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Breaking the silence of female genital schistosomiasis in Ghana's health system: A case of health workers within the FAST project --Manuscript Draft--

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1	Breaking the silence of female genital schistosomiasis in Ghana's health system: A case
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27 Abstract

Background: Female Genital Schistosomiasis (FGS) remains one a critical and neglected
topics in Neglected Tropical Diseases (NTDs) and the health of women and girls worldwide.
Health workers' knowledge of FGS is vital to the prevention and management of the disease.
This study conducted implementation research to identify and address the FGS knowledge gap
among health workers in Ghana.

Methods: This study was a 3-year (2020 -2022) implementation research applying a pragmatic uncontrolled quasi-experimental study design. The study involved a baseline assessment, an intervention phase involving the training of health workers about FGS and an endline assessment. A mixed-method approach was applied to data collection involving health workers in two schistosomiasis endemic districts and health workers across the country. NVIVO 12 and STATA 14 were used for qualitative and quantitative data analysis, respectively.

Results: Prior to the intervention, the level of awareness about FGS among health workers was
less than 8%, and most participants only understood FGS as merely urogenital schistosomiasis
in females.

In response to this gap, an FGS education intervention in the form of training of health workers, student nurses alongside the distribution of FGS educational materials were carried out. The intervention enhanced health workers' awareness of FGS to more than 61%, encompassing an enhanced understanding of the disease's signs and symptoms to more than 60%, as well as its management strategies.

47 Nevertheless, a key challenge remains in ensuring access to praziquantel, the primary48 medication for treating and preventing schistosomiasis.

49 **Conclusions:** The FGS intervention has improved health workers' awareness and 50 understanding of FGS. However, there is still a need for expanded training of health workers 51 as well as improvement in the access to praziquantel to facilitate FGS management. In addition, a holistic strategy encompassing all stakeholders at the individual, community, and healthsystem levels is required to improve the general knowledge and management of FGS.

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56 Keywords: Neglected Tropical Diseases, Schistosomiasis, Female Genital Schistosomiasis,
57 Mass Drug Administration, Ghana.

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59

60 Introduction

61 One of the most prevalent Neglected Tropical Diseases (NTDs) in Sub-Saharan Africa (SSA) 62 is called schistosomiasis, bilharzia or "snail fever." Schistosomiasis is a parasitic disease that 63 affects men, women and children living in tropical regions. Endemic in 78 countries, this 64 disease affects more than 250 million people with approximately 90% of the disease burden 65 found in Africa (1,2). Disease transmission occurs through contact with freshwater bodies 66 where aquatic snails breed and releases the parasite that burrows through the skin in contact 67 with water. Regular daily activities (washing, bathing, gathering water, swimming) put adults 68 and children at continuous risk of infection. Current strategies to control schistosomiasis focus 69 on preventive chemotherapy using donated praziquantel (1,2).

When a young girl or woman is infected with schistosomiasis, the worms mate producing millions of eggs every day inside her body. In the case of *S. haematobium*, the eggs are released into the genito-urinary tract embedding in the tissue causing inflammation that results in a granulomatous response around the eggs causing Female Genital Schistosomiasis (FGS)(3). Thus, FGS is a gynaecological disease caused by untreated urogenital schistosomiasis. FGS results in abdominal and pelvic pains, disorders of menstruation, pain during intercourse, vaginal bleeding after intercourse, inflammation of reproductive organs, genital lesions,
miscarriage, ectopic pregnancy and infertility (4).

Increasing evidence shows that a woman with FGS has a threefold increased risk of HIV infection when she becomes sexually active (5–7). Timely treatment can prevent the disease and reverse some of the associated biological risk factors even in chronic infection (8).

Nonetheless, FGS remains one of the most important neglected areas in women's and girls' health globally. An estimated 56 million women have FGS, nearly all in SSA (9). This infection is a greater concern for women and girls as their gender roles put them at a higher risk of being in contact with infested waters when completing household chores (10).

However, in Ghana, health workers' awareness of FGS and its associated consequences is
lacking, and unfortunately even in places where the disease is endemic (11,12).

