

# Incorporating the diagnosis and management of female genital schistosomiasis in primary healthcare in Liberia: a mixed methods pilot study

Motto Nganda<sup>a,\*</sup>, Anthony K. Bettee<sup>b</sup>, Karsor Kollie<sup>c</sup>, Gartee E. Nallo<sup>b</sup>, Matthews Juabeh<sup>d</sup>, Abednego Wright<sup>e</sup>,
Rachael Thomson oand Laura Dean<sup>a</sup>

<sup>a</sup>Department of International Public Health, Liverpool School of Tropical Medicine, Liverpool, L3 5QA, UK; <sup>b</sup>National Schistosomiasis Control Programme, National Neglected Tropical Disease Programme, Ministry of Health, 1000, Monrovia 10, Liberia; <sup>c</sup>National Neglected Tropical Disease Programme, Ministry of Health, 1000, Monrovia 10, Liberia; <sup>d</sup>Bong County Neglected Tropical Disease Programme, Ministry of Health, 1000, Monrovia 10, Liberia; <sup>e</sup>Nimba County Neglected Tropical Disease Programme, Ministry of Health, 1000, Monrovia 10, Liberia

\*Corresponding author: Tel: +44(0)1517053276; E-mail: motto.nganda@lstmed.ac.uk

Received 12 September 2022; revised 13 January 2023; editorial decision 16 January 2023; accepted 24 January 2023

**Background:** Liberia's national neglected tropical disease (NTD) master plan 2016–2020 adopted the need for integrated approaches to tackle the threat of specific NTDs including schistosomiasis. Female genital schistosomiasis (FGS) affects up to 75% of women and girls living in schistosomiasis-endemic areas. Liberia's Bong and Nimba counties are endemic for schistosomiasis. The communities affected are poor and dependent on primary healthcare services. Incorporating the diagnosis and treatment of FGS within primary healthcare is a critical step in the control and elimination of schistosomiasis in Liberia. The Calling Time for Neglected Tropical Diseases (COUNTDOWN) research programme partnership included the Liberia Ministry of Health NTD programme. Together, partners designed this study to co-develop, pilot and evaluate a primary healthcare package for clinical diagnosis and management of FGS in Liberia.

**Methods:** Mixed methods were applied to assess the intervention outcomes and process. Quantitative descriptive analysis of routine health facility (secondary) data was used to characterise women and girls diagnosed and treated for FGS. Qualitative rapid analysis of meeting reports and training observations, thematic framework analysis of in-depth interviews with women and girls and key-informant interviews with health system actors were used to establish the success and sustainability of intervention components.

**Results:** In 6 months, 258 women and girls were diagnosed and treated for FGS within routine service delivery across six primary health facilities. Diagnosis and treatment were completed by health facility staff who had been trained in the FGS intervention developed within this study. Some women diagnosed and treated had symptom relief or were optimistic about the intervention due to improved diagnostic and treatment communication by health workers. Health workers and stakeholders were satisfied with the care package and attributed intervention success to the all-inclusive approach to intervention design and development; cascaded training of all cadres of the health system; and the locally driven intervention rollout, which promoted local ownership and uptake of intervention components.

**Conclusion:** This study demonstrates the possibility of using a clinical care package to diagnose women and girls suspected of FGS, including the provision of treatment using praziquantel when it is made available at primary healthcare facilities.

Keywords: female genital schistosomiasis, Liberia, neglected tropical diseases, primary healthcare, quality improvement approach.

# Introduction

Women and girls living in schistosomiasis-endemic areas have an increased risk of female genital schistosomiasis (FGS), a neglected gynaecological condition affecting approximately 56 million women globally. Schistosomiasis is a neglected tropical disease (NTD) affecting deprived populations with limited access to quality health and WASH—water, sanitation and hygiene—services. Schistosomiasis is water-borne, caused by a parasitic worm of the genus Schistosoma that penetrates the skin during contact with fresh infested water.<sup>2</sup> Three main species of Schistosoma infect humans: Schistosoma haematobium, Schistosoma mansoni and Schistosoma japonicum.<sup>3</sup> Of these, only Schistosoma haematobium, which typically inhabits the lower pelvic region causing micro perforations in urogenital organ walls during the passage and deposition of eggs, is responsible for FGS.<sup>2,3</sup> FGS results from repeated exposure of the female genital track to eggs of Schistosoma haematobium that cause local infection and inflammation, resulting in symptoms including lower abdominal pains, vaginal itches and discharge, pain and bleeding during and after sex and local lesions such as sores. People living with schistosomiasis and consequently FGS depend on primary healthcare services due to their low cost and availability in rural areas and deprived urban settings.

