Understanding the socio-cultural determinants of health-seeking behaviour and health information trust among women at-risk for Female Genital Schistosomiasis in Ghana

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Abstract

Female genital schistosomiasis (FGS) is a chronic manifestation of schistosomiasis, a waterborne parasitic infection, and is estimated to impact 56 million women predominantly in Sub-Saharan Africa. Currently, there is scarce literature on FGS and related health-seeking behaviour (HSB) among at-risk women. The objective of this mixed-method study is to understand the socio-cultural determinants of HSB and the health information trust networks for women at-risk of FGS in Ghana. A cross-sectional survey and twelve focus group discussions (FGDs) were conducted in the North Tongu and Weija Districts of Ghana. A total of 863 cross-sectional surveys and 12 FGDs were administered in both districts. There was an overall lack of awareness of FGS among adult women (38.9%). Only 48.8% women reported HSB from the 86 women who choose to talk about their FGS-related symptoms. HSB was significantly associated with monthly steady income (p-value: 0.036) and level of education (p-value: 0.15,0.27), when controlling for age group and source of trusted health information. Some of the determining themes for HSB included: environmental and systemic context, shared norms, and apprehensions. Active and passive health information seeking behaviour also emerged through the FGDs. Taking a mixed-method approach allowed for the appraisal of both methodologies and provided validity to the results. The lack of awareness of FGS indicates the need for tailored health information campaigns in endemic communities. More research is required on the FGS diagnostic and treatment capabilities of health facilities to understand their impact on HSB of women. This investigation finds that social, environmental, and cultural determinants are involved in the HSB of women at-risk for FGS, in North Tongu and Weija.

1. Introduction

1.1. Neglected Tropical Diseases

Neglected tropical diseases (NTDs) are a group of infectious diseases and conditions that are present in the Global South, predominantly Sub-Saharan Africa (SSA) [1]. The global impact of NTDs is better illustrated by disability-adjusted life years (DALYs) rather than the mortality associated with these diseases as they result in various forms of disability [2]. Globally, the DALYS from NTDs accounts for 56% of years of life lost due to disability with approximately 26 million DALYs being attributable to NTDs in 2010 [1,2]. Beyond the physical health burdens, NTDs have a significant impact on the social and economic well-being of individuals through the introduction of disabilities, disfigurements, stigma, and discrimination [1,2]. This leads to children losing education opportunities, adults being unable to work, families incurring steep healthcare costs, and communities facing generational cycles of poverty [1,2]. NTDs are preventable through public health measures such as access to clean water, improved sanitation, vector control, mass drug administration, and One Health approaches [1,2]. As such, the World Health Organization (WHO) organizes NTDs into two groups through a prevention program perspective [1]. The first group type is preventive chemotherapy and transmission control which strives to administer medication through the WHO-directed drug donation programme to at-risk populations [1,2]. The second group type is innovative and intensified disease management which aims to address NTDs that do not have large-scale measures of prevention [1].

1.1.2. NTD Global Response

Over the years, the global response to NTDs has been led by innovative strategies coordinated by the WHO [2]. Starting in 2005, WHO planned to target NTDs by combining five public health approaches that surrounded disease management, preventative treatment, vector management, veterinary public health, and sanitation and hygiene [2]. This was based on the idea

that NTD may be controlled, prevented, and eliminated by bringing together various sectors and prevention measures [2]. Pharmaceutical companies demonstrated their support through the donation of medications that would be used in preventative treatments—leading to various public-private partnerships for medication for NTDs [2]. The WHO released an NTD roadmap in 2012 with major goals, related to the prevention, control, elimination, and eradication of NTDs, to be achieved by 2020 [2]. In the past nine years, at least one NTD has been eliminated from 34 different countries [3]. In 2020, it was reported that 2019 was the fifth consecutive year where more than a billion individuals were treated against NTDs, through the WHO drug donation programme [4]. Despite the accomplishments, various NTD control goals still need to be met. The 2021-2030 NTD roadmap targets 20 NTDs through scaling-up current interventions that align with the Sustainable Development Goals (SDG) [2,5]. The SDG target 3.3 highlights NTDs by encouraging global action to end epidemics of various diseases [5]. This target supports the other SDGs as interventions targeting NTDs function to address poverty, hunger, advocating for education, etc. [5]. The WHO is working towards goals related to the control and the elimination of NTDs by harnessing the impact of complex interventions and programs.

1.2. Schistosomiasis

Schistosomiasis is a parasitic NTD that predominantly impacts low-income countries and has a major impact on the populations of SSA [1,6,7]. Worldwide, the disease is estimated to have infected 140 million persons with 90% of the disease burden being attributed to SSA [6]. *Schistosoma mansoni* and *Schistosoma haematobium* are the main species that contribute to the burden of schistosomiasis in SSA [6]. Based on 2015 data, schistosomiasis accounted for 3512 thousand DALYs, which was a slight decrease from the 3971 thousand DALYs in 2010 [1]. Schistosomiasis can impact the intestinal and/or the urogenital tracts of the body and the chronic infection leads to fevers, anemia, genital lesions, stunted growth, and permanent organ damage

[6]. The infection results from parasites entering the host's body that have encountered snails, which are the intermediate hosts for the parasites, present in freshwater [8,9]. The *Schistosoma* eggs are present in freshwater bodies and once the eggs hatch, the miracidia enter snails and develop into cercariae [10]. The infectious cercariae exist in the snails and enter the human hosts when they are present in the water [10]. As the parasitic larvae mature, the worms utilize the circulatory system to spread across the body with females releasing eggs in body tissue, feces, and urine [8]. Eggs often become trapped in the body tissue cause further damage to organs and a severe inflammatory response [8]. Various species of parasites migrate through the body and occupy specific mesenteric venules [10]. The eggs that are present in the urine and feces may be eliminated into freshwater bodies, where the lifecycle of the parasite restarts [10].

A systematic review and meta-analysis found that children infected with schistosomiasis experience impaired cognitive development, reduced school attendance, and limitations in scholastic achievements [11]. With children, an increased vulnerability to the infection arises from their frequent social and recreational habits of swimming and fishing [8]. A study from Côte d'Ivoire found that children's prevalence of schistosomiasis increased with age as they may gain greater household responsibilities with their age leading to higher water contact [12]. As well, children with parents, who worked in sales, had a high prevalence as parents' occupations left children unattended, allowing them to partake in water recreational activities [12].

1.2.1. Risk Factors

Schistosomiasis has been noted to disproportionately impact those living in areas that are poor, disadvantaged, and have poor sanitation and hygiene measures in place [7]. As such, one of the main determinants of a schistosomiasis infection is the physical environment [7]. Generally, infection occurs when individuals encounter snail-infested water during domestic, occupational, and/or recreational activities [8]. Though common in rural areas, in the case of SSA,

schistosomiasis may present in urban communities due to migration patterns, poor urban planning, and unsanitary practices [7]. Unplanned and exponential urbanization contributes to inadequate management of clean water and sewage disposal, which leads to unsanitary conditions in crowded spaces [13]. Schistosomiasis foci are being found in urban and peri-urban settings, which is hypothesized to be mainly due to the migration of rural populations to urban areas in LMICs [14]. However, a systematic literature review of urban and peri-urban schistosomiasis found that the disease is not a new phenomenon, and the prevalence may be decreasing in these areas [14]. The reviewed studies indicated unorganized urbanization, lack of hygiene and sanitation, and lack of schistosomiasis awareness in urban populations leading to the presence of the disease [14].

From a social determinants of health (SODH) perspective, poverty contributes to the prevalence of schistosomiasis. A systematic review on socioeconomic inequalities in NTDs found that groups with high education, from rich households, and additional household assets had a lower risk of infection in various SSA countries [15]. Overall, poverty is a trigger for NTDs as it is accompanied by poor living and working conditions as well as a disadvantage to accessing health services [15]. The relationship between NTDs and poverty creates a down spiral in the health and well-being of populations [15]. Gender, another important SODH, plays important role in *Schistosoma* infections. The gender-based differences in schistosomiasis prevalence may be dictated by the social and occupational norms experienced by men and women [16]. Men frequent infested waters to fish and swim, which increases their susceptibility to infection [16]. While women are in contact with water for household chores and their occupations, which increases their susceptibility to infection [16]. A systematic review and meta-analysis conducted to under the gendered differences for *Schistosoma* infections in SSA found that males had a significantly greater baseline prevalence and the likelihood of infection for both species of *Schistosoma* in

comparison to females [16]. The study highlighted limitations including the underrepresentation of women in certain studies and the absence of morbidity measurement in females [16].

1.3. Female Genital Schistosomiasis

Female genital schistosomiasis (FGS) is a manifestation of schistosomiasis that results from physiological alterations occurring in the reproductive tract of girls and women [9, 17]. It results from a chronic infection with S. *haematobium* [18]. The social roles and gender norms experienced by women and men place each group at different risks for schistosomiasis [19]. Women and girls are at a greater risk of infection and developing chronic manifestation of schistosomiasis due to gender roles that require them to be in contact with water for a prolonged amount of time to complete household chores [19]. In some areas, FGS is found to occur in between 33% to 75% of females infected with the S. *haematobium* parasite in *Schistosoma*-endemic regions and is considered a common gynecological problem in Africa [9]. An estimated 56 million women in SSA have FGS [19]. FGS is not considered to be part of the burden of schistosomiasis and has been neglected to be assessed or reported at varying levels which contributes to the grave disconnect in the global movement to support the health of impacted women [5,17]. Moreover, it is commonly misdiagnosed and underdiagnosed due to a lack of awareness and training in health workers (HWs), leading to critical, long-term implication to the sexual and reproductive health of women and adolescent girls [18].

S. *haematobium* infection impacts the bladder, kidneys, and genitals producing chronic inflammation [20]. A common sign of an S. *haematobium* infection is haematuria and in endemic regions, it is perceived to be a natural indication of puberty in boys and girls [21]. The reproductive and urogenital health impacts resulting from FGS include bleeding during intercourse, incontinence, genital itch, abnormal discharge, genital ulcers, dyspareunia, pregnancy complications, infertility, and tumours in the afflicted area [9,18,19]. FGS tends to result in

irreversible reproductive organ damage and reduces the quality of life for the impacted women [17,22]. Cancerous pathologies are often found with the S. *haematobium* infections—specifically, in the bladder and cervix [21]. In the bladder, S. *haematobium* is associated with squamous cell carcinoma and it appears in younger groups from endemic regions [21]. As well, the presence of FGS may increase the susceptibility to HPV infections, and the subsequent presence of cervical neoplasia, due to the changes in the reproductive physiology [17,19,23]. Furthermore, the co-infection of HIV with FGS is common [17,19]. It is approximated that a 3-fold increased risk of HIV is associated with FGS with the coinfections spiking the HIV-1 viral loads, which may contribute to the rapid development of AIDS [20]. In FGS, the alteration to the genital epithelial tissue increases the susceptibility to HIV infection during sexual intercourse [21]. This alteration of the female reproductive physiology paired with an increased load of CD4-positive cells in male semen, resulting from an *S. haematobium* infection, leads to greater possibilities for HIV infections [21]. The physical health impacts of FGS severely impact the well-being and quality of life of the infected women.

1.3.1. Stigma and Discrimination

Women and girls infected with and presenting symptoms of FGS likely to be misdiagnosed with STIs and may be stigmatized by health workers and their communities due to a lack of knowledge surrounding the disease [24]. Furthermore, the health impacts and resulting physical impairments from NTDs tend to cause women to disproportionately experience stigma, mental distress, and intimate partner violence [25]. It has been found that health workers accuse girls, who are seeking health support for symptoms of FGS, with sexual promiscuity as the symptoms of FGS are commonly mistaken for sexually transmitted infections [9,24]. Kukula et al. [24] discovered in their investigation that HWs have low awareness of FGS, and this highly influences the experiences of women and girls in the health system. Girls and women reported facing

stigmatization and dismissal of their symptoms as sexually transmitted infections when trying to obtain health care [24].

1.3.2. Diagnosis Challenges and Opportunities

FGS is clinically diagnosed through the usage of colposcopy and histopathology, however, health facilities in endemic regions may not be properly equipped with the appropriate tools and expertise [18,22]. As well, medical textbooks and nursing curricula do not acknowledge FGS, in endemic regions, which further creates challenges in the diagnosis of the disease, particularly for HWs [18,22]. From the diagnostic perspective, many challenges exist for HWs in determining if symptoms women present with is FGS [26]. As such, the gaps in diagnostic abilities are likely to lead to a delay in and contribute to inappropriate treatments. In addition to clinician-led testing, self-sampling has also been studied as a viable option to diagnose FGS and other reproductive tract infections [26]. The BILHIV study from Zambia found that self-sampling of the cervix or vagina enhanced the FGS diagnosis process by increasing the number of PCR-based diagnoses [26]. The self-sampling was compared to a clinician-led cervicovaginal lavage [26]. The authors suggested that home-based sampling may be a scalable option for FGS diagnosis in endemic regions [26]. This non-invasive method of diagnosing FGS may improve the care of FGS and provide support to understanding the true burden of FGS in endemic regions [26].

1.4. Treatments and Prevention

The WHO recommends that schistosomiasis be treated with praziquantel, which aims to relieve some FGS symptoms and support reproductive health [22]. The WHO's recommendations for preventative chemotherapy (PC) are based on the presence of schistosomiasis in populations (i.e., low-, moderate-, or high-risk communities) [27]. For example, school-based MDAs may occur annually, bi-annually, or twice during the schooling process overall [27]. There are 241.3 million people in 51 countries across the globe requiring PC for schistosomiasis [28]. However,

of those requiring PC, the 2020 global coverage was only 31.9% for PC, which was a decrease compared to 2019 [28,29]. The global PC coverage for 2019 was 44.5% [29]. For school-aged children, the global coverage decreased from 66.8% to 44.9% between 2019 and 2020 [28]. Various research studies have found that praziquantel can reduce infection and prevalence rates of schistosomiasis as well as reduce HIV transmission among recipients [30-32]. A systematic review of the efficacy of praziquantel for pre-school and school-aged children found that repeated doses of 40mg/kg of praziquantel were more efficacious against schistosomiasis rather than a single standard dose [33]. The review suggested that *S. haematobium* is more sensitive to praziquantel in comparison to *S. mansoni* [33]. In addition to MDAs, other prevention and control programs for schistosomiasis and FGS include behaviour change interventions, community and HW engagement and training, and WASH activities [19]. A cluster-randomized trial comparing a biannual MDA alone, or with snail control, or behaviour change intervention found that the latter two interventions did not impact the efficacy of the MDA programming [34]. The study reported a decrease in the prevalence and infection rates of *S. haematobium* through the implementation of the biannual MDA program but noted no significant change in transmission [34]. Evidence illustrates the effectiveness of MDA to various degrees and points to opportunities for integrating other public health interventions to target schistosomiasis and FGS.

Despite the merits of praziquantel and MDA, it is important to understand the limitations. For example, praziquantel only targets adult schistosome worms and is not effective against immature larvae [21]. This indicates the need for repeated delivery of medication that targets the maturation of larvae in children and adults. Moreover, if MDA activities are inconsistent or community members do not participate regularly, then this can cause a disconnect in the effectiveness of the program. Various factors are related to the uptake and compliance of

schistosomiasis MDA. Fear of adverse events, the characteristics of the drug, perceptions surrounding schistosomiasis, doubt about MDA programs, and type of community engagement and sensitization were all contributing factors to the uptake of schistosomiasis MDA [35]. Factors at various levels (e.g., individual, community, policy, etc.) dictate the impact and function of MDA programs [35]. Torres-Vitolas, Dhanani, and Fleming [35] note that socio-cultural factors impact MDA decisions, and these preventative programs must be understood as complex interventions.

1.5. WHO Response

The 2021-2030 NTD roadmap, by the WHO, indicates various critical action points for schistosomiasis that must be enacted to reach the 2030 target [5]. The target for schistosomiasis surrounds the elimination of the disease as a public health problem, which will be measured by the "number of countries validated for elimination as a public health problem (defined as < 1% proportion of heavy intensity infections)" [5, p.11]. The intensified cross-cutting approaches to table NTDs highlighted by the WHO include expanding the implementation of MDAs, targeting vector control, targeting micro-mapping, improving diagnostic tools, and developing alternate interviews for MDAs and snail control [5]. Recently, the WHO released a policy brief on the deworming of adolescent girls and women of reproductive age with recommendations on expanding the scope of current activities and building capacities [36]. The document briefly notes that pairing praziquantel delivery with HPV vaccines provides the opportunity to prevent FGS and reduce the risk of HIV and cervical cancer [36]. Focus on the control and elimination of schistosomiasis and FGS is being prioritized by the WHO, however, there is a requirement for rigorous integrated interventions.

2. Review of Relevant Literature

2.1 Experience and Health-Seeking Behaviour

It is crucial to understand health-seeking behaviour (HSB), and the related determinants, as it determines actions to promote and maintain health and well-being [37]. Moreover,

comprehension of HSB allows for the development of health systems and health programs that are appropriate to the communities they are targeting [38]. HSB is broadly defined as any action or behaviour practiced, or lack thereof, by someone, who perceives that they have a health issue, to improve and/or return to a better health state; it is part of the greater understanding of health behaviours [37]. HSB is influenced by a variety of factors that include the perception of the disease, treatment, and care available, cultural practices, and socio-economic status [37,38].

A study on the community knowledge, attitudes, and practices about FGS reported community members from Northern Tanzania opted to seek care through traditional healers or self-treatment rather than going to a medical facility [39]. In Zanzibar, MDA programs were indicated as the main sources of schistosomiasis treatment [39]. Cronin, Sheppard, and de Wildt [38] conducted a systematic review of literature assessing HSB for schistosomiasis and reported six important themes influencing behaviour: biomedical knowledge, perception of treatment and health services, financial considerations, symptomology perceptions, stigma related to schistosomiasis, and local environment and community. The distrust in 'modern treatment' (i.e., clinical care, for the article), perceived inadequacy of health services, and using traditional medicine were common themes across literature that hindered HSB [38]. Alternatively, the perceived effectiveness of 'modern treatment' was cited by a significant amount of literature to influence HSB [38]. With respect to understanding symptoms severity, HSB was motivated by the belief that schistosomiasis symptoms are severe, and treatment needs to be sought [38]. A multiple regression analysis, based on data from Ghana, found that the perceived severity of the infection was an important predictor of HSB [40]. Yirenya-Tawiah, Ackumey, and Bosompem [41] reported similar findings for the Volta Basin region where the perceived severity of urogenital schistosomiasis, or lack thereof, dictated the choice of self-medication. Cost of treatment and

associated travel, when treatment was free, to health services is a large determinant of HSB [38, 40, 42]. A study from Zanzibar found that community members opted for home remedies and traditional healers when seeking care before reaching out to hospitals for support [42]. It is evident through the literature that trust and the understanding of schistosomiasis infection at the individual- and community-level play an integral role in HSB. It would be important to explore the interplay of health information trust and HSB, in the context of FGS, to understand community perceptions and their impact on health behaviours.

A delay and reluctance in seeking treatment were found in situations where schistosomiasis was perceived to be embarrassing, shameful, and/or stigmatizing [38]. It is important to note that these experiences of stigma are often paired with the threat of misdiagnosis, specifically for FGS, as HWs are sometimes unable to distinguish between symptomologies and turn to stigmatize the care seekers and refer them to insufficient treatment [24]. The threat of being ostracized by HWs was cited as a key deterrent to seeking care at 'formal health facilities' by girls [24]. Social pressures from community members and referral to 'modern treatment' from traditional healers also motivated HSB for patients and parents of children presenting with symptoms [38]. Koffi et al. [43] found in their investigation, from Côte d'Ivoire and Mauritania, that community knowledge socially influences the HSB for schistosomiasis. In the case of Côte d'Ivoire and Mauritania, the study found that the type of care sought is dictated by the understanding of the origin of schistosomiasis (i.e., natural form vs. mystic form of schistosomiasis) [43]. Koffi et al. [43] conclude that socio-environmental factors are great contributors to the HSB. The impact of social constructs is showcased by Wharton-Smith et al. [25] in their study looking at the interaction of gender and the HSB for NTDs. They find that it is more socially acceptable to communicate about NTDs that are on the 'visible' body parts, even if the diseases on the 'hidden' body parts may be

present in the community [25]. It was reported that women faced reluctance in opening up about NTD-related disfigurements as it causes shamed and brought upon social taboos [43]. Women's interactions with the health system are influenced by the gender norms that dictate financial control and familial power dynamics, in addition to the stigmatization of NTDs [25]. The stigma arising from social norms surrounding the discussion of diseases impacting reproductive tracts often proves to be a barrier to obtaining preventative and curative health services [25]. In the social and cultural context, the literature clearly illustrates that stigma plays a large role in determining HSB for those impacted by schistosomiasis. It would be crucial to understand the role of social and cultural context on the HSB for FGS among women due to the stigmatized and misunderstood nature of the disease.

3. Research Objectives

1. Establish the social and cultural determinants of HSB of women in Ghana that are at risk for FGS.
    a. Compare HSB in the two districts of study to understand the potential differences in the determinants.
2. Understand the network of trust in communities, in Ghana, in the context of health information related to the curative and preventative measures for FGS.
3. Explore the relationship between health information trust in communities and the HSB practiced by women at-risk for FGS in Ghana.

4. Methods

4.1. FAST Package Project

The FAST Package Project is an implementation research study that uses an uncontrolled quasi-experimental study design to develop scaled-up interventions to address FGS in Ghana and Madagascar. The overall aim of the project is to improve the health of girls and women with respect

to FGS. The FAST Package Project scales up four intervention areas that complement each other to target FGS, in Ghana and Madagascar. Combining the four intervention areas allows for the life course of women to be targeted. The four intervention areas of the FAST Package Project are: awareness, diagnosis and treatment, training of medical personnel, and prevention of new cases. The data for this project is provided by the baseline data collection that occurred in Ghana in June to August 2021. For the Ghana-arm of the study, research ethics approval was obtained from the Bruyère Research Institute (BRI; #M16-20-061), University of Ottawa (H-08-21-7345), Ghana Health Services (GHS-ERC 003/04/21), and the University of Allied Health Sciences (UHAS-REC A.5 [4] 20-21).

I ,Kruti Patel (KP), am part of the FAST Package Project team as a Research Assistant through the BRI. She supports the research activities through the involvement in activities led by the BRI and joined the project in October 2020. I was not involved in the initial planning and strategizing of the project and had no input in the baseline data collection instruments. I worked with the Ghanian quantitative researcher to clean and analyze the baseline cross-sectional community survey data from Madagascar. Prior to completion of my thesis data analysis, I was not involved with the Ghana baseline data analysis for the full project. My plan to analyze the HSB section and the health information section was a result of improving my understanding of health behaviours for women who are at risk for FGS in the study locations as per my thesis objectives. The research questions and objectives were developed following the background research on the topic and deliberation with Alison Krentel (AK), my supervisor. I took a social constructivist perspective through the social determinants of health to guide the inquiry and establish the objectives for this investigation. In social constructivism, truths and meanings are subjective with social processes and artefacts dictating worldviews [44]. It is important to understand the impact

of social factors on the health behaviours of women at risk of FGS. As such, the inquiry focuses on the social and cultural determinants of HSB and health information trust in the community-level context of FGS.

4.2. Study Regions

The Ghana study sites included Weija District, from the Greater Accra Region, and North Tongu District, from the Volta Region. These districts were selected for the study due to their high prevalence of schistosomiasis [45]. Refer to **Figure 1.** in the *Appendix* for a detailed map of *S. mansoni* and *S. haematobium* distribution in Ghana [45]. Cunningham and colleagues [46] reported a prevalence ranging from 30% to 78.3% and 3.3% to 19%, data not available disaggregated by sex, for *S. mansoni* and *S. haematobium*, respectively, in the Greater Accra Region. In the Lower Volta Basin, the prevalence of *S. haematobium* was reported to be approximately 29% [47]. The two districts were selected based on the higher level of prevalence in such communities and the advice of Neglected Tropical Disease Program Managers.

