

COR-NTD 2020
Virtual Meeting, November 12 – 14
Integrating for Impact

Female Genital Schistosomiasis: Using a systems-thinking approach

Session Date: 11/14/20

Session Time: 9:00 AM - 12:00 PM EST

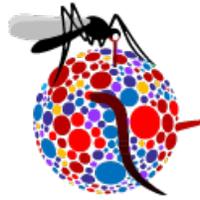
Session Description: *Research challenges to be addressed:* What are the optimal ways to reach women at risk of female genital schistosomiasis (FGS) with prevention measures? How can health systems most effectively tackle FGS? How should these interventions be scaled up to achieve universal health coverage by 2030?

Overall aim of the session: The aim of this session is to share evidence on progress in utilizing systems-thinking approaches to tackle FGS. Then, through a panel and multi-media group discussion, to elicit the priority operational research questions which will determine how best to measure the impact and deliver effective solutions to scale up these interventions.

As a result of the COR-NTD supported meeting in September 2019, key research gaps were identified relating to the social impact of FGS and the unmet potential for integration with existing health services. Following that meeting, progress has been made and during this session evidence from case studies on local perceptions and behaviors towards symptoms of FGS among adolescent and young women and their use of different treatment routes will be shared. Evidence, including community perspectives, and lessons learned through piloting iterative and participatory strategies for quality, effective integration with existing HIV and sexual health services will also be presented.

While this goes some way towards addressing the neglected issues surrounding FGS, the joint advocacy brief published by the WHO and UNAIDS in December 2019 highlights that there needs to be expansion of integrated programmes with improved training for medical, community and healthcare professionals. It also highlights that there is no treatment for FGS morbidity once it develops and the disease affects the poorest and most vulnerable communities. Furthermore, in many places in Africa, adolescent and young women are at higher risk of new HIV infections. Given that prevention remains the only current option, operational research to identify how women in the community can be reached with prevention measures, how to measure the impact of integrating FGS services and how to most effectively scale up these services, must be deliberated and planned.

Only by taking a systems-thinking approach will the complexity of the issues surrounding FGS be addressed in order to continue progressing towards reaching universal health coverage by 2030.



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Session Chairs: Ashley Preston and Fiona Fleming

Session Rapporteur: Helen Piotrowski

KEY DISCUSSION POINTS

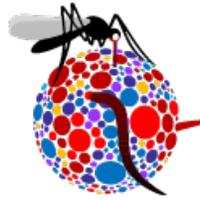
What key findings and data did the group identify via presentations? What issues were raised in discussions?

Implementation research across Cote d'Ivoire, Liberia, Nigeria, Madagascar and Ghana was presented. These three studies are working with health systems actors to co-design and evaluate interventions to support the integration of FGS management within the health system, including within primary health care (Bettee and Oluwole) and HIV and reproductive health services (Meite and Preston). Key progress so far includes:

1. Developing FGS training competencies for health workers from community level up to tertiary level (Jacobson). These will shortly be published by the World Health Organisation in collaboration with the Global Schistosomiasis Alliance.
2. Co-designing diagnosis, treatment and referral care packages with co-researchers to be piloted within primary care in Nigeria and Liberia (Bettee and Oluwole).
3. Co-developing sensitisation resources and a training package for health workers and women at risk (15-29 years old), to integrate preventive chemotherapy into HIV and female reproductive health services within Cote d'Ivoire (Meite and Preston).

These presentations inspired an interactive discussion with panelists and audience members which was supported by a FunRetro (now EasyRetro) activity, to identify key issues relating to FGS management (prevention, treatment and care, and integration). These include:

- Awareness of FGS within the health system is lacking and is a barrier to appropriate diagnosis, treatment, and referral (including from the community level). This could be counteracted through integration and appropriate training programmes for all levels of the system.
- There is limited awareness of FGS amongst governments and policymakers, which hinders engagement and appropriate implementation of policies, guidelines, resources and funding.
- Awareness of FGS at the community level is poor and can lead to stigma; it needs to be addressed for all members of the community, including men and children.
- Current diagnostics are insufficient, costly and required specialised training. Solutions to overcome these challenges could include developing and validating syndromic tools.
- Praziquantel is often only available during mass treatment campaigns, which acts as a barrier for women in the community accessing appropriate treatment. Therefore, it also needs to be accessible at the community and health centre level, at affordable prices.



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- At-risk groups such as pre-school age children, children who do not attend school and women of reproductive age, are often not reached through mass treatment campaigns.
- The importance of engaging all stakeholders, from the community level up, in the design of interventions and resources was reiterated throughout the discussion.

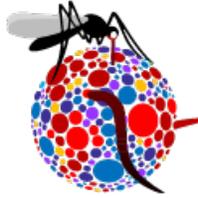
KNOWLEDGE GAPS IDENTIFIED

What data and tools need to be generated to address the issues raised by the group?

The need for more information and evidence was identified throughout the health seeking pathway, including in prevention, diagnosis, treatment and care. Furthermore, limited evidence about the best mechanisms to integrate FGS management were identified. There is also a need for robust monitoring and evaluation of interventions to assess feasibility, acceptability and sustainability of interventions. These should include health provider and patient perspectives, as well as any direct/indirect impacts on health systems, (these are summarized below). As an increasing amount of evidence in relation to how to prevent and treat FGS is gathered, there will be a need for guidelines and policies to support countries to plan strategically and implement appropriate interventions.