Prolonged FGS predisposes women to long-term physical and psychosocial complications including an increased risk of sexually transmitted infections (STIs), HIV and cancers, fertility issues like miscarriages, subfertility and infertility, mental health challenges like depression and loss of livelihood and family life. 4-6 The WHO has recommended women and girls with symptoms of FGS and recent contact with fresh water should be considered for FGS and treated with praziquantel and has produced a Pocket Atlas to guide health workers. <sup>7</sup> However, this Pocket Atlas has not been operationalised in resource-limited settings due to an absence of clear guidelines or training for health workers and the reliance on an invasive and specialised equipment for diagnosis called colposcopy within the atlas. Furthermore, the overlapping clinical manifestations between FGS and STIs and inadequate laboratory diagnostics for FGS leads to misdiagnosis by health workers and clinicians.8

Liberia has areas with high rates of schistosomiasis, such as the Bong (64.35%) and Nimba counties (43.37%). In areas with a high burden of schistosomiasis, FGS is very common.<sup>10</sup> Praziquantel is not readily available in primary health facilities outside mass drug campaigns that are focused on school-aged children, thus reaching women and out-of-school girls has been challenging. Thus, health workers at primary healthcare facilities are challenged by a lack of knowledge and guidelines on the diagnosis and management of women and girls who present with FGS.<sup>11</sup> Consultations with the Liberia Ministry of Health within the Calling Time for Neglected Tropical Diseases—COUNTDOWN (https://countdown.lstmed.ac.uk/)—research programme at the Liverpool School of Tropical Medicine, identified the will of the Liberia Ministry of Health's national NTD programme to undertake a scoping study to develop a systems approach to identify and treat FGS; and to prioritise an integrated health systems response to capacitate their health system.

Together, we utilised a quality improvement (QI) approach, to develop and implement a package of care for health workers at primary healthcare levels to diagnose, treat and manage

FGS. The QI approach is an iterative model of learning and modification to rigorously evaluate real-time changes and improve the outcomes and value of the system being developed. 12,13 Within health systems research, QI approaches often involve health system stakeholders working together to address systems weaknesses. QI utilises a plan, do, study and act cycle. 14 During the plan stage, an action plan for intervention design process and adaptation is created. In the do stage, the action plan, which in our study included training and the intervention rollout, is implemented and any deviation from the plan is documented. The study stage involves monitoring and evaluation of the action plan delivery, including frequent review meetings where plans can be adapted. The act stage entails adaptation and or modification of the action plan or intervention and development of strategies for uptake within the health system.

#### The FGS intervention

Intervention design

A series of collaborative workshops called 'learning sessions' involving core study researchers, health workers and health system stakeholders were used to co-design and develop a care package for women and girls presenting with symptoms of FGS in primary healthcare. The care package developed comprised:

- An FGS symptoms and risk factor checklist.
- A guide on speculum examination and possible findings.
- Treatment and referral guides.
- A clinical algorithm to guide decision making.
- Job aids for counselling, stigma reduction and community case identification.
- Associated training materials to cover all intervention components

The full intervention manual can be located on the COU**NTD**OWN website. The workshops led to the establishment of a subgroup of health workers and stakeholders called the QI team to support and supervise the intervention rollout. This QI team was composed of two national level NTD stakeholders, two gynaecology/obstetrician consultants, county NTD focal persons, district heads and four health workers including officers in charge of health facilities, nurses and midwives. All stakeholders and health workers who participated in the co-design of the intervention package rollout and evaluation were considered as coresearchers of the study.

# Training

Training of health workers and stakeholders on the care package was cascaded across all levels of the health system: national, county, district and community (Table 1). Community health volunteers/assistants (CHVs/CHAs) are employed by the Liberia Ministry of Health to promote health-seeking behaviours and referral of patients from the community to health facilities.

#### Service delivery

CHVs/CHAs and trained traditional midwives (TTMs) identified and referred women in the community with symptoms of FGS to the health facility using job aids and community referral forms. At

Health system level	Number of persons trained	Attributes of persons trained
National	17	Gynaecology consultants, national reproductive health supervisors and representatives from related divisions from the Ministry of Health: NTD programme, reproductive health, family health, policy and planning, health management and information system, board of nursing and midwifery and board of physician assistants
County, district and health facility	37	NTD focal persons, county health officers, reproductive health supervisors, gynaecology consultants, county clinical coordinators, district health officers district reproductive health supervisors, health facility officers in charge, midwives and nurses
Community	120	Close-to-community care providers including trained traditional midwives,

the health facilities, health workers clinically diagnosed and managed FGS in women presenting with symptoms of FGS using a clinical and risk factor checklist and speculum examination. Diagnosis was based on the presence of genital symptoms, recent contact with fresh water and the presence of lesions on the cervix and/or vaginal walls. Women diagnosed were treated with praziquantel 40 mg/kg and either referred if they presented with signs of severity or were followed up at home by CHAs/CHVs and TTMs. Praziquantel was made available within all intervention health facilities through donation from the WHO.

