**MASTERTHESIS**

# Dimensions of awareness of Female Genital Schistosomiasis among women and health care workers in rural Madagascar

## - A mixed methods approach

For the attainment of the academic degree

M.Sc. Health Sciences


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# Abbreviations

| | |
|---|---|
| BNITM | Bernhard Nocht Institute for Tropical Medicine |
| CC | Cervical cancer |
| CI | Confidence interval |
| CSB | *Centre de santé de base* |
| DALYs | Disability-adjusted life years |
| ESPEN | Expanded Special Project for Elimination of Neglected Tropical Diseases |
| FGD | Focus group discussion |
| FGS | Female Genital Schistosomiasis |
| HCW | Healthcare worker |
| HIV | Human Immunodeficiency Virus |
| IQR | Interquartile range |
| M | Mean |
| MC | Multiple choice |
| MDG | Millennium development goal |
| ME | Median |
| NTD | Neglected tropical disease |
| PCR | Polymerase chain reaction |
| PHCCs | Primary health care clinics |
| POC-CCA | Point-of-care circulating cathodic antigen |
| PZQ | Praziquantel |
| SD | Standard deviation |
| SDG | Sustainable development goal |
| SDI | Socio-Demographic Index |
| STI | Sexually transmitted infections |
| TB | Tuberculosis |
| UHC | Universal Health Coverage |
| UN | United Nations |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| WASH | Water, sanitation and hygiene |
| WHO | World Health Organization |

# Abstract

**Background** Water-borne infections with *S. haematobium* are endemic in tropical regions. Chronic infection can cause Female Genital Schistosomiasis (FGS), possibly leading to severe gynecological conditions, including infertility. However, awareness of FGS prevention, diagnosis and treatment is limited. This study aims to identify and investigate dimensions of FGS awareness among women and healthcare workers (HCW) in the Boeny region of Madagascar.

**Methods** Mixed methods data collection involved cross-sectional survey of adult women (n=694), HCWs (n=93), and focus group discussions (Women; n=24, HCW; n=29). Quantitative results were described including proportions and 95% confidence intervals (CI) and measures of central tendency. Additionally, a FGS knowledge score was calculated. Qualitative analysis was conducted using a framework analysis approach. Triangulation of quantitative and qualitative data is performed to determine the dimensions of awareness in the region.

**Results** Results show that 11.2% (CI [9.0–13.8%]) of women and 53.2% (CI [42.6–63.6%]) of HCW had heard of FGS. Among these, 34.6% (CI [24.1–46.2%]) women and 42.0% (CI [28.1–56.8%]) HCW were unaware of its characteristic gynecological symptoms. No significant differences were seen in the overall low knowledge score among HCW and women. In addition to confirming limited knowledge of the disease and treatment, qualitative analysis highlights influence on FGS awareness in the respondents' daily life. While some women are aware that contact with infested water carries a risk of infection, their livelihoods depend on rice-farming, making preventive behaviors challenging and possibly leading to resignation. Although HCWs demonstrated proportionally more FGS awareness, uncertainties about treatment were observed. The triangulation determined four key dimensions of awareness in the region: Infrastructure, delivery of information, health behavior, and socio-structural factors.

**Conclusion** Overall, results show low levels of FGS awareness in a representative sample of Madagascar. Findings align with existing literature describing underreporting and undertreatment of FGS. Identifying gaps, barriers and facilitators in FGS awareness can inform the design of targeted FGS awareness campaigns to improve the health of women affected in Madagascar.



**Keywords** Female Genital Schistosomiasis, Global Health, Neglected Tropical Diseases

# 1 Introduction

Neglected tropical diseases (NTDs) are a diverse group of diseases tightly interrelated with poverty and inequality, affecting more than one billion people worldwide (1). NTDs present a serious public health burden in already impoverished communities with poor access to health care, while affecting women and girls disproportionally due to lower education and social status (2,3). Despite the high morbidity caused by NTDs, awareness on the global health agenda and in the local communities is often drowned out by diseases like the Human Immunodeficiency Virus (HIV), malaria or tuberculosis (TB) (4). To facilitate awareness of NTDs, a holistic approach with engagement of the public is vital for the success of equitable, morbidity reducing and sustainable interventions (5,6).

One of the five most prevalent NTDs are water-borne infections with the trematode *S. haematobium*, causing the NTD schistosomiasis. Worldwide, over 200 million people are affected by schistosomiases with over 200,000 deaths annually. Over 95 percent of the worldwide burden of this disease can be found in Sub-Saharan Africa, affecting impoverished communities where frequent contact to water bodies is common (7–10). While *S. haematobium* is a known risk factor for urinary bladder cancer, women and girls are at risk for chronic infection with the helminth, causing Female Genital Schistosomiasis (FGS). Possibly, this can lead to severe gynecological conditions, including infertility and presents a risk factor for cervical cancer (CC) (11). Worldwide, up to an estimated 50 million women and girls are suffering from FGS (12). Nevertheless, adequate assessments of the prevalence as well as knowledge of the disease are missing. Misdiagnosis and mistreatment of the disease as sexual transmitted infections due to lack in training and awareness is common (13). Overall, awareness of FGS, disease prevention as well as equitable access to diagnosis and treatment is limited even in highly endemic settings, making this disease an especially neglected disease among the group of NTDs.

To archive the ambitious goal to end the epidemic of NTDs set in the Sustainable Development Goals (SDG) and furthermore to eliminate schistosomiasis as a public health problem, as stated in the 2030 NTD roadmap, accelerated actions are required (1,9,14,15). The time to contribute to equitable prevention, healthcare access and treatment of FGS is now.

## 1.1 Problem Definition

The rural Boeny region in Madagascar is a highly endemic setting for *S. haematobium.* Despite of this, adequate access to FGS diagnostic and care in primary health care settings is not established and even on tertiary level of care, policies and guidelines on diagnosis and treatment are missing. Key populations are the recipients of FGS diagnosis and care in the general population as well as the healthcare workers (HCWs) of different professions offering treatment. The overall knowledge of the disease among both key populations is hypothesized to be low. Additionally, reliable data on the awareness and prevalence of FGS are not available in the region. Therefore, a targeted assessment of the knowledge and the determination of barriers and facilitators of awareness are needed in the region. Building a baseline to better understand the challenges of improving knowledge and access to healthcare for the disease is vital for future projects in the region.

## 1.2 Research aim and objectives

Building on a small existing literature background, the aim of this master thesis is to investigate FGS awareness among women and health care workers in the rural Boeny region of Madagascar. Furthermore, this thesis aims to investigate the ways in which awareness can influence FGS treatment and diagnosis in the region. Specifically, the objectives, evaluated in a high prevalent area for *S. haematobium* and a consequently high estimated burden of FGS, are:

- To describe the extent of awareness of FGS and its diagnosis and treatment among health care workers in rural Madagascar
- To determine the level of FGS awareness among women in the rural communities
- To identify mechanisms through which awareness and related barriers and facilitators which can influence FGS treatment and diagnosis uptake among women in the Boeny region of Madagascar

To fulfill these objectives, qualitative data from focus group discussions (FGDs) and quantitative data from structured questionnaires are analyzed to provide a multidimensional assessment of the awareness of the disease in the region. This approach will be led by the overall research questions:

(i) "What are the levels of FGS awareness among women of the community and health care workers in rural Madagascar?",

(ii) "How does awareness relate to FGS diagnosis and treatment in rural Madagascar?".

## 1.3 Structural Arrangement

The content of this thesis is structured in overall eight chapters. Following the introduction an in-depth display of the background of the thematic complex around NTDs, FGS in Madagascar and the structure of the FIRM-UP project. Afterwards the methodological aspects of this thesis are contextualized, including eligibility criteria and the structure of the mixed method approach and description of the quantitative as well as the qualitative analysis. Subsequently, the result section is divided into the descriptive results of the awareness survey, the results of the framework analysis and a triangulation analysis of the quantitative and qualitative results to explore the influence of awareness on diagnosis and treatment of FGS.

The ensuing self-critical discussion displays the attained results in relation to the current literature and afterwards the limitations of this thesis are clarified. In conclusion, recommendations for action and future research are given and completed by a summarizing conclusion.

# 2 Background

This section thematizes the status of the literature on important key concepts around the disease class of neglected tropical diseases, followed by a general view on epidemiology and pathology of human schistosomiasis. Afterwards, FGS and its specifications and status of research on awareness of the disease is displayed, rounded off with a focused view on the particularities of schistosomiasis in Madagascar and existing epidemiological data of the disease in the country. Lastly, the FIRM-UP project and its trial structure is displayed.

## 2.1 Neglected tropical diseases

NTDs are a group of twenty diseases, defined by the WHO, inducing morbidity and social and economic hardship for more than a billion people worldwide (15). These diseases often disproportionately affect vulnerable populations, such as women and children, promoting a double burden of disease and social marginalization in these groups (16). Vulnerability and barriers in access to healthcare are elevated through gender, socio-economic status and other determinants of health (17). The most powerful tool in the fight against NTDs is the implementation of prevention and control mechanism into primary health care settings, in line with the WHOs Universal Health Coverage (UHC) goals. Through the UHC, the WHO aims to set guidelines to provide the full spectrum of essential health care services in a community based primary health care approach (18). The resolution of the UHC includes a wide set of essential health care services ranging from health promotion to prevention of diseases such as NTDs over the provision of adequate treatment and rehabilitation to the provision of palliative care (19).

The relevance of NTDs as the cause of disabilities in countries, categorized by a low Socio-Demographic Index (SDI), is increasing in recent years. In 2019, NTDs and malaria were the fourth biggest cause of disability-adjusted-life years (DALYs) for both sexes and across all ages in low SDI countries right after maternal or neonatal conditions and respiratory infections such as TB or enteric infections (20). NTDs are divided in four main groups (figure 1): Parasitic helminth diseases, parasitic protozoan diseases, viral diseases including other diseases such as snakebites, and bacterial or fungal diseases.