4.3. Data Source

The project utilized quantitative and qualitative data from the cross-sectional community survey and focus group discussions (FGDs) conducted in the two districts. The response rate for the community survey was 96.6%. The community survey covers topics such as water contact, general knowledge surrounding schistosomiasis and FGS, mass drug administration, signs, and symptoms, HSB, and health information trust. The survey included a micronarrative component for the HSB section in addition to the closed questions. The micronarratives allowed for participants to provide details regarding their experience seeking care for FGS/schistosomiasis-related symptoms. Micronarratives provide an opportunity for participants to distance themselves from close-ended/standardized questions and ground their responses in real experiences that happened to them [48].

The FGDs were conducted with two groups of men and four groups of women of reproductive age (WRA) in each district. The discussions were guided by a semi-structured interview guide. The discussion guide covers questions about schistosomiasis and FGS, mass drug administration, personal experiences with schistosomiasis and FGS, and community engagement opportunities. The FGD facilitators also presented small scenarios involving water contact and symptomology experienced by women related to FGS during the discussions. The choice to concentrate on the FGDs was guided by the understanding that focus groups elicit personal meaning, allow for "lay knowledge" to emerge, and introduce detailed information [49]. This is important for HSB as it is imperative to understand the women's stories and the processes associated with seeking care. The community surveys and FGDs were conducted concurrently in both districts starting at the end of June 2021 till the end of August 2021.

4.4. Sample Size

The sample size for the proposed project was pre-determined due to the secondary nature of the data collection process. Two different sampling techniques have been utilized to recruit participants for the community survey and the FGDs. The recruitment of participants for the survey and FGDs occurred from similar populations as the sampling frames were applied for each district.

4.4.1. Community Survey

To recruit the community members for the cross-sectional surveys, the FAST Package Project used a modified version of the EPI (Expanded Programme on Immunization) population proportion sampling frame. The EPI population proportion sampling frame comes from the EPI 30 cluster sampling method used to assess routine immunization coverage [50]. In selecting community members for the study, 30 clusters X 14 households per district strategy was utilized by the enumerators. The Ghanaian team collaborated with the district health office to create a list of clusters, or villages, from each district based on the population estimates of the communities.

Thirty (30) clusters were selected randomly from the curated list, based on the probability proportional to the most recent population size estimates. The households were selected by the enumerators after spinning a pen or a bottle in the centre of the village and choosing a household in the direction of the pen/bottle [50]. One individual (male or female; between 18 years and 59 years) from each selected household was asked to participate in the survey leading to approximately 14 participants per cluster. The inclusion and exclusion criteria for community survey participants can be found in **Table 1.** in the *Appendix*. The individual from each household was selected randomly from a list of eligible members made by the enumerator. If no one was available, or no one consented to be interviewed, at the household, then the next household was selected, or the pen or bottle was spun again. It was anticipated that the sample size for each district would be 420 participants, with an expected total of 840 participants in Ghana.

4.4.2. Focus Group Discussions

To recruit participants for the FGDs, the FAST Package Project used a purposive sampling frame. Purposive sampling is conducted based on the judgement of the country research team member by determining who would be able to provide useful insights for the overall project based on the research questions [51]. The Ghana team recruited participants from villages where the community surveys were carried out and considering the range of distance to health facilities. For the project, the aim was to collect twelve FGDs in Ghana, which included two FGDs with WRA (age group 29-49), two FGDs with WRA (age group 18-29), and two FGDs with men in each district. The inclusion-exclusion criteria for the FGD participants can be found in **Table 2.** in the *Appendix*.

4.3. Materials

The quantitative data was collected via the REDCap data collection software on tablet and/or mobiles [52,53]. Post-data collection, the data was exported from the servers to Microsoft

Excel. Stata v.17 statistical analysis software was used to label, clean, organize, and analyze the quantitative data [54]. The qualitative data was recorded using a voice recording device. The interviews were transcribed from the local Ghanian language and translated into English in Microsoft Word. NVivo qualitative data analysis software was used to organize, code, categorize, map, and analyze the qualitative data [55].

4.4. Mixed-Methods Approach

The quantitative data from the community survey and qualitative data from the focus group discussions were utilized from the FAST Package Project baseline data allowing for a mixed-methods research approach to the inquiry. This thesis project follows a convergent mixed method design, also known as concurrent triangulation design [56,57]. In the concurrent triangulation design, the data collection and analyses are conducted separately following which the results are converged, or triangulated [56,57]. This approach allowed for corroboration of the quantitative and qualitative data, which provides support to the validity of the findings as well as identifying places of discordance in the results [56,57]. The quantitative and qualitative methodologies support each other by balancing out the methodology's strengths and weaknesses [56]. The concurrent triangulation design is appropriate for the thesis as the data was collected approximately at the same time. As well, the design allows for independent data analysis techniques to be used for each component [56]. It was ensured that the data analysis for each dataset was conducted independently and the results from one dataset did not impact the analysis in the other. The mixed-method design approach is ideal for the proposed project as combining the quantitative and qualitative methods will create a comprehensive understanding of the HSB and health information trust among women from Ghana [2]. Rilkoff et al. [58] use a similar methodology of a "Concurrent Embedded Strategy" to understand the impact of gender in treatment program behaviour for NTDs in Uganda. As highlighted in Section 2., there are various research objectives that this project aims to address.

As such, having multiple methodologies in place ensures that the research questions are accommodated with appropriate data analysis strategies [56]. Pairing the quantitative and qualitative methodologies ensures there is a comprehensive understanding of HSB and health information trust for women at-risk FGS.

4.5. Positionality Statement

Having an understanding of my position in society and experiences is integral to this research inquiry. It is important that I practice reflexivity when trying to understand the experiences of these women by keeping my biases, norms, and knowledge in check. As an educated immigrant cis-gender woman, who was born in India, I have various experiences that shape my worldview and influence my perspective on health behaviours. I have faced challenges at various stages in my life when trying to seek care/treatment that have influenced my view of HSB. Being in Canada has also allowed for positive experiences when practicing HSB. My experiences with HSB inherently put a biased lens on my understanding of the behaviour. However, I understand that these experiences differ from the women who are trying to seek care in Ghana. I cannot say that I have experienced health risks similar to these women, but there have been situations where my reproductive health concerns have led me to seek care. I can reflect on my experiences and identify certain biases I may hold for women in similar situations. My educational training also influences my understanding of health behaviours and has the potential to impact the inquiry. My academic background allows me to retain knowledge about varied determinants of health behaviours and their interactions with one another. Various academic deliverables have required me to critically analyze literature and data, which inherently influence my understanding of the data from the FAST Package project. It is important that I keep these biases and preconceived notions in check when pursuing this investigation. Nevertheless, I recognize that my positionality as a woman has supported the interpretation of the results and informed the conclusions that I have formed in this inquiry.

4.6. Quantitative Data

4.6.1. Data Management and Cleaning

The quantitative data from the 869 cross-sectional, community surveys were downloaded from the REDCap software and saved to secure excel files by the Project Coordinator, upon the completion of the baseline data collection. The Project Coordinator shared the excel files with the research team from Ghana, where the files were converted to STATA .dta files and returned to label the variables. Following the labeling process, a data analyst from Ghana created a .do file and cleaned the Ghana dataset. The .do file and .dta files were shared with KP. The dataset from Weija and North Tongu were merged in STATA and one more review of the data was completed to ensure all variables were cleaned. The male participants, and those with a missing sex identification, were deleted from the dataset to ensure that the quantitative information was from confirmed women participants. Two new variables were created from the data to indicate the sex of the interviewer (options: male or female) and the decision to speak about symptoms (options: yes or no).

4.6.2. Quantitative Data Analysis

Firstly, the demographic information about the female participants was calculated for the Ghana District, Age, Primary Source of Income, and Health Status variables. Frequencies and percentages for the biggest health concerns and water contact for the women surveyed were calculated. Descriptive statistics for variables related to the awareness and understanding of schistosomiasis and FGS were developed for the analysis. The descriptive statistics tabulations were paired with bivariate analysis using Chi-square analysis and Fisher's exact test (in the case of small cells) to understand preliminary relationships between variables [59,60]. The bivariate analyses involved variables of awareness and understanding of schistosomiasis/FGS, water contact, and Ghana districts. As well, the frequencies and percentages of the variables exploring women's experiences with MDA were generated. This was followed by a bivariate analysis of

some of these variables and Ghana districts. A p-value of 0.05 was followed to determine the significance of the analyses.

Objective 1

Frequencies and percentages were calculated for variables in the HSB section for objective one. As well, a bivariate analysis was conducted for the HSB variable and various demographic, knowledge/understanding of schistosomiasis/FGS, choice of symptom, and health information trust variables. The bivariate analysis used the t-test, Chi-square analysis or the Fisher's Exact test [59,60]. Certain variables with many answer options were collapsed to address small cells as the sample size for the HSB section was smaller. Following the bivariate analysis, a simple logistic regression analysis was conducted on the variables from the bivariate analysis with the outcome being seeking treatment for the selected symptoms. The HSB was measured through the variable asking women if they sough treatment for schistosomiasis/FGS-related symptoms they experienced in the two weeks prior to the survey. The simple logistic regression allowed for crude associations to be determined between variables of importance [60]. A p-value of 0.2 was followed to determine the significance and inclusion of the variable in the multiple logistic regression analysis based on the direction of Hosmer and Lemeshow [40,60]. The variables that did not reach a p-value of 0.2 but were part of the conceptual model were included in the modeling, as well. Refer to **Figure 2.** In the *Appendix* for the conceptual model.

Various multiple logistic regression models were conducted for the outcome of seeking treatment of a selected symptom by women at-risk for FGS [60]. The multiple logistic regression approach was suitable for this investigation as it would indicate the impact of predictors variables on the outcome of seeking treatment of any type [40]. This approach is similar to Danso-Appiah et al.'s [40] methodology in their study to understand HSB for schistosomiasis-related symptoms. The clustering effect, as a result of the EPI cluster sampling frame, was not addressed in the model

due to a smaller than expected sample size. This limitation is addressed in Section 6. Discussion. The 10-to-1 rule was followed for the models due to the smaller sample size. The rule indicates that for every 10 occurrences of the outcome, one variable can be included in the model [61]. Alongside the model, three model diagnostics tests were conducted: Hosmer-Lemeshow Goodness of Fit Test, the ROC Curve coefficient, and the Akaike Information Criterion [60]. These diagnostics supported KP in choosing the most appropriate and fitting model for the data available. The p-value of 0.05 was followed to determine significance. In addition, the Standard Error and 95% Confidence Interval were assessed to determine significance. Multicollinearity was also considered for variables in the finalized model by assessing variance in inflation and tolerance [62]. Confounding was assessed by comparing the crude and adjusted ORs [60]. Effect modification was not assessed as it was not part of the hypothesis, conceptual model, or evaluation plan.

A bivariate analysis was also conducted between the decision to talk variable and the sex of the interviewer, demographic variables, and variables focusing on knowledge of schistosomiasis/FGS and trusted sources of health information. A p-value of 0.05 was followed to determine the significance between differences in groups. The significant differences between the groups would illustrate the defining features of the groups that decided to talk about their symptoms, or not.

Objective 2

To inform objective two, frequencies and percentages were calculated for the health information trust section variables. Location of health information, trusted sources of health information, and most trust sources of health information variables were assessed to understand health information network for the women. The variables of community health meetings and belonging to any community groups were also assessed to understand women's group

membership. A bivariate analysis using a Chi-square analysis was conducted to understand if groups differed based on district for group membership and most trusted health information source. A p-value of 0.05 was followed to determine the significance of the analyses.

Objective 3

Simple and multivariable logistic regression models were created for the outcome of HSB and most trusted source of health information to inform this objective. The most trusted source of health information variable was collapsed to reduce the number of small cells. The collapsed variable was analysed through a bivariate analysis through the fisher's exact test. Following, the variable was included in a simple logistic regression model for the HSB outcome. A multivariable logistic regression model, including the collapsed variable, was developed to understand the impact of various predictors on the outcome of HSB. The p-value of 0.05 was followed to determine significance in the multivariable logistic regression. The model building process followed the steps of objective one.

4.7. Qualitative Data

4.7.1. Data Management

The research team from Ghana conducted the 12 FGDs using the pre-set semi-structured interview guides. The FGDs with men were also included in the analysis as the male participants provided important information on women's health behaviour in the communities. The discussions were recorded following the consent of the participants. The Ghanian team transcribed and translated the FGDs following their completion. The transcript was shared with KP after they were finalized by the team. The transcripts were uploaded onto the NVivo Qualitative Data Analysis Software to support the coding process. Folders for both districts were created with six transcripts in each file. At the beginning of the coding process, a codebook was established to organize codes, their definitions, and suitable examples through Microsoft Excel.

4.7.2. Qualitative Data Analysis

A thematic content analysis (TCA) approach was pursued in the data analysis as it is a realist approach to qualitative data analysis [63]. As the interview guides were created with the objectives of the FAST Package Project, the TCA approach is a flexible methodology for the qualitative data from the FGDs as it is not immersed in a specific type of inquiry [63].

The transcripts were initially reviewed twice each, before any coding occurred, to familiarize with the documents. The codes were determined through an inductive coding approach while keeping the objectives of the project in mind. Words, phrases, and passages were highlighted and coded in each transcript. The transcripts and codes were reviewed various times by KP to ensure that all important information was coded, and data saturation was achieved. While the coding was taking place, KP wrote down notes about important themes, recurrent experiences, and reflections to address in the discussion. Important questions and points of confusion were also noted to be checked with the data analyst from Ghana. The clarifications were provided from the Ghanaian researcher and AK.

Objective 1

For objective one, the codes were developed to describe and explain the women's perceptions, knowledge, and awareness of schistosomiasis and FGS. As well, codes were created to represent the treatment and HSB behaviours, the locations and type of care of accessed, important people mentioned in their experience, and any barriers experienced or perceived. Codes related to preventative health behaviour, specifically for MDA, were also developed for this objective. Following the coding process, mind maps were created using the codes and categories developed during the review of the transcripts [64]. Mapping the codes and categories illustrated various relationships and parallels within and between HSB and obtaining MDA medication. The mind maps also supported the development of themes for the determinants of HSB. The themes

were based on common/recurring understandings and experiences of HSB but also reflected conflicting experiences of the community members [65]. It was important to consider experiences and meanings that were recurrently, and sparsely, mentioned to get the correct understanding of HSB in women. Braun and Clark [65] mention that themes are not based on just quantifiable measures, they should include information that is important to the overall objective, which may include uncommon experiences. The themes were finalized based on their contribution to the objectives of the project.

The data saturation was achieved through the critical reflection on the codes, themes, and overall findings; there were no strict cut-offs defined for the process. Braun and Clarke [66] disagree with the operationalization of data saturation, where it is not intuitive to have specific criteria that must be met for data saturation. In reflexive thematic analysis, data saturation maybe subjective and must be determined as the qualitative analysis progresses [66]. As such, data saturation for this project was decided when there no more emerging codes or themes, pertaining to the objectives, from the data. It was ensured that the presence of codes in each FGD was appropriate for the data that was collected and transcripts with missing codes were properly assessed. Also, codes from each transcript were charted using NVivo's visualization function and compared to ensure coding consistencies. Any coding discrepancies in the transcripts were addressed by re-reading them and ensuring all appropriate codes were present. In developing the themes, saturation was determined when the codes and categories did not contribute to any more emerging themes, which were able to answer the research questions.

The rigor for the qualitative analysis was practiced through the validation of the qualitative findings by the lead qualitative research from Ghana (Dr. Maxwell A Dalaba), iterative discussion process with KP's supervisor, and presenting findings to the FAST Package research team

members and government partners. The qualitative findings were validated by comparing the findings from this project with the qualitative data analysis of the researcher from the Ghanaian research team. It was ensured that KP's interpretations were aligned with Maxwell A Dalaba's interpretations of the FGDs transcripts, who was also involved in the FAST Package data collection and management. Working with a Ghanaian researcher for the collaborative coding process allowed for local understanding regarding schistosomiasis and FGS to be incorporated in the interpretation of the data and avoid the possibility of any assumptions being introduced [67]. The on-going discussions with AK ensured that KP's interpretation were consistent with her objectives and there were no misinterpretations. Preliminary results were shared with the Thesis Advisory Committee (TAC) to ensure result consistency with objectives. As well, KP was able to present the final findings of her thesis to the Ghanian and Madagascan team members, which included national NTD programme officials. Discussing and presenting the findings to researchers and NTD program officials ensured the validity of the qualitative results.

Objective 2

The codes for this objective reflected health information sources and who women trusted for information on schistosomiasis/FGS prevention and treatment. Following the coding, a mind map was created to organize important sources of health information and the perceptions of women regarding these sources. The common experiences, practices, and meaning surrounding health information trust and information networks for women in the communities influenced the themes. Similar to objective one, it was ensured that themes also represented sparse experience of health information trust and health information seeking behaviour. The validation and rigor practice of the developed themes followed the process outlined in objective one.

Objective 3

For the third objective, the relationship between HSB and trust in health information, and its source, was assessed through the established themes. Many codes and categories paralleled for HSB and health information trust themes. As well, there were overlaps in HSB and behaviours involving health information trust for women in both districts, which were reflected in the themes.

4.7.3. Theoretical Domain Framework

The qualitative analysis also applied the Theoretical Domains Framework (TDF) domain to the developed themes [68]. The TDF aims to understand behaviour change by providing a theoretical lens on cognitive, affective, social, and environmental determinants [68]. It was initially developed for implementation research and to understand the behaviours of health professionals but has been expanded to be used to understand various health behaviours [68]. There are 14 domains with a total of 84 associated constructs that may be applied to data [68]. There are various methods for using the TDF to understand the determinants of behaviour change [69]. The approach to link the TDF domains to developed themes takes a less rigid approach that allows for non-TDF-related findings to emerge [69,70]. The mapping of the TDF domains supports the matching of health behaviour change activities to guide future interventions of the FAST Package Project.

4.8. Triangulation

The quantitative and qualitative data analysis findings were integrated through a triangulation protocol. The two datasets were independently analyzed concurrently, which refers to the study design approach of concurrent triangulation design [56,57]. Following O'Cathain, Murphy, and Nicholl [71] description of triangulation, the important findings from both datasets were listed and match with the quantitative or qualitative counterparts. Each finding, and its counterpart, were assessed for convergence, dissonance, or complementarity [71]. The silence was also attributed to findings when there was so quantitative or qualitative counterpart emerging [71]. The triangulation process ensures that the validity of the data and findings is appropriately assessed

[72]. Tokin-Crine et al. [72] used a similar triangulation protocol for their study to understand the experiences of doctors and patients in a randomized control trial (RCT) through quantitative and qualitative approaches. They noted that triangulation provided a more comprehensive understanding of the RCT as well as highlighted important points of dissonance that should be further investigated [72]. The triangulation protocol ensures that the findings are integrated and produce the most comprehensive answers to address the objectives of the investigation.

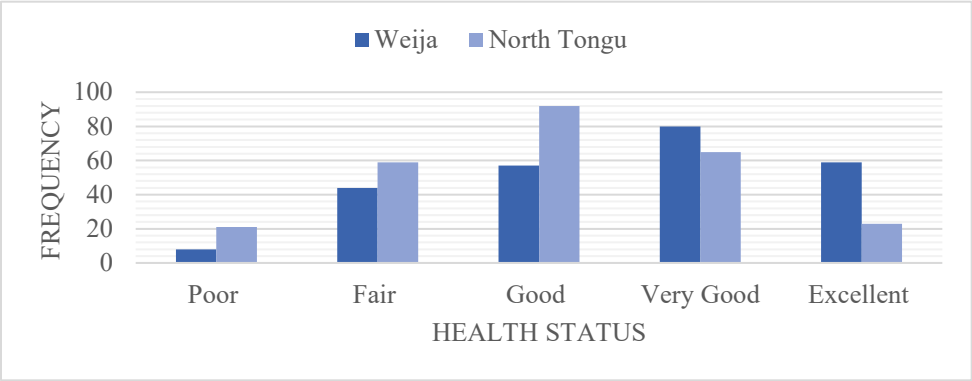
5. Results

5.1. Community Survey

5.1.1. Health Concerns and Water Contact

A total of 508 females were surveyed in Ghana. Refer to the *Appendix* for all descriptive tables of the variables mentioned in this section. Two hundred and sixty (260;51.18%) females were from North Tongu District and 248 (48.82%) females were from Weija District. The mean age of the group of females was 35.7 years with a standard deviation of 11.2 years. In age groups, 199 (39.17%) females were 18-39 years, 176 (34.65%) were 31-43 years, and 133 (26.18%) were 44-59 years. Only 29 (5.71%) females indicated their overall health to be poor. Over half of the females (294; 57.87%) indicated their overall health to be good or very good. There was a significant difference (p-value: 0.000) between the overall health status of females from North Tongu and Weija with females from Weija reporting better health. **Figure 3.** outlines the health status of the females in both districts. It was reported that malaria was the biggest health concern in the community with 317 (62.40%) females choosing it as a significant concern. Only 24 (4.72%) females identified schistosomiasis to be an important concern for their community.

Figure 3. Overall Health Status of Females from Weija and North Tongu (n=508)



For health concerns in their households, malaria was also identified as the greatest concern in the household. Schistosomiasis was not reported to be a significant health concern for females in their households— with only 13 females identified the disease to be of concern.

Table 3. provides an overview of activities for females involved daily water contact. A majority of the females (399; 78.54%) reported that they did not have access to the river water in their communities, without being in direct contact with the water. There was a significant difference (p-value: 0.000) between the females from North Tongu and Weija with 58.9% of females from North Tongu not having access to the river, without direct water contact, in their communities.

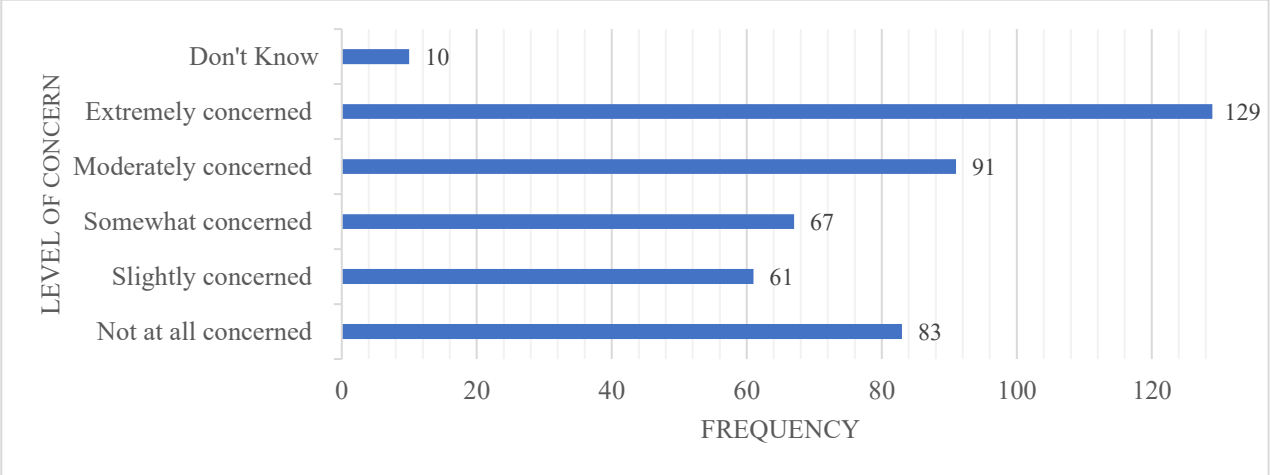
Table 3. Fequency of Water Contact Activities by Females (n=508)

Water Contact Activities	Daily	Once Weekly	Twice Weekly	>Twice Weekly	Very Rarely
Bathing	79	7	13	16	48
Washing Clothes	67	58	29	30	44
Washing Utensils	70	9	2	14	36
Washing Vehicles	22	4	2	1	14
Swimming	30	18	5	26	40
Fishing	41	14	8	13	29
Fetching Water	130	58	14	53	70

5.1.2. Schistosomiasis Knowledge and Awareness

Overall, most females had heard about schistosomiasis (441;86.81%) and there was no significant difference (p-value: 0.939) in the awareness between the females from Weija and North Tongu. One hundred and twenty-nine (129; 29.25%) females reported being extremely concerned about schistosomiasis and 83 (18.82%) indicated that they were not at all concerned about schistosomiasis. Refer to **Figure 4.** for the distribution of concern of schistosomiasis among females. There was also a significant difference (p-value: 0.000) between North Tongu and Weija with respect to the females' concern about schistosomiasis.