#### Monitoring, supervision and evaluation

Regular support and supervision were provided by the QI team using WhatsApp group communications, weekly telephone calls and site visits to health facilities. Review meetings were also held midway and at the end of the intervention to discuss challenges, adapt and refine the intervention and to collate data for evaluation. The end review was used to make final adaptations to the care package and to develop a strategic plan for uptake within the health system.

This paper presents the results of the evaluation and makes recommendations for the use of this approach in the future in Liberia and beyond.

# **Methods**

This study drew on QI theory and utilised mixed methods to evaluate the process and outcome of the design and delivery of an FGS intervention in Liberia. Observation notes were taken during training sessions and review meetings, supervision reports were developed for every site visit per implementing health facility, review meeting reports were developed for every review meeting and qualitative interviews were used to elicit the perspectives of service users, intervention implementers and stakeholders on the process of the design and rollout of the intervention (as described above).

# Study setting

Liberia has a recent 14-year history of conflict followed by the Ebola epidemic, which aggravated the socioeconomic status of the majority of the population. The health system is struggling with few hospitals; hence the population is largely dependent on primary healthcare. 15 This study was carried out in six health facilities across two bordering districts and counties in Liberia (Figure 1). The counties and districts were purposively selected because of known high endemicity for schistosomiasis. Health facilities were selected for their proximity to the St. John River, a water body perceived as a schistosomiasis foci, 16 commonly used by the community for daily activities. The prevalence of schistosomiasis haematobium in Bong and Nimba counties is among the highest in the country (68.9% and 50.0%, respectively) and is even higher in the Panta-Kpai and Saclepea-Mah districts at 82.74% and 61.69%, respectively. While the burden of FGS in Bong and Nimba (and Liberia) is unknown, it is estimated that women in schistosomiasis-endemic areas are at a higher risk of FGS.8

# **Data collection**

#### Qualitative data

Interviews with women, health workers and stakeholders. Interviews were conducted from June to August 2021 by six field researchers trained in qualitative research methods. Included in this study were women diagnosed and treated for FGS, primary care health workers who were trained in and used the diagnostic and treatment package and health system stakeholders at the national, county and district levels who participated in the design and delivery of the intervention. We excluded girls aged <18 year, health workers who were not trained or who did not use the diagnostic and treatment package and health system stakeholders who were not part of the design and delivery of the intervention.

We conducted 18 in-depth interviews with women diagnosed and treated for FGS to assess patients' experiences of living with the disease condition, including a specific focus on stigma,

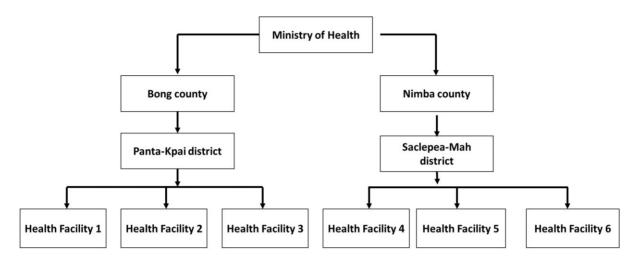


Figure 1. Study setting sampling.

as well as their perceptions on the diagnosis and treatment process. Maximum variation on age and health facility attended by women was aimed for. Women were invited to participate after having received treatment and counselling on FGS.

We also conducted 12 key informant interviews (KIIs) with primary care health workers to elucidate their experiences and reflections of using the algorithm and other resource materials developed. The participants were nurses and midwives who were trained in the use of the intervention materials to diagnose, treat and manage women and girls with FGS, and they were actively involved in the delivery of the intervention.

We conducted a further 11 KIIs with health system stakeholders across national, county and district levels to document their experiences on the design and rollout of the intervention. The participants were part of the intervention development and implementation process and were considered co-researchers of the study. They included public health officials of the national NTD programme and its county and district representatives; obstetricians and gynaecology consultants; and officials of the national health management and information system (HMIS), the reproductive health division and the national AIDS control programme. Participants were informed of the interviews during the series of collaborative workshops (learning sessions) but were invited to participate during the review meetings and were handed participant information sheets. They were contacted at least 24 hours later for consent and interview.

All interviews were conducted in person at a location convenient to participants while ensuring privacy, were audio-recorded and lasted for about 1 hour. Interviews were guided by pretested topic guides developed by the research team; for example, we interviewed women on the duration and frequency of symptoms, their health-seeking attitudes and on patient satisfaction after having received a diagnosis, treatment and any follow-up; we interviewed health workers on the ease, acceptability and usability of the guides; and health system stakeholders on the sustainability of such an intervention after project funding ends, including how successful study components could be embedded within the routine health management information system in Liberia.

Review meetings and real-time telephone calls/WhatsApp discussions. Review meetings were conducted midway (May 2021) and at the end (August 2021) of the implementation phase of the project. This enabled us to make necessary amendments to intervention materials and intervention rollout processes. Feedback from telephone calls and WhatsApp group discussions were also discussed during review meetings. Review meetings were facilitated by the QI team and involved health workers from implementation health facilities, including officers in charge, nurses, midwives and physician assistants, district and county stakeholders. These day-long meetings were observed by field researchers using a pretested observation grid, with notes taken on the style and content of discussions. Meeting reports were produced at the end.