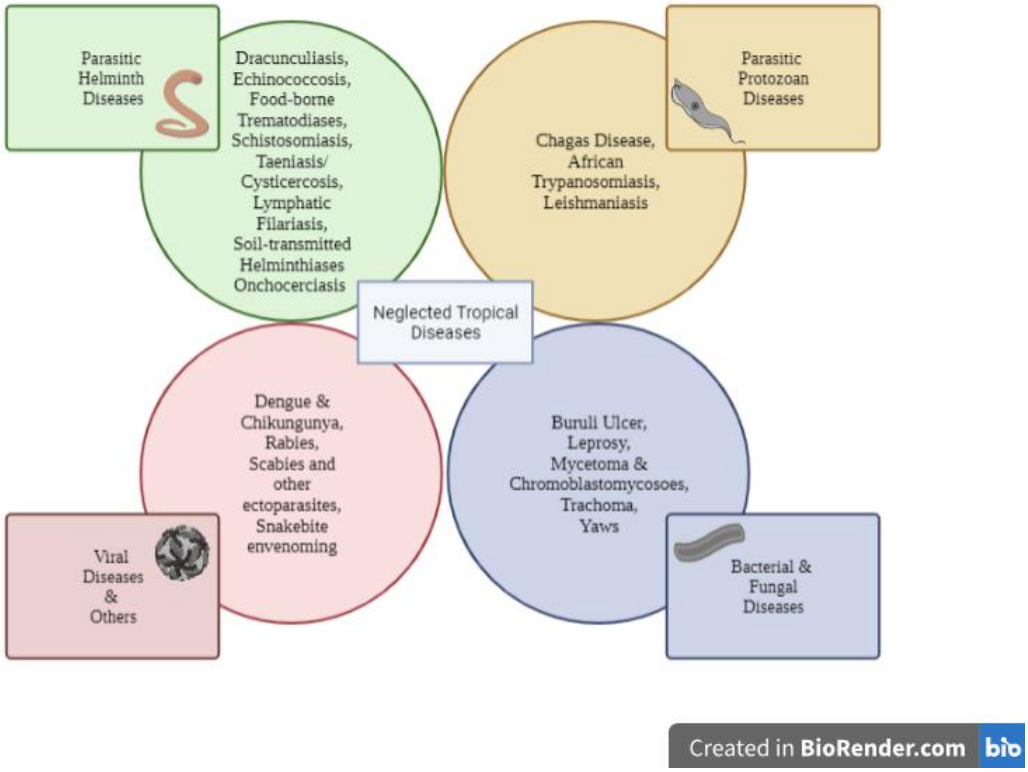


**Figure 1** **Classification of neglected tropical diseases**
Displayed are the four main cluster of NTDs: Parasitic helminth diseases (green), parasitic protozoan diseases (yellow), viral disease and others including snakebites (red) and bacterial and fungal diseases (purple). (Own visualisation, created with BioRender.com)

With nearly 40 percent of the overall global cases of NTDs, the major burden of the diseases can be observed in the African region. All 47 countries in the African region are endemic for at least one NTD. Furthermore, 78 percent of the African countries present co-endemic for at least five of the diseases (21).

The movement to construct a framework around NTDs started at the beginning of the millennium with the rebranding of the "other disease" category of the Millennium Development Goals (MDGs) of the United Nations (UN). The rebranding of the disease from the MDG was a combined effort of scientists to put an accent onto the neglect of these diseases to facilitate research and accelerate treatment (22). In 2005 a first proposed list of thirteen diseases was published in *PLOS Medicine* and later expanded by the WHO in the same year (23). This medical group of diseases was based on the characteristics of the pathogens as diseases highly prevalent among the poor and their pervasiveness within these populations.

Another contributing factor in the clustering was the geographic location of these targeted diseases as well as a co-endemicity among several of the pathogens (24). Despite the clinical diversity, the grouping provided a starting point for a targeted and aligned strategy to combat these diseases (25). After being neglected in the MDGs, the end of the epidemic of NTDs by 2030 is one of the main targets of the SDG. The overall goal of SDG 3 is to ensure healthy lives and promote well-being for everybody at all ages, further defined in the indicator 3.3.5 as the number of people requiring interventions against NTDs (26). The introduction of the SDGs provided official indicators to measure progress in the fight against NTDs for the first time.

In line with SDG 2 in 2020, the WHO published a new roadmap for the elimination of NTDs between 2021 and 2030, which aims to strengthen programmatic response against NTDs. For example one of the most ambitious goals of the current roadmap is to eliminate the parasitic disease schistosomiasis in all 78 countries where it is prevalent today by 2030 (1). In many cases the offered resources to fight against these diseases are not meeting the existing need, even though interventions for the elimination of NTDs hold one of the most efficient investments in global health policies in comparison to other diseases. Ending the epidemic of NTDs is estimated to give an estimated net benefit of 25 US dollar in health care costs for every US dollar that is invested in measures like preventive treatment of NTDs (1). Common key challenges for NTDs are the lack of availability of drugs, underreporting of cases and difficulties in the accessibility of specialized, adapted diagnostic tools in endemic countries. Resource distribution involves several stakeholders on international and local level such as manufacturers that support programmes through donations and additional research on new possible treatments and diagnostic tools for NTDs (27).

Another major challenge experienced in the past and during the upcoming decade in the control and prevention of NTDs is the lack of sufficient and reliable data. To further promote the acquisition of reliable data and technical assistance for national governments, the Expanded Special Project for Elimination of Neglected Tropical Diseases (ESPEN) was launched in April 2016 with the goal to accelerate the elimination of the five most endemic NTDs that can be addressed by preventive chemotherapy, namely lymphatic filariasis, onchocerciasis, schistosomiasis, soil-transmitted helminthiasis and trachoma (28). Initially funded until 2020 to contribute to alleviation of poverty and improved quality of life in the African region (28), the ESPEN program was

extended until 2025. One of the main new introductions with the 2021–2025 ESPEN period is the ESPEN data portal to further improve the scarcity of data surrounding NTDs.

## 2.2 Human schistosomiasis

### 2.2.1 Disease

Human schistosomiasis is a NTD caused by blood flukes with a zoonotic life cycle. Six different *Schistosoma* spp. are known to be pathogenic for humans. Global distribution is dominated by three main species: *Schistosoma mansoni*, *Schistosoma japonicum* and *Schistosoma haematobium.* Intermediate snail hosts for the different *Schistosoma* spp. are the genus *Biomphalaria*, *Bulinus* and *Oncomelania* spp. found in fresh water bodies (7). The disease schistosomiasis leads to a chronic process of inflammation induced by deposited, partly calcified *Schistosoma* eggs , causing implications on an individual's metabolism with acute and chronic consequences (29).

Infection with *S. mansoni* or *S. japonicum* can produce gastrointestinal symptoms and severe clinical consequences, such as multiple organ lesions in liver or spleen (30) as these parasites reside in the mesenteric veins of the bowel. Egg excretion of the parasites is found in the stool of the host. Infection with *S. haematobium* generates urogenital symptoms as the parasites are hosted by the venous plexus of the bladder. Egg excretion can be found in the urine of the affected individuals, with deposition of eggs in the cervix or prostate. Urogenital schistosomiasis is a known risk factor for prostate or bladder cancer (7). Worldwide, schistosomiasis was accountable for 1.64 million DALYs in 2019. Annually, the disease costs more than 200,000 lives (8). In over 250 million schistosomiasis infections, Africa countries carry by far the highest burden of the disease with 201.5 million infections in 2019 (7,31).

Low- and middle-income countries (LMIC) present higher DALYs for schistosomiasis in comparison to high income countries, affecting impoverished countries with populations unable to avoid infested water or individuals that are unaware of the transmission pathways of the disease (32). Focal distribution in close relationship to environmental risk factors such as living in close proximity to an open water body have been determined as risk factors for *Schistosoma* infections (7).

An increased burden of the disease can be seen in Sub-Saharan African countries with the majority of affected countries in the bottom half of the SDI (31). Most of the countries that are endemic for schistosomiasis are also characterized by lacking water, sanitation and hygiene (WASH) infrastructure generating elevated risk of contact with contaminated open water sources such as rivers or lakes either during domestic, recreational or professional activities (7,12,33).

The numbers included in the global burden of disease report, which states the DALYs for each disease, represent solely the official reported and documented numbers of schistosomiasis cases. Therefore, the true burden of disease is likely to be higher, as in general for NTDs under- and misreporting presents a major problem in management and control. The WHO estimated that for the 1.7 million DALYs reported in 2002 , the true burden of the disease is likely to be around 4.5 million DALYs (7). In the frame of the NTD roadmap, schistosomiasis is listed as targeted for elimination as a public health problem. In 2020, 26 countries or 33 percent of the endemic countries were listed as validated for elimination of schistosomiasis as a public health problem, which is defined as less than 1 percent of heavy intensity *Schistosoma* infections within the general population (1).

### 2.2.2 Diagnosis

Diagnosis of human schistosomiasis in endemic areas can be conducted through several testing methods. These test strategies can include parasitological diagnosis like the Kato-Katz (34) microscopy identification of eggs in stool for intestinal schistosomiasis or the microscopy of urine for urogenital schistosomiasis (35). Methods involving microscopy are assessing the count of eggs per 10ml of urine or one gram of stool. Microscopy is defined by the WHO as the gold standard of diagnosis. These methods are showing a 100 percent specificity but a rather low test sensitivity (7).

Another diagnostic tool not on the list of WHO pre-qualified diagnostics is the Point-of-Care Circulating Cathodic Antigen (POC-CCA) test for *S. mansoni*, using urine as biological specimen. The test assesses the presence of circulating cathodic antigen, which is released by adult parasites into the blood and subsequently into the urine. The lateral flow cassette assay provides good usability in field settings, even though the POC-CCA test can be distorted by other cross infections with different helminthic species and common trace readings need to be considered. High specificity and sensitivity

can be seen in the analysis of stool, blood, or urine for of *Schistosoma* species via polymerase chain reaction (PCR). This method requires extensive laboratory equipment and the quality of the results might be influenced by the quality and storage of the samples (7,36).