This study, therefore, conducted an implementation study to identify and address the FGS knowledge gap among health workers in Ghana. This involved a baseline assessment to examine the knowledge and understanding of FGS among health workers followed by an FGS intervention in the form of training and provision of educational materials to health workers.

91 Methods

92 Study Design

This was a 3-year (2020 -2022) implementation study applying a pragmatic uncontrolled quasiexperimental study design (pre and post-intervention) design. This paper is part of a bigger study called "FGS Accelerated Scale Together (FAST) Transition to scale project: improving women's health by reducing morbidity from female genital schistosomiasis in Ghana (FAST Project)". The main aim of the FAST project was to improve adolescent girls and women's health by reducing morbidity associated with FGS through preventive and curative efforts. 99 For this aspect of the paper, we report the study activities that involved heath workers in three100 phases of the study as described below:

101 **Phase 1: Pre-intervention**

102 This phase was a baseline assessment of the FGS knowledge gap among health workers in the103 country.

104 Firstly, interviews were held with health workers including directors of health and medical 105 superintendents in two schistosomiasis-endemic districts in Ghana: North Tongu District and 106 the Weija-Gbawe Municipality. The two districts were selected because they have several 107 communities along the Volta Lake (the largest artificial reservoir in the world) and Wieja Dam 108 (the second largest water reservoir in the country after the Volta reservoir), where the Ghana 109 Health Service reports that schistosomiasis prevalence is at least 80% (13). Hence, these 110 regions were chosen for the interviews to learn about the knowledge gaps among health 111 workers, which can then be applied to other regions.

Secondly, we engaged relevant stakeholders such as Ghana Neglected Tropical Diseases Programme (NTDP) to identify policy gaps in FGS control. Following the discussions, the Ghana National FGS Committee was established to work towards helping to integrate FGS into routine health services.

116

117 **Phase 2: Intervention**

Phase two was the implementation of FGS intervention activities which was based on thebaseline assessment. Four main activities were undertaken:

120 Online training of health workers

121 The FAST Package team, together with the Geneva Learning Foundation, Bridges to122 Development, conducted an online, interactive, peer-to-peer training on FGS targeting

healthcare professionals. The goals of the training were to train healthcare providers to
integrate FGS into their clinical practice so that they can improve women's reproductive health
by decreasing the burden of FGS and to encourage learners to co-create solutions within their
local context to address FGS.

Of the 119 applicants who participated in the online FGS course/training held between May and June 2021, 62 successfully completed the entire session. The participants were a mix of doctors, obstetrics and gynecology specialists, nurses/midwives, physician assistants, health information officers, nursing educators, and public health professionals and lecturers from the northern, middle-belt, and southern geographical regions in Ghana.

As part of the training, participants developed feasible action plans to integrate FGS into their practice and establish and maintain awareness in their context. The action plans were designed to reflect actions that could be undertaken without additional budgetary support and within the learners' own domains of influence.

136 Face-to-face Subject Matter Experts (SME) training

To create a sustainable system of training healthcare providers within the health systems in Ghana, the FAST Package team, carried out a 3 day FGS training March 2022 to create a cohort of national FGS Subject Matter Experts. Individuals were first identified from the the online training program. These individuals had demonstrated intrinsic motivation to learn about FGS through their online participation. This resulted in a multidisciplinary range of training SMEs including obstetricians / gynecologists, doctors, nurses, midwifes and health information officers. This training had 30 participants.

After the training, participants were given 100 copies (5 copies each) of FGS booklets to distribute to their constituents to help disseminate FGS awareness and management. Expects in the field of FGS, home and abroad, collectively developed the FGS booklet to fit the context of Ghana. The content of the FGS book included the causes, treatment and prevention of schistosomiasis and FGS (9). All participants (trainees and facilitators) were officially recognized as SMEs on FGS through the awarding of certificates upon completion of the training.

151 Training of frontline health workers on schistosomiasis at endemic districts

Training of frontline health workers was carried out in two schistosomiasis endemic districts (North Tongu and Weija-Gbawe Municipality). The total number of participants for the training was 116, of which 41 and 75 were from North Tongu and Weija-Gbawe Municipality respectively. After the training, 234 copies of the FGS booklets were distributed to health workers in North Tongu and 429 copies were distributed to health workers in Weija-Gbawe Municipality.