Supportive supervision. Two in-person supervision visits were carried out per implementing health facility by the QI team. A supervision checklist was used for this exercise that comprised cases diagnosed, as well as challenges and lessons learnt from the use of the intervention tools. Supervision checklists were used to produce supervision reports per county.

## Quantitative data

Health facility data were collated from clinical registers to document and characterise women diagnosed and treated during the intervention. Being a 'new diagnosis' in context, no woman was diagnosed prior to the intervention, hence no comparison of preintervention and postintervention could be performed. Analysis was conducted on routine health facility data from April to August 2021. Data were collected from health facility registers at the outpatient and maternity units by field researchers in collaboration with health facility data managers and the QI team. The data collation tool comprised patient demographics, medical history including exposure to fresh water, diagnosis, treatment and relevant observations (Figure 2).

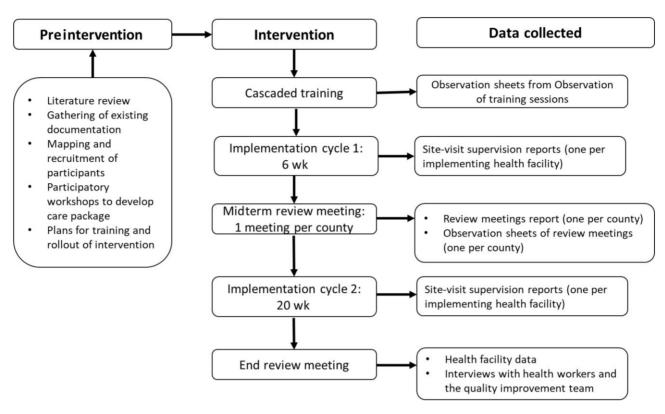


Figure 2. Key evaluation methods used at different time points of the intervention.

## Data analysis

### Qualitative analysis

Interviews were transcribed verbatim, and reports were written in collaboration with co-researchers. We conducted a framework analysis using rapid analysis spreadsheets for reports, observation notes and images, and a thematic framework analysis using NVivo version 12 for Windows by QRS International, Burlington, Massachusetts, USA, for the interviews. Deductive codes were developed based on topic guides and inductive codes added from reading and familiarisation with the transcripts, reports and notes. Coding, charting and mapping of emerging themes was carried out by researchers independently (MN, AB and GN) and reviewed by MN and LD.

#### Quantitative analysis

Data were screened and analysed using an Excel spreadsheet. Descriptive statistics were used to characterise case numbers and the frequency of symptoms presented by women and girls diagnosed and treated.

#### Results

# **Quantitative results**

During the intervention period, 582 women and girls were screened for FGS of which 258 were diagnosed (44.3%). The per-

centage of women diagnosed with FGS in Bong County (68.1%) was more than twice the percentage of women diagnosed in Nimba County (29.5%). Of the 258 women diagnosed, 242 were treated at the time of diagnosis, while three were treated during follow-up; a total of 245 women were diagnosed and treated during the intervention period (see Supplementary Table 1). All non-treated cases were pregnant women and the three women treated during follow-up had delivered at least 1 week before treatment. Women and girls diagnosed with FGS generally presented with multiple symptoms, of which the dominant symptoms were vaginal discharge (238) and pelvic or lower abdominal pain (201), followed by genital itches (129) and painful urination (101). Although reported by fewer women, it is worth noting the presence of other symptoms such as pain and bleeding during and or after sex (72) and blood in urine (28).

#### **Qualitative results**

#### Experience of the FGS intervention

Knowledge and skills gained. Health workers and stakeholders showed good knowledge of the signs, symptoms and long-term impacts of FGS following the training provided. Health workers were content with the skills gained to diagnose, treat and communicate FGS with women and girls. Health system stakeholders were also content with experience gained on the process of developing a context-specific intervention using literature and emulating other countries. They also described the importance of

learning to develop research tools for the evaluation of health interventions.

Everything is learning process, we were to read a lot of things from other countries, I didn't even know that this female schistosomiasis process is being carried out in any country. So, we were able to look at other documents and then develop our own in our own context that is now being used by the two county health workers (national health system stakeholder, female).

Case identification and referral. Health workers valued the intervention, indicating that urogenital symptoms and complications in women are key presenting complaints at their health facilities. They reflected on how the intervention has led to a marked difference in how they approach and manage women with urogenital symptoms. For example, they now consider FGS as a differential diagnosis for women and girls who present with urogenital symptoms. They also described an attitudinal change in how they manage women and girls who frequently attend the health facility with urogenital complaints. They described how previously they would have assumed that women had not adhered to the treatment already provided for STIs and urinary tract infections or had multiple sexual partners, whereas now they would suspect FGS and offer alternative treatments in the form of praziquantel. A few cases were referred to higher level health facilities due to genital ulcerations and or rashes, particularly when the health facility did not have inpatient services.