### 2.2.3 Treatment

Treatment of schistosomiasis and control measures of the disease are based on the drug Praziquantel (PZQ). PZQ is used for administration in individual treatment or in mass drug administration (MDA) campaigns as prophylactic chemotherapy. The main target group of MDA campaigns are school-aged children, therefore excluding adults, pregnant women, and children under five from the treatment scheme. Although the WHO is recommending the treatment of pregnant women since 2018, they are in practice still excluded due to a lack of guidelines adaptations in endemic countries (37). Pregnant women, adults, and children under five suffer from schistosomiasis induced morbidities. Excluding these groups from treatment induces a cascade of health implication and might facilitate the infection with other diseases such as HIV (38).

Though PZQ is the preferred treatment for schistosomiasis, it is ineffective against immature stages of the parasite, representing the main reason for high variations of cure rates. PZQ shows overall rare side effects with cure rates, that can range from 60-95 percent (7). Drug resistant strains of the parasite are hypothesized to be a possible explanation for additional variation in cure rates, even though currently no data from isolated resistant natural strains is available to support this hypothesis (39).

In addition, the drug is not preventing reinfections. Epidemiology and transmission pathways of schistosomiasis are constantly evolving with emerging hybrid species for example between the zoonotic *S. bovis* and the human *S. haematobium* or *S. mattheei* and *S. haematobium*, opening the plausibility for new zoonotic transmission routes (40,41). Hybrids can play an important role in establishing endemicity of the parasite in novel areas, as lately seen with the developing endemicity of *S. bovis* and *S. haematobium* hybrids in Corsica, France (42,43).

### 2.2.4 Female Genital Schistosomiasis

Prolonged chronic infection with *S. haematobium* can cause FGS (44). Chronic urogenital schistosomiasis in the form of FGS is likely to increase the susceptibility for infection with HIV and to elevate the risk for CC (45). Clinical symptoms of FGS can include vaginal bleeding, itching, vaginal discharge, or pain during sexual intercourse. Left untreated, the condition can lead to infertility and miscarriages (12).

An estimated 40 to 56 million women and girls are affected by the condition and impacted by physical as well as psychological consequences due to stigma and infertility (12). While the global burden of disease report includes DALYs for overall schistosomiasis, no DALYs are available for the condition of FGS, making it a neglected condition among the neglected diseases. First epidemiological evaluations such as in Cameroon were demonstrating 58.6 percent positivity of FGS in a *S. haematobium* endemic area (46).

Figure 2 is describing the lifecycle of *S. haematobium* including the chronic manifestation of FGS in three infection stages including migratory, acute, and chronic infection. A person acquires the parasitic cercariae through contact with an infested freshwater body, where free swimming cercariae penetrate the skin and enter the body. Once inside the human body, the cercariae lose their tails and become schistosomula which circulate within the bloodstream of the body. The schistosomula migrate through the portal vein into the liver, where they mature into adults and mate (47). Paired, the adult parasite migrates through the venous plexus and anastomose blood vessels into the bladder and cervix, where the eggs are deposited. Eggs in the female genital tract can be found in the fallopian tubes and the vagina as well as the cervix itself (48). In the active stage of the disease, intensive tissue inflammation through immune reaction and increased vascularity with live eggs is characteristically for FGS. In the chronic state of the infection, sandy patches with clusters of calcified eggs are the cause of inflammation and scarring instead of the alive parasite.

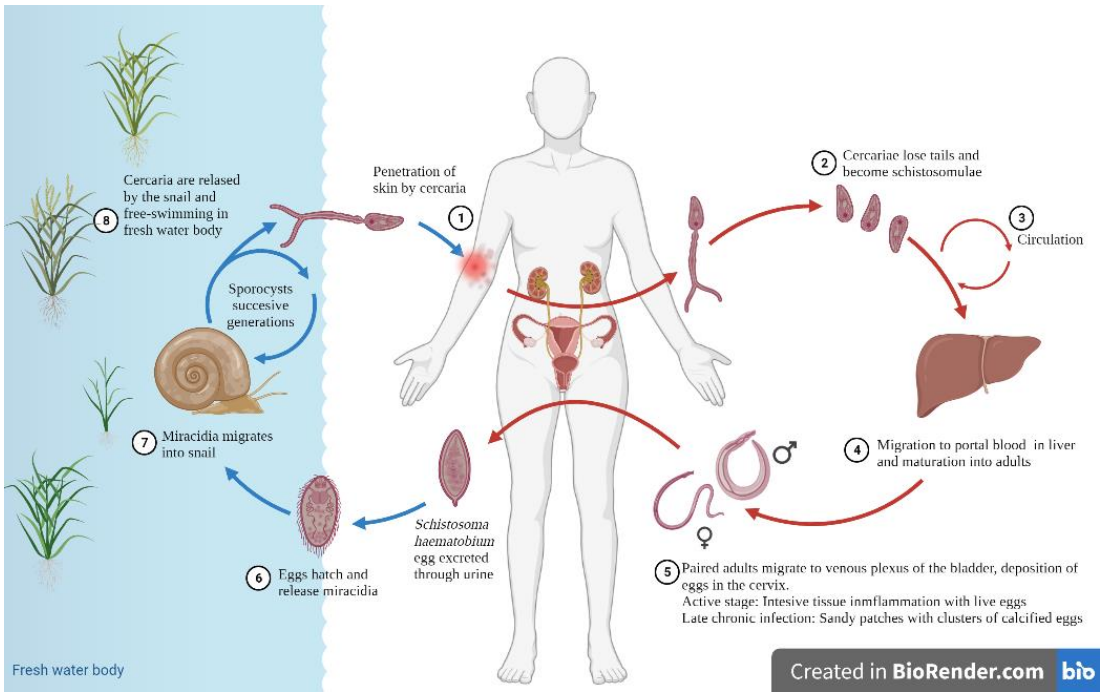


**Figure** *2* **Lifecycle *S.haematobium,***

Lifecycle of *S. haematobium* in the female body, from (1) entering the body through the skin, (2) loosing tails and becoming schistosomulae, (3) circulation in the body, (4) migration through the portal blood into the liver and maturation, (5) Pairing and migration to venous plexus of the bladder and deposition of eggs, (6) leaving the body though urine, (7) hatching and entering intermediate host and (8) free swimming cercaria in fresh water body.
Own visualisation, adapted from "Schistosoma mansoni infection cycle", by BioRender.com (2022). Retrieved from https://app.biorender.com/biorender-templates

The diagnosis of the disease is challenging. In contrast to the detection of the presence of *S. haematobium* in urine, which is not applicable for the diagnosis of FGS due to the possibility that a patient with a negative urine sample can still have a gynaecological manifestation of the disease. FGS is mostly diagnosed by visual inspection of the cervix via colposcopy, the gold standard of diagnosis. During colposcopy, a magnifying binocular and illuminating device is used to inspect the cervix through an inserted speculum (49), checking for visual signs of FGS. These four signature lesions of FGS are depicted in Figure 3 showing abnormal blood vessels (a), rubbery papules (b) , homogenous sandy patches (c) and in grainy sandy patches (d) (13).

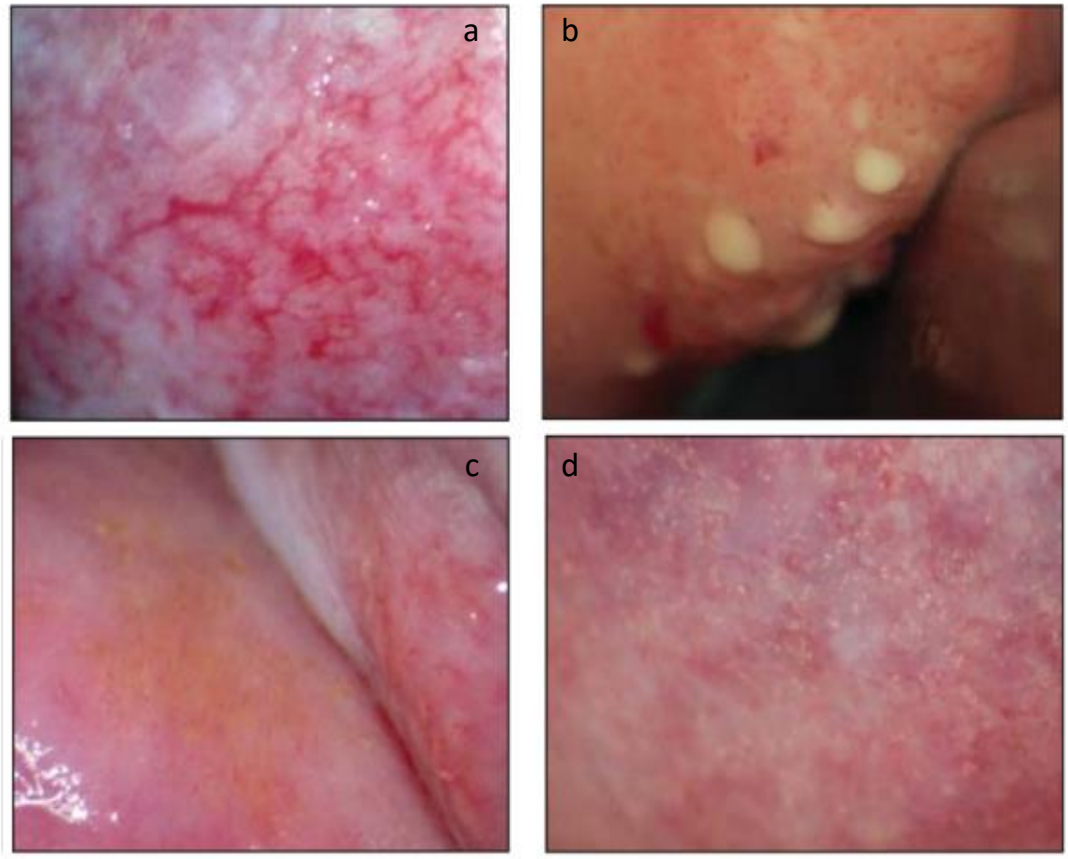


**Figure 3** **Signature FGS lesions on the cervix**

Lesions caused by FGS on the cervix, pictured during colposcopy. Displayed are abnormal blood vessels (a), rubbery papules (b), homogenous sandy patches (c) and grainy sandy patches (d). World Health Organization. FEMALE GENITAL SCHISTOSOMIASIS A POCKET ATLAS FOR CLINICAL HEALTH-CARE PROFESSIONALS [Internet]. Genève: Organisation mondiale de la Santé; 2018 [cited 2022 Aug 28]. Available from: https://apps.who.int/iris/handle/10665/260289

Other more invasive diagnostic methods for FGS, such as biopsy of suspected lesions, do present a higher likelihood for cross infections. Pathogens entering through the open biopsy wounds, present a risk for affected women and might require additional laboratory and diagnostic capacities. Therefore, these methods of diagnosis for FGS are not as applicable as colposcopy, nevertheless colposcopy presents a set of challenges in implementation especially on primary health care level (50). Due to these challenges, alternative solutions such as mobile visual inspection devices in combination with a phone are currently in the experimental phase of development and might be a future diagnostic tool with improved accessibility as well as usability. The introduction of these mobile tool could be a possibility to solve the challenges of reliability

of electricity source and might eliminate the problem of interpretation of the screening outcome in primary health care settings (51,52).

