health seeking behaviour, unnecessary treatment, and clinical investigations that fail to treat symptoms. Unnecessary treatment can also be damaging, for example, if an FGS lesion is mistaken for a cancerous lesion and removed. Multiple visits to healthcare services **increase the burden on the health system** as well as on individuals.

There is a high risk of **loss of confidence in the health system** with repeat visits that do not resolve FGS symptoms. Additionally, lack of awareness of FGS by healthcare professionals may lead to misdiagnosis of symptoms as STIs, leading to stigmatisation of affected individuals by healthcare professionals. People with FGS may stop going to health services and may also stop engaging with other health programmes for themselves and their families.



Nancy Ogweche is a nurse working in Sexual and Reproductive Health Services in Homa Bay County, Kenya

The majority of health policies and guidelines at all levels fail to recognise FGS. This reflects the lack of visibility of FGS in health information management systems, the lack of robust data to inform policy and programming, and the lack of reference within health budgets at all levels.

High quality and comprehensive sexual and reproductive health services must include FGS. The continued neglect of FGS undermines the achievement of health and development goals. As a cross-cutting issue, an emphasis on FGS provides an opportunity for developing holistic, integrated healthcare services for all.

[FIG]

The FGS Integration Group, also known as FIG, is a global coalition that is galvanising joint action across neglected tropical diseases, sexual and reproductive health and rights (SRHR), HIV, HPV/cervical cancer and WASH sectors to address the neglected and harmful condition of FGS.

FIG nurtures partnerships across the coalition and among its allies to pilot and scale up FGS integration programming. We are raising awareness of FGS to improve FGS diagnosis, treatment and prevention with and for women and girls through sustainable integration of FGS into SRHR and NTD programmes at scale.

FGS integration is a powerful opportunity to demonstrate that cross-sector coordination results in systems efficiencies, high quality care, universal healthcare, and resilient and sustainable health systems for women and girls.

Email fgs.integration@gmail.com to find out more about FIG and what you can do for FGS integration