I choose to refer patient because this patient, they are ulcerated, because this is a clinic, we don't do 24 hours service here we are only here for eight hours, I refer them to health center or hospital where they be treated (Nimba county health worker, female).

The role of TTMs in the identification and referral of women from communities to health facilities was described as central to the success of the intervention, particularly due to the trust that women placed in this community cadre. Consequently, health workers felt it was now a key part of their role to motivate TTMs and encourage them to frequent facilities.

...[A]nother big lesson learned was it was very important to train the traditional midwives because these people, the women [are] comfy in [with] them...if you go to the facility, the referral slip, you find more TTMs referring, because the women in the community come to them and [are more] comfy [with] them than the male CHV (Bong county health system stakeholder, female).

Clinical diagnosis and communication. The symptom checklist and process surrounding speculum examination were described as the most useful tools in supporting clinical diagnosis. However, in a few facilities, challenges in completing speculum examinations were identified because of a lack of necessary resources, including speculum, swabs and lubricants. Pictorial guides sur-

rounding FGS were described as particularly useful to health workers in supporting how to communicate diagnosis to women. Health workers also carried out person-centred counselling of women diagnosed and treated, particularly focusing on the disease condition, preventive measures and potential complications. A major focus of counselling was on infertility-related issues, as health workers observed that many women attending the health facility with FGS symptoms had fertility issues. Some had also been referred by the TTMs, who had explained to them that FGS might have been the cause of their fertility issues. Through counselling, women were supported to understand that praziquantel is aimed at treating FGS and it was not guaranteed that this would lead to them getting pregnant; however, if their infertility was due to FGS, praziquantel might increase their chances of conceiving.

I will start telling you about the condition, what the condition does and the signs and symptoms, besides that go through all of the screening and diagnostic process and pronounce your condition to you. Around here there are lot of people that come they can't born [unable to give birth] five years, this one she take belly and it spoilt [had miscarriage], we make them feel relaxed and tell them if FGS spoiled belly [caused miscarriage], they can get lucky to get belly [get pregnant] next time (Bong county health worker, male).

Treatment for FGS. Health workers, in particular midwives, valued the availability of praziquantel in health facilities to treat women after they had delivered their babies, as opposed to "…before, they take back all the medicine so belly [pregnant] women don't have even when they born [deliver] (Nimba county health worker, female)".

Some health workers reported supporting women to take praziquantel treatment by purchasing food for them in advance so as to reduce their experience of side effects. Many health workers also described the intervention, and their new approach to management and treatment had received positive feedback from women and girls, with some describing symptoms subsiding in 2–3 weeks.

A lady came to the facility, like 2 or 3 weeks after, she said when she took the medication that I gave her, she was not getting that itching, discharge, even passing urine and the end part be like bloody or brownish urine she was na [not] really experiencing it again (Bong county health worker, male).

Illness experience of women and girls

Recurrent symptoms with no diagnosis and treatment. Many women expressed their frustration of experiencing recurrent urogenital symptoms like vaginal discharge, often brown in colour, and abdominal pain and discomfort, with multiple health-seeking attempts without relief. However, many were also optimistic about being treated for FGS following health talks carried out by health workers. Health workers reflected that no

women had been diagnosed with FGS in intervention health facilities prior to the intervention, despite persistent/recurrent symptoms and relapse after having received treatment based on antibiotics.

When you get the sickness sometimes when you ready to receive [menstruate], certain water can be coming from on you, brown, it is not good. Sometimes your stomach can be... pinching, so I came to the clinic throughout and X [names health worker] put me under treatment but, there was no way. We tried harder there was no way. So he give me this one now, so it can make me feel fine (Nimba county patient, female).

Subfertility or infertility and stigma. Subfertility or infertility was a key issue described by midwives, health system stakeholders and women. Midwives had experienced women with repeated or persistent symptoms of FGS having miscarriages in their first trimester and this had an impact on their family lives, such as loss of relationships. Health workers and women described experiences of enacted stigma through mockery and name calling. For example, one health worker described a woman being referred to as "a witch who sold her stomach to the dark world (Nimba county health worker, female)".

Stigma linked to subfertility or infertility frequently left health workers 'feeling bad', particularly when prior to the intervention they felt unable to help women beyond empathising with their situation despite repeated health visits.

Sustainability of intervention uptake/health-seeking and enabling factors

Collaborative intervention design and development to promote local ownership. Participants expressed delight that the intervention package was designed and developed with the participation of health workers and stakeholders across all levels of the health system. They reflected that the process was interactive, participatory and engaging. They enjoyed working in groups, providing support to each other and carrying out a peer review of group outputs. Intervention materials were developed to cover all aspects of the health chain, from patient identification through diagnosis, treatment and management. The participants described how intervention materials were developed to local standards to ensure long-term update within the system; for example, the national HMIS health facility data collection tools were modified to capture FGS; and the communication level was adapted for intended users, including primary health workers and community health workers.