The disease does not only affect physical and mental health, but has also a significant impact on labor productivity as a result of disease-associated decreased ability to perform physical exercise and can therefore act as an additional driver for poverty (7,53). FGS has a direct impact on the health system both through immediate and long-term health consequences, such as cancer and higher susceptibility to other chronic illnesses like HIV. These chronic and long-term conditions do create a multiple burden of disease, especially in low- and middle-income countries, as the health systems in these countries are often designed with a short-term vision in mind. Long-term consequences of FGS such as CC presenting the leading cause of female cancer death in Sub-Saharan Africa and 24.55 percent of global CC mortality (54). In addition, FGS is associated with stigma. For example the disease is commonly misdiagnosed as a sexually transmitted infection (STI) and might result in infertility, which can induce psychological strain on already marginalized populations (12,55). In addition to this psychological strain, misdiagnosis as STI leads to an unnecessary administration of antibiotics, facilitating the risk for future antimicrobial resistance further impacting the health system.

### 2.2.5 Awareness on Female Genital Schistosomiasis

Awareness represents the 6$^{th}$ dimension added by Saurman (2015) to the framework of access to health care by Penchansky & Thomas (1981), which previously included availability, accessibility, accommodation, affordability and acceptability as defining dimensions of access to health care (56,57).

Since the past decade the number of preventive, diagnostic and treatment guidelines as well as the policies on FGS, for example by the WHO as well as the Joint United Nations Programme on HIV/AIDS (UNAIDS), are increasing (13,58). Nevertheless, only a small percentage of the women suspected to suffer from FGS are receiving a clinical consultation for the diseases (46). Another contributor to the low detection rate of FGS is that the knowledge of urogenital schistosomiasis in highly endemic areas is relatively good but, given the scarce detection of the female genital manifestation awareness on FGS is hypothesized to show significant gaps.

Awareness is crucial to achieve community participation and adherence to treatment, prevention, and control measures against FGS (12). The lack of FGS awareness can not only be seen in the general population as described, by Mazigo et. al. (2021) and Masong et. al. (2021) but in front line health care workers as well (12,46) or in a combined sample of HCWs and community (9,12,46,59,60). Assessments of the awareness of FGS were conducted in few cases such as in in Tanzania, Ghana, Cameroon or Egypt (9,46,59–63), with the recurring image of overall low awareness for FGS.

Among healthcare workers, gaps in awareness of correct treatment and diagnosis as well as assumptions of the disease as a sexual transmitted infection were observed in these first few studies (9,59,60). High FGS awareness among healthcare workers could prevent mis-diagnosis of FGS as a sexually transmitted infection as well as unnecessary invasive surgery or unnecessary treatment with antibiotics (13). Nevertheless, it needs to be noted that most of the literature on the awareness of FGS is novel, and the number of publications limited.

### 2.2.6 Schistosomiasis in Madagascar

Madagascar is one of the countries with the highest prevalence of schistosomiasis worldwide, the disease is highly endemic in the general population with a prevalence of over 50 percent in several parts of the country (64). Among a population of 26.97 million citizens on the fifth biggest island in the world, 6.8 million people are in need of treatment for schistosomiasis (65). Next to a poverty headcount ratio of over 70 percent, the island off the coast of southern Africa presents a low human capital index of 0.39 indicating the status of education and health in the country (66).

Urbanization in the country is low, with 80 percent of the population living in rural, hard to reach areas (67). A challenge in the management of schistosomiasis in Madagascar is the remoteness of a big part of the population (68). More than 60 percent of the population lives more than five kilometer away from a health care center (69). Poverty in Madagascar is unequally distributed between urban and rural areas, presenting rural poverty double the rate of urban poverty. Most of the families with a low household income are employed in the agricultural sector (67).

The distribution of the two dominant species in Madagascar, *S. mansoni* and *S. haematobium,* is geographically divided with S. *mansoni* in the south-eastern part of the country as well as the highlands and S. *haematobium* in the north-western part (70). This is corresponding with the geographical distribution of the intermediate snail hosts *Bulinus* and *Biomphalaria* (8). In four regions a co-endemicity of both *Schistosoma* species can be found on Madagascar (68). At the moment, schistosomiasis is a significant public health challenge in the country, due to the lack of regular monitoring and accelerated treatment efforts (8). The areas endemic for schistosomiasis on the island of Madagascar in 2020 can be seen in figure 4.

Areas with a prevalence of over 50 percent are depicted in red, medium prevalence of 10 to 49 percent in pink, low prevalent areas with a prevalence of one to nine percent in yellow and non-endemic areas with a prevalence of under one percent in green. In a survey conducted by the WHO in 2008, 95 out of 111 surveyed districts in Madagascar showed infections with *Schistosome* (71). Among the endemic, a high prevalent region for *S. haematobium* is the Boeny region in the north-western part of Madagascar, with a suspected prevalence of schistosomiasis of over 50 percent (72).

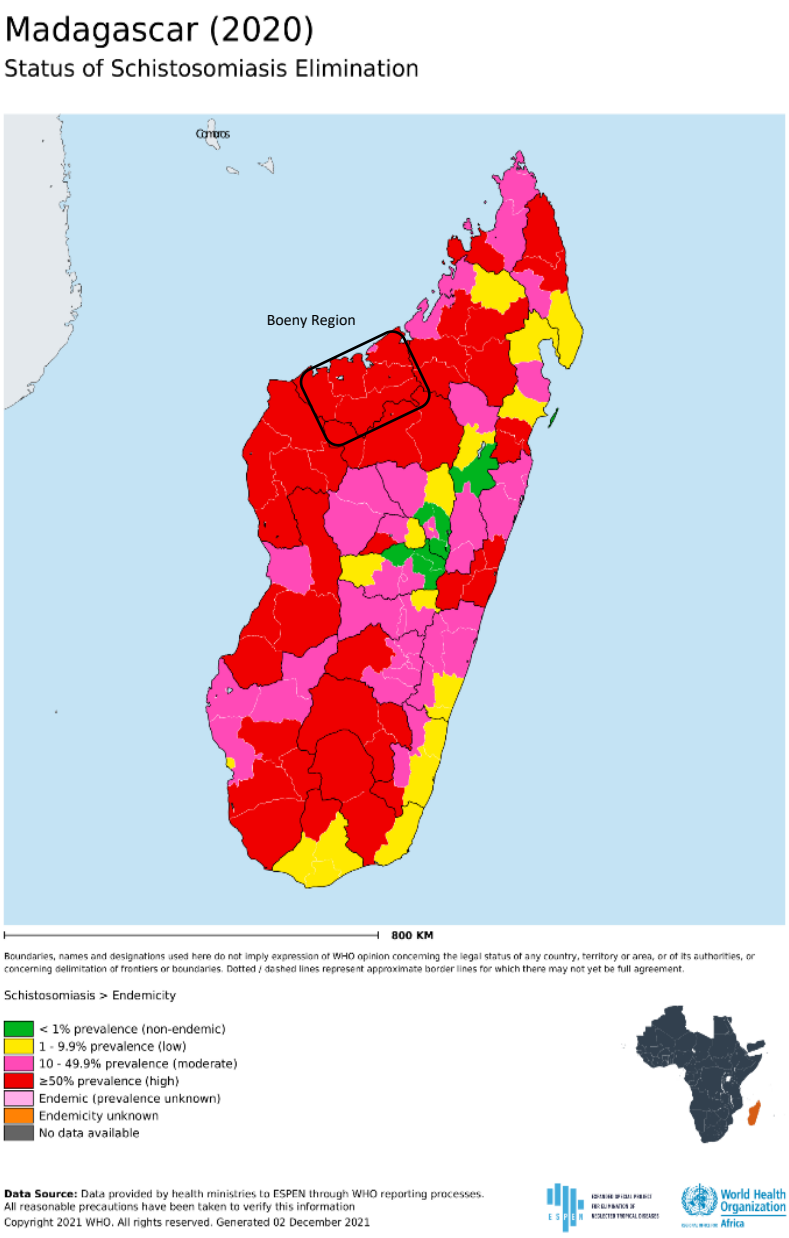


**Figure 4** **Prevalence of schistosomiasis in Madagascar**

Map of Madagascar displaying the endemicity status within the country explained in legend, Expanded Special Project for Elimination of Neglected Tropical Diseases. Endemicity Madagascar (2020) [Internet]. 2022 [cited 2022 May 20]. Available from: https://espen.afro.who.int/diseases/schistosomiasis

## 2.3 FIRM-UP study

The datasets and transcripts of Focus Group Discussions (FGD) analyzed in this thesis are provided by the project "Female Genital Schistosomiasis in rural Madagascar: improving community understanding and promoting integration into primary health care services" (FIRM-UP) conducted by the research group Fusco of the Bernhard Nocht Institute for Tropical Medicine (BNITM) in the Boeny region of Madagascar, which is highly endemic for *S. haematobium*. The study aims at investigating the operational gaps laying behind FGS in order to identify solutions for a better management of the disease. The multi-stage cross-sectional design provides three study phases. The material used as data basis for this thesis is collected during phase one of the FIRM-UP study. The study scheme can be seen in figure 5.