Figure 4. Females' Level of Concern about Schistosomiasis (n=441)



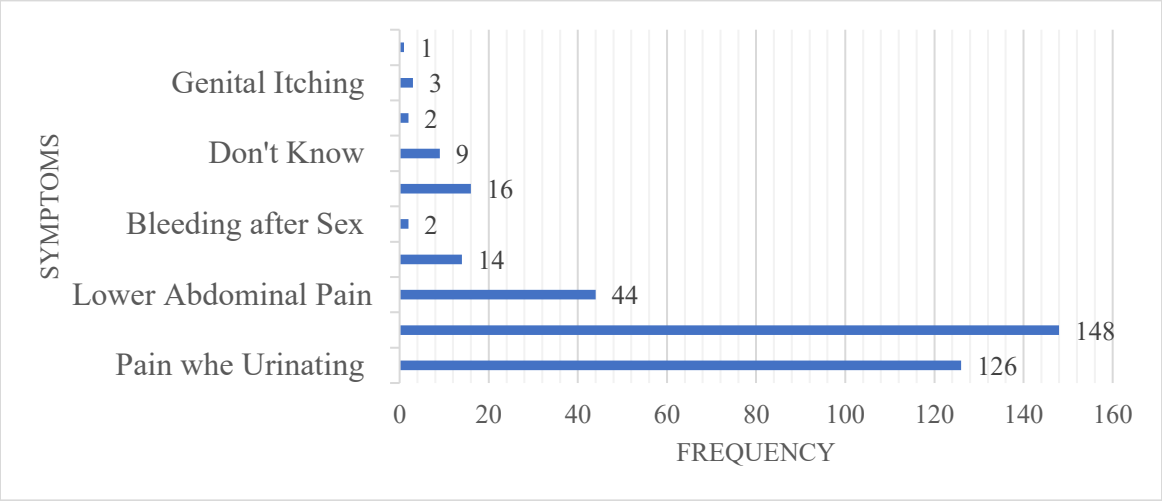
Most females (192; 43.54%) were unsure about the number of people in their village with schistosomiasis. Similarly, the presence of "blood in urine" was perceived to be rare by 120 women (23.62%) in the two districts with most women (211; 41.54%) not knowing about its presence. The awareness of "blood in urine" was significantly different (p-value: 0.000) in the two districts for females; in North Tongu a higher proportion (55.92%) of females indicated "Don't Know" about the occurrence of "blood in urine". A majority of females frequently identified pain when urinating (229;51.93%) and blood in the urine (319; 72.34%) to be common symptoms of schistosomiasis. Two hundred and thirteen (213; 48.30%) females identified that the symptoms for schistosomiasis

were the same in boys and girls. There was no significant difference (p-value: 0.611) between the females from North Tongu and Weija regarding their knowledge of symptom similarities among boys and girls.

5.1.2. FGS Knowledge and Awareness

Overall, two-thirds (270; 61.22%) of females indicated a lack of awareness regarding FGS, conditional upon their awareness of schistosomiasis, in the two districts. More females (120;70.18%) from North Tongu indicated having heard of FGS, which was significantly different (p-value: 0.000) from females' awareness of FGS in Weija (51;20.82%). Females indicated Never (15;8.77%), Rarely (64; 37.43%), and Sometimes (34; 19.88%) when reporting about the presence of FGS in women/girls in their communities. Participants from North Tongu displayed a significantly (p-value: 0.000) greater understanding of FGS's presence in their communities in comparison to Weija. **Figure 5.** outlines all the symptoms identified for FGS. Similar to schistosomiasis, females frequently identified pain when urinating and "blood in urine" as common symptoms of FGS. However, pain during sex, bleeding after sex, and infertility were not frequently identified as common symptoms. An understanding of the reproductive pathology was missing from the females surveyed.

Figure 5. Symptoms of FGS Identified by Females (n=171)



5.1.3. MDA Experience and Opinion

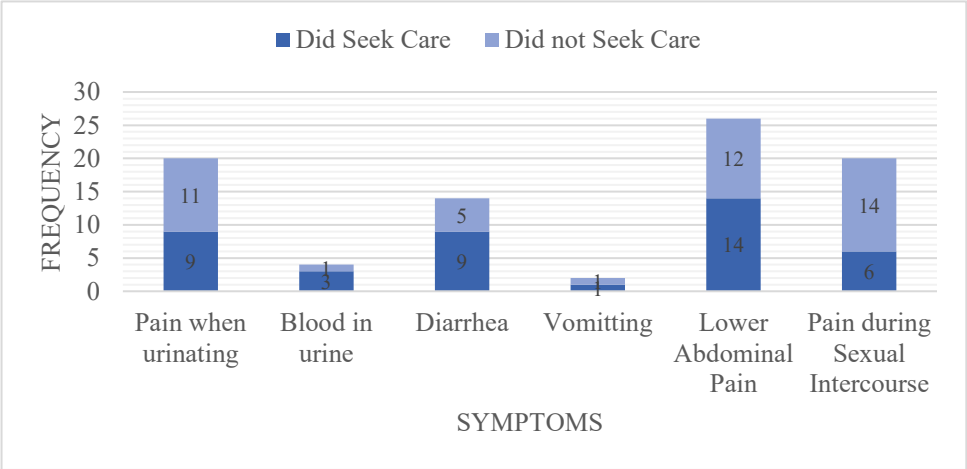
A majority of females (349; 79.14%) reported no one in their household receiving a schistosomiasis tablet for MDA in the 12 months before the survey. More females in Weija (52.44%) reporting no one receiving the tablet within their household in the last 12 months than in North Tongu (47.56%); this differed significantly (p-value: 0.002) between the two districts. Only 27 (43.55%) females reported their daughter/sister/niece/female cousin receiving the tablet, compared to the 40 (64.52%) sons/brothers/nephews/male cousin. Less than half of the females interviewed (187; 42.40%) perceived the schistosomiasis tablet to be safe. A hundred and sixteen (116;51.33%) females in North Tongu perceived the tablets as 'Safe', versus 71 (33.02%) of females in Weija (p-value: 0.001). Most females (193; 43.96%) agreed that the tablet can be taken without feeling sick (e.g., asymptomatic), however, some females (72; 16.40%) indicated 'Don't Know' for the question. Only a third of the females (147; 33.33%) reported receiving information regarding MDA in the previous delivery.

5.1.4. Health Seeking Behaviour

All females who reported experiencing a schistosomiasis – FGS-related symptom within the last two weeks, were asked if they would like to speak about their symptom in more detail. A

total of 86 females, out of 149, decided to talk about their symptom with the enumerator. **Figure 6.** provides an overview of all the symptoms talked about by the female participants. They did not frequently identify blood in the urine as a symptom to talk about with the interviewer.

Figure 6. Overview of Symptoms Chosen to Talk About by Women (n=86)



Forty-two (42;48.94%) females chose to seek care from the 86 females who choose to talk about a symptom they have experienced. Females were asked to share a short story about their treatment. Following that story, females (21;50.0%) identified themselves as the most important person in their stories while health professionals (e.g., nurses, doctors, pharmacists) were noted as the most important for 13 females (30.95%). Most of the females named themselves to be the final decision-makers on treatment, but a few identified the health professionals, their husbands, and sisters to be the decision-makers. Treatment was accessed through hospitals, health centers, and clinics by most of the women (30) and traditional healers were accessed by four females. Seven females approached pharmacists for treatment. Most females (27) indicated they received oral tablets as treatment. Praziquantel was only reported as the named treatment by seven females. Only 17 (39.53%) females indicated that they were informed of the cause of their symptoms. Three (7.14%) females reported that they were informed the cause to be swimming in the river and two

(4.76%) females indicated that the reasoning was related to infections from men/sex. Thirty (30; 71.4%) females who sought care reported that their symptoms improved after the treatment they received.

5.1.5. Females' HSB and Characteristics

Table 4. provides an overview of the characteristics of females who displayed HSB. Of the 42 females who sought treatment, the average age of the group was 34.4 years (SD: 10.36). There was a significant difference in the average age of females who did and did not, seek treatment. Through a Chi-square analysis, there was no association (p-value: 0.498) between the females' district and the decision to seek care/treatment for their symptoms. There were more females (40; 53.33%), who sought treatment, that did not have a steady income every month. There was a significant difference (p-value: 0.05) between the decision to seek treatment and having a steady income each month. There was a borderline significant association (p-value: 0.056) between the primary source of income and the decision to seek treatment.

Table 4. Characteristics of Females who displayed Health Seeking Behaviour (n=86)

	Yes (n=42)	**No (n=44)**	**p-value**
Age	34.38 (10.36)	29.64 (9.12)	0.0266
Ghana Districts			
Weija	16 (44.44%)	20 (55.56%)	0.489
North Tongu	26 (52.0%)	24 (48.0%)	
Wealth Quintile			
First	5 (38.46%)	8 (61.53%)	
Second	10 (66.67%)	5 (3.33%)	
Third	10 (23.81%)	8 (18.18%)	0.374
Fourth	12 (28.57%)	13 (29.55%)	
Fifth	5 (11.90%)	10 (22.73%)	
Income Same Every Month			
Yes	2 (18.18%)	9 (81.82%)	0.05
No	40 (53.33%)	35 (46.67%)	

Primary Source of Income			
Fishing	15 (53.57%)	13 (46.43%)	0.056
Daily Labour	3 (37.50%)	5 (62.50%)	
Trading	20 (62.50%)	12 (37.50%)	
Formal Employment	1 (11.11%)	8 (88.89%)	
Other	3 (33.33%)	6 (66.67%)	
Level of Education			
No Education	20 (71.43%)	8 (28.57%)	0.027
Primary School	10 (41.67%)	14 (58.33%)	
Middle School	11 (40.74%)	16 (59.26%)	
High School	1 (20.0%)	4 (80.0%)	
Post Secondary	0 (0.00%)	2 (100%)	
Heard about Schistosomiasis			0.695
Yes	35 (47.95%)	38 (52.05%)	
No	7 (53.84%)	6 (46.15%)	
Heard about FGS			0.305
Yes	18 (54.55%)	15 (45.45%)	
No	17 (42.50%)	23 (57.50%)	
Concern about Schistosomiasis			0.665
Not at all/Slightly	13 (37.14%)	16 (42.11%)	
Somewhat/Moderate	10 (28.57%)	9 (23.68%)	
Extremely	12 (34.29%)	11 (28.95%)	
Don't Know	0 (0.00%)	2 (5.26%)	
Schistosomiasis can be Treated			1
Yes	31 (47.69%)	34 (52.31%)	
No	1 (50.0%)	1 (50.0%)	
Don't Know	3 (50.0%)	3 (50.0%)	
Schistosomiasis can be Prevented			0.072
Yes	26 (42.62%)	35 (57.38%)	
No	3 (100%)	0 (0.00%)	
Don't Know	6 (66.67%)	3 (33.33%)	
Choice of Symptoms to Talk About			
Pain when urinating	9 (45.0%)	11 (55.0%)	0.321
Blood in Urine	3 (75.0%)	1 (25.0%)	
Diarrhea	9 (64.29%)	5 (35.71%)	
Vomiting	1 (50.0%)	1 (50.0%)	
Lower Abdominal Pain	14 (53.84%)	12 (46.15%)	
Pain during Sex	6 (30.0%)	14 (70.0%)	

Overall Perception of Health			
Poor Health	8 (53.33%)	7 (46.67%)	0.702
Moderate Health	24 (51.06%)	23 (48.94%)	
Good Health	10 (41.67%)	14 (58.33%)	
Trusted Groups for Health Information			
Friends/Family	5 (27.78%)	13 (72.22%)	0.213
Health Professionals	33 (54.10%)	28 (45.90%)	
Community Members	2 (66.67%)	1 (33.33%)	
Other	2 (50.00%)	2 (50.00%)	

Most females had a primary school or middle school education for both groups but the group of females who sought care had a greater proportion of those without education (20; 71.43%). There was a significant difference (p-value: 0.027) in education for the females who did and did not seek care/treatment for the symptoms they experienced. Of the females who had heard of schistosomiasis, 18 (54.55%) were aware of FGS and sought care/treatment while 15 (45.45%) were aware of FGS but did not seek treatment. As well, there was no significant difference (p-value: 1) between being aware that schistosomiasis can be treated and the decision to seek care/treatment. Similarly, there was no significant difference (p-value: 0.072) between being aware that schistosomiasis can be prevented and the decision to seek care/treatment. Thirty-three (33) females who sought treatment reported trusting health professionals the most for health information (54.10%) while 28 (45.90%) females, who did not seek care/treatment, reported trusting them the most. However, there was no significant difference (p-value: 0.213) found between the trusted group for health information and the decision to seek care/treatment.

The simple logistic regression analysis between the HSB outcome and various predictors is outlined in **Table 5.** Many variables were not statistically significant in the crude associations. A steady income every month was one of the variables found to be statistically significant (p-value:0.0450). This crude association indicates that the odds of seeking care were 80.6% lower for

those who have a steady income in comparison to those who do not have a steady income. There was also a crude statistically significant (p-value 0.031) association between the seeking care and age. The odds of seeking care increased by 5.2% for each increase in the year of age for the females surveyed. The level of education for females was also a significant (p-value: 0.012;0.019) predictor of HSB. The crude associations indicates that the odds of seeking care decrease with an increase in level of education.

Table 5. Crude Odds Ratios of Predictors of Health Seeking Behaviour in Females (n=86*)

	Crude Odds Ratio	**p-value**	**SE**
Ghana District			
North Tongu	1.354	0.490	0.594
Weija	1.00	(-)	(-)
Income Same Every Month			
Yes	0.194	0.045	0.159
No	1.00	(-)	(-)
Primary Income Source			
Daily Labour	0.520	0.427	0.428
Trading	1.444	0.485	0.760
Private/Public Sector	0.108	0.048	0.122
Other	0.433	0.297	0.348
Fishing	1.00	(-)	(-)
Age	1.052	0.031	0.0246
Age Groups			
18-29 yrs.	0.216	0.091	0.196
30-49 yrs.	0.533	0.481	0.0926
50-59 yrs.	1.00	(-)	(-)
Education Completed			
Primary/Middle Completed	0.28	0.012	0.142
High School /Post-Secondary	0.0667	0.019	0.0772
No Education	1.00	(-)	(-)
Wealth Quintile			
First	1.00	(-)	(-)
Second	3.20	0.141	2.530
Third	2.00	0.350	1.483
Fourth	1.478	0.576	1.029
Fifth	0.800	0.778	0.632

Schistosomiasis Can be Prevented			
Yes	1.00	(-)	(-)
No	(-)	(-)	(-)
Don't Know	2.692	0.188	2.027
Schistosomiasis Can be Treated			
Yes	1.00	(-)	(-)
No	1.097	0.949	1.575
Don't Know	1.097	0.914	0.936
Concern about Schistosomiasis			
Not at all	1.00	(-)	(-)
Somewhat/Moderate	1.368	0.597	0.810
Extreme	1.343	0.599	0.752
Don't Know	(-)	(-)	(-)
Choice of Symptom to Talk About			
Gastro. Issue	1.667	0.438	1.097
Lower Ab. Pain	1.167	0.786	0.661
Pain during Sex	0.429	0.183	0.273
Urine Issues	1.00	(-)	(-)
Heard of FGS			
Yes	1.624	0.306	0.769
No	1.00	(-)	(-)
Heard of Schistosomiasis			
Yes	0.789	0.695	0.477
No	1.00	(-)	(-)
Overall Perception of Health			
Poor Health	1.00	(-)	(-)
Moderate Health	0.913	0.878	0.542
Good Health	0.625	0.478	0.414
Trusted Groups for Health Information			
Health Professionals	3.064	0.056	1.794
Community Members	5.20	0.216	6.93
Other	2.6	0.398	2.94
Friends/Family	1.00	(-)	(-)

* Heard of FGS Model: n=73, Concern about Schistosomiasis: n=71

5.1.6. Determinants of HSB in Females

The multiple logistic regression model indicated that there were two statistically significant predictors of HSB for women at risk for FGS. **Table 6.** outlines the predictor variables and the

adjusted ORs for the model. The predictors that were significantly associated with HSB in women at-risk for FGS are steady monthly income and level of education.

Table 6. Overview of the Model Predicting Health Seeking Behaviour (n=86)

Predictor Variables	Adjusted ORs	p-value	Standard Error	95% Confidence Interval
Trusted Group for Health Information				
Health Professionals	3.255	0.070	2.128	[0.909, 11.71]
Community Members	7.578	0.142	10.481	[0.504, 113.979]
Other	5.285	0.184	6.627	[0.453, 61.709]
Friends/Family	1.00	(-)	(-)	(-)
Steady Income				
Yes	0.132	0.036	0.128	[0.0120, 0.876]
No	1.00	(-)	(-)	(-)
Education				
Primary/Middle School	0.227	0.015	0.137	[0.0691, 0.747]
High School / Post-Secondary	0.0563	0.027	0.0733	[0.00439, 0.722]
No Education	1.00	(-)	(-)	(-)
Age Group				
18-29 yrs.	0.200	0.155	0.227	[0.0218, 1.84]
30-49 yrs.	0.187	0.154	0.220	[0.0186, 1.87]
50-59 yrs.	1.00	(-)	(-)	(-)

The odds of seeking care were 86.8% lower for those with a steady monthly income in comparison to those without a steady monthly income, when controlling for trusted health information sources, level of education, and age group contact, for females at-risk for FGS (p-value: 0.036). As well, the odds of seeking care were 77.3% for females with either a primary or middle school education in comparison to no education, when holding trusted health information sources, steady monthly income, and age group constant (p-value: 0.015). While the odds of seeking care were 94.4% lower for females with a high school or post-secondary education in

comparison to no education, when holding trusted health information sources, steady monthly income, and age group constant (p-value: 0.027). This model was the most appropriate for the data available based on the model diagnostics. The Hosmer Lemeshow Goodness of Fit test indicated the p-value for the model to be 0.5983. The ROC Curve was 0.7687. While the Akaike Information Criterion was 114.93. The model diagnostic scores provide support to the relative strength of the model compared to other models.

5.1.7. Health Information Source Trust

Two hundred and ninety-two (292; 57.48%) females indicated the radio to be one of the locations from where they get their health information. As well, 235 (46.26%) females identified local health centers/community health workers (CHWs) to be where they receive their health information. Other frequently reported locations of gaining health information included public announcements (198; 38.98%) and television (238; 46.85%). Social media (23; 4.53%), school/colleges (19; 3.74%), and internet websites (12; 2.36%). Doctors (307; 60.43%), nurses (251; 49.41%), and CHWs (129; 25.39%) were frequently reported to be trusted by females in the community for health information. Internet/social media (6; 1.18%) and teachers (5; 0.98%) were the least frequently reported sources of health information by the females surveyed. Doctors (264; 51.97%), nurses (95;18.70%), and community HWs (35; 6.6.89%) were the *most* trusted sources of health information for females in North Tongu and Weija.

Female family members were much more trusted that the male family members by the females survey. Twenty-nine (29) females indicated trusting female family members most for health information, while only 11 females indicated trusting male family members. There was some trust displayed in traditional healers, religious leaders, and community leaders. Three hundred and sixty-six (366; 72.91%) females indicated that there were not part/aware of any community health meetings in their communities while 414 (82.14%) indicated that they did not

belong to any community groups. There were 90 (17.86%) females who were part of community groups which included: financials/loan groups, church groups, and women's groups/associations. More females from North Tongu (90; 66.18%) reported attending community health meetings than those from Weija (46;33.82%); this differed significantly between the two districts (p-value: 0.000). Similarly, more females from North Tongu (56; 62.22%) indicated being part of community groups compared to females from Weija (34; 37.78%); the community group membership was significantly different (p-value: 0.023) between the two districts.

5.1.8. Important Differences between Females Who Experienced Symptoms

There were 149 females who experienced schistosomiasis/FGS-related symptoms in the two weeks before the survey was administered. However, only 86 (57.72%) decided to talk about their symptom for the survey. There were 63 (42.28%) females who choose not to talk about their symptoms and therefore skipped the HSB section. Many characteristics differed between the females who decided to talk about the symptoms and those who did not. **Table 7.** provides an overview of these characteristics. Of the 63 who did not choose a symptom, 59 (47.20%) refused to speak to male enumerators while no females refused to speak with female enumerators.

Table 7. Overview of the Characteristics of Females who did and did not talk about their symptoms (n=149)

Characteristics	Decision to Talk = Yes (86)	Decision to Talk = No (63)	p-value
Interviewer Sex			
Male	66 (52.80%)	59 (47.20%)	0.000
Female	18 (100%)	0 (0.00%)	
Ghana District			
Weija	36 (76.60%)	11 (23.40%)	0.002
North Tongu	50 (49.02%)	52 (50.98%)	

Level of Education			
No Education	28 (48.27%)	30 (51.72%)	0.047
Primary / Middle School	51 (68.0%)	24 (32.0%)	
High School / Post-Secondary	7 (46.67%)	8 (53.33%)	
Age	31.95 (9.97)	37.62 (12.29)	0.0023
Steady Income			
Yes	11 (64.71%)	6 (35.29%)	0.581
No	75 (57.69%)	55 (42.71%)	
Concern about Schistosomiasis			
Don't Know	2 (100%)	0 (0.00%)	0.052
Extremely	23 (46.0%)	27 (54.0%)	
Somewhat/Moderately	19 (52.78%)	17 (47.22%)	
Not at all / Slightly	29 (70.73%)	12 (29.27%)	
Trusted Groups for Health Information			
Community Members	7 (38.89%)	11 (61.11%)	0.095
Friends/Family	18 (72.0%)	7 (28.0%)	
Health Professional	61 (57.55%)	45 (42.45%)	

All females who were being interviewed by female enumerators chose a symptom to talk about and recall their HSB. There was a significant difference (p-value: <0.000) between the two groups of females choosing to talk about a symptom based on if they were speaking to male versus female enumerators. There was also a significant difference (p-value: 0.002) between the groups of females, choosing a symptom to talk about, based on their home district. The females who choose to talk about symptoms were more proportionally educated in comparison to those who did not choose symptoms, which significantly differed (p-value: 0.047). The concern about schistosomiasis was borderline significant (p-value: 0.052) between the females choosing to talk about symptoms, or not. Significant differences exist between the females who choose symptoms to talk about and those who did not from the two districts.

5.2. Focus Groups Discussions

A total of 12 FGDs were conducted in the Weija and North Tongu District with ~ 9 community members being part of each group. **Table 8.** provides an overview of the participants for the FGDs.

Table 8. Overview of the Focus Group Discussions

Category of Participant	Weija District FGDs	North Tongu District FGDs
Women (18 – 29 yrs.)	2	2
Women (30 – 49 yrs.)	2	2
Men (18 – 59 yrs.)	2	2
Total	6	6

Seventy (70) inductive codes were developed from the review and analysis of the 12 transcripts. Two (2) mind maps, *available in the Appendix*, to understand the relationship between codes and categories were created following the coding process. These mind maps supported the development of the nine (9) themes related to women's HSB and health information trust.

