

Experiences with Female Genital Schistosomiasis: A Neglected and Misunderstood Disease

Vida A. Kukula, Margaret Gyapong, Sheila Addei, Irene H. Tsey, Eleanor MacPherson, Sally Theobald

Background

The World Health Organization (WHO) strategy for schistosomiasis recommends both school-based and community-based programs, but a priority of the global program has been on the mass drug administration (MDA) of praziquantel to school-age children (1). Ghana is an endemic country with high schistosomiasis prevalence. Prevention and control activities of the neglected tropical disease program mainly use mass drug administration among school children, and access for other at-risk groups has been poor.

There is little or no data on female genital schistosomiasis (FGS) from endemic areas, but FGS is suspected to affect up to 56 million African women and girls. The WHO produced *Female Genital Schistosomiasis: A pocket atlas for clinical health-care professionals* to aid with diagnosis of the disease, but there is a lack of research on health workers' understanding and management of FGS. Studies in this region of Ghana suggest that prevalence of FGS is approximately 11% (2,3).

This study explored community and health provider knowledge, attitude and practices to FGS related symptoms and identified possible strategies to meet the reproductive health needs of women and girls.

Recommendation: There is a clear imperative for the national control program to better engage on FGS. There is a need for awareness on FGS, training of frontline health workers and the inclusion of FGS into the broader screening and management of gynaecological conditions.

Key messages

- The risk of schistosomiasis infection due to contact with unsafe water is perceived to differ for women.
- Awareness of urogenital schistosomiasis was reported and believed to be commonly experienced by boys.
- Women/girls are mostly believed to be infected directly through sex.
- Knowledge of FGS was lacking among front-line health workers and community members.
- Frontline health workers lack the knowledge to effectively diagnose and manage symptoms of FGS.
- Women/girls felt stigmatized because health workers confuse gynaecological symptoms of FGS with sexually transmitted infection.
- Stigma about the disease was a major barrier for girls/women seeking care at formal health clinics.

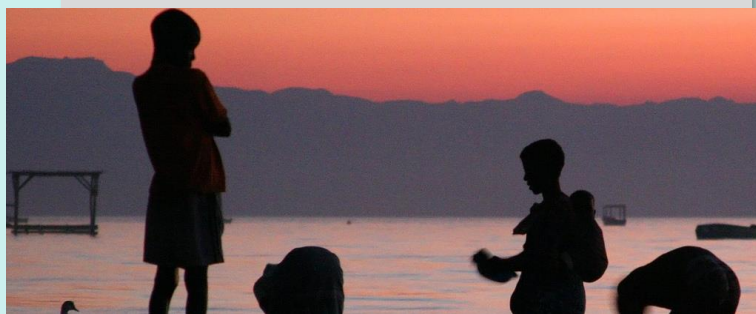


Photo: Courtesy of Andrew Whalley

What is FGS?

Female genital schistosomiasis (FGS) is a neglected disease manifestation of schistosomiasis resulting from infection of girls with *S. haematobium*. A significant gap in accurate epidemiological data on the disease exists with estimates ranging from 20 and 150 million girls and women being at risk (4, 5).

FGS occurs when the damage of schistosome eggs specifically occurs in any part of the female reproductive system. The damage can range from the formation of sandy patches in the uterus and cervix to the development of vulva nodules in the lower genital tract (6, 4). The disease causes gynaecological symptoms in women and adolescent girls which include vaginal discharge, vaginal bleeding, vaginal discomfort and pain during sex (5).

Risks FGS poses to women

When untreated, the damage that FGS causes include infertility, miscarriage, ectopic pregnancies, spontaneous abortions, prematurity, social stigma, depression, vulva nodules, genital and cervical lesions (5). There is evidence that FGS can increase vulnerability to HIV and Human Papillomavirus (and the corresponding risk of cervical cancer) (7, 8).

Methods

The study took place in the Osudoku sub-district of Greater Accra region. The Volta River runs through the north-eastern part of the district and is the main source of water.

Fifteen communities were purposively selected because of their proximity to the lake.

- Twelve focus group discussions with adult women.
- Twelve focus group discussions with adult men.
- Six focus group discussions and vignettes with school pupils.
- 34 in-depth interviews with health providers, teachers, traditional leaders, over-the-counter medicine sellers, and girls and women who ever suffered schistosomiasis.

Results

Community and health workers' beliefs about schistosomiasis

There was wide recognition in the community of the existence of schistosomiasis and that it originates from lake water, but gender-based differences in symptoms were not clearly expressed. Some community members gave alternate reasons for transmission. There is a belief that women and girls get the disease through sexual contact with infected males.

Gendered understandings of symptoms for schistosomiasis

Schistosomiasis is associated with bloody urine and the local word for the disease means 'blood in the urine'. Men, women and some community-based health workers believe that women do not get schistosomiasis or are less at risk from it because they do not have this cardinal symptom. Men commonly believe that the disease is spread to women through sexual contact with infected males.

"I have never heard the girls complain about urinating blood, it is only the boys. Girls have some kind of defence against the schistosomiasis from the lake that affects the boys, only the men can pass it to them."