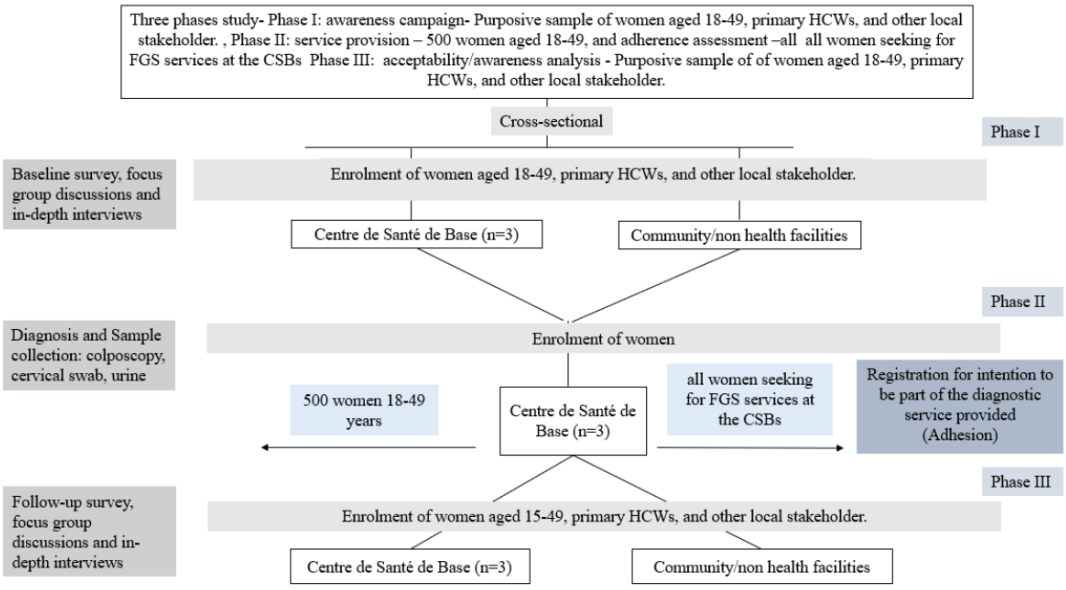


**Figure 5** **Study scheme FIRM-UP study**

The study of the FIRM-UP study is displaying from top to bottom the overall sampling, study phase I with baseline survey, focus group discussions and in-depth interviews at primary health care centers and non-health facilities, study phase II with colposcopy and sample collection and Phase III with the follow-up survey, focus group discussions and in-depth interviews.
Own visualization.

Phase one of FIRM-UP is combining an awareness-raising campaign for the disease FGS with a quantitative and qualitative baseline assessment of the awareness of FGS among women of reproductive age and HCWs in three primary health care centers, named *centre de sante de base* (CSB) in the Boeny region of Madagascar. Two of these CSB are located in rather rural areas, namely the CSBs of Antanambao-Andranolava and Ankazomborona. One of the CSBs, Ville de Morovoay, can be categorized as peri urban. Phase two of the FIRM-UP study assesses service provision and diagnostic adherence to a diagnostic package for a maximum of 500 women at the three CSBs. The third study phase conducts a post-assessment of the acceptability of offered screening as well as a post-assessment of the awareness.

In an amended longitudinal design, the 500 women sampled in phase II will be followed up and resampled during 2022 in the second roll out of the FIRM-UP campaign.

# 3 Methodology

The methods of this thesis are following a triangulation mixed- method design, composed by statistical analysis of an awareness questionnaire and framework analysis of focus group discussions. Lastly, a linking analysis is completing the mixed-method design.

## 3.1 Eligibility Criteria

Sampling of this thesis study has been conducted following preset inclusion- and exclusion criteria. Inclusion criteria are defined as following:

- Healthcare professionals working at the primary health care clinics (PHCCs) of Antanambao-Andranolava, Ankazomborona and Ville de Morovoay, OR
- Female community members of Boney who had received schistosomiasis care at the three participating PHCC, OR
- Community leaders or traditional community representatives of Boney area, OR
- Community mobilizers engaged in mass drug administration coordinated from the Antanambao-Andranolava, Ankazomborona and Ville de Morovoay PHCCs, AND
- Older than 18 years AND
- Fluent in French and/or Malagasy language, AND
- Willing and able to provide written informed consent

Exclusion criteria are defined as following:

- All individuals younger than 18 years
- All individuals not meeting all of the above listed inclusion criteria and those unwilling to provide written informed consent for their participation in this research

Individuals not complying with these criteria were excluded from the study. No person who meets the inclusion criteria was excluded as a participant in this study based on their sexual orientation, gender identity, political, ethnic affiliation, or socioeconomic position. The initial study design planned to include women up from the age of 15 years, this was readjusted, and all persons younger than 18 years were excluded from the study. The study was approved by the ethic commission of Hamburg, Germany (protocol number PV7309) and the ethic commission of Antananarivo, Madagascar (protocol number 052/MSANP/SG/AGMED/CERBM).

## 3.2 Study setting

The study was conducted in the Boeny region of Madagascar. The Boeny region has an estimated population of 543,200 inhabitants and is an overall rural region. Three broader communities within the region have been selected for the conduction of the study. The communities of Ankazomborona are estimated to comprise a population of 23,000 inhabitants, the communities of Antanambao with 3,000 and the city of Morovoay with 34,000 inhabitants. Antanambao is in a rural setting, Ankazomborona in a peri-urban setting and Morovoay represents an urban setting. The study sites have been selected due to the expected high prevalence of *S. haematobium* of more than 50 percent of the population (72).

## 3.3 Study design

The analysis design is constructed in a mixed-method research approach after Johnson et. al. (2007), combining quantitative and qualitative data collection in the concluding combining analysis (73,74). A between method triangulation design, as displayed in table 1 next to the different possible designs of a mixed method research approach, was applied in this thesis. Through the mixed method approach, both inductive and deductive logical schools of thinking were applied in this thesis (75). Sampling was conducted through purposive sampling in a type 4 non-random, non-random design as defined by Onwuegbuzie & Collins (2010) (76).

**Table 1** **Mixed method designs**
Own visualisation after Johnson et. al. (2007)

| Design Type | Time sequence of survey | Method of mixing data |
|---|---|---|
| *Triangulation* | Parallel | Merging the data in the analysis |
| *Experiment* | Parallel or sequential | Embedding data from one survey methodology in a larger design of the other survey methodology |
| *Explanatory* | Sequential, first quantitative, afterwards qualitative | Linking the data between the two phases |
| *Exploratory* | Sequential, first qualitative, afterwards quantitative | Linking the data between the two phases |

## 3.4 Data collection

### 3.4.1 Quantitative data collection

A structured awareness survey was conducted from 24th of August to 4th of September 2020. Data collection was conducted based on a cross-sectional design. The participating women out of the general population and HCWs were selected and interviewed at markets, schools, health facilities including primary health care center, and at the participant's home through a purposive sampling approach. Recruitment was performed by trained Malagasy staff who administered the questionnaires in the local language.

The participants interested in participating in the study were asked to give informed consent prior to their participation. All participant data is pseudonymized through the generation of a participant ID, all form containing the signature of the participants were stored separately from the questionnaires to protect the pseudonymization. Data entry in Madagascar was conducted by trained data clerks using the electronic data capture tool REDCap (Vanderbilt University, Nashville, USA), hosted on secured servers of the BNITM. The database included branching logic to ensure correct data entry, as questions are partly conditioned for specific respondent groups. Only the assigned data manager is given access to extract the data from the REDCap tool.

The investigation tool included socio-demographic and occupational questions, followed by a multiple-choice knowledge assessment of FGS. Choices that are affiliated with FGS were offered as along with FGS unrelated choices to check the status of the true knowledge of the disease. The third section of the instrument was designed to capture respondents' awareness and attitudes towards FGS diagnosis and treatment. HCW were interviewed on their knowledge of correct medication and their previous experience with FGS patients, while members of the community were asked about their health seeking behavior and personal experience with FGS diagnosis and treatment. The investigation tool of FIRM-UP is attached in the digital annex A of this thesis.

### 3.4.2 Qualitative data collection

Qualitative data collection was performed through FGDs among women of reproductive age, healthcare workers, community leaders, and other stakeholders. The FGDs were designed to provide an in-depth look on FGS awareness and perceptions, and FGS service acceptability and uptake, enriching the results of the baseline awareness survey.

Cross-sectional data was collected through purposive sampling to identify potential adult respondents in reproductive age (18-49). Lists including patients infected with schistosomiasis, CSB staff, and community contributors to the mass drug administration supporters' campaigns were prepared. A selection was performed to allocate individuals in each specific sub-list which represents information rich cases. Recruitment was performed by local trained co-researchers. Individuals from each group were contacted either via phone or directly at the PHCC. All FGDs took place in settings where participants' privacy and confidentiality were maintained. Women interested in participating in the study were asked to give informed consent prior to their participation.

The discussion groups for the FGDs were divided into healthcare professionals and general community. Pseudonymization of the participants was ensured through the generation of a participant ID that was used in the transcription of the FGD. Age and occupation were recorded to give a socio-demographic background of the participants.

FGDs following a semi-structured topic guide were used, attached in the digital annex E of this thesis. The structure of the topic guide is displayed in Figure 6, providing instructions on the guidance of the interview and gives example questions for each topic. The participants were asked about their knowledge of schistosomiasis in general FGS in particular, prior to the ongoing FIRM-UP awareness campaign, as well as their perception of the offered screening and the campaign material.