The development process was actually interactive and... participatory; can you imagine that health worker[s] at the facility level who are there having the practical experiences were also a part of the development process and they all provided their inputs? We had our medical Doctors, our Gynaecologist and also some National agencies that are health related and the Ministry of Health including partners (Bong county health system stakeholder, male).

Cascade training across health system levels. Cascade training of health workers across all levels of the health system was perceived as effective, successful and strategic. Participants described the training style as 'hands-on', involving active participation rather than theory; from which they are able to diagnose and treat women with symptoms of FGS at primary care level. Cascading the training across the health system was reassuring to participants and perceived as a boost to the referral system. For example, one health worker felt that women referred from their facility will receive the right care at the higher level health facility because they had also been trained on what to do when they receive such a referral.

[T]o diagnose FGS I don't have to look in book again. I sit here anybody give history I can do my examination and so it was really hands on, there was no writing, you know to say I am writing this in note pad, even though they gave us note pad but we were doing everything hands on... (Bong county health worker, female).

Locally driven intervention rollout with regular support. The intervention was rolled out within routine health facility activities and led by the various officers in charge with support from the district and county teams. Health workers reflected how the use of telephone calls to reach QI team members facilitated troubleshooting of urgent challenges, while QI team members reflected that WhatsApp messaging enabled them to convey messages to multiple implementing partners at the same time as they were all part of one WhatsApp group. Embedding FGS site visits within routine monthly health facility supervision by county and district health teams was perceived by QI teams to be time- efficient, cost-effective and workload-efficient. Ensuring supervision planning meetings were not held specifically for FGS meant there was no extra time or budget for such planning meetings. FGS was also included within routine health facility reports (routine outpatient consultation ledger, routine health facility weekly and monthly reports), which meant no extra forms to be completed by health workers. This increased the acceptability of the intervention and boosted local ownership.

### **Discussion**

Diagnosis and treatment for women and girls with symptoms of FGS are possible within routine health service delivery in the primary healthcare system in Liberia. This study diagnosed and treated 245 women and girls within routine service delivery over a pilot period of 6 months. The 44.3% proportion of women and girls diagnosed with FGS in this study (of those presenting at health facilities) lies within the percentage range of 33–75% reported by Kjetland et al. and Hotez et al. on the percentage of women and girls also living in schistosomiasis-endemic areas affected by FGS.<sup>8,17</sup> The most frequent self-reported symptoms in our study—abdominal pain and discharge, painful urination, postcoital pain and bleeding—were similar to the study performed by Kjetland et al., which assessed urogenital symptoms in women and girls.<sup>18</sup> While this study based diagnosis

of FGS on the presence of urogenital symptoms, recent exposure to fresh water and visible genital lesions, <sup>19</sup> Livingston et al. and Nemungadi et al. used laboratory<sup>20</sup> and immunological<sup>21</sup> methods, respectively, to confirm diagnosis, which might account for the lower proportion of women diagnosed with FGS. Despite this, our study shows that it is possible and feasible to diagnose and treat women living with FGS in endemic areas within the routine health system while also providing standard treatment (praziquantel 40 mg/kg single dose) within health facilities.<sup>19</sup>

Developing the intervention collectively with health systems stakeholders from all levels of the health system in Liberia supported us to understand context-specific needs, thus promoting inclusivity and local ownership of the intervention and its perceived success. In recent years, the Liberia national NTD programme has adopted the need for an integrated approach to tackle the threat of specific NTDs, including schistosomiasis, aiming to reduce the disease burden of targeted NTDs so that they are no longer deemed to be a public health problem, ultimately contributing to socioeconomic development in the context of universal health coverage.<sup>22</sup> Incorporating FGS within primary care in areas highly affected by schistosomiasis directly responds to this national priority, while contributing to improving the lives and livelihoods of women and girls living with FGS through person-centred approaches. The allinclusive approach to intervention design and locally driven rollout promoted local ownership, boosted the uptake of intervention components and incorporation of FGS case reporting into the routine health management information system, together supporting the WHO NTD roadmap 2021-2030 (pillar 3), which calls for increasing the culture of country ownership for NTD programmes and interventions.<sup>23</sup>

Using a QI approach in intervention rollout led to real-time troubleshooting, problem solving and promoted the culture of learning. Capacity strengthening of health actors on FGS and the provision of praziquantel outside mass drug administration campaigns strengthened the health system's capacity to manage FGS at the local level. The QI approach, with repeated capacity strengthening of health actors and often provision of resources, has been successfully used in maternal health interventions to improve health outcomes in sub-Saharan African countries.<sup>24,25</sup> We have shown that such an approach is also applicable in ensuring the sustainable management of FGS, with opportunities to pilot this approach in other sub-Saharan African settings. Good knowledge, attitudes and practices of endemic communities; health provider education; and health systems strengthening with provision of medicines, play a significant role in attaining sustainable disease management for FGS.<sup>26,27</sup> In Liberia, the inclusion of TTMs in the intervention was a key influencing factor in the identification of women and girls with FGS symptoms. TTMs in Liberia have a history of good collaboration with the health system to increase community awareness of disease conditions and improve maternal health outcomes.<sup>28,29</sup> Engaging this cadre of community care providers in primary healthcare and community health interventions may boost intervention uptake through unplanned service user sensitisation and peer training and could be something to be considered in other settings embarking on the integration of FGS services.