Adolescent male

One doctor, one midwife and a medicine seller described other gynaecological symptoms of FGS.

Treatment and care-seeking practices for schistosomiasis

Most men, women, boys and girls described that they use home-based remedies and seek treatment from herbalists before visiting a health facility. Adolescent girls and younger women were especially reluctant to visit facilities and described being stigmatized because their symptoms were confused with an STI.

"Even sometimes they can tell your mother that you are having sex and so you can get HIV; they will talk for a long time and will not tell you that you have schistosomiasis or request you to do any test but they will say you have STI and give you drugs for STI."

17-year old female

"When I reported to the clinic with bloody urine, vaginal itch, discharge and lower abdominal pain, they referred me to the family planning clinic where the nurse asked me the last time I had sex, number of men I slept with and told me the symptoms were STI. She gave me some medicine and told me to abstain from sex. But I have never had sex in my life, I am only 14 years then. The medicine she gave me did not work and I finally went to the drug store where they treated me and said it was schisto."

Adolescent female

Some community members described the MDA of praziquantel as a treatment for schistosomiasis. However, parents, teachers and adolescents attending school did not feel that there was adequate information about school-based MDA and some students said they had been told the drugs were for intestinal worms.



Photo courtesy of Emmanuel Arthur

Knowledge and understanding of FGS and gender

None of the community members had heard of FGS as a specific disease, even women who described experiencing the gynaecological symptoms of FGS. Most frontline health workers also did not know the causes, prevention, transmission, symptoms or complications of FGS.

Water usage and risk of schistosomiasis

Community members acknowledge that women and girls use the lake for many purposes, and this puts them at risk for schistosomiasis. Women describe user fees and broken equipment as barriers to using safe sources of water, like boreholes or standpipes. Teachers, health workers and opinion leaders saw a lack of toilets as the key driver of community use of the lake for toileting.

One teacher and some adult males suggested limiting their access to the lake, while all groups requested enhanced health education initiatives, access to a clean water supply, and sanitation facilities. Health workers, a teacher and a queen mother argued for expanded treatment for women and girls.

Recommendations

- Strategies and interventions should be designed to meet the needs of women and girls for greater awareness, prevention and access to friendly diagnosis and treatment of FGS.
- Develop tools for community sensitization and educational materials on FGS for teachers, students and health workers in endemic areas.
- Review and update the medical, nursing and midwifery curricula to include FGS in gynaecological diseases.
- Incorporate FGS screening and treatment into the national STI algorithm for treatment.
- Explore opportunities to decrease risk through the provision of clean water and sanitation facilities.

References

1. Humphries D, Nguyen S, Boakye D, Wilson M, Cappello M. The promise and pitfalls of mass drug administration to control intestinal helminth infections. *Current Opinion in Infectious Diseases* 2012;25(5):584-9.
2. Malterud K. The art and science of clinical knowledge: evidence beyond measures and numbers. *The Lancet*. 2001;358(9279):397-400. 588
3. Pope C, Mays N. Qualitative research: reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *The BMJ* 1995;311(6996): 42-5
4. Hotez P, Whitham M. Helminth infections: a new global women's health agenda. *Obstetrics & Gynaecology*. 2014;123(1):155-60. 565
5. Christinet V, Lazdins-Helds JK, Stothard JR, Reinhard-Rupp J. Female genital schistosomiasis (FGS): from case reports to a call for concerted action against this neglected gynaecological disease. *International Journal for Parasitology*. 2016;46(7):395-404
6. Poggensee G, Kiwelu I, Weger V, Göppner D, Diedrich T, Krantz I, et al. Female genital schistosomiasis of the lower genital tract: prevalence and disease-associated morbidity in northern Tanzania. *Journal of Infectious Diseases*. 2000;181(3):1210-3
7. Stoeber K, Molyneux D, Hotez P, Fenwick A. HIV/AIDS, schistosomiasis, and girls. *The Lancet*. 2009;373(9680):2025-6. 572
8. Downs JA, Dupnik KM, van Dam GJ, Urassa M, Lutonja P, Cornelis D, et al. Effects of schistosomiasis on susceptibility to HIV-1 infection and HIV-1 viral load at HIV-1 seroconversion: A nested case-control study. *PLoS Neglected Tropical Diseases*. 2017;11(9):e0005968

COUNTDOWN

Calling time on Neglected Tropical Diseases

COUNTDOWN (grant ID PO 6407) is a multi-disciplinary research consortium dedicated to investigating cost-effective, scaled-up and sustainable solutions to control and eliminate the seven most common NTDs by 2020.



This is an output of a project funded by UK aid from the UK government. However the views expressed do not necessarily reflect the UK government's official policies.



COUNTDOWN Consortium
Liverpool School of Tropical Medicine
Pembroke Place
Liverpool, L3 5QA

Contact: vida.kukula@gmail.com

Visit: <https://countdown.lstmed.ac.uk>

Follow: [@NTDCOUNTDOWN](https://twitter.com/NTDCOUNTDOWN)