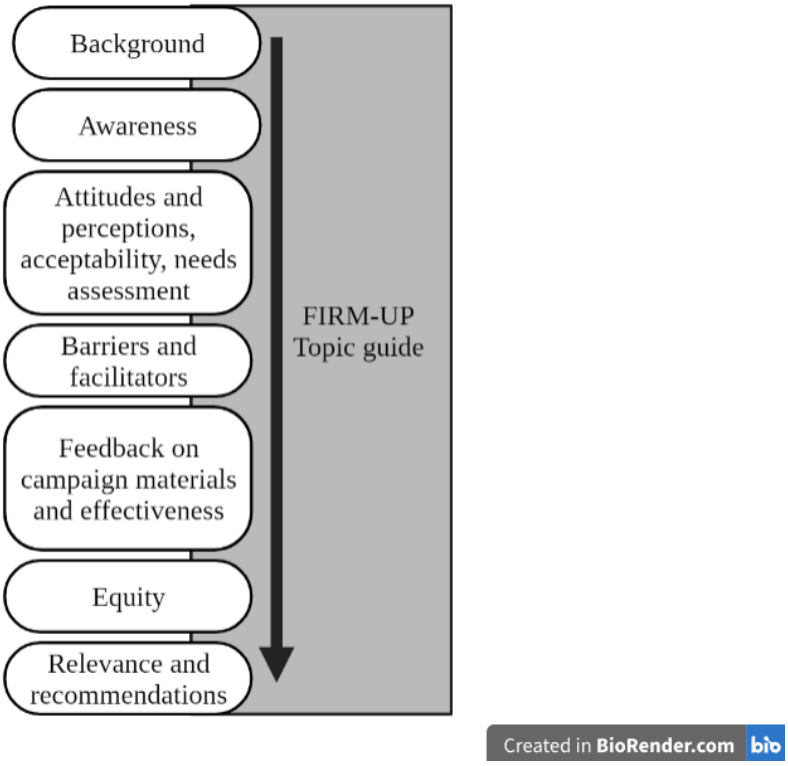


**Figure 6** **Structure FIRM-UP topic guide**

The topic guide of FIRM-UP is following the displayed structure to guide the FGD. From top to bottom, the topic guide includes general background information of the participant, awareness of schistosomiasis and FGS, attitudes, and perceptions as well as a health care needs assessment, the assessment of barriers and facilitators of awareness, feedback on the campaign material, a reflection of equity in access to health care and the assessment of relevance and recommendation on the study process.

Own visualization created with BioRender.com

The FGDs with the women of the general population were conducted from 24th to 27th of November 2020. The FGDs with the health care professionals took place on the 17th and 18th of August 2021 and were all conducted by the same interviewer in the local Malagasy language at four primary health care centers such as the CSBs of Marovoay, Antanambao Andranolava, Ankazomborona and Mahavoky Mahajanga in the Boeny region of Madagascar. The targeted individuals interested in participating in the study were asked to give informed consent prior to their enrollment in the study. A maximum number of ten participants were included in the discussion to guarantee a lively but in-depth group discussion. The respondents were sat in a circle with the moderator and the recording devices were placed in the middle. The FGDs were audio recorded and then transcribed in verbatim. The transcribed FGDs were subsequently translated from Malagasy into French and English (Digital annex F). A language cross check by a native speaker was provided.

The three FGDs with the women took on average 39.62 minutes, ranging from 36.77 minutes to 43.89 minutes, while the FGDs with the HCW are 45.74 minutes long on average, ranging from 33 minutes to 53.07 minutes. Two of the focus group discussion with the general population are characterized by a very lively discussion, one discussion slightly more dominated by the moderator due to the lack of pre-existing knowledge of the disease among the participating women. A priori themes from the topic guide were followed up, among the discussions of the women and HCW, also novel themes emerged.

## 3.5 Data analysis

### 3.5.1 Quantitative analysis

The analysis of the quantitative surveys was conducted using R version R-4.1.2 (R Foundation for Statistical Computing, Vienna, Austria). A French dataset (Digital annex B), retrieved from the REDCap database, was translated to English for the purpose of this thesis. Analysis of the awareness survey was divided into two groups: general population and HCW. An initial data cleaning, extracting all minors from the dataset and checking for any systematically missing values, was performed and non-conformities were excluded from the analysis. The survey reached overall 93 HCWs and 727 female representatives of the general population. During the process of data cleaning

33 participants were excluded from the analysis due to not fulfilling the inclusion criteria previously determined (e.g. Age over 18 years), leaving 694 representatives of the general population and 93 HCWs for analysis. Furthermore, multiple-choice items with the option to add additional free text were screened and full text choices labelled with “other” and assigned to an existing category if applicable.

A subset of each HCW and community was created and stratified by previous knowledge status. The analysis was conducted using descriptive statistics, including frequencies and proportions with 95% binominal confidence intervals (CI) were calculated using the Clopper-Pearson method. Measures of central tendency such as median (ME) and interquartile range (IQR) or mean (M) and standard deviation (SD) were calculated for continuous variables. Afterwards, multiple-choice categories of the knowledge assessment from the participants that were previously knowledgeable of FGS were graphically displayed and described using proportions.

A score evaluating the knowledge of FGS was calculated. All FGS related choices were scored with 1, all unrelated choices were scored with 0. All choices were summed up. A maximum quality of knowledge score of 30 was determined, comprised of the items displayed in table 2. Knowledge in the range from 0-9 points was classified as low knowledge, knowledge in the range from 10-19 as moderate knowledge and 20 and more points were classified as good knowledge. After checking the preconditions of homoscedasticity using a Levene test and normal distribution under the usage of histograms (Annex A), a two-sample t-test was performed to compare differences in the mean quality of knowledge score of HCW and general population.

**Table 2 Contributing items of the components of the knowledge score**

| Components knowledge score | N Items | Items contributing |
|---|---|---|
| Knowledge urological symptoms | 3 | Painful urination, Frequent urination, Blood in urine |
| Knowledge gynaecological symptoms | 10 | Vaginal discharge, bloody discharge, bleeding after sex or blood spots, burning sensation, pelvic pain, pain during/after sex, contact bleeding, intermenstrual bleeding, rash/pruritus, infertility |
| Knowledge infection protection | 6 | Drug treatment for all infected, mass drug treatment for all, chemical treatment of water body, protect water body, don't swim in river/lakes, use well water, more latrines/Improved hygiene |
| Knowledge transmission pathways | 5 | Bringing in contaminated water, fishing in contaminated water, washing dishes/ laundry in river/ lake, bathing/ swimming in lake, working in rice fields |
| Knowledge of consequences | 6 | Infertility, ectopic pregnancy, involuntary urination, genital ulceration, tumours, or oedema (vulva, vagina, cervix), increased risk of cervical cancer |
| Total | 30 | |

### 3.5.2 Qualitative analysis

The transcripts of the FGDs were analyzed using the approach of the framework analysis described by Richie & Spencer (1994) (77–79).

The investigation followed the standard procedure of the framework analysis, which consists of five systematical and analytical steps, following the suggested workflow as displayed in figure 7. Firstly, for data familiarization self-reflecting reports for each discussion were established. Familiarization reports and reflection on the understanding of the researcher are attached in Annex B.

Secondly the identification of a coding framework and subsequent indexing of the data against the framework were applied on the translated transcripts of the FGDs. In the third step of the framework analysis, data was coded with the assistance of MAXQDA 2022 (VERBI GmbH, Berlin, Germany), and is attached in the digital annex G of this thesis. Subsequently, in the fourth step, a priori and emerging themes were

summarized through charting the data. In the final step of the framework analysis, data was mapped in a matrix format including corresponding quotes of the participants and information rich passages and analyzed comparatively for patterns found within the charts (78). Quotes were identified in the chart via the ID of the participant and the location of the FGD. For example, (*9-TT-T1,* Focus group discussion HCW Mahavoky Mahajanga) for a HCW from Mahavoky Mahajanga.

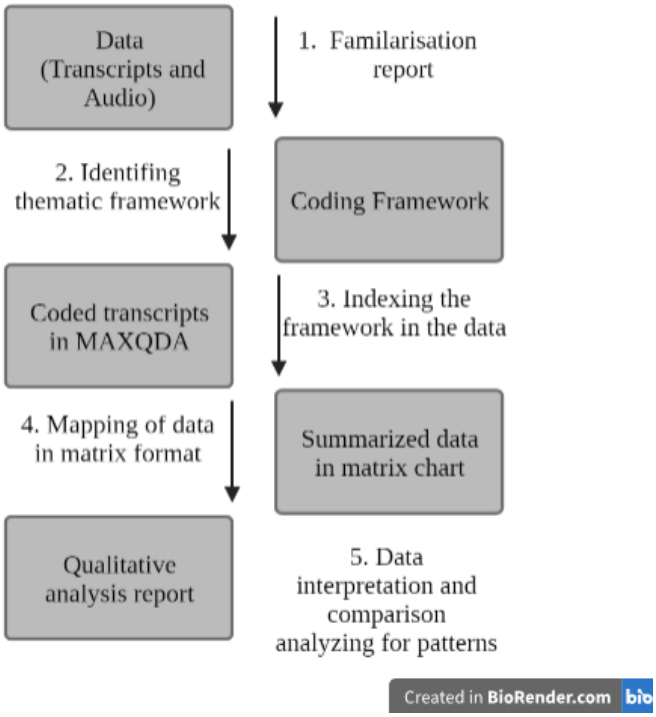


**Figure 7** **Workflow framework analysis**
From top to bottom following the workflow of the framework analysis: Firstly, transcripts are screened using familiarization reports, secondly a coding framework is established through identifying thematic framework, thirdly indexing of the framework is performed using MAXQDA and lastly a qualitative analysis report is established interpreting data

Each matrix table derived from the framework analysis is displaying example quotes for the theme to show the sentiment of the theme in the charting. *A priori* themes for the women from the topic guide include for example awareness of schistosomiasis and FGS, feedback on campaign and perceptions of screening. An excerpt of the emergent themes among the women do include treatment of the disease in the community and rice farming as the main income source. Some of the categories were only mentioned by one participant in the group like the offering of treatment only to children, nevertheless shaped the interaction of the focus group. The *a priori* themes of awareness, treatment, and access to information as well as the emerging themes of risk perception and previous experience with schistosomiasis were discussed within the qualitative

analysis. The framework analysis is divided between representatives of the community and HCW. As in the group of the community, the analysis of the focus group discussions of the HCW is analysing *a priori* and emergent themes in charting system with example quotes. Further discussed are the *a priori* themes of awareness, treatment, and access to information. An emerging theme discussed in the group of the HCW is for example risk perception.

To ensure theory-based construction of this thesis, quality criteria of qualitative research after Steinke (2000) were taken into account during the research process (80).

