



Case study: Understanding the Knowledge and Perceptions on Female Genital Schistosomiasis within Affected Communities in Ghana

Ghana is a high schistosomiasis incidence country with high prevalence rates across regions and districts, however, female genital schistosomiasis is an unrecognized and unexamined aspect of health challenges experienced by girls and women living in these endemic areas. Research explored community and health provider perspectives on female genital schistosomiasis to inform programme and policy makers to specially target girls/women for identification, outreach and care.

This study explored community and health provider knowledge and perceptions of schistosomiasis and female genital schistosomiasis, and the communities' understanding of broader social and environmental risk factors. It examined specifically women's understanding of their risk of becoming infected and the interpretation of symptoms for female genital schistosomiasis and identified potential strategies for improved access to treatment and prevention of schistosomiasis.

Study Design and Findings

- Research conducted in the Shai Osudoku district, situated in South-Eastern Greater Accra region of Ghana
- Based with rural populations predominately involved in rice farming and fishing
- 15 communities purposively selected due to proximity and use of lake and river water
- 34 in-depth interviews, 12 focus group discussions and 6 vignettes¹ with school pupils

Community norms, power dynamics and gender

Men, women, girls and boys living in the schistosomiasis endemic areas had knowledge and awareness of schistosomiasis and they discussed schools and district information services as key sources of information. Participants (both community members and health workers based in the communities) saw boys facing the greatest risk from the disease.

From the community perspective, there was complex understanding of the ways in which schistosomiasis was transmitted and the reasons people became infected which often went beyond biomedical explanations of the transmission pathways.



"When you eat sugar cane from the river bank you will swallow the snail and it will hatch in your stomach and cause schistosomiasis."

Adult female, focus group discussion

"Boys and men like to follow girls and also take peoples wives, God always punishes them with schistosomiasis."

Adult female, focus group discussion

¹guided discussions around specific scenarios and concepts

Knowledge and Perceptions of Schistosomiasis

In the study, few health workers reported to have heard of female genital schistosomiasis and there were very few participants with knowledge of the disease. Participants reported that women and girls tended to have a different form of schistosomiasis and was perceived to be from sexual promiscuity rather than from the river. There was confusion of female genital schistosomiasis and sexual transmitted infection symptoms by health workers which led to stigmatization of young girls, creating barriers for them to seek care affecting access to health care. Participants also reflected that women and girls, unlike men and boys, do not usually report bloody urine, hence, it is believed they do not get the type of schistosomiasis infection males usually get.

"I have worked here for 12 years and have never seen a girl report with bloody urine. It is always the boys. I do not think girls get it much"

Midwife, in-depth interview

"I have never heard the girls complain about urinating blood, it is only the boys. Girls have some defence against the schistosomiasis from the lake, only the men can give them"

Vignette male/female/mixed group



Strategies for Treatment of Female Genital Schistosomiasis

Women and girls had schistosomiasis said they were stigmatized by health providers when they reported their symptoms. The symptoms were mostly seen as STIs and treatment decisions were made on this basis. Young girls reflected that health providers chastised them and accused them of sexual promiscuity instead of treating them for their symptoms. They discussed using home remedies, community medicine sellers and herbalist to treat their symptoms rather than going to the clinic.

"When I reported to the clinic with bloody urine, vaginal itch, discharge and LAP, 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 was STI. She gave me some medicine and told me to abstain from sex. But I have never had sex in my life, I was 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, in-depth interview

Preventive Strategies for Female Genital Schistosomiasis

Ensuring there is awareness of the disease within the community through health education campaigns and training of health workers delivering care in highly endemic areas is vital. Providing equitable access to screening and treatment of girls/women for schistosomiasis and extending the school-based mass drug administration to a community wide treatment would reach everyone infected. Participants discussed how challenging it can be to avoid contact with the river due to the lack of alternatives. Action on the broader social environment improving access to safe water and sanitation is also required.

Gender and Equity

Gender roles and relations can shape peoples' vulnerability to and experience of neglected tropical diseases, how they experience poverty, and their ability to access care and treatment. COUNTDOWN's research has highlighted how stigmatised adolescent girls can be when they report gynaecological symptoms at the community health level. Schistosomiasis was viewed as a disease of boys rather than girls and women. Yet, women and girls' roles in the household also meant they have interact with water and have nearly constant exposure to infected water bodies. This leaves women and girls vulnerable to disease with poor access to treatment and care.

Impact

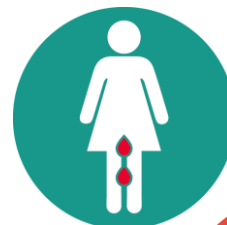
Female genital schistosomiasis causes suffering to approximately 20 million women and girls who are infected. Control of schistosomiasis has focused on the distribution of donated drugs to treat school age children. However, in there has been very little action or attention to female genital schistosomiasis. This research provides important insights into the lack of awareness that community members and health workers have on the disease. This lack of knowledge can mean women and girls may have more complex pathways to care and are being misdiagnosed if they present at the health care facilities. These findings are important because they highlight the urgent need for training of front-line health care workers to improve care and treatment of women suffering from female genital schistosomiasis. COUNTDOWN's research also highlights the need to ensure the international and national control strategy for schistosomiasis does not only focus on the distribution of drugs.

Eradication of schistosomiasis as a public health goal for the 2020 roadmap. This research further strengthens the case for increased attention on female genital schistosomiasis. It also aligns with the Sustainable Development Goal Indicators to target 3.3 - to "end the epidemics of HIV, tuberculosis, malaria and neglected tropical diseases" by 2030, as well as Goal 5 ensuring Gender Equality.

The overall purpose of this research is to help women and girls living in affected communities who continue to be infected with female genital schistosomiasis. Through providing clear findings on how women are receiving poor treatment this research is helpful to neglected tropical disease programmes and the Ministry of Health in affected communities to provide clear guidance to where health care practice needs to be improved.

By using qualitative methods, COUNTDOWN have captured and explored women and adolescent girls lived experiences of schistosomiasis and have also explored health worker's knowledge and practice highlighting key gaps in treatment. Capturing and identifying these areas are important for making changes that reflect the context in which policy will be implemented.

The key audience for the work are policy makers, medical training facilities and non-Government organisations. For policy makers, the need to ensure that treatment and care for female genital schistosomiasis are considered in programmes for schistosomiasis. Medical training facilities and those that develop curriculum include training on schistosomiasis and female genital schistosomiasis to ensure women and adolescent girls are correctly treated.



Key Recommendations

- ✓ Community-wide education and sensitization on female genital schistosomiasis is required along with community-wide screening and mass drug administration for schistosomiasis
- ✓ Teaching tools are required on female genital schistosomiasis for teachers to use in schools
- ✓ In-depth education of health practitioners in endemic areas on female genital schistosomiasis is essential with a review and update of medical, nursing and midwifery curriculum to include female genital schistosomiasis in gynecological diseases
- ✓ Multisector action is required to change the broader social environment and improve access to safe water and sanitation
- ✓ Health service should develop and incorporate female genital schistosomiasis screening and treatment into sexual transmitted infection treatment services

References and Further Reading



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COUNTDOWN (grant ID PO 6407) is a multi-disciplinary research consortium dedicated to investigating cost-effective, scaled-up and sustainable solutions, necessary to control and eliminate the seven most common NTDs by 2020. COUNTDOWN was formed in 2014 and is funded by UKAID part of the Department for International Development (DFID).