5.2.1. Schistosomiasis Knowledge and Awareness

The level of awareness of schistosomiasis was present across all groups, however, the participants from North Tongu portrayed a higher understanding of schistosomiasis. It was commonly identified as "blood in urine." In Weija, the problem of "blood in urine", or schistosomiasis, was identified to be an old problem. As indicated by a woman in Weija: "it used to be very common some time ago, but these days you don't hear it as much." Many community members identified males and boys to be the members to be predominantly impacted by schistosomiasis. Many community members agreed that the signs and symptoms of schistosomiasis were similar among boys and girls. Overall, there was a lack of awareness of FGS

among the participants. A male participant from North Tongu stated that, "[he understands] that the female genital schistosomiasis is not common in female but common among male[s]." Certain participants noted menstruation and/or STIs being the reason women experience blood in their urine and accompanying symptoms. A woman from Weija indicated that, "every time [her friend] urinated, she saw some blood at the end so she thought it was her menses."

Most community members identified their local water bodies to be the cause behind "blood in urine" with a few participants mentioning organisms in the water being the cause of the problem. Participants identified various occupational, recreational, and household chore-related activities conducted in local bodies of water. Many participants urged the government needed to provide them with pipe water to prevent the occurrence of "blood in urine." Some community members, from North Tongu, indicated that there may be a spiritual cause to schistosomiasis, in addition to the river-schistosomiasis. As well, some male participants noted "blood in urine" being similar to an STI with transmission occurring through sexual intercourse. In discussing the steps to take when a woman has schistosomiasis/FGS, a male participant indicated, "for me if I [do not] have money in my pocket and for instance my girlfriend is the one having the disease, I will no longer sleep with her again but I will let her get treatment." There were varied understandings of schistosomiasis and FGS present in the community members from the Weija and North Tongu districts.

5.2.2. Health Seeking Behaviour

Most participants were able to provide detailed information on the process of seeking care, for themselves or someone they know (i.e., family member, friend), in both districts. The community members from North Tongu had greater experience with seeking care to address "blood in urine." Most participants reported going to a hospital, health center, or clinic to obtain care or health services for themselves or those in their care. Some participants reported going to

the pharmacy or the local drug distributor to get the medicine needed to manage symptoms. Mainly women mentioned turning to pharmacies to get medication for their symptoms. Very few participants reported the use of traditional herbs/medicine to address the disease. Most of the experiences shared about seeking care for "blood in urine" were about how the participant helped their child, advised their friend, or heard about someone about it. There were few instances of participants identifying themselves as the ones seeking care. Certain participants indicated that some members of the community waited for MDA delivery to manage "blood in urine" and related symptoms.

All participants were aware of MDA programming and understood the importance of taking the medication provided during the delivery. Most participants were able to discuss their experience with school-based MDA programming with children and adults getting medication through schools. Participants seemed to understand the distribution process of the medication with many participants mentioning height and weight to determine the amount of medication delivered to each child in the community. As well, they understood the importance of eating, or feeding their child, before medication was consumed. There was much discussion around the adverse events (AEs) related to the consumption of the medication delivered during MDA programming. However, many participants acknowledged the effectiveness of the medication, regardless of the AEs. Some participants did highlight that AEs or lack of information regarding the drug had deterred them, and/or their parents, from taking the medication provided through MDA programming. There was also an indication of community members having misinformation about MDA medication. A woman from North Tongu shared, "some people too said the drug is like a family planning pill that when they take it, they no longer have their menses."

The first mind map created to illustrate the connections between codes and categories to understand HSB in women at-risk for FGS is shown in **Figure 6.** in the *Appendix*. HSB was influenced by affordability and accessibility of care, health system issues, decision making power, the influence of the social networks and communities, and stigma/fear. These connections were present in participants seeking care for the symptoms and/or obtaining medication through MDA.

5.2.3. Environmental and Systemic Context

Environmental and health system context were prominent themes in the discussions around HSB among the participants. The affordability and accessibility of health services and treatments are important determinants of HSB. Being able to pay the fees for the hospital visit and the medication required to manage symptoms seemed to dictate where community members sought care. Many participants noted going directly to pharmacies to buy drugs as they did not have money to access support from health professionals. A woman from North Tongu shared "some of us who don't have money, we go to drug store to get some medicine so that the next time that we have money, we will go to the hospital for the treatment." MDA delivery is the main form of treatment for certain community members since it is free with one woman from North Tongu stating, "some people [do not] do anything and wait on the white because is free of charge." A participant noted the funds to travel to the government hospital can pose to be a barrier, she shared, "concerning the hospital,… [the] lorry fare to just go to the hospital and come is a big challenge for us." Many participants noted inconsistencies in the coverage of medication through insurance cards at the private clinics and hospitals. A man from North Tongu reported, "we are saying that they should let us know the actual drugs that the health insurance cover before we can also be going." Being unable to understand what medication is covered and what members have to pay may cause challenges in comprehending the type of care to access.

There were many requests for government health clinics or centers to be established closer to the communities—this discourse was mainly among the Weija participants. This was highlighted by a woman from Weija, "we want a government one, not a private one. We have private clinics here but when you go, the card alone is 2 million. If you [do not] have that money you have to go to the government hospital. The government ones are too far." The accessibility of treatment and medication is also influenced by HWs that community members interact with the hospitals and clinics. Many participants described dismissive and coercive behaviour from HWs they interacted with, which may dissuade community members from seeking care. A woman from North Tongu shared, "they [will not] pay attention to whatever health problem that you brought. Some of them too when you tell them your health condition, then they will say that it is your own doing that is why it is affecting you. They [will not] pay attention to take care of you." Most of the poor experiences in the health system were reported by participants from North Tongu. A man from North Tongu asserted, "they [do not] give us any respect. Like you are ahead of someone in a queue, by the time you realized a lot of people are passing ahead of you. So here I am, I decided that if am sick, [will not] even go to the hospital."

The accessibility of MDA delivery and medication was also a determinant of preventative HSB among community members. A woman indicated that having the free MDA meant that she could spend money on essential items rather than treatment by sharing, "that small money that I should have used to visit the hospital, I can use it to buy food." However, the school-based delivery posed challenges for certain community members as they indicated their inability to access the medication. A man from North Tongu shared "they tell us that we are adults so there is no way that they will give us because they are serving only students." This poses a challenge for those relying on MDA delivery to be the only treatment they seek for schistosomiasis/FGS-related

symptoms. Many participants noted that MDA had not occurred or they were unaware of MDA programming happening consistently in their communities. A woman from North Tongu reported, "please is not every year nor every month. There are some months that they will come." There are various challenges to preventative HSB through the delivery and access of MDA experienced by the community members in Weija and North Tongu.

5.2.4. Shared Norms

The shared perceptions surrounding schistosomiasis, FGS, and their treatment plays an important role in determining HSB for women at-risk for FGS. From the discussions with the participants, it was clear that the word of mouth, sharing stories and experiences, and community perceptions influenced which, where, and how the treatment was sought in communities. There was a normalization of the condition, where schistosomiasis was perceived to be a common and well-understood problem. Most participants were able to identify what the disease looked like, where the disease came from, how it was contracted, and how to identify it – from their shared understanding within their community. A woman from North Tongu shared, "schistosomiasis affects people a lot. It affects children too. The adults can hide it when suffering from it but for the children, I know it affects them." A man from North Tongu asserted, "schistosomiasis is the only disease worrying us here in the community." This was a common understanding in North Tongu. It was also stated that schistosomiasis was a reality for the communities as they are near a river. The shared understanding in the community of schistosomiasis functions to make apparent the reality of community-level health.

In North Tongu, there were discussions of an alternate explanation for schistosomiasis. A group of young women from Vome shared their spiritual understanding of schistosomiasis. One woman explained, "[…] in every household, there is a witch, but if some other witches from different houses come together with that in your house, it makes one gets the schistosomiasis and

it will last for long." Another woman later added, "it means that someone who is a witch can bewitch a child of schistosomiasis." When prompted to discuss treatment, it was shared that, "if [it is] ordinary [schistosomiasis], it can be treated but if [it is] not the ordinary [schistosomiasis], it [cannot] be treated." It appears in these statements to indicate a shared perception of schistosomiasis that can directly impact HSB as the root of the problem influences if care/treatment will be sought.

In Weija, different perceptions surrounding schistosomiasis were reported. A woman from the Weija reported, "people [do not] usually fall sick in this community. When the sickness comes it is not very serious." HSB may be dictated by the understanding of the occurrence of the disease in the community. Some women from Weija argued that schistosomiasis is not much of a problem anymore due to medication being available to prevent it. One woman stated, "this disease should be very common here, but you [do not] hear it as much as before. It used to be very common some time ago, but these days you [do not] hear it as much." Another woman followed up with "because there are several drugs on the market, people take it when they realize that they have the disease. Because they know that the disease will be a problem." Within the district, some groups shared a specific understanding of the disease and the treatments available for it.

Outside of the communities' understanding of schistosomiasis/FGS, the shared perceptions around treatment and care influence the HSB of the women in these communities. The effectiveness of the MDA medication is well-received in the communities, which leads to members sharing their thoughts and opinions of the treatment with their friends and family. Having the "blood in urine" stop after taking the medication has shown to leave a significant impact on the communities. A woman from North Tongu reflected, "you see the people who took the drug when it works for them, they share their experiences with their friends that when they were urinating

blood, this is the pill that they took and the sickness was over." Similarly in Weija, the participants understand the impact of the medication and are eager to receive it during the MDA delivery. A women from Weija recounted, "please the medication it really works. So when we realize that they have brought some then we all run to get it." The collective understanding of the effectiveness of the medication encourages preventative and curative HSB among the women in these two districts.

The negative perceptions around the treatment and MDA programming create a shared understanding in the community that deters from HSB. During the FGDs, there were strong feelings expressed regarding the AEs associated with the medication distributed during MDA. A man from Weija explained, "I've heard from a woman that I stayed with, she told me that, when they take the medicine, because of continuous defecation they [do not] like to take it again." Similar views were expressed amongst participants in North Tongu with community members being concerned about the safety of the medication for their children. A woman from North Tongu reported, "so when they swallow the tablet, it made them feel dizzy […] became weak [… so] everybody was saying that the medicine that they gave to the students [is not] good." The negative perceptions appear to be amplified in situations where medication has been thought to cause death in children. A man from North Tongu shared, "[it is] about 5 or 6 years now that some children took it and died at Sogakope area, so when they bring it now, the parents have been telling the children not to accept it." The impact of the negative shared perceptions is indicated through the comments made by a man from Weija, "so when the mothers who bring their children for weighing come, we ask them to go out and make the announcement to others that now the place is safe." They explain that mothers need to spread the word that children should be brought to health facility for care. The negative views of medication are being propagated around, and across, communities,

which contribute to poor adherence with the MDA regime and dissuade HSB among men and women.

5.2.5. Conflicting Roles of Women and Men

There were distinct manners in which the men and women talked about their preventative and curative health behaviours surrounding schistosomiasis. From the conversations, it appeared that men and women had specific roles in their familial relationships when it came to HSB. There were instances of women taking direct actions regarding their or their child's health when they experience "blood in urine" or related symptoms. A woman from North Tongu explained, "Yes, because the reason why I said so is that it happened to me before and when I took my child to the hospital, they run test for him to determine the kind of things that happened before [he] was urinating blood." Equally, women mentioned getting advice from their friends or mothers, and giving advice to their friends in situations when they were experiencing "blood in urine." A women from North Tongu shared, "she tells you herself that my sister, this is the disease disturbing me, then you will tell her to visit the hospital." Most women displayed knowledge of HSB and shared instances where they have taken action for themselves, their children, or friends. Women understand their roles as caretakers of their families and friends, which influences their HSB with respect to FGS/schistosomiasis.

Many mothers mentioned their husbands or children's fathers would be the individuals making the *final* decision about taking the child to a clinic or hospital. A woman from North Tongu shared about her son falling ill and "[she] told his father and he took him to the hospital." Moreover, the husbands and fathers are responsible for discipline and encouraging children to be safe around water as children listen to them more than mothers. An older woman from North Tongu reported, "there are some children, that [do not] respect their mother. They fear their fathers, so if their fathers should stand up [againts children going swimming]." However, many times the

men stated for matters like “blood in urine” the discussion would remain between the mother and child or the women would not open up to them about it. A man from Weija reflected, “they can know whether the disease is affecting their children or not because for us the men, we cannot look after children like the women do.” A man mentioned that he would need to have the money to provide treatment funds for his girlfriend if she is sick. Outside of children, the men may be responsible for the care of their wives and/or girlfriends. Some men are in the decision-maker role which contributes to the HSB of women in the communities. However, seeking care for schistosomiasis/FGS creates a conflict between the roles of men and women, which may prove to be a challenge for HSB.

5.2.6. Apprehensions

Most participants indicated that there was no shame and/or stigma associated with the disease. Some participants offered the reasoning for the lack of shame/stigma being that the problem is not visible to other people in the community with a woman from North Tongu reporting, “when you get infected and you [do not] tell anyone the person [would not] know so you would not be ashamed.” And, others indicated that it is a common occurrence in the community which contributed to a lack of shame associated with schistosomiasis. A woman from North Tongu shared “it is known to everyone in the community so nobody is ashame of it.” Most participants were quick to dismiss when directly asked about the stigma associated with schistosomiasis/FGS. However, it consistently states that “blood in urine” was a private issue and it would be a sensitive topic with the detail not being shared with just anyone in the community. A woman from North Tongu shared, “when people get the disease, there are some that the disease will be on them and they [will not] like to share it with anyone else.” Another woman from Weija reflected on the topic of conversation by saying, “Oh but this is someone’s private issue so I [cannot] just talk about it like that.” The privacy of the issue was well-portrayed when a male participant, from North Tongu,

directed the conversation away from the topic with him saying, “let’s put that matter aside for now.” There were some apprehensions associated with the disease that limits the disclosure of information in communities and may deter conversations around seeking care for it.

A group of men from North Tongu disclosed that there is some mockery of the women who experience symptoms. A man explained, “when some of the women has it, it shows some signs on them […] when their colleagues realize it, they also laugh […].” Men also noted that children, specifically daughters, may not be able to easily disclose to their fathers about experiencing “blood in urine.” A man from North Tongu shared, “it is true that the child will not tell you because your own daughter will find it difficult disclosing it to you her father, maybe when she tells the mother before you will know what is happening to her.”

The participants frequently mentioned children hiding their symptoms, specifically “blood in urine,” from parents and teachers in the communities. There may be apprehensions experienced by the children regarding their symptoms that deter them from talking about their health and seeking help. A woman from North Tongu shared, “if there is a child suffering from it and the child [does not] disclose it to you, as a parent, you [will not] know.” There were similar experiences in Weija with a woman reporting, “because we know that even some of the children when they have symptoms like this they [do not] say it. They hide it.” The hesitation to disclose their symptoms may be related to the punishments children receive as a result of entering rivers in their communities. Many participants noted that children would be physically reprimanded by parents, community members, and soldiers/guards if there were found to be going into the rivers. A man from North Tongu shared, “because if the child swims in the river, he must pay for it. So if someone sees him and punishes him and he comes to the house, take the child to the person who beats him and thank him for doing that.”

5.2.7. Teachers as Gatekeepers

The role of teachers is significant for HSB for children experiencing "blood in urine" and those at risk in the communities. Some participants described the teachers and educators as gatekeepers of care in the two districts. The teachers are sometimes the first to notice when the child is feeling ill and they will inform the parents about it. A woman participant from North Tongu shared, "when they go to school, their teachers [will] notice [the symptoms], they inform the parents." Teachers may be the initail step for the HSB for children by parents. A woman from North Tongu reported, "the teachers too ask the students when they go to schools or they go to see it in the urinal, they know that someone has schistosomiasis and when they give the children some drugs, then it is over." However, their focus on children is also a cause of strain in communities where teachers may refuse to provide adults with any medication as it is only meant for students. A woman from North Tongu reflected on this reality by saying, "but the community members too will be asking to take the drug, some teachers find it difficult allow the community members to participate." However, parents also trust that teachers understand the process of getting care for students/children when they get sick/experience "blood in urine." Teachers play an important role in the HSB for children as they promote the delivery of medication to children and guide parents in seeking appropriate care.

5.2.8. Trusted Health Information Sources

The participants displayed trust in their communities and health professionals for health information relating to schistosomiasis, and related care and prevention. There was mention of different channels and sources of versatile information during the conversations with community members from North Tongu and Weija. Health information was sourced from media, the community, health professionals, and teachers by the participants in the FGDs. Overall, the participants displayed trust in one another with only a few participants noting their hesitancy in

believing health information. A woman participant from North Tongu shared, “to me here, there is nobody in this community who will deliver the information and I will believe him.” However, it is important to understand that this was not a frequent sentiment. **Figure 7.** in the *Appendix*. provides an overview of the mind map created to understand health information trust among community members regarding schistosomiasis and FGS.

5.2.9. Trust in Health Professionals

Participants seemed to prefer health professionals for health information and, subsequently, health support in both Weija and North Tongu. Many participants indicated that they got most of their health information and advice from health professionals. A woman from North Tongu shared, “if you are not a doctor or you [do not] have any position but government gives him the opportunity to come and deliver such information, for me here, I [do not] think we will believe it apart from doctors or assemblymen.” It was clear that the trust held for the professionals motivated community members to access health services frequently when faced with schistosomiasis-related symptoms. This understanding was common for both districts. Many participants indicated that they relied on media for their health information as nurses and doctors were giving them information through those channels. The trust in health professionals for information was reflected in the requests by participants to deliver more health information regarding schistosomiasis in their communities. A man from North Tongu argued, “the health service should come and be giving us education and advise us on ways to pass in order not to get the disease.” The relationship of health professionals with community members ensures that the members take the appropriate steps when seeking care when ill.

5.2.10. Community Varied Source of Knowledge

During the FGDs, the participants highlighted various avenues of obtaining and receiving health information in the communities that could support their understanding of schistosomiasis,

preventative actions, and HSB. It seemed that the commnity was a source of diverse, and sometimes conflicting, information for women. Participants identified family, friends, their community, teachers, health professionals, and the media as a source of health information. The knowledge of schistosomiasis and its care was spread by education through health professionals and teachers as well as anecdotes from friends, family, and community members. A woman from North Tongu shared, "our headmasters and teachers have been telling us that schistosomiasis is a disease that can destroy us women/girls or boys/men" displaying her understanding of the impact of schistosomiasis. The participants also indicated being sensitized about schistosomiasis at the point of care in their communities. A man from North Tongu shared, "those people at the hospital whiles you are waiting for your folder before you go, they also talk to us about the diseases before we go to see the doctors." However, there are indications of health professionals providing misinformation to patients regarding schistosomiasis as a man from Weija shared her experience, "if you have your menses and you have sex, it can give you the disease. The doctor is the one who told me that, I went to school with him. So, I [do not] think she got the disease from the river." Here, it is clear that health professionals have the ability to instill incorrect knowledge in the health decision-makers of households. There is trust in educators and health officials to provide sound health information, but they can provide conflicting messages to community members.

Many participants shared experiences of obtaining their knowledge and understanding about schistosomiasis from family members and respected community members. Many participants pointed to schistosomiasis as being well-known condition in the communities, especially around the rivers. A woman from North Tongu shared "most often, our mothers are aware that we get it from the river so they cease us from swimming in the river." Family members were important to the network of trust about health information. One participant even indicated

that she turned to her mothers for information on care and support for “blood in urine”. Another woman participant from Weija shared individuals going to their mothers for support when they experience “blood in urine.” In addition to parents, the elders of the communities are important guides to schistosomiasis care and related health information. They were identified to share preventative information with parents as a woman participant from North Tongu recalled “the elderly in the community informed us to take care of our children because our children are swimming and urinating in the river, so they should stop.” These experiences were similar for both Weija and North Tongu with family members and community elders being important sources of health information.

Health information is also shared through anecdotes and experiences of community members with schistosomiasis and their HSB. Participants indicated many times experiences of other individuals in the community aiding their knowledge of the disease and what it looks like in women and girls. For example, a women from Weija recalled, “every time she urinated, she saw some blood at the end so she thought it was her menses. But later on her menses stopped coming so she felt relieved. Little did she know that it was the organisms causing that. It was later that she went to the hospital and they almost took out her womb.” There was mention of shared beliefs about why women should not enter the water, mainly in Weija, and the spiritual understanding of schistosomiasis in North Tongu. A groups of men from Weija discussed river gods not allowing women to swin with a participant sharing, “so if [you are] on your menses and you go inside, it is a taboo. The water hates that thing […] but if you enter the water, the gods [do not] like it […].” The community experiences highly influenced members’ knowledge and awareness of preventative measures for schistosomiasis/FGS. A woman from Weija shared her experience with learning about schistosomiasis as she recalled “So I told her to tell her mother. She said that after

urinating, she experienced a burning sensation in her vagina.so I asked her to tell her mother. It was that time that I got to know about the sickness." A lot of health information in the communities is propogated through anecdotes and experiences of other members that influence individuals.

5.2.11. Active vs. Passive Information Acquisition

The discussions with the participants revealed an trend in the acquisition of health information by community members. Community members were either active or passive in obtaining information about schistosomiasis, its care, and prevention measures. The active acquisition of inforamtion is portrayed by community members asking for advice when dealing with illness, the requesting for more education on schistosomiasis in the community, and inquiring about schistosomiasis/FGS to the FGD facilitator. For example, a male participant from North Tongu shared, "our churches must take it to the leaders to give education on it that this and that can bring us disease. If they are telling us, we will stop and it means we are preventing the disease." A woman from North Tongu shared her experience with her friend, "she tells you herself that my sister, this is the disease disturbing me, then you will tell her to visit the hospital." Some community members were vocal about their need to understand schistosomiasis, the care avaialble for it, and preventative measures.

The passive translation of information was dispalyed through education from health professionals at point of care, children sharing information with parents, and community-based health messaging. A woman from North Tongu recalled getting informed on the transmission of schistosomiasis, "doctors came to screened us in the past and they told us that the disease is from the river disturbing the children." Children get informed by teachers about the drug distribution, information meetings to occur, and the teaching about schistosomiasis. As such, children are intermediaries of information to their parents. An example of this comes from a man from North Tongu sharing, "sometimes our pupils come to tell us at home that they have announced to them

at school that there will be officials from somewhere to come and talk to us about schistosomiasis." A woman from North Tongu expressed a conflicting opinion, where she stated, "please, the school people [do not] really tell us anything but when weighing people come for weighing, that is when they talk to us about the disease." There are some community members who rely on other health programs to give them information on schistosomiasis. Overall, the passive delivery of information occurs through various sources, which are part of the health information network.

5.2.12. Mistrust and Hesitancy

The COVID-19 pandemic had a significant impact on the participants and communities focused on the study. The MDA program delivery was ongoing during the pandemic but the uncertainties surrounding the pandemic introduced mistrust and hesitancy in the communities. A woman from North Tongu reflected, "in this era of COVID-19, when they bring such drugs again, we [do not] know whether it's blood tonic, or buying new sickness to oneself." This mistrust and hesitancy were mainly related to the preventative medication provided to the community members with many members believing misinformation regarding the impact of the medication. A woman from Weija shared: "we are trying to say that when the Corona came, that was when they brought the medications. So we were afraid that it was one of the corona medications. We [did not] know it was the medication to the disease from the water." It was perceived that the medication would give community members COVID-19. This deterred many participants from taking the medication or parents ordering their children to not partake in the MDA programming. A woman from North Tongu reported, "when they bring it, our parents told us not to go and take it because when we go and receive it, we will go and carry coronavirus infested drug home." These experiences were apparent in both districts but mainly shared by women rather than men. The COVID-19 pandemic introduced a wave of misinformation and fueled distrust towards health information that has a great impact on the health of women and girls in the communities.