### 3.5.3 Triangulation quantitative and qualitative analysis

Triangulating the quantitative and qualitative analysis conducted in this thesis, the previous results were combined to determine and visualize the dimensions of awareness of FGS. Furthermore, awareness related barriers and facilitators which can influence FGS treatment and diagnosis uptake among women in the Boeny region of Madagascar were determined.

This synthesis was considering communication, context and health behavior after Saurman (2015) to further embed awareness as a contributing factor to access of health care within the framework of Penchansky & Thomas (1981) (56,57). To achieve this visualization, dimensions of the awareness of FGS, which emerged during the quantitative and subsequent qualitative analysis of this thesis, as well as influencing factors were visualized and synthesized.

Barriers and facilitators were linked to the dimensions and a dynamic framework is established. The influence of awareness and its corresponding dimensions on correct diagnosis and treatment of FGS was determined in the discussion of this result triangulation.

# 4 Results

This section will describe the results of the awareness survey analysis. Afterwards, the qualitative results will determine influencing factors as well as barriers and facilitators of the awareness and asses the access to diagnosis and care in the Boeny region.

To conclude the result chapter, the data of the quantitative and qualitative research section will be linked and displayed in a visualisation of the dimension of awareness among women and HCW in the Boeny region of Madagascar.

## 4.1 Awareness survey

Firstly, the characteristics of both HCW and women are described stratified by previous knowledge of FGS. Secondly, an assessment of the knowledge of the participants that stated in the initial question that they have knowledge of FGS for both the HCW and women through computing a knowledge score and displaying the individual multiple-choice components of the score. Thirdly, additional to the comparing knowledge score, the access to information and treatment seeking behaviour among the women is described as well as the knowledge of treatment and diagnosis among the HCW.

### 4.1.1 Sample characteristics healthcare worker and community

In total 93 HCW were surveyed in the awareness campaign, the sample characteristics of these HCW are displayed in Table 3. Stratified by previous knowledge of FGS, 43 (46.2%, 95CI [35.8–56.9%]) stated that they never heard of FGS or have no knowledge about the disease and 50 (53.8%, 95CI [42.6–63.6%]) HCW had previous knowledge of FGS before the survey. For both HCW groups, the hospital was the most frequent survey location with 90 percent of the aware and 72.1 percent of the non-aware respondents respectively.

While just eight percent of previous aware HCW were surveyed at a CSB, 25.6 percent of the unaware HCW were surveyed at the location of a CSB. HCW with previous knowledge were mainly in the age group of 18–35 with 72 percent of the respondents. In contrast to this, 46.6 percent of HCW without previous knowledge were in the age group 18–35 and 41.9 percent were in the age group 36–45. University was the most frequent educational degree among HCWs, with 93.9 percent of aware HCWs and 88.4 percent of the unaware HCW having a university degree. The dominating religion in

the sample was Christian, 86 percent, and 86.1 percent of HCW with previous and without previous knowledge, respectively.

The assessment of the occupation of the HCWs in both groups was under the influence of a systematically appearing missing values. Most of the remaining HCWs in the assessment of the occupation that have previous knowledge of FGS were physicians with 38.5 percent of the answers. In the other group, the most frequent named occupation was nurse with 38.5 percent of the answers.

**Table 3 Sample characteristics HCW**

| HCW | Previous knowledge of FGS | No previous knowledge of FGS |
|---|---|---|
| A: Background characteristics | **n (%)** | **n (%)** |
| **Total** | 50 (100) | 43 (100) |
| **Place of interview** | | |
| CSB | 4 (8.0) | 11 (25.6) |
| Hospital | 45 (90.0) | 31 (72.1) |
| Community | 1 (2.0) | 1 (2.3) |
| **Age in years** | | |
| 18- 35 | 36 (72.0) | 20 (46.6) |
| 36- 45 | 5 (10.0) | 18 (41.9) |
| 46- 65 | 9 (18.0) | 5 (11.7) |
| **Education** | | |
| Secondary Education | 2 (4.1) | 2 (4.7) |
| Professional Course | 1 (2.0) | 3 (7.0) |
| University | 46 (93.9) | 38 (88.4) |
| **Religion** | | |
| Christian | 43 (86.0) | 37 (86.1) |
| Muslim | 3 (6.0) | 3 (7.0) |
| Other | 2 (4.0) | 3 (7.0) |
| **Occupation**[†] | | |
| Physician | 5 (38.5) | 3 (11.5) |
| Nurse | 2 (15.4) | 10 (38.5) |
| Midwife | 2 (15.4) | 6 (23.1) |
| Paramedic | 2 (15.4) | 3 (11.5) |
| Medical Student | 1 (7.7) | 1 (3.8) |
| Other | 1 (7.7) | 3 (11.5) |

Notes: [†] Systematical missing values (n=54)

In total, 694 women were surveyed in the general population. The background characteristics of this population are displayed in table 4. Out of this total sample, 78 (11.2%, 95CI [9.0–13.8%]) surveyed women stated to have knowledge of FGS and 616 (88.8%, 95CI [86.2–91.0%]) of surveyed individuals stated that they never heard of FGS before. The place of interview was differing between the group of women that heard of FGS before and the group that did not. While 81.7 percent of the respondents that were aware of FGS were interviewed in the setting of a hospital, the most common place with 83.2 percent of interviews in the population of the unaware women was the community, such as markets or homes of the participants.

The most common age group for both the aware and the unaware proportion of the general population was the age group from 18–35. This group was representing 73.1 percent of the respondents that stated to previously have heard of FGS and 67.2 percent of the participant that were not aware of FGS. In both groups 50 percent of the respondents had secondary education or less and 50 percent of the respondents had secondary education and more. In the group of the respondents with previous knowledge, secondary education was the most common education level with 52 percent followed by primary education with 30.7 percent and university with 16 percent. In the group of the non-aware respondents, 54 percent of the respondents had secondary education, 33.5 received primary education and 7.1 percent had attended a university. Christianity was the most common religion in both groups, 66.8 percent of the surveyed persons from the group of the FGS aware stated to be Christian as well as 66.9 percent from the group of the FGS unaware respondents.

The most named employment status corresponds in both groups is self-employment, with 55.2 percent of the FGS aware respondents and of 68.2 percent of the FGS unaware participants. In the group of participants that stated previous knowledge of FGS 50 percent worked 8.9 months and less per year and 50 percent worked 8.9 months and more per year with an interquartile range of 5. More worked months per year were observed in the group of the respondents that are not aware of FGS. This group showed 50 percent and less of the respondents worked 11 months and 50 percent and more worked 11 months with an interquartile range of 4.

**Table 4 Sample characteristics community**

| Community | Previous knowledge of FGS | No previous knowledge of FGS |
|---|---|---|
| A: Background characteristics | **n (%)** | **n (%)** |
| **Total** | 78 (100) | 616 (100) |
| **Place of interview** | | |
| CSB | 15 (16.2) | 92 (12.7) |
| Hospital | 76 (81.7) | 30 (4.1) |
| Community | 2 (2.2) | 605 (83.2) |
| **Age in years** | | |
| 18- 35 | 57 (73.1) | 414 (67.2) |
| 36- 45 | 15 (19.2) | 102 (16.6) |
| 46- 65+ | 11 (7.7) | 96 (15.5) |
| **Education** | | |
| Primary education and less | 23 (30,7) | 224 (33.5) |
| Secondary education | 39 (52.0) | 314 (54.0) |
| Professional course | 1 (1.3) | 2 (0.3) |
| University | 12 (16.0) | 41 (7.1) |
| **Religion** | | |
| No Religion | 6 (7.7) | 86 (14.0) |
| Christian | 52 (66.8) | 413 (66.9) |
| Muslim | 2 (2.6) | 22 (3.6) |
| Other | 18 (23.1) | 93 (15.1) |
| **Employment status** | | |
| Public sector employee | 4 (5.1) | 16 (2.6) |
| Private sector employee | 4 (5.1) | 45 (7.3) |
| Self-employed | 43 (55,2) | 420 (68.2) |
| Housewife | 9 (11.5) | 41 (6.7) |
| Student | 7 (9.0) | 34 (5.5) |
| Other | 11 (14,1) | 59 (9.5) |
| **Months worked (Median, IQR)** | 8.9 (5) | 11.0 (4) |

### 4.1.2 Components female genital schistosomiasis knowledge score

Following the description of the sample characteristics of HCW and community is a description of the components of the FGS knowledge score. The described components of the knowledge score are combined in the calculation of the overall FGS-Knowledge score, displayed in this chapter. The FGS knowledge score consists of the concepts of knowledge namely transmission, prevention of infection, knowledge of urological and gynaecological symptoms of FGS and is concluded by the knowledge of the consequences of FGS. To calculate this score, the subsample of the 78 members of the community that claimed to have heard of FGS before and the subsample of the 50 HCW that have previous knowledge of FGS were selected and asked to fill in a multiple-choice (MC), in-depth assessment of the quality of the stated knowledge.

*Transmission*

The knowledge of possible transmission pathways of the parasite is a component of the FGS quality of knowledge score and displayed in figure 8.

The main way of transmission listed is to bath in a river, 46 percent of the HCW and 43.6 percent of the community are identifying bathing in a river as a possible pathway of transmission. Collecting water is identified by 40 percent of the HCWs and 34.6 percent of the community as a possible pathway.

Work related transmission pathways such as fishing (6% HCW) or working in a rice field (2% HCW, 1.2% general population) are scarcely as possible transmission pathways. Additionally, 6 percent of the HCW and 8 percent of the community choose the option that they are not aware of the pathway of transmission for FGS.

Important to note is, that next to the water related pathways of transmission, 6 percent of the HCW as well as 14.1 percent of the community wrongly identified sexual contact as a possible pathway of transmission and 10 percent of the HCWs identified poor hygiene habits as a pathway of transmission of FGS. Displaying misconceptions about the transmission of the disease in these elements. Oral pathways such as the consumption of unwashed food was also wrongly identified as a pathway of transmission by members of the community.