#### Operational recommendations

- This study demonstrates the possibility of using a clinical care package to diagnose women and girls suspected of FGS within routine service delivery. However, due to the scope of the study, the pilot was only implemented for a 6-months period.
- We recommend a larger scale and more in-depth study that could support in establishing epidemiological mapping and the burden of schistosomiasis and FGS, and work to ensure sustainability of the gains made through our approach to FGS diagnosis and management at primary healthcare level in Liberia.
- The clinical diagnosis process and the focus of our evaluation approach means that we are limited in ensuring that other diseases, such as STIs, which have similar presentations as FGS, are still prioritised within the primary healthcare system.
- Finally, work is still to be done through global and local advocacy to ensure long-term provision of praziquantel within primary healthcare facilities, although this study provides good evidence that this is possible in endemic areas.

#### Conclusion

This is the first study that investigates the clinical diagnosis and treatment of FGS in Liberia. Learnings from this study can serve as a baseline for future and more in-depth studies on FGS in Liberia and other schistosomiasis-endemic contexts. We have shown that it is possible to develop and use a clinical care package to diagnose and treat women and girls with symptoms of FGS, with the availability of praziquantel, at the primary healthcare level. This intervention has also contributed to improving the lives and livelihoods of women and girls in Liberia.

**Authors' contributions:** The authors wish it to be known that, in their opinion, the first two authors (MN and AB) should be regarded as joint First Authors. LD, RT, MN, AB and KK conceived the study and designed the study protocol. All authors contributed to the study design and implementation. AB, KK, GN, MJ and AW collected data; MN, AB, GN, RT and LD carried out analysis of the data and interpreted the results. MN, AB and LD drafted the manuscript and all the authors read, reviewed and approved the final manuscript.

**Acknowledgements:** The authors would like to state their appreciation for the Liberia Ministry of Health, the Liberia national and county schistosomiasis and NTD programmes and all health workers at the intervention health facilities. We also say thank you to the members of the QI team who participated in the design, development and rollout of the FGS intervention in Liberia.

**Funding:** The research was funded by the COUNTDOWN programme [Grant ID—PO 6407], which is a multidisciplinary research consortium dedicated to investigating cost-effective, scaled up and sustainable solutions, necessary to control and eliminate the seven most common NTDs. COUNTDOWN (2014–2021) was funded by UK Aid, part of the Foreign, Commonwealth and Development Office (FCDO).

**Conflict of interest:** All authors declare that they have no conflict of interest.

**Ethical approval:** This study was approved by the Liverpool School of Tropical Medicine Research Ethics Committee (Ref: 20-021), and the University of Liberia, Pacific Institution of Research and Evaluation Institutional Review Board (Protocol 20-04-212). Participation in this study was voluntary and written informed consent was obtained for each section of the study from all participants. All data were anonymised and stored in a password-protected cloud database with access only for designated researchers. A key component of the researcher training involved managing the sensitivity of discussing new disease diagnosis with affected persons and ensuring that researchers had the skills to link participants to necessary and available support services should they be required, such as referral to health workers at their health facilities.

**Data availability:** The authors confirm that data supporting the findings of this study are available within the article and its supplementary material.