5.2.13. Theoretical Domains Framework

Table 9. provides the themes from the qualitative findings with the domains of the Thoeretical Domains Framework (TDF). The themes were matched to domains from the TDF to outline the standardized determinant of beahviour that may be addressed by behaviour change interventions [68]. The mapped domains will support the development of health interventions for furture iterations of the FAST Package Project.[1]

Table 9. Matched TDF Domains with the Themes from the Qualitative Inquiry

Qualitative Inquiry Themes	Matched TDF Domains
Environmental and Systemic Context	Environmental Context and Resources
Shared Perceptions/Norms	Knowledge, Social Influences
Conflict in Roles of Women vs. Men	Beliefs about Capabilities & Intentions
Apprehensions	Emotion
Teachers as Gatekeepers	Social/Professional Role and Identity
Trust in Health Professionals	Social/Professional Role and Identity
Community Source of Varied Knowledge	Social Influence, Environmental Context and Resources
Active vs. Passive Information Acquisition	Intentions, Goals, Knowledge
Mistrust and Hesitancy	Emotion, Social Influence

5.3. Triangulation

Table 38. in the *Appendix* provides an overview of the triangulation process and alignment of the key findings from the quantitative and qualitative data. There was an equal distribution of convergence, dissonance, and complementarity between the findings. There were a few places of silence—predominantly on the quantitative side. Section 6. will cover the triangulation outcome in detail.

[1] The definitions for the matched domains can be found in an article by Cane, O'Connor, and Michie [73], who used the American Psychological Associations' Dictionary of Psychology [74], to develop the definitions.

6. Discussion[2]

The results of this mixed-methods study demonstrated that women face many challenges in their HSB for symptoms related to schistosomiasis and FGS. There are various social, cultural, environmental, and personal determinants of HSB that women, at-risk for FGS, face in deciding and trying to obtain treatment. Though the findings were not able to provide information on the health behaviour surrounding FGS, the information on schistosomiasis-related symptoms' health behaviours is still relative to the project's inquiry. The project did not clinically identify cases, so all the findings relate to signs and symptoms of FGS and schistosomiasis. The challenges associated with the availability and accessibility of health services indicate a need for improvements in the health system to deal with schistosomiasis/FGS-related illnesses. The community-based education and information sharing as seen in the results highlights the opportunities for innovative health interventions that use social ties and networks for FGS-related sensitization. The unspoken stigma around schistosomiasis, and likely FGS, proves to be a barrier to HSB, which will require rigorous health education. Teachers are important stakeholders that require further training for their role in the preventative HSB for schistosomiasis and FGS. Sharing stories and anecdotes were common methods of propagating health information and lay knowledge across communities; storytelling may be supportive of health education. There was active and passive health information-seeking behaviour portrayed by women in the communities. The COVID-19 pandemic had a negative impact on the health behaviours of women in both study districts, indicating a need for more community sensitization during MDA.

[2] For the discussion all females from the community survey are assumed to identify with the woman gender. This was confirmed with the local research team in Ghana as per context

6.1. Knowledge and Understanding of Schistosomiasis/FGS

There was a high level of awareness of schistosomiasis among the women from North Tongu and Weija. This was demonstrated through the quantitative and qualitative results. This finding aligns with the study conducted by Yirenya-Tawiah, Ackumey, and Bosompem [41] that found 88.7% of female respondents were aware of schistosomiasis as a disease. The community survey however, indicated only a few female respondents had heard of FGS. However, the FGDs illustrated a gap in the knowledge and understanding of FGS. Schistosomiasis is commonly perceived as a 'boy disease,' also illustrated in the FGDs, which may lead to the female condition being undermined and disregarded, leading to the lack of knowledge surrounding FGS [24]. Women's experiences of schistosomiasis, or 'blood in urine,' was frequently equated to menstruation and STIs by men and women in the FGDs and community survey. This investigation is validated by Kukula et al.'s [24] findings as the symptoms of FGS mimicked STIs, which contributed to misdiagnoses by HWs.

The concern around schistosomiasis was equally high in the surveys with the concern between the districts being distinctly different. Similarly, the FGDs indicated that schistosomiasis was of concern to mainly the North Tongu communities. This is understandable as North Tongu is a rural area. Literature indicates that schistosomiasis is perceived as a rural disease, however, slowly more research is emerging on understanding schistosomiasis in the urban and peri-urban context [14]. The lack of concern among the participants for Weija was identified may be explained by the disease being an "old problem" and participants understanding that it could be prevented via medication. The findings from the survey and FGDs converged on women being aware of the common symptoms of schistosomiasis, regardless of location. Other studies have found similar results with participants noting blood in urine and painful urination as common symptoms for

schistosomiasis [41,43]. These findings illustrate that across various countries and regions, it is apparent that schistosomiasis is predominantly known for its impact on the urinary system.

With respect to FGS, the symptoms frequently identified were pain when urinating and blood in urine with very few women identifying the reproductive pathologies. The survey finings converged with the FGDs as no one could identify FGS through the scenarios presented to them via the facilitators. Mazigo et al.'s [39] knowledge, attitudes, and practice study similarly found that participants were not familiar with FGS, its symptomology, cause, and its modes of transmission [39]. The lack of understanding of FGS at the community level is justified as HWs remain uninformed about the disease and are not met with appropriate training [22,24]. Moreover, the understanding of the presence of FGS in communities may be limited due to gaps in its diagnosis [18,22,26]. Overall, populations need to be sensitized about FGS, its causes, its long-term health outcomes, and care options due to the gaps in knowledge at the community- and household-level.

6.2. Health Seeking Behaviour

The findings from the quantitative and qualitative data converged on the locations of treatment sought by women. There was consistent mention of hospitals, clinics, and health centers to obtain care. The study conducted by Danso-Appiah et al. [40] found, that outside of no treatment, a limited number of participants indicated seeking treatment for their schistosomiasis-related symptoms at hospitals or clinics. Many participants reported self-medication [40], which was the case for some women in this investigation. There was a mention of pharmacies and turning towards traditional healers by some women with the rationale behind the choice being that it avoided hospital fees and there was direct access to medication. In a study from Nigeria, it was reported that blood in urine was managed through the access of medication stores, drug vendors, and herbalists likely due to the inaccessibility or unacceptability of hospitals, as theorized by the

authors [75]. In the FGDs, it was apparent that women held health professionals in high regard and trusted them for health information, which may have influenced their decision to seek treatment at hospitals/clinics. The increased trust in health professionals for health information was illustrated by the survey findings, as well. The trust in health professionals may have promoted the usage of hospitals, health centers, and clinics for healthcare for women who needed support.

In the FGDs, passive HSB was also identified where those afflicted with symptoms would wait on MDA programming to manage their sickness. The need to rely on drug distribution may be due to the costs associated with hospitals, medication not being available, or the lack of knowledge regarding where to seek appropriate care for 'blood in the urine.' This was also found in Zanzibar, where MDA was reported as the main source of treatment for schistosomiasis [39]. The reliance on MDA programming was not a key finding in the community survey. Many women, in the FGDs, mentioned the problems with adverse events (AEs), due to MDA medication, and negative perceptions that they fuel in the community among health decision-makers. Danso-Appiah et al. [76][3] conducted a rigorous systematic review and meta-analysis to investigate the safety of praziquantel in those with and without schistosomiasis. The authors concluded that praziquantel is a safe drug and only presents mild-to-moderate AEs, but also indicated a strong need for methodologically rigorous research on its safety [76]. Literature may point to the safety of praziquantel, but community views have not found balance in the negative and positive perceptions of the medication. This may be an outcome of insufficient community sensitization regarding MDA as found in the surveys. The hesitancy behind MDA due to AEs, and incomplete community sensitization, may prove to be a challenge for preventative HSB.

[3] This article is still in preprint, as such, paper is undergoing the peer evaluation process.

For treatment, women were aware of a tablet being provided to them as treatment but did not specifically call it praziquantel. This was consistent between the community survey and FGDs with the surveys indicating some awareness of praziquantel being the treatment. There may be a lack of knowledge surrounding the name of the drug being provided to the women, as they just call it medicine or tablet, or they may be provided with an alternate treatment to manage symptoms [75]. Praziquantel may not be available in certain health facilities, which introduces challenges to HWs trying to support women who seek treatment [77]. Moreover, this may contribute to the lack of knowledge about the medication among women furthering their barriers to accessing appropriate care.

In the surveys, most women choose to talk about symptoms that were pain-related (e.g., pain when urinating, lower abdominal pain, and pain during sexual intercourse) rather than visible symptoms (e.g., blood in urine, diarrhea, and vomiting). Many women in the FGDs indicated that 'blood in urine' was a private issue that not everyone would talk openly about with just anyone. The privacy around the visible symptoms may be the reasoning behind women choosing to not talk about them *alone* with the enumerator for the survey. However, there was a variation in the qualitative findings. Women mainly spoke about the symptoms associated with the urinary tract (e.g., blood in urine and pain when urinating) in the group setting, however, there was limited mention of reproductive pathologies, which was validated through the community surveys. Wharton-Smith et al. [25] noted distinctions in HSB based on NTDs impacting community members' "hidden" versus "visible" body parts. Based on social norms, it was more acceptable to talk about sicknesses on the "visible" body parts (i.e., non-sex organs) [25]. These findings validate that the women's narrative around "blood in urine" being a private issue.

The community survey had a low response rate for the HSB section when women were asked to choose a symptom to talk about. A reason behind the reluctance to talk about symptoms may also be due to the privacy surrounding such issues as mentioned by the women. The stigma associated with schistosomiasis/FGS may also be a reason why many women choose not to speak about the symptoms one-on-one with enumerators [78]. A systematic review by Hofstraat and van Brakel [78] reported that enacted, anticipated, and internalized stigma may be found among those with schistosomiasis, however, they did not have information on FGS. Women fearing and anticipating stigma may not want to talk about their symptoms or disclose detail regarding treatment due to the negative social consequences it may bring [78]. These experiences are common for women/girls with sexual and reproductive health concerns. Hall et al. [79] reported the label of *"bad girl"* for girls who were perceived as promiscuous in the community due to unmarried pregnancies, abortions, and STIs. Both internalized and enacted stigma were reported for young girls from Accra and Kumasi in Ghana [79]. This understanding can be mirrored in the situation with schistosomiasis/FGS, where both are either perceived to be or mistaken for STIs. Women and girls may not be open to talking about their experiences out of the fear of enacted stigma and view the issues as private due to internalized stigma. In the surveys, the sex of the survey enumerator impacted women's decision to choose symptoms to talk about HSB with all women opting to talk to the female enumerators. Only half of the participants paired with male enumerators chose a symptom to talk about with them. Wharton-Smith et al. [25] noted a similar finding where female and male participants did not talk to the opposite sex individual, regardless of them being an HW, about diseases in their "hidden" body parts. The identify of the enumerator may have an impact on the willingness of women to open up about their personal health issues.

This investigation highlights that women may be more likely to talk in groups with other women about personal health related issues rather than one-on-one with a possibly male enumerator.

6.3. Determinants of Health Seeking Behaviour

The community surveys and FGDs indicated that seeking care/treatment for ailments has a relationship with income and costs of hospitals/treatment. However, there was dissonance in the type of relationships that existed. The surveys indicate that having an inconsistent income every month is a determinant of women's HSB for schistosomiasis-related symptoms. This finding is the opposite of commonly reported research findings and indications from the FGDs. The steady income may be reflective of a husband's or father's income for the women, who were surveyed, and thus the inverse relationship may be highlighting a factor that was not measured in the data collection process. As well, it may be a possibility that those with steady incomes are not at-risk for schistosomiasis as it is considered a disease of poverty [7]. This study indicates that the availability of funds and affordable treatments can make a difference in HSB. Literature finds that having enough money guides the decision to seek treatment/care for schistosomiasis-related symptoms, as mentioned earlier [38,40,42]. Proximity to appropriate treatment facilities was also an important determinant of HSB in the FGDs but was not assessed in the surveys. The availability of appropriate health services is an important determinant of HSB as outlined by Mazigo et al. [38]—they noted participants requesting improved diagnostics for FGS to address the burden of disease in untreated women. It is crucial to make affordable diagnosis and treatment of FGS and schistosomiasis easily accessible to support HSB. The availability and accessibility of health services prove to be important determinants of HSB and highlight crucial socio-environmental barriers in North Tongu and Weija.

The community survey also indicated that education had an impact on the decision to seek treatment/care for schistosomiasis-related symptoms. Women with no education were more likely

to seek care in comparison to women who had any type of education. In the FGDs, there is no specific discussion around the education of women but there was mention of health education and having knowledge of identifying signs and symptoms and the steps to take to address issues for themselves, their family, or friends. The health education was propagated through the community partially as shared norms and perceptions, which subsequently influenced HSB. For example, the understanding of river-schistosomiasis and spiritual-schistosomiasis dictated if treatment would be sought or not by the women in the community. This understanding was also found in the northern Côte d'Ivoire and southern Mauritania HSB study where community members reported natural and mystic schistosomiasis [43]. FGDs found schistosomiasis to be a normalized condition in the communities with members sharing their experiences and anecdotes in their communities to create a shared understanding of the disease and its treatment. The positive perceptions regarding MDA were formed through the sharing of the effectiveness of the drug, through word of mouth, and on social networks. Mitchell et al.'s [80] scoping review found a socially bound comprehension of MDA programming in the Asia-Pacific, where community perceptions were in part formed via word-of-mouth. The lack of formal education among women may have been compensated by the health education and perceptions shared across and within communities, which could have influenced them to seek treatment. From a quantitative perspective, it would be meaningful to include the measurement of social networks and community influence on education, knowledge, and HSB. This potential for education on FGS to be shared through formal education or social networks in communities—both would fill in the existing gaps in the knowledge and awareness of the disease.

Shared norms, or shared perceptions, were also an important determinant of HSB for women at-risk for FGS. The specific norm or perception sometimes dictated what type of treatment

was going to be sought and where it would be accessed. The qualitative findings shed more light on the social and cultural impacts of HSB than the quantitative findings. The qualitative findings highlighted the varied understanding of schistosomiasis and FGS, and their causes, signs/symptoms, and treatments. The understanding of schistosomiasis, the community-level concern, and perceptions around treatment all contributed to shared norms that women from North Tongu and Weija possessed. Danso-Appiah et al. [40] found that perceived severity of infection dictated HSB among community members. HSB may be a social experience, as much as it is a personal experience, due to pre-existing social norms that surround women in both districts. The negative and positive perceptions surrounding treatment and MDA programming formed shared understandings among women to dictate their actions around curative and preventative measures. A study from Uganda noted societal norms deterred adolescent girls from obtaining modern contraception as it was an unacceptable practice [81]. Maritim et al. [82] discovered that sometimes HSB for lymphatic filariasis was discouraged by gender and social norms where patients with hydrocele were embarrassed about their condition or, in certain cases, hydrocele is viewed as a sign that a man was supposed to be a "headman." In this case, negative and positive perceptions of hydrocele negatively influenced HSB among community members. Shared norms can also be experienced by HWs, influencing HSB and healthcare delivery in a community setting [83]. A cross-sectional survey of HWs, from 10 LMIC countries, reported normative attitudes about sexual and reproductive health and right (SRHR) influenced the SRHR practices of these HWs [83]. Shared norms and perceptions may influence HSB about schistosomiasis and FGS as health decisions are made in a social environment and/or have community influence. This study highlights that HSB must be understand in the context of social influences and shared norms.

Relationships were important determinants of HSB for the women as reported in the community surveys and FGDs. Many women were the final health decision-makers for themselves and their children when seeking treatment for schistosomiasis/FGS-related symptoms. There was convergence in the quantitative and qualitative findings. In the community surveys, health professionals, husbands, and sisters were also identified to be decision-makers for health care. Similarly, the discussions indicated that women were advised by family members and friends regarding their health and sometimes husbands/boyfriends would dictate HSB as they controlled the household finances. Literature indicates that in many settings, husbands bare the financial responsibility for their wives' treatments and acted as gatekeepers by making the final health decisions [84,85]. Das et al. [85] reported that sometimes wives were not pleased with the health decision, which led them to seek care through alternate practices. This study showed that health decision-making may introduce conflicts between husbands and wives as women have all the health information regarding their, or their child's, sickness but may have to wait on the husband to decide to go to the hospital/clinic. Moreover, in the FGDs, HW behaviour was identified to be a barrier to seeking care at hospitals/clinics due to the reports of dismissiveness and coerciveness displayed to patients. Similarly, a systematic review of HWs' behaviour when providing sexual and reproductive healthcare (SRH) to women in SSA found that negative behaviours deterred women from accessing SRH services [86]. Based on their experiences with the health system, wives and husbands may hold different perspectives on where they can get the best treatment. Women may experience an internal struggle to make the right choice regarding their, or their child's health, as they are bound by social norms, but they lack financial autonomy to act independently. In the case of FGS, this internal struggle may be exacerbated as the privacy around the issue stops them from openly disclosing the health problem to their husband.

Apprehensions, rooted in personal perceptions and social cues, played an important role in determining HSB for women and children in North Tongu and Weija. The "blood in urine" condition was perceived to be a private problem among women which hindered the open discussion in the community. Women, and some men, indicated that there was no stigma associated with schistosomiasis in their communities, but when discussing actions around the disease, it was clear that there was internalized and enacted stigma surrounding "blood in the urine" [79]. The need to hide signs, keep conditions private, and laugh at the health condition all point to an unspoken stigma existing in the communities that may have an impact on HSB. Globally, it is understood that HSB is negatively influenced by stigma, which subsequently impacts community- and population-level health outcomes [87]. "Blood in urine" may be stigma marking[4] for women which are followed by stigma experiences in their communities [87]. Stigma experiences and practices can dissuade these women from seeking treatment leading to a chronic manifestation of schistosomiasis, leading to FGS. In the context of schistosomiasis, HSB is greatly influenced by the stigma experienced by community members [25,38]. Further understanding the role stigma plays for FGS HSB will support the development of tailored care for women in these communities. For children, apprehensions about seeking help may present in the form of fear of punishment, rather than stigma. Mothers and women of the community shared that physical punishment would result when children were found playing, or going to play, in the river in their communities. These prevention methods may prove to be barriers to HSB among young girls, who may experience "blood in the urine. The HSB of young girls may be influenced by apprehensions due to fear of punishment and stigma.

[4] Stigma marking refers to the application of stigma to a person or group due to their health condition or distinct difference [87].

Teachers posed to be an important part of the HSB narrative for children, who experience "blood in the urine." The qualitative findings highlighted the crucial role of teachers in supporting the health of children. This makes sense as school-based MDA is the predominant method to targeting urogenital schistosomiasis in communities, which puts educators in the spotlight [88]. However, the quantitative findings did not converge on this topic. The surveyed women illustrated little-to-no trust in teachers for health information and the community survey did not inquire closely about teachers' involvement in HSB. The lack of trust among women for teachers may be arising from their perceptions around the teachers' lack of training for MDA, the onset of adverse drug events in children, and limiting medication distribution to adults [79]. However, teachers proved to be enablers to the HSB of children and parents through their involvement in MDA medication distribution as indicated in the FGDs. They provide useful health information to parents seeking care for their children and notify them when students are experiencing "blood in the urine." A cross-sectional survey on the knowledge of urogenital schistosomiasis among students and teachers in Eastern Ghana found that teachers had a considerable understanding of urogenital schistosomiasis [88]. The teachers' knowledge regarding the disease had a small correlation with students' knowledge level with the authors noting a lack of appropriate curriculum available to teachers to educate students [88]. This investigation highlights that the impact of teachers' knowledge may not be quantified through a standardized tool, but qualitative evidence shows that teachers have an important role in the health of children of the communities.

6.4. Health Information Trust

Women identifying a variety of trusted health information sources in their communities illustrates the range of health information available to them. Health professionals, teachers, community elders, peers, friends, and family members were identified by women as health information sources in the FGDs. Similarly, women in surveys identified various health

professionals, community leaders/elders, religious leaders, family members, and friends as trusted health information sources. Both the quantitative and qualitative findings aligned to illustrate the trusted health information sources for women at risk for FGS/schistosomiasis. Women indicated that they had greater trust in their mothers, female friends, and/or female family members for health information. They relied more on the female figures in their lives than males, including husbands. These findings aligned through the quantitative and qualitative data. Interestingly, the quantitative findings portrayed a lack of trust among community leaders, elders, and religious leaders for any type of health information by women. The qualitative findings showcased some trust in community elders for health information relating to preventative HSB. Overall, it appears that leaders in the community may not impact the knowledge and health behaviour of women at-risk for FGS. These findings on trusted information sources guide where to aim FGS health education interventions and the important stakeholders to involve in the dissemination of information.

6.5. Health Information Trust Networks

The impact of social capital and social support in making health decisions is extremely significant for women who are at risk for FGS. The quantitative and qualitative findings illustrate a diverse social network that provides health information to women in their communities. A study from Madagascar identified the importance of social and provider (i.e., HW) ties to gaining information and subsequent HSB [89]. Women were much more likely to use contraceptives if they had social and provider ties, over no ties, to give them health information [89]. Having a wider network of informed individuals can help women make the correct choices about their health as they guide them in seeking care. The lack of understanding of FGS in communities may hinder women from obtaining the correct care for their symptoms if they rely solely on their social ties for information as FGS awareness is low in communities. Anecdotes and word-of-mouth were

common mechanisms to share health information and HSB processes among the community members. Stories shared among women propagated within and across communities to inform the understanding of schistosomiasis, its causes, transmission, prevention, and treatment practices. Storytelling may be an effective tool to further support the health education of women, introduce FGS into communities, and have community members be accommodated for their level of education. It is argued that storytelling may be a useful, supportive mechanism to improve the health literacy of individuals as it would introduce important information in a humanized, personal perspective [90]. This method of health education introduces the concept of experiential learning, which, according to the FGDs, is a common way community members communicate their health experiences [90].

The privacy surrounding "blood in urine" indicates that a strong trust must exist between women and their health information source when they are deciding on seeking care. There must be a significant level of trust in the women's health network to allow them to share their ill-health status and gain supportive information. Moreover, trust must be fortified between women and HWs to ensure that information and care for FGS are appropriately received. In the context of FGS, building relationships may prove to be challenging as prior misinformation or lack of information about FGS among HWs (i.e., stigmatization and discrimination due to the belief that symptoms are from STIs) has stigmatized women in communities [24]. There are many considerations to the health information networks of women at risk for FGS and these findings can guide better health information delivery to improve their access to care and treatments.

The health information network for women at risk for FGS is not without its challenges. A drawback to having this many information sources would be the introduction of uncertainties and confusion regarding which source to believe when trying to make informed health decisions. A

vaccine hesitancy study from Tamil Nadu, India found that social capital and source of health information determined if parents consented to their children getting the measles-rubella (MR) vaccine [91]. Greater physical social capital deterred parents from accepting the MR vaccine with the authors explaining that social ties led to the propagation of social norms and beliefs that may dissuade HSB for parents [91]. However, there was a significant association between receiving information from teachers and the acceptance of the MR vaccine by parents [91]. Having too many social ties and inaccurate health influences can work against supportive health behaviour if incorrect or conflicting health information is shared via social networks.