158 Face-to face training of health workers and students

A series of FGS training of health workers and students in the nursing, midwifery and medicine was carried out by the SMEs in their various continuants. For instance, within the period, series of lectures on FGS was delivered to over 300 nursing students, 100 midwifery students and 100 medicine students at UHAS, Ho in the Volta Region of Ghana. In addition, lectures on FGS were held for over 600 nursing and midwifery students at Nursing and Midwifery training college (NMTC), Berekum in the Eastern Region of Ghana.

<sup>Further, FGS presentations/education were made to about 700 health workers in the eastern
region. The participants included: District directors of health, SHEP coordinators, nurses and
NTD coordinators.</sup>

¹⁶⁸ The Ghana National FGS Committee in collaboration with the Ghana NTDP organised 169 schistosomiasis and FGS face-to-face awareness training for health workers in 15 districts in

the Volta, Western and Central regions of Ghana. Over 600 health workers were involved inthe training on FGS.

172 **Phase 3: Post-intervention**

Phase three was the evaluation of the intervention. A cross-sectional mixed method approach
was applied in data collection involving In-Depth Interviews (IDIs) with health workers as well
as quantitative data of health workers in a pre- and post-training assessment format.

176 Data Collection, Management and Analysis

Graduate-level Research Assistants (RAs) who were trained for five days were used to collect the qualitative data. Interview guides were pretested before the actual data collection. The interviews were face-to-face, and the participants were purposively sampled to include Doctors, Nurses and Midwives based on their involvement in Obstetrics and gynaecology activities. A total of 4 IDIs and 16 IDIs were conducted at baseline and endline respectively.

182 All qualitative interviews (IDIs) were audio recorded and later transcribed. The transcripts were 183 reviewed for accuracy and completeness. Guided by the objectives of the study and the themes 184 from the transcripts, a codebook was developed. Thematic analysis was carried out using 185 NVIVO 12 software to interpret themes or patterns in the data pertinent to the study aims.

In addition, quantitative data were collected from 116 training participants in the form of pre and post-training evaluations to determine the changes in FGS knowledge among the health workers. This was done among health workers in the schistosomiasis endemic districts of North Tongu and Weija districts. The quantitative data were collected using a paper-based questionnaire and then entered STATA 14.0 for cleaning and analysis. The data were analysed using simple frequencies and percentages.

192 **Ethical consideration**

193 Ethical clearance for this study was obtained from the GHS Ethics Review Committee (GHS-

194 ERC 003/04/21) and the University of Health and Allied Sciences Research Ethics Committee

195 (UHAS-REC A.5 [4] 20-21). Written informed consent was obtained from all respondents in196 the study.

197

198 **Results**

199 This section presents quantitative results from pre- and post-training evaluations of health 200 workers from North Tongu and Weija districts as well as online training evaluation across 201 health workers in Ghana. The section also presents the qualitative findings from baseline and 202 endline IDIs from North Tongu and Weija districts.

203

204 Socio-demographic characteristics

Table 1 presents the sociodemographic characteristics of frontline Health workers from the North Tongu and Weija districts who participated in the qualitative interviews (IDIs). The majority of the participants at the endline were females and the average age of the participants at baseline and endline was 34 and 48 years respectively.

209 Table 1 : Sociodemographic characteristics of IDI participants

	Endline		Baseline	
Variable	Freq (16)	Percent (100%)	Freq (4)	Percent (100%)
Sex				
Female	14	87.5	2	50
Male	2	12.5	2	50
Rank				
CHN	3	18.75	0	0
Medical Officer	3	18.75	2	50
Medical Superintendent	1	6.25	2	50
Midwife	2	12.5	0	0
Nurse	5	31.25	0	0
Physician Assistant	2	12.5	0	0

Education				
Degree	6	37.5	0	0
Diploma	7	43.75	0	0
Masters	3	18.75	4	100
Average age	34		48	
Average number of years			8	
of services	5			

211 Awareness about schistosomiasis and FGS

In the quantitative assessment in the two schistosomiasis endemic districts, the results showed that before FGS training, health workers' level of awareness (very aware) about FGS was less than 8% (North Tongu 7.3%; Weija 4.1%). Nonetheless, after the FGS training, more than 68% (North Tongu 68.3%; Weija 69.4%) of the participants mentioned that they were now very aware of FGS (Figure 1 and 2), representing more than 61% improvement in the level of level of awareness of FGS.