#### References

- 1 World Health Organization. Women and health: today's evidence tomorrow's agenda. World Health Organization, 2009.
- 2 Stothard JR, Stanton MC, Bustinduy AL, et al. Diagnostics for schistosomiasis in Africa and Arabia: A review of present options in control and future needs for elimination. Parasitology. 2014;141(14):1947– 61.
- 3 Colley DG, Bustinduy AL, Secor WE, et al. Human schistosomiasis. Lancet. 2014;383(9936):2253–64.
- 4 Christinet V, Lazdins-Helds JK, Stothard JR, et al. Female genital schistosomiasis (FGS): From case reports to a call for concerted action against this neglected gynaecological disease. Int J Parasitol. 2016;46(7):395–404.
- 5 Friedman JF, Mital P, Kanzaria HK, et al. Schistosomiasis and pregnancy. Trends Parasitol. 2007;23(4):159–64.
- 6 Nour NM. Schistosomiasis: Health effects on women. Rev Obstet Gynecol. 2010;3(1):28.
- 7 World Health Organization. Female Genital Schistosomiasis: a pocket atlas for clinical health-care professionals. Geneva, Switzerland: World Health Organization, 2015.
- 8 Kjetland EF, Leutscher PD, Ndhlovu PD. A review of female genital schistosomiasis. Trends Parasitol. 2012;28(2):58–65.
- 9 Ministry of Health and Social Welfare. Ministry of health and social welfare 2012 annual report. Monrovia: Liberia Ministry of Health and Social Welfare, 2012.
- Mazigo HD, Samson A, Lambert VJ, et al. "We know about schistosomiasis but we know nothing about FGS": A qualitative assessment of knowledge gaps about female genital schistosomiasis among communities living in Schistosoma haematobium endemic districts of Zanzibar and Northwestern Tanzania. PLoS Negl Trop Dis. 2021;15(9):e0009789.
- 11 Oluwole A, Bettee A, Nganda MM, et al. A quality improvement approach in co-developing a primary health care package for raising awareness and managing Female Genital Schistosomiasis (FGS) in Nigeria and Liberia. Int Health. (In print).
- 12 Martineau T, Raven J, Aikins M, et al. Strengthening health district management competencies in Ghana, Tanzania and Uganda: Lessons from using action research to improve health workforce performance. BMJ Global Health. 2018;3(2):e000619.

- 13 Murtagh Kurowski E,Schondelmeyer AC, Brown C, et al. A practical guide to conducting quality improvement in the health care setting. Curr Treat Options Pediatr. 2015;1(4):380–92.
- 14 Powell A, Rushmer R, Davies HJGQIS. A systematic narrative review of quality improvement models in health care. Edinburgh: NHS Quality Improvement Scotland; 2009.
- 15 Nabyonga-Orem J, Gebrikidane M, Mwisongo A. Assessing policy dialogues and the role of context: Liberian case study before and during the Ebola outbreak. BMC Health Serv Res. 2016;16(4):315–25.
- 16 Saladin B, Saladin K, Dennis E, et al. Preliminary epidemiological survey of schistosomiasis in central and southern Liberia. Acta Trop. 1980;37(1):53–62.
- 17 Hotez PJ, Fenwick A, Kjetland EF. Africa's 32 cents solution for HIV/AIDS. San Francisco, USA: Public Library of Science, 2009: e430.
- 18 Kjetland EF, Kurewa EN, Ndhlovu PD, et al. Female genital schistosomiasis-a differential diagnosis to sexually transmitted disease: Genital itch and vaginal discharge as indicators of genital schistosoma haematobium morbidity in a cross-sectional study in endemic rural Zimbabwe. Trop Med Int Health. 2008;13(12): 1509-17.
- 19 World Health Organization. Trends in maternal mortality: 1990-2015: estimates from WHO, UNICEF, UNFPA, World Bank Group and the United Nations Population Division. World Health Organization, 2015.
- 20 Livingston M, Pillay P, Zulu SG, et al. Mapping schistosoma haematobium for novel interventions against female genital schistosomiasis and associated HIV risk in KwaZulu-Natal, South Africa. Am J Trop Med Hyg. 2021;104(6):2055.
- 21 Nemungadi TG, Kleppa E, van Dam GJ, et al. Female genital schistosomiasis lesions explored using circulating anodic antigen as an indicator for live schistosoma worms. Front Trop Dis. 2022;3:821463.
- 22 Ministry of Health and Social welfare. Master Plan for neglected tropical diseases. Monrovia: Government of Liberia, 2016–2020.
- 23 World Health Organization. Ending the neglect to attain the sustainable development goals: One health: approach for action against neglected tropical diseases 2021-2030. World Health Organization, 2022
- 24 Hagaman AK, Singh K, Abate M, et al. The impacts of quality improvement on maternal and newborn health: Preliminary findings from a health system integrated intervention in four Ethiopian regions. BMC Health Serv Res. 2020;20(1):1–12.
- 25 Taylor MJ, McNicholas C, Nicolay C, et al. Systematic review of the application of the plan-do-study-act method to improve quality in healthcare. BMJ Quality Safety. 2014;23(4):290–8.
- 26 Desta KT, Masango T, Nkosi ZZ. Performance of the National Tuberculosis Control Program in the post conflict Liberia. PLoS One. 2018;13(6):e0199474.
- 27 Mwanga JR, Lwambo NJ. Pre-and post-intervention perceptions and water contact behaviour related to schistosomiasis in north-western Tanzania. Acta Trop. 2013;128(2):391–8.
- 28 Brault MA, Kennedy SB, Haley CA, et al. Factors influencing rapid progress in child health in post-conflict Liberia: A mixed methods country case study on progress in child survival, 2000–2013. BMJ Open. 2018;8(10):e021879.
- 29 Lori JR, Munro ML, Rominski S, et al. Maternity waiting homes and traditional midwives in rural Liberia. Int J Gynecol Obstetr. 2013;123(2):114–8.