6.6. Health Information Seeking Behaviour

The manner in which community members, specifically women, obtained health information in North Tongu and Weija can inform the development and future delivery of health education programs for FGS. There were active and passive means for women to gather health information in their communities. This pattern of health information-seeking behaviour (HISB) was only found in the qualitative findings as the surveys did not assess this topic area. The active and passive health behaviours were found in obtaining health care and health information in communities. The active HISB was portrayed through seeking advice for care options, asking teachers about medication, consulting with HWs, and asking the FGD facilitators questions. Active HISB among individuals results from situations of uncertainty and/or dealing with illnesses, in themselves or someone close [92]. Most HSB would involve active HISB if symptoms are unknown, or not much is known about the treatment. However, in the case of FGS, active HISB can provide misinformation or inaccurate guidance to care-seeking women as FGS is frequently mistaken for menstruation and STIs as HW remain unfamiliar with the condition [24]. To support active HISB, there need to be existing channels of accurate information on FGS available in the communities, so women are not misled when they are experiencing signs and symptoms. The

passive HISB was illustrated through getting information from community campaigns, HWs informing mothers of preventative measures, health experience storytelling, and children being intermediaries for information. Kelly et al. [92] outline that passive HISB is the most common mechanism for obtaining health information as individuals come across many sources without specifically looking for it. Community sensitization on FGS can be achieved through passive HISB if knowledge is shared at the point of care (i.e., health clinic) or through existing groups. A review conducted by Cass Ball, and Leveritt [93] found that passive health education interventions were successful in improving the knowledge of patients in primary healthcare facilities. Having passive health education about FGS available in communities has the potential to improve the health knowledge and behaviour of at-risk women.

6.7. Impact of COVID-19 Pandemic

The COVID-19 pandemic had a significant impact on the trust in health information and preventative HSB among community members. The misinformation and lack of clear information, about the virus contributed to an aura of mistrust and hesitancy among some of the community members. The qualitative findings highlighted an important barrier to the prevention of schistosomiasis and FGS, where COVID-19 misinformation contributed to dismissal and lack of adherence to MDA. A cross-sectional survey conducted in Africa found almost a third of their sample population was unsure about false statements on COVID-19 being true [94]. Osuagwa et al. [94] found being older, female, unemployed, and having a bachelor's degree was significantly associated with believing in misinformation about COVID-19. These findings illustrate intervention areas for the MDA program planner to address and support areas of preventative HSB. USAID has an MDA training and implementation guidance document, in the context of COVID-19, that highlights steps to take to address COVID-19 misinformation [95]. Correct health information regarding COVID-19 and MDA delivery needs to be provided to community members

to ensure that they make appropriate health decisions. HWs and teachers need to be adequately trained about the impact of COVID-19 to ensure that they accurately educate community members during MDA delivery.

6.8. Inter-Method Discrepancies

The majority of the findings from the quantitative and qualitative data converged on topics or provided complementarity between the final results. However, there were a few places where the was dissonance in findings as explained by O'Cathian, Murphy, and Nicholl [71]. The authors identified inter-method discrepancies to be important to investigations as they allow for clearer answers to research questions [71]. There was a discrepancy between the survey data showing an inverse relationship between the level of education and HSB, and the qualitative data pointing to lay knowledge educating women influencing their health behaviours. Here the qualitative findings highlighted gaps in the quantitative data collection process where certain factors were not assessed but should have been to attain a comprehensive understanding of HSB. There was also a discrepancy when the qualitative findings highlighted active versus passive HISB, but the survey did not address this topic area. The qualitative methods' flexibility and openness allow for spontaneous information to be uncovered, which is not the case with the standardized quantitative methods. Moffatt et al. [96] summarize that discrepancies in mixed methods findings that can support the appraisal of both datasets and provide more comprehensive answers to the investigation. Taking different methodological approaches for the objectives of the investigation allowed for two different perspectives. The mixed-methods approach in this project ensured a diverseness to the inquiry.

6.9. Strengths and Limitations

6.9.1. Strengths

The main strength of this investigation is that it utilizes a convergent mixed methods design. This approach allows for the quantitative and qualitative results to validate and fill in the

gaps for either of the methods [56]. The quantitative findings were supported by the details in the qualitative findings, which allowed for the results to have a more personalized meaning [97]. The quantitative and qualitative analysis allowed for the population under study to provide responses to both close-ended and open-ended questions [57]. Comparing the two datasets allowed for the validity of the findings to be measured ensuring more rigorous approach to the inquiry. Moreover, the qualitative findings highlighted some places where there is need for further research through quantitative methods. The quantitative findings provided numerical reference points to some of the qualitative findings. Overall, the convergent mixed method design allowed for a more robust approach to the investigation, which provided strength to the final results.

Another strength of the investigation emerges from the rigor behind the qualitative data collection and analysis. The training of the FGD facilitators was conducted by the Ghanaian research team, who is well-versed in qualitative research methodologies. KP, and the Canadian research team, were not able to be in Ghana for the training due to the COVID-19 pandemic. The team in Ghana ensured that the facilitators understood the objectives of the project, encouraged participants to engage within the focus groups, which resulted in rich and detailed data. They probed the important topics repeatedly as well as questioned non-verbal cues (this is noted explicitly in the transcripts) shared by the participants. The rigor in the qualitative data analysis process was another strength of the investigation. The validation of results and their interpretations through KP's supervisor, the TAC members, the FAST Package team members, experienced national researchers, and a government official from Ghana provides credibility.

6.9.2. Limitations

A limitation of this project comes from the smaller sample size for the HSB section with only 86, out of 149, women choosing to talk about symptoms they experienced in the two weeks before the survey. The small sample size made it difficult for the clustering to be addressed in the

logistic regression models. Initially, it was proposed that a random-effects model would be used for the multiple logistic regression model to account for the correlation in responses [60]. This was not possible due to only 86 women (only 42 outcomes) being assessed for the HSB model. The correlation between the data was not accounted and multivariable logistic regression models were developed for the analysis. As the smaller sample size was the outcome of the decision made by the women to talk, it constitutes a non-response bias [98]. The non-response bias is an outcome of differences between those who responded and those who did not [98]. The bivariate analysis in Section 5.1.9. points to there being significant differences between women who chose to talk about symptoms and those who did not, based on various factors. Going forward, it will be important to consider these differences in the data collection process.

The social desirability bias may be another limitation of the qualitative data collection process. The bias presents in the responses of participants who aim to have their responses align with what is socially acceptable [99]. During the discussions, it is plausible that women provided answers that matched the groups' understanding and opinion over their own to ensure they are not speaking out of line. The potential presence of this bias may remove the heterogeneity of the responses in the FGDs, if a woman's opinions differ from the norm [99]. This bias cannot be measured as facilitators cannot ascertain when participants may not be offering their most honest answers [99]. However, the transcripts do indicate that the facilitators tried to engage all participants and picked up on non-verbal signs to ask participants about their opinions.

There are many merits to mixed method research, however, there are some drawbacks that must be considered. For the concurrent triangulation design, the data collection and analysis occurring independently does not allow for flexibility in the investigation or the enhancement of either methodology [100]. With sequential designs, the investigation from one methodology allows

for the next methodology to be meaningfully adjusted, however, this flexibility is not present in the concurrent design. As well, there may be uncertainties behind the reasoning behind the discrepancies in the findings [100]. It is difficult to ascertain the cause of the discrepancies (e.g., methodologies, populations, inherent differences in topic) without studying the topic further and adjusting the methodologies for different investigations.

The quantitative and qualitative data sources also have their limitations. There was some potential for misclassification in the HSB section of the survey as females only talked about one symptom from a list of symptoms, they noted experiencing. Most symptoms of schistosomiasis/FGS are not specific to these two diseases, as such, there is a chance that symptoms may be unrelated to a schistosomiasis infection. However, assessing the HSB of these symptoms does provide important information about the women under study regardless of the cause of the symptoms. There is a chance that certain details of HSB of women were missed as the qualitative data was conducted by facilitators aiming to fulfill the inquiry for the FAST Package project. KP was unable to conduct the FGDs and probe specific comments shared by the participants that would be pertinent to the thesis project.

7. Conclusion

Women interviewed for this study displayed an overall lack of awareness of FGS. In contrast, schistosomiasis is commonly known, presenting an opportunity to leverage and promote community-level sensitization of FGS. Research results suggest that women may need to be targeted by intensive health education interventions about FGS, its care, and treatment to facilitate knowledge and understanding of the condition. In addition, social networks, community connections, and educators can be supportive of health programming that aims to improve the knowledge of FGS among at-risk women and girls. The HSB patterns of women in the study indicate that some health system improvements are necessary to make diagnostic and treatment

services, for schistosomiasis and FGS, easily accessible. Moreover, internalized stigma, surrounding urogenital pathologies, is present in communities so HWs should be vigilant toward these barriers in seeking care and actively support women at-risk for FGS. This research suggests that HWs with the knowledge of FGS and its preventative/curative measures should build effective relationships with women and their health decision markers. Overall, this study suggests that various environmental, social, and cultural factors influence the HSB of women at-risk for FGS, which must be addressed to improve their reproductive health and well-being.

The small sample size for the HSB section highlights women's likely discomfort in openly talking about their experiences with urogenital symptoms. The hesitancy surrounding the sex of enumerators seems to be an important barrier to rigorous health research on sensitive health topics. Taking a qualitative approach and encouraging sharing experiences through group settings may be more supportive of the research of HSB for urogenital pathologies. Future research endeavors must consider sensitivity training for enumerators if they are going to be speaking to women about reproductive and sexual health issues. Moreover, pairing participants with interviews of the same sex/gender may encourage more conversation about personal health issues. Various mechanisms may support enumerators in gaining the trust of community members to talk about their health problems.

The findings from the baseline research of the FAST Package Project highlight the need for more research specifically on FGS knowledge, awareness, and practices among women in Ghana. Moreover, a close look is required into the diagnostic and treatment capabilities of health facilities, in the region where *S. haematobium* is endemic, which can provide a more holistic view of the HSB of the women at-risk for FGS. The role of stigma needs to be further studied in the context of FGS, its care, and prevention in vulnerable populations. The HSIB of women should be

studied in the context of HSB to further understand the relationship between the two behaviours. The research and advocacy for FGS must be viewed from the women's rights perspective as various environmental, social, and cultural determinants impact women's health behaviour and subsequently dictate health outcomes.

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9. Appendix A – Important Figures and Tables

Figure 1. Maps outlining the distribution of *S. mansoni* and *S. haematobium* in Ghana [45]

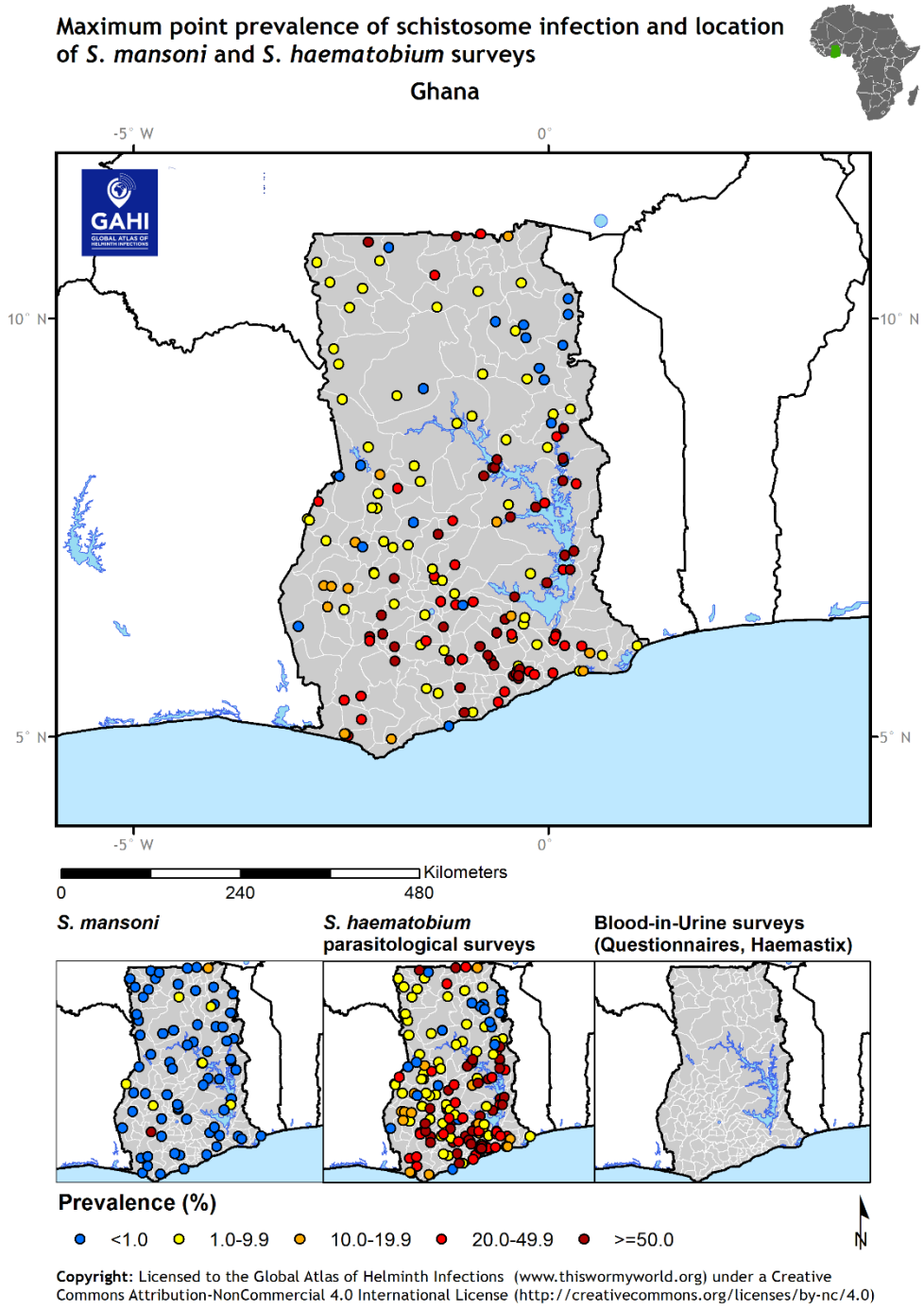


Photo:
"Distribution of schistosomiasis survey data in Ghana" by Global Atlas of Helminth Infections is licensed under CC BY-NC 4.0.

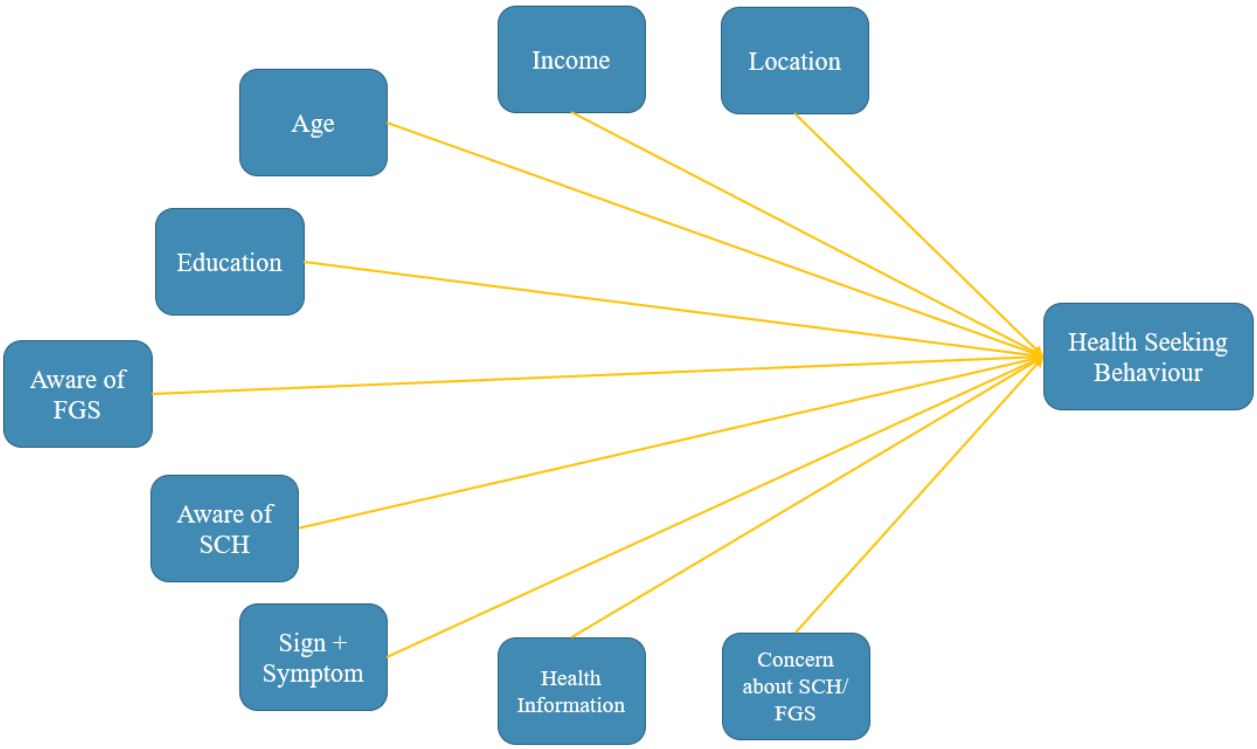
Table 1. Inclusion – Exclusion Criteria for Community Survey

Inclusion Criteria	Exclusion Criteria
• Community member needs to be residing in the selected district • Community members needs to be at least 18 years and less than 60 years	• Community members who is sick, bedridden, or not mentally sound • Community member who is confirmed presenting signs and symptoms of COVID-19 • Community member who does not, or cannot, provide consent

Table 2. Inclusion – Exclusion Criteria for Focus Group Discussions

Inclusion Criteria	Exclusion Criteria
• Women of Reproductive Age (WRA;18-49 years) from the selected district • Men who are at least 18 years but less than 60 years from the selected district	• WRA or men who are sick, bedridden, or not mentally sound • WRA or men who are confirmed presenting signs and symptoms of COVID-19 • WRA or men who are not able to, or cannot, provide consent

Figure 2. Conceptual Model for the Quantitative Data Analysis*



*The model is based on the findings from the literature [25,38-43] in Section 2. and discussions with AK.

Table 3. Descriptive Table of the Distribution of Females by District (n=508)

Ghana District	Frequency	Percentage
Weija	248	48.82%
North Tongu	260	51.18%
Total	508	100%

Table 4. Descriptive Table of the Distribution of Females by Age Group (n=508)

Age Group	Frequency	Percentage
18-30 years	199	39.17%
31-43 years	176	34.65%
44-59 years	133	26.18%
Total	508	100%

Table 5. Descriptive Table of the Distribution of Health Status of Females (n=508)

Overall Health Status	Frequency	Percentage
Poor	29	5.71%
Fair	103	20.28%
Good	149	29.33%
Very Good	145	28.54%
Excellent	82	16.14%
Total	508	100%

Table 6. Distribution of the Biggest Health Concern in the Community for Females (n=508)

Health Concern	Frequency	Percentage
COVID-19/Coronavirus	41	8.23%
Malaria	317	63.65%
Diarrhea and/or Vomiting	7	1.41%
Respiratory Infections	15	3.01%
Tuberculosis	1	0.20%
Schistosomiasis/Blood in Urine	24	4.82%
Other	93	18.67%
Total	498	100%

Table 7. Distribution of the Biggest Health Concern in the Households for Females (n=508)

Health Concern	Frequency	Percentage
COVID-19/Coronavirus	60	12.00%
Malaria	286	57.20%
Diarrhea and/or Vomiting	14	2.80%
Respiratory Infections	27	5.40%
Schistosomiasis/Blood in Urine	13	2.60%
Other	100	20.0%
Total	500	100%

Table 8. Distribution of Females' Frequency in Bathing (n=508)

Bathing	Frequency	Percentage
Daily	79	17.21%
Once a Week	7	1.53%

Twice a Week	13	2.83%
More than 2 times a Week	16	3.49%
Very Rarely	48	10.46%
Not Applicable	296	64.49%
Total	459	100%

Table 9. Distribution of Females' Frequency of Washing Clothes (n=508)

Washing Clothes	Frequency	Percentage
Daily	67	14.44%
Once a Week	58	12.50%
Twice a Week	29	6.25%
More than 2 times a Week	30	6.47%
Very Rarely	44	9.48%
Not Applicable	236	50.86%
Total	464	100%

Table 10. Distribution of Females' Frequency of Washing Utensils (n=508)

Washing Utensils	Frequency	Percentage
Daily	70	15.32%
Once a Week	9	1.97%
Twice a Week	2	0.44%
More than 2 times a Week	14	3.06%
Very Rarely	36	7.88%
Not Applicable	326	71.33%
Total	457	100%

Table 11. Distribution of Females' Frequency of Washing Vehicles (n=508)

Washing Vehicles	Frequency	Percentage
Daily	22	5.01%
Once a Week	4	0.91%
Twice a Week	2	0.46%
More than 2 times a Week	1	0.23%
Very Rarely	14	3.19%
Not Applicable	396	90.21%
Total	439	100%

Table 12. Distribution of Females' Frequency of Swimming (n=508)

Swimming	Frequency	Percentage
Daily	30	6.70%
Once a Week	18	4.02%
Twice a Week	5	1.12%
More than 2 times a Week	26	5.80%
Very Rarely	40	8.93%
Not Applicable	329	73.44%
Total	448	100%

Table 13. Distribution of Females' Frequency of Fishing (n=508)

Fishing	Frequency	Percentage
Daily	41	9.05%
Once a Week	14	3.02%
Twice a Week	8	1.77%

More than 2 times a Week	13	2.87%
Very Rarely	29	6.40%
Not Applicable	348	76.82%
Total	453	100%

Table 14. Distribution of Females' Frequency of Fetching Water (n=508)

Fetching Water	Frequency	Percentage
Daily	130	27.25%
Once a Week	58	12.16%
Twice a Week	14	2.94%
More than 2 times a Week	53	11.11%
Very Rarely	70	14.68%
Not Applicable	152	31.87%
Total	477	100%

Table 15. Distribution of Females' Access to River Water Without Direct Contact (n=508)

Access to Water	Frequency	Percentage
Yes	76	14.96%
No	399	78.54%
Don't Know	33	6.50%
Total	508	100%

Table 16. Distribution of Females' Knowledge of Schistosomiasis (n=508)

Heard of Schistosomiasis	Frequency	Percentage
Yes	441	86.81%

No	67	13.19%
Total	508	100%

Table 17. Distribution of Females' Knowledge of Schistosomiasis's Symptoms (n=441)

Pain when Urinating	**Frequency**	**Percentage**
Yes	229	51.93%
No	212	48.07%
Total	441	100%
Blood in the Urine	Frequency	Percentage
Yes	319	72.34%
No	122	27.66%
Total	441	100%

Table 18. Distribution of Females' Concern of About Schistosomiasis (n=441)

Concern about Schistosomiasis	**Frequency**	**Percentage**
Not at all concerned	83	18.82%
Slightly concerned	61	13.83%
Somewhat concerned	67	15.19%
Moderately concerned	91	20.63%
Extremely concerned	129	29.25%
Don't Know	10	2.27%
Total	441	100%

Table 19. Distribution of Females' Opinion on the number of people with Schistosomiasis (n=441)

Number of People	Frequency	Percentage
None	85	19.27%
Few	84	19.05%
Some	38	8.62%
Many	42	9.52%
Don't Know	192	43.54%
Total	441	100%

Table 20. Distribution of Females' Knowledge of Schistosomiasis Symptoms Being Same for Boys and Girls (n=441)

Symptoms Same	Frequency	Percentage
Yes	213	48.30%
No	22	4.99%
Don't Know	206	46.17%
Total	441	100%

Table 21. Distribution of Females' Knowledge of Female Genital Schistosomiasis (n=441)

Heard of FGS	Frequency	Percentage
Yes	171	38.78%
No	270	61.22%
Total	441	100%

Table 22. Distribution of Females' Opinion on the Presence of FGS in their Community (n=171)

Presence in Community	Frequency	Percentage
Never	15	8.77%
Rarely	64	37.43%
Sometimes	34	19.88%
Often	15	8.77%
Always	6	3.51%
Don't Know	37	21.64%
Total	171	100%

Table 23. Distribution of Females' Knowledge of FGS's Symptoms (n=171)