218 Similarly, in the qualitative assessment, the majority of the health workers who participated in 219 the baseline and endline assessments indicated that they had heard of schistosomiasis. 220 However, with regard to FGS, the knowledge level was low before the FGS training 221 intervention. Furthermore, some of the health workers confessed that before the FGS training, 222 they were not aware that women can get schistosomiasis and therefore they did not know about 223 FGS prior to the training. They therefore acknowledged that the FGS intervention (FGS 224 training and FGS booklet) has improved their competencies around FGS. These results suggest 225 that the FGS training was effective in raising health workers' awareness of FGS.

226 Figure 1: Awareness about schistosomiasis and FGS (North Tongu)



229 Figure 2 : Awareness about schistosomiasis and FGS (Weija)



233 "Before this training, I knew nothing about FGS. What I knew about was the normal
234 schistosomiasis (IDI-Health worker, North Tongu, Endline)"

235

"At first, I didn't know females get schistosomiasis. I knew about only the males. However, after the training, I am now aware of FGS...However, I did not get any FGS case after the training yet. In fact, I told one of my colleagues that I missed an FGS case because I encountered a lady before the FGS training and all the complaints she presented to me were related to FGS but because I was at that time not aware of FGS, I think a missed her. And there is no way I could trace her up (IDI-Health Worker, Weija, Endline).

242

243 Health workers knowledge in FGS diagnosis

244 Following the implementation of a FGS training intervention, there was a significant increase 245 in healthcare workers' ability to diagnose FGS. In North Tongu, the percentage of health 246 workers reporting confidence in FGS diagnosis rose from 26.8% to 97.6%, demonstrating an 247 impressive 70.8% improvement. Similarly, in Weija, the proportion of confident healthcare workers increased from 35.4% to 95.8%, representing a notable 60.4% rise (Table 2). These 248 249 findings illustrate the positive impact of training on healthcare workers' capacity to diagnose 250 FGS effectively. This improved diagnostic ability will ultimately lead to earlier detection and 251 treatment of FGS, contributing to improved patient outcomes and enhanced public health 252 efforts.

253

254 Health workers knowledge in FGS Recording in DHIMS 2 System

The District Health Information Management System–2 (DHIMS 2) serves as the central database for capturing disease data within the healthcare system. However, prior to a recent training initiative, health workers lacked the necessary knowledge to identify and record Female Genital Schistosomiasis (FGS) cases within the DHIMS 2 system. This resulted in an underreporting of FGS prevalence within the region. Following the implementation of a dedicated training program, a significant improvement in FGS data recording was observed. Health workers indicated that the training equipped them with the necessary knowledge and skills to effectively identify FGS cases and accurately record the information within the DHIMS 2 system. Thus, knowledge to identify and record FGS increased by 100%(Table 2).

264 Table 2 : Knowledge to diagnose, record and treat FGS

	North Tongu		Weija	
			Pre-	Post-
	Pre-Training	Post-Training	Training	Training
Knowledge to diagnose FGS				
No	30 (73.2)	1 (2.4)	42 (64.6)	3 (4.2)
Yes	11 (26.8)	40 (97.6)	23 (35.4)	69 (95.8)
Total	41 (100)	41 (100)	65 (100)	72 (100)
Knowledge to treat FGS				
No	30 (73.2)	2 (4.9)	48 (75)	0 (0)
Yes	11 (26.8)	39 (95.1)	16 (25)	71 (100)
Total	41 (100)	41 (100)	64 (100)	71 (100)
Knowledge to refer FGS				
No	24 (58.5)	0 (0)	26 (39.4)	4 (5.7)
Yes	17 (41.5)	41 (100)	40 (60.6)	66 (94.3)
Total	41 (100)	41 (100)	66 (100)	66 (100)
Knowledge to record FGS				
No	28 (68.3)	0 (0)	29 (44.6)	0 (0)