Prevention

- There is a need for social mobilisation and sensitization strategies for community members, including men. Awareness-raising campaigns need to be adequately funded, have information, education and communication (IEC) materials and utilise local knowledge. Sensitisation should increase knowledge of FGS symptoms, treatment and also behaviour change interventions, such as avoiding infected water sources where possible.
- There is a need to increase awareness in school-age children; this may be achieved through targeted health education.
- There is a need to understand how to most effectively utilise community health workers (CHWs) to raise awareness and support prevention of FGS. This will require development of tools for training and to support the sensitisation activities. These should be developed using a participatory approach.
- Adaption of the WHO WASH NTD tool for the FGS context could support integration and development of partnerships with HIV/AIDS, reproductive health, WASH and NTD MMDP.
- Development of tools for advocacy to support government and policymaker engagement will be essential to overcome the lack of awareness amongst these key stakeholders.
- More needs to be done to understand how to tackle stigma effectively in the community, including which stakeholders to involve and how to scale up.



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Treatment and Care

- FGS needs to be integrated into training for health workers at all levels. For those already practicing, the development of online training packages may support learning.
- Countries face challenges in procurement of sufficient praziquantel, and strategies are needed to support its provision (throughout the health system) affordably.
- Greater understanding is needed of the chronic morbidity associated with FGS, and of treatment and clinical outcomes. There is also a need to explore morbidity management strategies for women and girls with FGS and how this could be integrated into existing NTD MMDP strategies. This could be supported through the development of a care package for FGS morbidity management, with input from all relevant health workers. It should include supporting mental health and reducing stigma.
- Another gap to address is around how to reach women with praziquantel most effectively and at scale. This may need to include different platforms to reach different target populations, including children who do not attend school or young women. This should also include the further guidelines, evidence required to support countries to treat pregnant and breastfeeding women.
- Current diagnostics are inadequate and there is a need for point-of-care tests and rapid diagnostics; however, syndromic management (as used in sexual and reproductive health services) could be developed and validated to support suspected diagnoses. There is also a need to understand what tools are effective and how the tools required may differ for different levels of the health system. All diagnostics must be affordable.

Integration

- There is need for further evidence on the optimal strategies to integrate and what tools will be required to support this.
- There is a need to be able to measure the effectiveness of integration, and this could include adding indicators for FGS into DHIS2, developing an M&E framework, measuring the number of trainings including FGS, and determining the perceptions of patients.

In addition, it was suggested that there is a need for further epidemiological and clinical studies to explore:

- Prevalence and intensity of FGS infection in relation to prevalence of schistosomiasis infection
- Mechanisms and diagnostics to predict severity of FGS infection
- Factors which increase vulnerability of developing FGS, for example, demographics, intensity of infection, co-infections.
- Relationship between FGS and with other conditions including cervical cancer, HIV, infertility, mental health, bladder pathology
- Associations between MGS and FGS



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RECOMMENDED NEXT STEPS

What operational research and other actions need to be taken to address the knowledge gaps identified by the group?

There has been considerable progress in the last five years, and a number of operational research studies as well as clinical research are currently ongoing. Through the results of these studies, evidence-based interventions can be planned and scaled up to effectively integrate FGS into existing health systems and provide appropriate diagnosis, treatment and referral packages. Sustainability of these interventions will require development of advocacy tools to support partnership and collaboration with governments, civil society and key health system actors.

A Community of Practice (CoP) should be established to share learnings, especially training and sensitization tools which are currently being developed. This CoP could also determine the overall package that is needed to address the lack of awareness of FGS amongst health workers at all levels of the health system and the resources required for effective diagnosis and treatment of FGS. This could help standardize all the tools. Furthermore, as more evidence is collected through research, the CoP should consider developing a guide for national NTD programmes to provide a comprehensive list of the measures needed to help prevent FGS for women in the community. Engagement of the appropriate multi-sectoral partners and stakeholders is important to facilitate this effort.

Operational research and actions required to optimally reach women at risk of FGS with prevention measures:

- Determine most effective strategies for community sensitisation (including men) and stigma reduction; for example, establishing peer support groups, or engaging CHWs
- Develop standardised resources and IEC material to support this
- Develop standardised teaching materials and engage with Ministries of Education to incorporate FGS into the curriculum
- Adapt existing resources, for example the WHO WASH NTD tool, to support integration and development of partnerships with HIV/AIDS, reproductive health, WASH and NTD MMDP
- Establish networks with community organizations
- Understand more about the epidemiology and risk factors associated with FGS

Operational research and actions required to provide effective and integrated treatment and care:

- Develop and evaluate training tools for health workers, including online tools and validation of the FGS competencies which have already been developed through multi-sectoral collaboration



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- Evaluate effectiveness of diagnostics at different health system levels and develop a syndromic management tool which can be used in low resource settings.
- Design and evaluate morbidity management strategies for chronic FGS and how this could be integrated into existing MMPD strategies
- Determine which platforms are most effective to reach girls and women of childbearing age with preventive chemotherapy at scale
- Evaluate the feasibility and impact of routine screening for FGS

Operational research and actions required to understand how these interventions should be scaled up:

- Evaluate strategies for optimal integration of FGS into existing health services and determine how the impact of this can be measured
- Develop tools for advocacy to support government and policymaker engagement; this will be essential to advocate for and support provision of adequate and affordable praziquantel
- Next steps for Ministries of Health:
 - Establish reporting mechanisms for FGS
 - Embed training tools for FGS into medical curriculum at all levels of the health system and consider online training platforms
 - Establish effective monitoring, evaluation and supportive supervision of FGS management