Pain when Urinating	Frequency	Percentage
Yes	126	73.68%
No	45	26.68%
Total	171	100%
Blood in the Urine	**Frequency**	**Percentage**
Yes	148	86.55%
No	23	13.45%
Total	171	100%
Lower Abdominal Pain	**Frequency**	**Percentage**
Yes	43	25.15%
No	128	74.85%
Total	171	100%
Pain During Sex	**Frequency**	**Percentage**
Yes	14	8.19%

No	157	91.81%
Total	171	100%
Bleeding after Sex	**Frequency**	**Percentage**
Yes	2	1.17%
No	169	98.83%
Total	171	100%
Infertility	**Frequency**	**Percentage**
Yes	16	9.36%
No	155	90.64%
Total	171	100%

Table 24. Distribution of Females' Knowledge of MDA being Distributed to Someone in their Household (n=441)

MDA Distribution	**Frequency**	**Percentage**
Yes	62	14.06%
No	349	79.14%
Don't Know	30	6.80%
Total	441	100%

Table 25. Distribution of Females' Knowledge of Who Received MDA (n=62)

Daughter/Sister/Niece/ Female Cousin	**Frequency**	**Percentage**
Yes	27	43.55%
No	35	56.45%
Total	62	100%
Son/Brother/Nephew/ Male Cousin	**Frequency**	**Percentage**

Yes	40	64.52%
No	22	35.48%
Total	62	100%

Table 26. Distribution of Females' Opinion on the Schistosomiasis Tablet (n=441)

Opinion on Tablet	Frequency	Percentage
Very Dangerous	14	3.17%
Not Very Dangerous	7	1.59%
Neutral	28	6.35%
Somewhat Safe	42	9.52%
Safe	187	42.40%
Don't Know	163	36.96%
Total	441	100%

Table 27. Distribution of Females Receiving Information about MDA (n=441)

Received Information	Frequency	Percentage
Yes	147	33.33%
No	294	66.67%
Total	441	100%

Table 28. Distribution of Females Indicating Schistosomiasis/FGS-related Symptom to Talk About (n=86)

Symptom of Choice	Frequency	Percentage
Pain when Urinating	20	23.36%
Blood in Urine	4	4.65%

Diarrhea	14	16.28%
Vomiting	2	2.33%
Lower Abdominal Pain	26	30.23%
Pain during Sexual Intercourse	20	23.26%
Total	86	100%

Table 29. Distribution of Females Indicating Seeking Care for their Chosen Symptom (n=86)

Sought Care	Frequency	Percentage
Yes	42	48.84%
No	44	51.16%
Total	86	100%

Table 30. Distribution of Females' Opinion of Most Important Person in their Story (n=42)

Most Important Person	Frequency	Percentage
Yourself	21	50.0%
Nurse	8	19.05%
Doctor	3	7.14%
Friend/Family Member	6	14.29%
Other	4	9.52%
Total	42	100%

Table 31. Distribution of Females' Choice of Where Treatment was Sought (n=42)

Private Clinic	Frequency	Percentage
Yes	3	7.14%
No	39	92.86%

Total	42	100%
Health Center	**Frequency**	**Percentage**
Yes	7	16.67%
No	35	83.33%
Total	42	100%
Hospital	**Frequency**	**Percentage**
Yes	20	47.62%
No	22	52.38%
Total	42	100%
Teacher	**Frequency**	**Percentage**
Yes	0	0%
No	42	100%
Total	42	100%
Traditional Healer	**Frequency**	**Percentage**
Yes	4	9.52%
No	38	90.48%
Total	42	100%
Church	**Frequency**	**Percentage**
Yes	1	2.38%
No	41	97.62%
Total	42	100%
Friend/ Family Member	**Frequency**	**Percentage**
Yes	1	2.38%
No	41	97.62%
Total	42	100%
Pharmacy/Chemical/Drug Store/Drug Peddler	**Frequency**	**Percentage**

Yes	7	16.67%
No	35	83.33%
Total	42	100%

Table 32. Distribution of Treatment Received by Females (n=42)

MDA/Praziquantel	**Frequency**	**Percentage**
Yes	7	16.67%
No	35	83.33%
Total	42	100%
Oral Tablet	**Frequency**	**Percentage**
Yes	24	57.14%
No	18	42.86%
Total	42	100%
Treatment Injection	**Frequency**	**Percentage**
Yes	7	16.67%
No	35	83.33%
Total	42	100%
Traditional Medicine	**Frequency**	**Percentage**
Yes	5	11.90%
No	37	88.10%
Total	42	100%
Other	**Frequency**	**Percentage**
Yes	5	11.90%
No	37	88.10%
Total	42	100%

Table 33. Distribution of Females' Informed the Cause of their Symptom (n=42)

Informed of Cause	Frequency	Percentage
Yes	17	40.48%
No	25	59.52%
Total	42	100%

Table 34. Distribution of Females' Whose Symptom Improved Post-Treatment (n=42)

Improved Symptom	Frequency	Percentage
Yes	30	71.43%
No	12	28.57%
Total	42	100%

Table 35. Distribution of Females' Most Trusted Source of Health Information (n=508)

Trusted Source of Health Information	Frequency	Percentage
Friend	6	1.18%
Female Family Member	29	5.17%
Male Family Member	11	2.17%
Husband	22	4.33%
Doctor	264	51.97%
Nurse	95	18.70%
Community Health Worker	35	6.89%
Religious Leader	1	0.20%
Traditional Healer	11	2.17%
Community Leader	1	0.20%
Internet/Social Media	3	0.59%

Other	30	5.91%
Total	508	100%

Table 36. Distribution of Females Reporting to Attend Health Meetings (n=508)

Attend Health Meetings	Frequency	Percentage
Yes	136	27.09%
No	366	72.91%
Total	502	100%

Table 37. Distribution of Females Belonging to a Community Group (n=508)

Belong to Community Group	Frequency	Percentage
Yes	90	17.86%
No	414	82.14%
Total	504	100%

Figure 6. Mind Map Outlining the Health Seeking Behaviour of Women at-risk for FGS

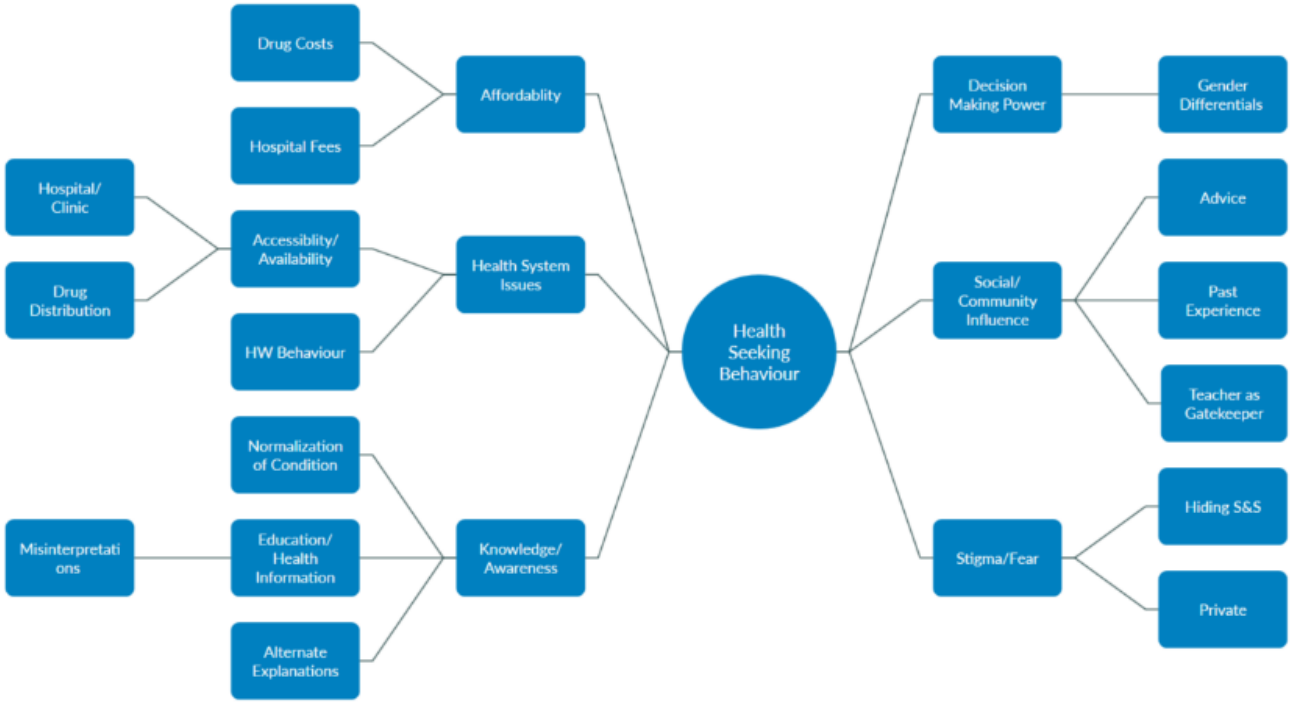


Figure 7. Mind Map Outlining the Health Information Trust of Women at-risk for FGS

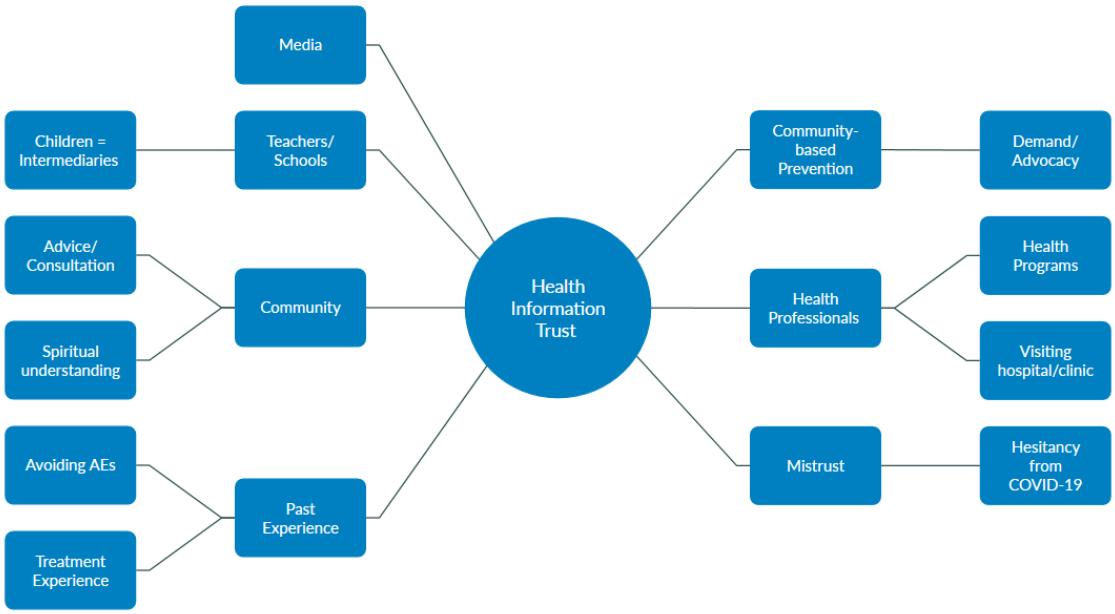


Table 38. Triangulation of the Main Quantitative and Qualitative Findings

Quantitative	Alignment	Qualitative
High Schistosomiasis Awareness	Convergence	High Schistosomiasis Awareness
Low FGS Awareness	Dissonance	No Awareness of FGS
Great Concern for Schistosomiasis	Dissonance	Mixed Concern for Schistosomiasis
Blood in urine = Menstruation, STIs	Convergence	Confusion w/ STIs and Menstruation
No District based Differences in Awareness	Dissonance	Difference in District Trends
Almost No Safe Access	Complementarity	High Water Contact
Low Response Rate	Complementarity	Private Issue
High Access of Hospitals/Clinics	Convergence	Reliance on Hospitals/Clinics
Lower access/trust of pharmacies	Convergence	Women Access Pharmacies
Praziquantel = Safe	Convergence	Support for MDA/Medication
Not many received information on MDA	Complementarity	High Concern for AEs
Steady Income X HSB	Dissonance	Costs and Accessibility/Availability of Services
Level of Education X HSB	Complementarity	Lay Knowledge / Shared Norms
HSB not determined by District	Silence	
	Silence	Problems with Availability of Services
	Silence	Alternate Explanation of Schistosomiasis
	Silence	Negative Perceptions of MDA
Final Decision = Themselves, Husbands, Sister, Health Professionals	Complementarity	Various Final Decision Makers for Health

Low-to-no Trust in Teachers	Dissonance	Trust in Teachers
Various Source of Trusted Health Information	Convergence	Many Sources of Information
	Silence	Self Stigma and Enacted Stigma
	Silence	Mistrust due to COVID-19
Trust in Health Workers	Convergence	Trust in Health Professionals
Low trust in community leaders, religious leaders, and traditional healers	Convergence	Some Trust in Community and Religious Leaders
More Trust in Female Family Members	Convergence	Trust in Mothers

10. Appendix B – Data Collection Tools

10.1. Baseline Community Survey

Identification
IDENTIFICATION NUMBER:
ENTER GPS LATITUDE COORDINATES
ENTER GPS LONGITUDE COORDINATES
INTERVIEW DATE:
INTERVIEWER NAME:
COUNTRY:
DISTRICT:
VILLAGE / COMMUNITY:
START TIME OF INTERVIEW: _____

Do not forget to use local terms for Schistosomiasis.

Thank you for taking the time to speak with me today.

A. GENERAL INTRO QUESTIONS

As we begin our conversation today, I'd like to ask you some general questions about community and health.

1. What local public health campaigns are you aware of?

a. Child / maternal health programmes
b. Immunization programmes
c. HIV/ TB
d. Malaria
e. Mass Drug Administration campaign for Schistosomiasis
f. Mass Drug Administration campaign for Lymphatic Filariasis
g. Mass Drug Administration campaign for Onchocerciasis
h. Not aware
i. Others, please specify

1.1 Please, specify the other public health campaigns you are aware of?

2. Over the last year, what would you say is the biggest health concern in your community? [DO NOT READ ANSWERS, ONLY ONE ANSWER IS POSSIBLE]
    a. Covid-19 / Coronavirus

b. Malaria
c. Diarrhea and/or vomiting
d. Respiratory infections (cough, pneumonia)
e. Tuberculosis
f. HIV/AIDS
g. Schistosomiasis / blood in urine
h. Other, specify _____

2.1. Please specify the other health concern in your community.

3. Over the last year, what has been the biggest health concern in your household? ONLY ONE ANSWER IS POSSIBLE"
   a. Covid-19 / Coronavirus
   b. Malaria
   c. Diarrhea and/or vomiting
   d. " Respiratory infections (cough, pneumonia)
   e. Tuberculosis
   f. HIV/AIDS
   g. Schistosomiasis/blood in the urine
   h. Other, please specify

3.1. Please specify the other health concern in your household.
   i. _____

B. WATER CONTACT QUESTIONS

In this next section of questions, I would like to understand a bit more about how your household accesses the river,freshwater lake, running water, borehole or well
MORE THAN ONE ANSWER IS POSSIBLE BUT IF NONE IS SELECTED, NO OTHER OPTION IS POSSIBLE"

4. In your household, do you have access to any of the following?
   a. Running water
   b. Borehole
   c. Well, with a water pump.
   d. Well without pump
   e. None

"MORE THAN ONE ANSWER IS POSSIBLE BUT IF NONE IS Well without pump SELECTED, NO OTHER OPTION IS POSSIBLE" None

5. Which of these activities do you perform in the river and how frequently?

	Daily	Once a week	Twice a week	More than 2 times a week	/ very rarely	Not Applicable
Bathing / washing						
Washing clothes						

Washing cooking utensils						
Washing vehicles						
Swimming						
Fishing						
Fetching Water						

6. At the river in your community, is there any way that you can access the water without having contact with it?

a. Yes
b. No
c. Don't know

7. Do any other members of your household have activities in the river/lake?
    a. Yes
    b. No
    c. Don't Know

(IF NO OR DON'T KNOW, SKIP TO Q.9)

8. If yes, can you please indicate who goes to the river/lake? [DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE]
    a. Son / brother/nephew/male cousin
    b. Daughter / sister/ niece/female cousin
    c. Husband
    d. Wife
    e. Father
    f. Mother
    g. Grand Father
    h. Grand Mother
    i. Friends
    j. Other, specify: _____

    Please specify the other member(s) that go to the river or freshwater lake.

C. QUESTIONS ABOUT SCHISTOSOMIASIS (use local name)

9. Have you ever heard about schistosomiasis (local name)?
    a. Yes
    b. No

    (IF NO, SKIP TO Q. 41)

10. How does someone get schistosomiasis?
    "DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE"
    a. Entering rivers (swimming, washing, bathing)
    b. Entering lakes (swimming, washing, bathing)
    c. Drinking water from a river
    d. Black magic/curse
    e. Poor hygiene
    f. Sexual Intercourse
    g. Don't know

h. Other, please specify

10.1. Please, specify the other ways someone can get schistosomiasis

11. What do you think causes schistosomiasis? [DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE]
    a. Snails
    b. Parasites
    c. Dirty water
    d. Black magic / curse
    e. Other, please specify _____
    f. Don't know

11.1. Please specify the other cause of schistosomiasis.

12. In your opinion, how many people in your village have schistosomiasis (local name)?

None (2) Few (3) Some (4) Many (5) Everyone (
(X) Don't know [DO NOT REACH THIS OPTION OUT LOUD]

13. Are you concerned about schistosomiasis (local name) personally?

(1) (2) (3) (4) (5)

(1) Not at all concerned
(2) Slightly concerned
(3) Somewhat concerned
(4) Moderately concerned
(5) Extremely concerned

(X) Don't know [DO NOT REACH THIS OPTION OUT LOUD]

14. Do you think that schistosomiasis (local name) can be treated? [DO NOT READ ANSWERS]
    a. Yes
    b. No
    c. Don't know

15. Do you think that schistosomiasis (local name) can be prevented? [DO NOT READ ANSWERS]
    a. Yes
    b. No → SKIP to #17
    c. Don't know → SKIP to #17

16. How can schistosomiasis be prevented? [DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE]
    a. Taking medication / MDA / Praziquantel
    b. Taking other medication (e.g. not during MDA)
    c. Taking herbal medications (traditional remedies)
    d. Using a bed net

e. Not walking over the banks of the river / contact with snails at the river
f. Not going to the river for washing, bathing, swimming, fetching water
g. Other, specify: _____
h. Don't know [DO NOT REACH THIS OPTION OUT LOUD]
i.

16.1. Please specify other preventative measures.

17. What are the common symptoms of schistosomiasis: [DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE]
    a. Pain when urinating
    b. Blood in the urine
    c. Diarrhea
    d. Vomiting
    e. Lower abdominal pain
    f. Don't know [DO NOT READ THIS OPTION OUT LOUD]
    g. Other, specify: _____

18. Do you think the symptoms are the same for boys and girls?
    a. Yes
    b. No
    c. Don't know [DO NOT READ THIS OPTION OUT LOUD]

(IF YES OR DON'T KNOW SKIP TO Q.20)

19. If No, What are the symptoms for boys?

19.1.If No, What are the symptoms for girls?

20. Have you ever heard of a condition called female genital schistosomiasis?
    a. Yes
    b. No → SKIP to #24

21. If yes, can you explain what you understand about it:

22. In your opinion, what are the common signs and Pain when urinating symptoms of Female Genital schistosomiasis?
    DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE"

    a. Blood in the urine
    b. Lower abdominal pain
    c. Pain during sex
    d. Bleeding after sex
    e. Infertility
    f. Don't know
    g. Other, please specify

23. In your community, how common is it for women and girls to have female genital schistosomiasis?

(1) (2) (3) (4) (5)

(1) Never
(2) Rarely
(3) Sometimes
(4) Often
(5) Always

(X) Don't know [DO NOT READ OUT THIS OPTION]

D. QUESTIONS ABOUT MASS DRUG ADMINISTRATION

In this next set of questions, I'd like to ask about a campaign for mass drug administration that happened here in schools in this community in [MONTH/YEAR].

24. Have you ever heard of the mass drug administration (or mass treatment) for schistosomiasis (local name) that happened in your community?

    a. Yes
    b. No [IF NO, INTERVIEWER TO EXPLAIN: ANNUAL TREATMENT WITH PRAZIQUANTEL GIVEN TO SCHOOL CHILDREN UP TO 14 YEARS. IF INDIVIDUAL STILL DOESN'T KNOW →SKIP TO #28]

25. Have you ever heard of the mass drug administration (or mass treatment) for schistosomiasis (local name) that happened in your community?

"IF NO, INTERVIEWER TO EXPLAIN: ANNUAL TREATMENT WITH PRAZIQUANTEL GIVEN TO SCHOOL CHILDREN UP TO 14 YEARS
a. Yes
b. No

26. Within the last 12 months, has anyone in your household taken the schistosomiasis (local name) tablets (praziquantel) on their own or during the Mass Drug Administration? (IF NO OR DON'T KNOW SKIP TO Q.37)
    a. Yes
    b. No
    C. Don't Know

26.1. If yes, who in your household?
DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE"
a. Son / brother / nephew / male cousin
b. Daughter / sister / niece / female cousin
c. Husband
d. Wife
e. Father
f. Mother

g. Grand Mother
h. Grand Father
i. Friends
j. Myself
K. Other, please specify

26.2 Please specify the other person in your household who has taken the schistosomiasis (local name) tablets? _____

27. Let's talk about someone in your household who took the praziquantel in the last 12 months. Please specify who you'd like to talk about?

DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE"

a. Son / brother / nephew / male cousin
b. Daughter / sister / niece / female cousin
c. Husband
d. Wife
e. Father
f. Mother
g. Grand Mother
h. Grand Father
i. Friends
j. Myself
K. Other, please specify

27.1 Please specify the other person in your household you'd like to talk about?

28. Here are some faces expressing various feelings. Which face comes closest to how you or the person noted above felt about the praziquantel received?

INTERVIEWER SHOULD SHOW THE RESPONDENT THE JOB AID 5.Happy
FOR FACES SCALE"

a. Sad
b. Little sad
c. Neutral
d. Happy

e. Little Happy

[X] N/A e.g. never taken tablets

After this person noted above (the respondent or the person they noted) took the schistosomiasis tablets (praziquantel), what level of change did you or they experience with the following

29. Blood in the urine
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

30. Burning during urination
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

31. Stomach/gut pain
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

32. Diarrhea
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

33. Fever
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

33. Fever
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

34. Dizziness
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

35. Quality of sleep
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

36. Physical Strength
    a. Worse
    b. No change
    c. Improved
    d. Not Applicable

37. In your opinion, the tablets for schistosomiasis are [READ ANSWERS, ONLY ONE ANSWER IS POSSIBLE]:
INTERVIEWER SHOULD SHOW THE RESPONDENT THE JOB AID FOR SCALES
    a. Very dangerous
    b. Not very dangerous
    c. Neutral
    d. Somewhat safe
    e. Safe
    f. Don't know [DO NOT REACH THIS OPTION OUT LOUD]

38. Do you think you should take these tablets even if you don't feel sick?
    a. Yes
    b. No
    c. Don't know [DO NOT REACH THIS OPTION OUT LOUD]

39. DID YOU RECEIVE ANY INFORMATION ABOUT THE LAST MASS DRUG ADMINISTRATION?
A. YES
B. NO
(IF NO SKIP TO Q.41)

40. How would you rate the information you received about the treatment before the tablets were given to you:
DO NOT READ THE OPTION DON'T KNOW. INTERVIEWER SHOULD SHOW THE RESPONDENT THE JOB AID FOR SCALES"

i. (2) (3) (4) (5)

1. Not useful
2. Somewhat
3. Neutral
4. Fairly useful
5. Very useful

[X] Don't know

E. PERSONAL SYMPTOM QUESTIONS

In this next set of questions, I'd like to ask about your personal health a little bit.
41. How would you describe your overall health?