Yes	13 (31.7)	41 (100)	36 (55.4)	71 (100)
Total	41 (100)	41 (100)	65 (100)	71 (100)
Knowledge to prevent FGS				
No	22 (53.7)	0 (0)	24 (38.1)	0 (0)
Yes	19 (46.3)	41 (100)	39 (61.9)	71 (100)
Total	41 (100)	41 (100)	63 (100)	71 (100)

266 Knowledge of FGS from Online Training

Similarly, pre- and post-training evaluation of the FGS online training showed improvement in knowledge to diagnose, treat, record and prevent FGS (Figure 3). For instance, there was a 75.1% increase in knowledge to diagnose, amongst those who completed the course (Figure

270 3).

271 Figure 3: Knowledge of FGS from Online Training



274 Scarcity of praziquantel hamper schistosomiasis and FGS treatment efforts

Healthcare workers reported encountering difficulty in obtaining praziquantel, often finding it unavailable at both health facilities and pharmacies. This scarcity forced them to adopt alternative approaches, such as occasionally resorting to antibiotics as a treatment option. In some cases, they would prescribe praziquantel to patients, leaving them to independently search for and purchase the medication at pharmacies, where its availability was uncertain.

280

281 "When they come to the health facility and we do not have praziquantel at the facility, I 282 prescribe it to them to go buy from the pharmacy shop. Mostly we do not have praziquantel in 283 the health facilities (IDI, Health Worker, Weija, Endline)"

284

285 "I think some of my colleagues sometimes give them antibiotics and painkillers if there is no
286 praziquantel. Sometimes, after MDA, they give us the remaining praziquantel. If a patient
287 comes and fortunately we have some, then we can give the praziquantel (IDI, Health Worker,
288 North Tongu, Endline)"

289

290 FGS health seeking

Health care workers highlighted the occurrence of delayed care-seeking for schistosomiasis among women, often due to a lack of awareness about the disease and its potential progression to FGS. These women often remain unaware of their infection until they present for antenatal care (ANC) services. Notably, during ANC examinations, trained health workers can identify suspected cases of schistosomiasis/FGS. This was exemplified by a medical superintendent who recounted an instance where he implemented routine testing for schistosomiasis during ANC, leading to the identification of multiple cases.

299 "the very young ones do not know how they contracted it (schistosomiasis). ..like the routine 300 tests that we do for the pregnant women, occasionally some of them test positive for 301 schistosomiasis. I think we discharged a woman treated for FGS a month ago. I think we were 302 just doing routine testing and then, schistosomiasis ova was present..."(IDI, medical 303 superintendent, North Tongu).

304

305 The cost of treatment for schistosomiasis and FGS presents a barrier to seeking appropriate 306 care, particularly for vulnerable populations. Healthcare workers reported that many 307 community members either forgo treatment entirely or resort to low-cost alternatives due to 308 financial constraints. These alternatives, such as herbal remedies or delaying treatment until 309 mass drug administration (MDA) campaigns, may not be effective and can lead to further 310 complications. The high cost of treatment can be attributed to the scarcity of praziquantel, the 311 primary medication for schistosomiasis and FGS, at both health facilities. This scarcity often 312 forces individuals to seek treatment at chemical shops, where prices are typically higher.

313

314 "Sometimes due to cost, parents do not treat the child when the child has schistosomiasis. They 315 wait till it is time for MDA because, during that period, they can get it for free (IDI-Health 316 worker, North Tongu, Baseline)"

317

318

319 **Discussion**

Gender roles expose females to schistosomiasis and FGS and therefore the need for strategicinterventions, particularly in schistosomiasis endemic communities. The study sought to use

an implementation design to identify and address the FGS knowledge gap among healthworkers in Ghana.