(1) (2) (3) (4) (5)

(1) Poor
(2) Fair
(3) Good
(4) Very Good
(5) Excellent

In the next set of questions, please tell if you observed or experienced any of the following symptoms within the last two weeks:

42. Pain when urinating:
    a. Yes
    b.No
    c. Respondent did not answer

    43. Blood in the urine):
        a. Yes
        b. No
        c. Respondent did not answer

44. Diarrhea:
    a. Yes
    b.No
    c. Respondent did not answer

    45. Vomitting
        a. Yes
        b. No
        c. Respondent did not answer

    46. Lower abdominal pain.
        a. Yes
        b. No
        c. Respondent did not answer

    47. Pain during sexual intercourse [
        a. Yes
        b. No
        c. Respondent did not answer
        d. Not applicable

    48. In your community how common do people have blood in their urine?
        DO NOT READ THE OPTION DON'T KNOW. INTERVIEWER SHOULD SHOW THE RESPONDENT THE JOB AID FOR SCALES"

(1) (2) (3) (4) (5)

(1) Never
(2) Rarely

(3) Sometimes
(4) Often
(5) Always

(X) Don't know [DO NOT READ OUT THIS OPTION]

49. If people do have blood in their urine, what do you think it means? [DO NOT READ THE ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE]
    a. Normal
    b. Part of puberty
    c. Menstruation
    d. Sign of Sexually Transmitted Infection
    e. Because they have schistosomiasis infection
    f. Curse
    g. Other, please specify: _____
    h. Don't know

    49.1. Please specify other meanings of blood in your urine.

You have noted that you have experienced some of these symptoms within the last two weeks. I'd like to hear a little more about how you handled those symptoms.

50. Interviewer to mark if participants have symptoms within the last two weeks?
    a. Yes
    b. No

(IF NO TO ALL OF THE ABOVE SYMPTOMS OR RESPONDENTS DID NOT ANSWER ALL OF THE ABOVE SYMPTOMS QUESTIONS, SKIP TO Q.61)

F. HEALTH SEEKING BEHAVIOUR

If you have had any of the symptoms described in the last section of questions, I'd like to ask how you treated or managed the symptom.

51. What symptom(s) would you like to talk about: _____
    "ONLY ONE ANSWER IS POSSIBLE"

    a. Pain when urinating
    b. Blood in the urine
    c. Diarrhea
    d. Vomiting
    e. Lower abdominal pain
    f. Pain during sexual intercourse

    (IF NO SKIP TO Q.61)

Let's talk about the last time you experienced this symptom(s).

52. Did you seek any care or treatment?
    a. Yes
    b. No
53. When you sought care for treatment, who made thatfinal decision for you?
    _____

54. Please tell me one thing you remember about the last time you sought care for this symptom:

Ask “is there anything else?” two times
At the end of the story, read the story back to the respondent for confirmation.

The following questions (#55- #60) are related to the story you just shared.

55. Who was the most important person in your story?
    a. Yourself
    b. Nurse
    c. Doctor
    d. Midwife
    e. Traditional healer
    f. Teacher
    g. Pastor
    h. Friend / family member
    i. Other, specify: _____

55.1. Please specify the other individual(s) important to your story.

56. Where did you go for treatment / help?
    a. Private clinic
    b. Health center
    c. Hospital
    d. Traditional healer
    e. Church
    f. Friend / family member
    g. PharmacyPharmacy/chemical/drug store/drug peddler
    h. Other, specify: _____

56.1. Please specify the other place(s) you visited for treatment

57. What are the treatments/care that you receive for treatment?
    DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE"
    a. Praziquantel
    b. Treatment – oral tablet (not praziquantel)
    c. Treatment – injection
    d. Traditional medicine
    e. Other, specify: _____

57.1. Please specify other treatments.

58. Were you told what caused your symptoms?
    a. Yes, specify what: _____
    b. No

(IF NO, SKIP TO Q.60)

59. If yes, what were you told caused your symptoms?

_____

60. After treatment/care did your symptoms get better?
    a. Yes
    b. No
    c. Can't remember

G. HEALTH INFORMATION AND COMMUNITY LIFE

In this next section I'd like to understand where you get information about health.

61. From where do you get your health information?
    DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE"
    a. Public announcement
    b. Radio
    c. Television
    d. Church
    e. School/College
    f. Local health center/community health workers
    g. Internet websites
    h. Social media (Facebook, Instagram, Whatsapp)
    i. Other, please specify

    61.1. Please specify other sources of health information.

    _____

62. Who do you trust for health information? [DO NOT READ ANSWERS, MORE THAN ONE ANSWER IS POSSIBLE]
    a. Friend
    b. Female Family member (mother, sister, daughter, auntie, grandmother, female cousin)
    c. Male Family member (father, brother, son, uncle, grandfather, male cousin)
    d. Husband
    e. Wife
    f. Doctor
    g. Nurse
    h. Midwife
    i. Community health worker
    j. Teacher
    k. Religious leader
    l. Traditional healer
    m. Community leader

n. Internet/social media
o. Other, specify: _____

62.1. Please specify other trusted sources of information.

_____

63. Who do you trust most for health information? [DO NOT READ ANSWERS, ONLY ONE ANSWER IS POSSIBLE]
    a. Friend
    b. Female Family member (mother, sister, daughter, auntie, grandmother, female cousin)
    c. Male Family member (father, brother, son, uncle, grandfather, male cousin)
    d. Husband
    e. Wife
    f. Doctor
    g. Nurse
    h. Midwife
    i. Community health worker
    j. Teacher
    k. Religious leader

    l. Traditional healer
    m. Community leader
    n. Internet/Social media
    o. Other, specify: _____

63.1 Please specify the other person (s) you trust for health information?

64. Does your community have health meetings?
    a. Yes
    b. No

65. Do you belong to any community groups?
    a. Yes, specify: _____
    b. No

(IF NO SKIP TO Q.67)

66. If yes, specify which community group

_____

H. SOCIOECONOMIC QUESTIONS

67.	Is your household income the same amount (fixed) every month?	a. Yes
		b. No
		c. Don't know
68.	From where does the primary source of your household income come?	a. Fishing or farming (agriculture)
		b. Daily laborer
		c. Small scale enterprise
		d. Private employment
		e. Formal non-Governmental employment / private sector
		f. Government / civil servant

		g. Other
68.1	Please specify your primary source of income.	
69.	Can you tell me which of the following items you own? **[READ ALL ANSWERS TO RESPONDENTS AND MARK ALL THAT APPLY]**	a. Clock / watch
		b. Radio
		c. Refrigerator
		d. Television
		e. Fixed telephone line
		f. Mobile phone
		g. Bed net
		h. Bicycle
		i. Motorcycle / scooter
		j. Car / Jeep
		k. Generator
		l. Solar panels
		m. Electricity from power company / government
		n. Canoe
		o. Fishing net
70.	In your household, do you have a toilet?	a. Yes b. No (IF NO, SKIP TO Q.70.2)
70.1	In your household, do you have a toilet? If so, what kind of toilet?	c. Flush toilet
		d. Pit toilet / latrine
		e. Manual flush toilet / water-seal with pour
70.2	A. If no, where do you and your family defecate? **[DO NOT READ RESPONSES]**	a. Forest / bush
		b. Beach
		c. Other
70.3	Please specify the place your family defecates. _____	
		a.
		b.
		c.
		d.
		a.
		a.

71.	What is the highest level of education you have completed : **[WRITE OUT GRADE LEVEL: _____]**	a. No school at all b. Completed primary school c. Completed middle school (junior high) d. Completed secondary school e. Completed college / university
7 71.1	What is the last year of education that you have completed (starting from primary level)? _____	
72.	What is your age? **[USE YEAR OF BIRTH IF RESPONDENT DOES NOT KNOW AGE]**	
73.	**[Interviewer to mark without asking]** Primary type of roof:	a. Metal / corrugated iron b. Thatched c. Ceramic tile d. Concrete e. Wood f. Leaf and mud / soil g. Other
7 73.1	Please specify other type of roof. _____	a.
74.	**[Interviewer to mark without asking]** Primary type of floor	b. Tile c. Mud / dirt d. Wood e. Concrete f. Other
7 74.1	Please specify other type of floor.	a.
75.	**[Interviewer to mark without asking]** Gender	b. Male c. Female

Thank you for your participation.

END TIME OF INTERVIEW: _____
RESULT OF INTERVIEW :

COMPLETE : _____ INCOMPLETE: _____ REASON : _____
INTERVIEW NOTES :

10.2. Interview Guide for Focus Group Discussions

Begin interview after introducing yourself, reading the information sheet and the informed consent sheet has been read and signed.

A. GENERAL INTRO QUESTIONS

Thank you once again for taking the time to speak with me today.

As we get started, I'd like to know a little bit more about your community. What can you tell me about your community?
Probe with:

- Primary occupations of people living here
- Any special cultural festivals
- Languages

I understand that there is a river / pond / lake near this village. Can you tell me about how people in your village use this water source?
Probe with:

- Frequency during the day / week
- Activities at the water – bathing, swimming, fetching water, washing
- Seasonality of use? (rainy season / dry season)
- Differences for women / men / girls / boys?

What are the main health concerns people have here?
Probe with:

- Seasonality? (rainy season / dry season)
- Part of the community or the whole community affected?
- History of this health concern (new concern? Been here for a long time?)
- Are these the same concerns for you and your household?

B. QUESTIONS ABOUT SCHISTOSOMIASIS

I understand that there is a disease called schistosomiasis (use local name) in this community. Can you please tell me what you know about this disease?
Probe with:

- Local names (different for girls / women and boys / men)
- How do you get it? (If respondent mentions water, prompt with: what in the water causes disease?)
- Who do you think gets it most? (prompt with girls, boys, women, men)

- Do you know anyone who has schistosomiasis?
- Is it a problem here?

When someone gets infected with schistosomiasis, what happens to them?
Probe with:
- How do they know they are infected?
- Symptoms different for girls and boys? Why?
- Length of time that the symptoms last?

One of the symptoms of schistosomiasis infection is blood in the urine. Can you tell me what people in your community say about this symptom and where it comes from?
Probe with:
- Is it different for boys and girls?
- Cultural explanations
- How long does it last?
- Can it be treated?
- Do the students say something different?

Please describe for me what people do if they experience blood in their urine.
Probe with:
- Health provider – who?
- Traditional healer?
- Any home remedies
- Do nothing at all
- Is this different for boys and girls?
- Do the students do something different?

I'd like to talk about schistosomiasis infection in girls and women specifically. Can you talk about any ways that girls or women may be affected differently than boys with schistosomiasis?
Probe with:
- Symptoms?
- Treatment options?
- Stigma related to symptoms

Have you ever heard of the term – Female Genital Schistosomiasis. Can you tell me what you understand about FGS?
Probe with:
- Symptoms?
- Treatment options?
- Stigma related to symptoms
- Common disease for girls in your school / women in your community?

You have told me about what you know about schistosomiasis, can you tell me where you got your information?
Probe with:
- Government Ministry of Health
- Media (radio, TV, internet)
- NGO or local partner

- School colleague
- Health facility
- (If relevant) Is the source the same for the information on FGS?

C. QUESTIONS ABOUT SCHOOL-BASED MDA

In this next section of questions, I'd like to talk a bit about the distribution of tablets for schistosomiasis at the local school.

Can you tell me about the school-based distribution programme?
Probe with:
- What did you understand about the distribution?
- When did it happen?
- What were people talking about in the community when the distribution took place?
- What were the students talking about in school when the distribution took place?

I'd like us to talk a bit more about the good and bad parts about the schistosomiasis pills (or Praziquantel) to students.

Let's think about the good things first.
Probe with:
- What do you think is good about the treatment?
- How did it help?

Let's do the same for the bad things.
Probe with:
- What do you think is bad about the treatment?
- Do you know anyone who suffered in some way after taking the treatment? What happened?

Let's talk about the pills themselves a bit. Can you tell me about how children react to the pills?
Probe with:
- Difficulty swallowing the tablets? Ways to mitigate choking?
- Did you hear about anyone who didn't take the tablets? Who? Why?

D. PERSONAL EXPERIENCE WITH FGS AND/OR SCHISTOSOMIASIS

In this next group of questions, I'd like to understand a bit more about your own experiences with schistosomiasis.

Has anyone in your household had schistosomiasis or symptoms like it (remember that bloody urine is a main symptom?
Probe with:
- What happened?

- What did you do? Where did you go first? Medical facility? Home remedy? Traditional healer?
- Did this happen to more than one child?
- Was there different treatment for boys and girls? Why / why not?
- Did the treatment work?
- Who made the decision to seek treatment?

Where did you get information about treatment?
Probe with:
- Is this newly available or been available for some time?
- Clinician attitude?
- Free treatment or paid?

What activities are in place to control and prevent schistosomiasis infections in the community?
Probe with:
- Water use
- Do community members / the respondent do anything different now (if so, why?)
- Information

E. COMMUNITY ENGAGEMENT FOR FGS AND/OR SCHISTOSOMIASIS

How can community members support the promotion of diagnosis and treatment for schistosomiasis?
Probe with:
- Specific messages?
- Differences for girls and boys?
- How can fathers, husbands or uncles participate? Mothers, wives and aunties?
- School? Church groups?
- Health facilities?

In order to support prevention for schistosomiasis, the community themselves could help to promote the school-based treatment. Can you talk about the current level of support and cooperation in the community for the school-based distribution?
Probe with:
- How would you improve it?
- What groups or clubs in the school/community would be good ambassadors to teach about schistosomiasis?
- What activities could we do with children/women/men to get them to change their behavior that puts them at risk of schistosomiasis?
- Who should deliver information on schistosomiasis?
- Different materials for girls and boys? Why?

Is there anything you'd like to add?

Thank you for your time!
- Make sure they know where to get further information.

Please probe continually throughout with things like:

- Why did you say that?
- What do you mean by that?
- Could you tell me a bit more?
- Can you say what you mean by that?
- So then what happened?
- Oh, that makes sense…
- That's interesting…

11. Appendix C – Research Ethics Approvals

10/09/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Lettre d'approbation administrative | Letter of administrative approval

Numéro de dossier / Ethics File Number	H-08-21-7345
Titre du projet / Project Title	"The Female Genital Schistosomiasis Accelerated Scale Together (FAST) Package transition to scale project: Improving women's health by reducing morbidity from FGS in Ghana and Madagascar
Type de projet / Project Type	Recherche de professeur / Professor's research project
CÉR primaire / Primary REB	Soins continus Bruyère / Bruyère Continuing Care
Statut du projet / Project Status	Approuvé / Approved
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	10/09/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	28/01/2022

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Alison KRENTEL	Département d'épidémiologie et santé publique / Department of Epidemiology and Public Health	Chercheur Principal / Principal Investigator
Kruti PATEL	Département d'épidémiologie et santé publique / Department of Epidemiology and Public Health	Étudiant-chercheur / Student-researcher
Kazeem AROGUNDADE	Bruyere Research Institute	Coordonnateur de recherche / Research Coordinator

Conditions spéciales ou commentaires / Special conditions or comments:

Bruyere REB Protocol # M16-20-061
University of Health and Allied Sciences REB Protocol # UHAS-REC A.5 [4] 20-21
Ministry of Health Madagascar (Comite d'Evaluation ethique
pour la recherche biomedicale): 01/21MSANP/SG/INSPC/CEER
Ghana Health Service ERC: GHS-ERC 003/04/21

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10/09/2021

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

L'Université d'Ottawa a signé une Entente, conforme aux exigences de la plus récente version de l'EPTC et tout autre règlement ou législation applicable, permettant au CÉR ci-haut nommé d'être désigné comme CÉR primaire pour les projets de recherche où

1) les activités principales de recherche sont menées sous l'autorité ou sous les auspices de l'établissement lié au CÉR primaire et

2) Une partie du projet est également réalisé sous l'autorité ou sous les auspices de l'Université d'Ottawa.

Cette lettre confirme que l'Université d'Ottawa a autorisé que le CÉR primaire soit le CÉR officiel pour l'évaluation et la supervision de ce projet de recherche. Ceci n'est pas une approbation éthique.

Afin de nous aider à garder votre dossier à jour, veuillez soumettre une copie de toutes demandes de modification, renouvellement d'approbation éthique etc. soumis à et approuvé par le CÉR primaire dès qu'elles sont disponibles.

Cette approbation administrative est valide pour la durée indiquée ci-haut et est sujette aux conditions énumérées dans la section intitulée « Conditions spéciales ou commentaires ».

The University of Ottawa has signed an Agreement, compliant with current TCPS guidelines and any other applicable guidelines or legislation regarding multisite review, allowing the REB named above to serve as Board of Record (BoR) for research projects where

1) the main research activities are conducted within the auspices or jurisdiction of the BoR's institution and

2) parts of the project are also conducted under the jurisdiction or auspices of the University of Ottawa.

This letter confirms that the University of Ottawa has authorized the REB named above to serve as Board of Record for the review and oversight of this research project. This is not an REB approval.

In order to help us keep your file up to date, please submit a copy of all amendment requests, project renewals or any other changes submitted to and approved by the BoR, as they become available.

Administrative approval is valid for the period indicated above and is subject to the conditions listed in the section entitled «Special conditions or comments».

Catherine PAQUET
Directeur / Director
Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board**

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27/01/2022

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Lettre d'approbation administrative | Letter of administrative approval

Numéro de dossier / Ethics File Number	H-08-21-7345
Titre du projet / Project Title	"The Female Genital Schistosomiasis Accelerated Scale Together (FAST) Package transition to scale project: Improving women's health by reducing morbidity from FGS in Ghana and Madagascar
Type de projet / Project Type	Recherche de professeur / Professor's research project
CÉR primaire / Primary REB	Soins continus Bruyère / Bruyère Continuing Care
Statut du projet / Project Status	Renouvelé /
Date d'approbation (jj/mm/aaaa) / Approval Date (dd/mm/yyyy)	Renewed 10/09/2021
Date d'expiration (jj/mm/aaaa) / Expiry Date (dd/mm/yyyy)	29/01/2023

Équipe de recherche / Research Team

Chercheur / Researcher	Affiliation	Role
Alison KRENTEL	Département d'épidémiologie et santé publique / Department of Epidemiology and Public Health	Chercheur Principal / Principal Investigator
Kruti PATEL	Département d'épidémiologie et santé publique / Department of Epidemiology and Public Health	Étudiant-chercheur / Student-researcher
Kazeem AROGUNDADE	Bruyere Research Institute	Coordonnateur de recherche / Research Coordinator
Moussa SANGARE	École interdisciplinaire des sciences de la santé / Interdisciplinary School of Health Sciences	Étudiant-chercheur / Student-researcher

Conditions spéciales ou commentaires / Special conditions or comments:

The uOttawa expiry date is set in accordance with the one from the Bruyère-REB.

27/01/2022

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

L'Université d'Ottawa a signé une Entente, conforme aux exigences de la plus récente version de l'EPTC et tout autre règlement ou législation applicable, permettant au CÉR ci-haut nommé d'être désigné comme CÉR primaire pour les projets de recherche où

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Cette lettre confirme que l'Université d'Ottawa a autorisé que le CÉR primaire soit le CÉR officiel pour l'évaluation et la supervision de ce projet de recherche. Ceci n'est pas une approbation éthique.

Afin de nous aider à garder votre dossier à jour, veuillez soumettre une copie de toutes demandes de modification, renouvellement d'approbation éthique etc. soumis à et approuvé par le CÉR primaire dès qu'elles sont disponibles.

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In order to help us keep your file up to date, please submit a copy of all amendment requests, project renewals or any other changes submitted to and approved by the BoR, as they become available.

Administrative approval is valid for the period indicated above and is subject to the conditions listed in the section entitled «Special conditions or comments».

Safaa LAMHOUJEB
Coordonnateur de l'éthique / Ethics Coordinator
Pour/For **Daniel LAGAREC** Président(e) du/ Chair of the **Comité d'éthique de la recherche en sciences de la santé et sciences / Health Sciences and Sciences Research Ethics Board**

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Monday, July 5, 2021

Dr. Alison Krentel

Re: "The Female Genital Schistosomiasis Accelerated Scale Together (FAST) package transition to scale project: Improving women's health by reducing morbidity from Female Genital Schistosomiasis (FGS) in Ghana and Madagascar" (Bruyère REB Protocol # M16-20-061)

Re: Bruyere Project # M16-20-061 - FAST Package

Dear Dr. Krentel,

This letter is to confirm that the Bruyere REB approves the role and participation of Ms. Kruti Patel on the research team and in the subset analysis for the referenced project.

Sincerely,

Gordon DuVal, SJD
Chair, Research Ethics Board
Bruyère Continuing Care
gduval@bruyere.org

www.bruyere.org

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uOttawa

January 29, 2020

Dr. Alison Krentel

Re: "The Female Genital Schistosomiasis Accelerated Scale Together (FAST) package transition to scale project:" (Bruyère REB Protocol # M16-20-061)

Final Approval

Dear Dr. Krentel,

The Bruyère Continuing Care Research Ethics Board (REB) is pleased to give you ethical approval for the above noted study for the period of January 29, 2021 to January 29, 2022 **under the condition that research will only take place in Ghana until the ethical clearance certificate is received in Madagascar.**

The following documents have been approved:

- Ethics application;
- Information and consent form for baseline and endline data collection (surveys – teacher and community), version date: Nov. 17, 2020;
- Information and consent form for baseline and endline data collection (in depth interviews);
- cInformation and consent form for baseline and end-line data collection (focus group discussion): Nov. 17, 2020;
- Survey for community members – Baseline and End-line v.2;
- E)Survey for teachers – Baseline and Endline v.1;
- Recruitment script for in-depth interview;
- In-Depth Interview Guide for endline data collection (Health Care Providers);
- In-Depth Interview Guide for endline data collection (Parents);
- In-Depth Interview Guide for baseline and endline data collection (District Medical Officer);
- In-Depth Interview Guide for baseline and endline data collection (Teachers);
- Recruitment script for In-depth Interview;
- Recruitment script for Focus Group Discussion;
- Focus Group Discussion Guide for baseline and end-line data collection;
- Budget;

The following document has been acknowledged:

- Ethical clearance certificate for the Fast package project in Ghana;
- Pledges of confidentially

The Bruyère Continuing Care REB complies with the membership requirements and operates in compliance with the Tri-Council Policy Statement 2: Ethics Conduct for Research Involving Humans; the International Conference on Harmonization - Good Clinical Practice: Consolidated Guideline; the provisions of the Personal Health Information Protection Act 2004; and the Food and Drug Act of Health Canada and its applicable Regulations.

Please be advised that any complaints made by participants must be reported to the REB. All changes to the approved protocol must be approved by the REB.

Please complete an Annual Project Update/Notification of Termination form 6 weeks prior to the approval end date as noted above.

We wish you the best of luck with your research endeavors.

Sincerely,

Gordon DuVal, SJD
Chair, Bruyère Research Ethics Board
Bruyère Continuing Care
gduval@bruyere.org

www.bruyere.org

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Monday, July 05, 2021

Dr. Alison Krentel

Re: "The Female Genital Schistosomiasis Accelerated Scale Together (FAST) Package Transition to Scale Project: Improving Women's Health by Reducing Morbidity from Female Genital Schistosomiasis (FGS) in Ghana and Madagascar." (Bruyère REB Protocol #M16-20-061)

Amendment Approval

Amendment dated: June 24, 2021

Dear Dr. Krentel,

Thank you for submitting an amendment request for the above named project.

The following has been approved:

- ✓ Survey for Community Members – Baseline and End-line v.2;
- ✓ Survey for teachers – Baseline and Endline v.1;
- ✓ Revised BREB

The following has been acknowledged:

- ✓ Ghana Health Service Ethics Review Committee Approval

The information received has been reviewed and I hereby give approval on behalf of the REB.

Sincerely,

Gordon DuVal, SJD
Chair, Research Ethics Board
Bruyère Continuing Care
gduval@bruyere.org