324 The findings of the study revealed that the level of awareness of urogenital schistosomiasis as 325 well as some common symptoms of schistosomiasis such as blood in the urine was high among 326 health workers. However, it was observed that at the time of baseline assessment and before 327 FGS training intervention, very little was known about FGS awareness, diagnosis and 328 treatment. This finding is in tandem with previous studies in Tanzania and Nigeria that reported 329 high knowledge about schistosomiasis among healthcare workers but limited knowledge about 330 FGS (14,15). FGS is frequently given little attention in medical education and continues to be 331 poorly understood by health workers, which commonly results in FGS being misdiagnosed or 332 mistakenly diagnosed as an STI or cervical cancer and then given improper treatment (9). 333 Traditionally, urogenital schistosomiasis has been primarily associated with male symptoms 334 and this focus on male-specific manifestations has led to the neglect of FGS, which primarily 335 affects women and often presents with less obvious symptoms (16,17).

336 Nonetheless, due to the study intervention, the level of awareness and knowledge on diagnosis 337 and treatment of FGS among health workers was reported to have improved within the period, 338 demonstrating the impact of the intervention. Continuous FGS education among health workers 339 is very important in controlling FGS. The Ghana National FGS Committee mentioned that they 340 would continue with the in-service training of nurses across the country and will also engage 341 the Nurses and Midwifery Council concerning curriculum revision to incorporate FGS 342 diagnosis and management. With these initiatives, FGS discussion will be reinforced at the 343 school and practice levels. Improved competency about FGS among health workers will 344 facilitate the prevention, diagnosis and treatment/management of FGS and therefore calls for 345 more efforts to sensitize health workers about FGS beyond this study.

The result also showed that the intervention has improved knowledge and skills to effectively identify FGS cases and accurately record the information in the DHIMS 2 system. This will data capturing skills obtained will ultimately provide a more accurate picture of FGS prevalence, enabling targeted interventions and improved patient care.

350 Although praziquantel is the recommended medication for the treatment and prevention of 351 schistosomiasis and FGS in Ghana (18–21), access and use of the medication is a challenge. 352 Praziquantel is usually not available at health facilities for the treatment of schistosomiasis(15). This is not surprising given that praziquantel is a programmed medicine and it is only available <u>2</u>53 354 during MDA and sparsely available in health facilities and pharmacies/drugs shops. In addition, 355 those found at some of the pharmacies/drug shops are not affordable for community members. 356 For instance, the price of a single 600mg tablet of Praziquantel is about GHc50 (USD5) and 357 given that praziquantel is prescribed at a single dose of 40 mg per kilogram of body weight 358 (9,18), if a child weighs 45kg, he or she will require as many as three tablets. The cost of 359 treatment with praziquantel can be disastrous if a complete dose is considered, as single dose 360 is more than three times the daily minimum wage (GH 14.88)(22) of a worker in Ghana. These 361 findings highlight the need for continued efforts to address supply chain issues to ensure 362 effective and accessible treatment for FGS patients (23).

363

364 Conclusion

There has been a lack of awareness and knowledge about Female Genital Schistosomiasis (FGS) among healthcare workers, leading to missed diagnoses and inadequate treatment. While the study intervention has improved some health workers awareness and the knowledge to diagnose and treat FGS, continued efforts are crucial to achieving greater impact.

369 We therefore recommend the following to expand FGS knowledge and awareness:

- Curriculum Integration: Incorporating FGS diagnosis and management into the training
 curriculum for healthcare workers at all levels is essential for equipping them with the
 necessary skills to identify and treat the disease.
- Equipped Facilities: Ensuring health facilities are adequately equipped with
 praziquantel, medical equipment, and supplies is crucial for effective diagnosis and
 treatment of FGS.
- Continued training and refresher courses: Providing ongoing training and refresher
 courses for healthcare workers helps ensure they stay up-to-date on the latest FGS
 information and treatment protocols.
- Public awareness campaigns: Raising public awareness about FGS symptoms, risk
 factors, and available treatment options is crucial for encouraging people to seek timely
 medical attention.
- Community Engagement: Engaging community leaders and health workers in raising
 awareness and promoting FGS prevention strategies can contribute significantly to
 reducing the disease burden.
- Collaboration and Partnerships: Fostering collaboration and partnerships between
 healthcare systems, research institutions, and NGOs can accelerate progress toward
 FGS elimination.
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