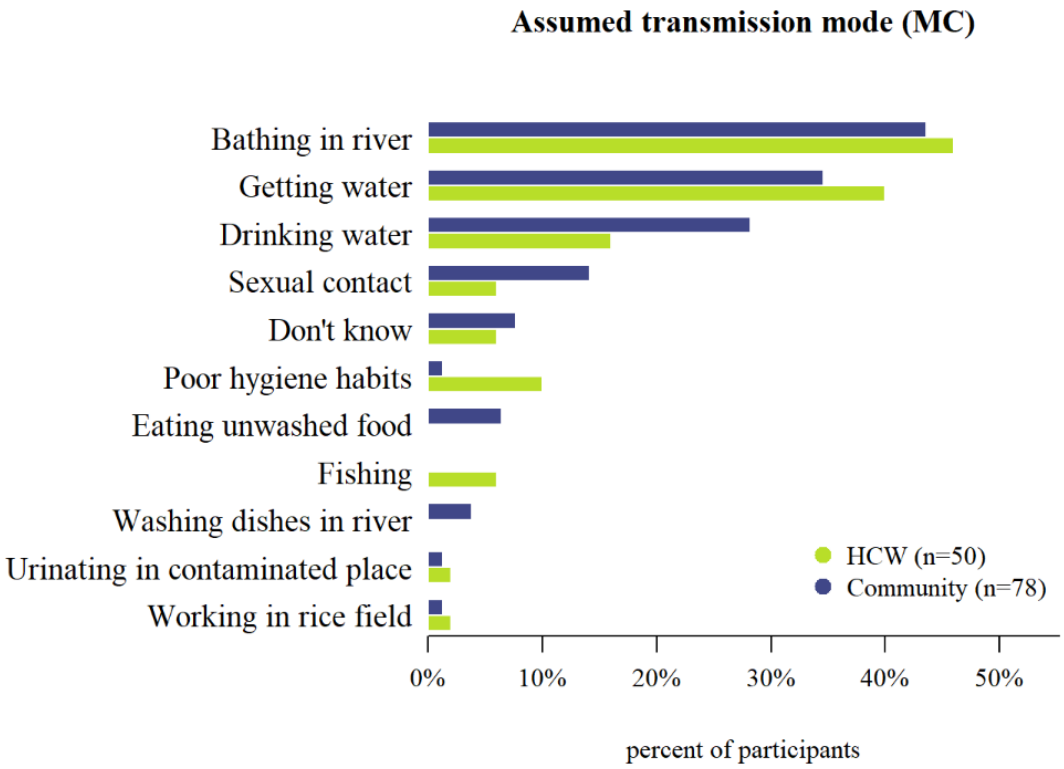


**Figure 8** **Display multiple choice assumed transmission mode**
Own visualization

*Prevention*

Awareness on how to protect from an FGS infection is considered in the calculation of the FGS knowledge score. The awareness of protective measures to adopt for preventing FGS is visually displayed in figure 9. The way of protection that was selected the most by 50 percent of the HCW and 46.1 percent of the women is not to bathe in a river. Protecting the waterbody was seen to protect from infection by 16 percent of the HCW and 31 percent of the community. Another prospective protection method is seen in the chemical treatment of the water body, which was identified by 14 percent of the HCW and 17 percent of the community. Improvement of hygiene is proportionally rather chosen by the community, where 15.4 percent registered this as a way of protection from infection in comparison to 4 percent of the HCW.

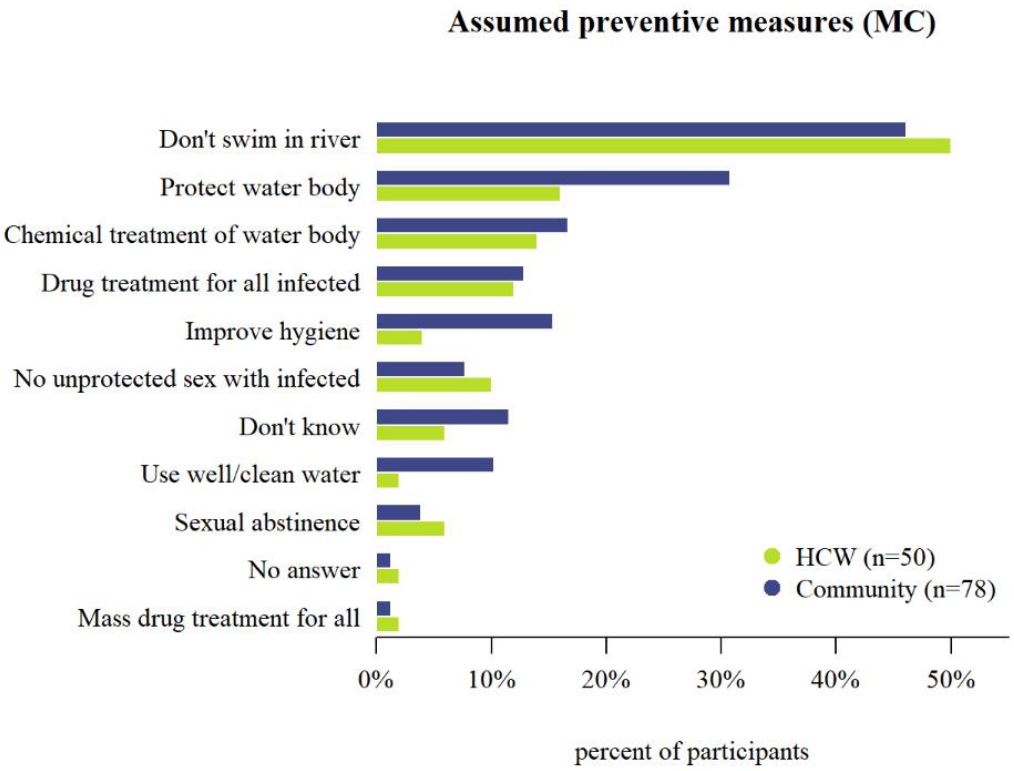


**Figure 9** **Display multiple choice assumed preventive measure**
Own visualization

In line with the assumed sexual pathways of transmission, the avoidance of having unprotected sex with infected persons was identified to protect by 10 percent of the HCW and 8 percent of the community. In 6 percent of the HCWs and 11.6 percent of the community, participants were not able to identify a way to prevent infection and choose the option “Don’t know” and in 2 percent of the HCW and 1.3 percent of the community, no answer was chosen.

*Symptoms*

The suspected symptoms of FGS were asked giving the possibility to select multiple choices among related and unrelated FGS symptoms. The proportional results are displayed in figure 10. Overall, 23 out of the 26 of the offered symptom choices were selected. The most selected assumed symptom of the community and the HCWs was blood in urine which was chosen by 44 percent of the HCWs and 53 percent of the community. Pelvic pain was listed as the next frequently chosen symptom among the general population, here 27 percent stated that pelvic pain is a suspected symptom of FGS.

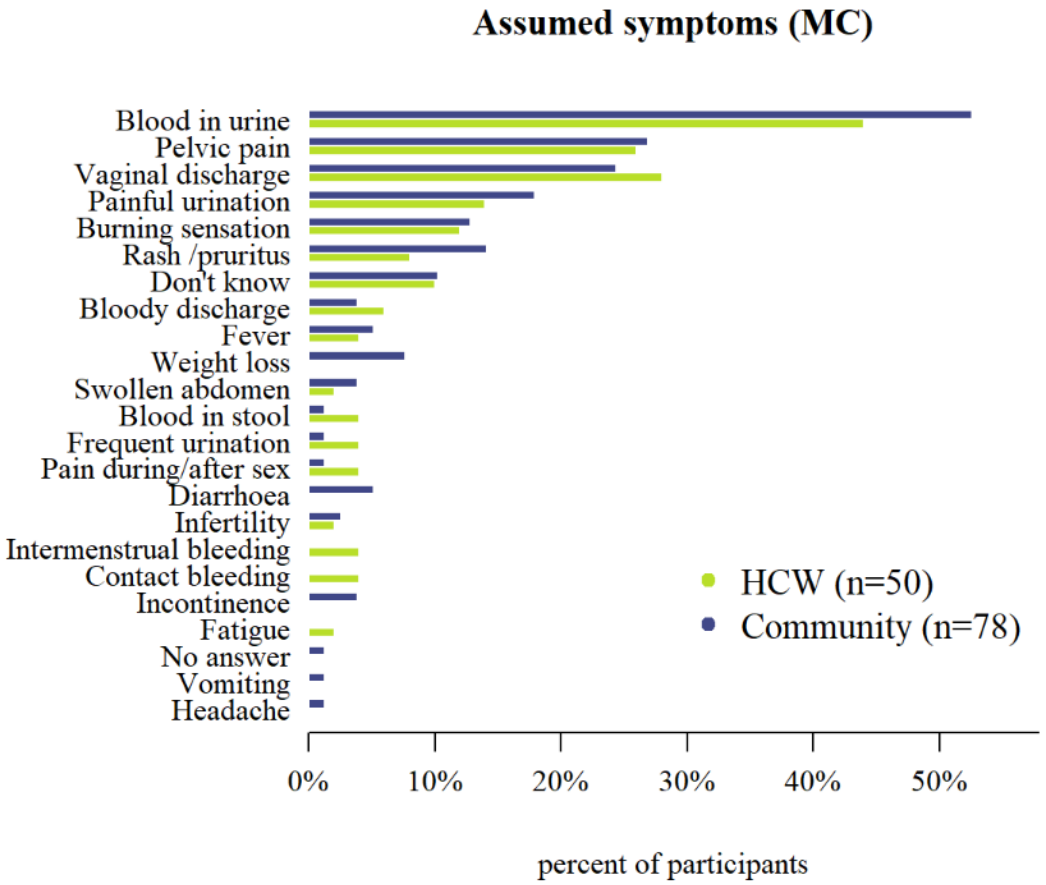


**Figure 10** **Display multiple choice assumed symptoms of FGS**
Own visualization

Additionally, 26 percent of the HCWs listed pelvic pain as a symptom of FGS. Vaginal discharge was identified by 28 percent and 24 percent of the HCW and the community, respectively. 10 percent of each HCW and community stated that they don't know a symptom. Following, the systematic complexes are divided in gynaecological symptoms of FGS, computed out of a symptomatic complex of 10 symptoms, and urological symptoms of FGS, consisting of three valid symptoms. All other symptoms cannot be linked to FGS and are not considered in putting together the number of symptoms known represented in the figure 11 and figure 12.

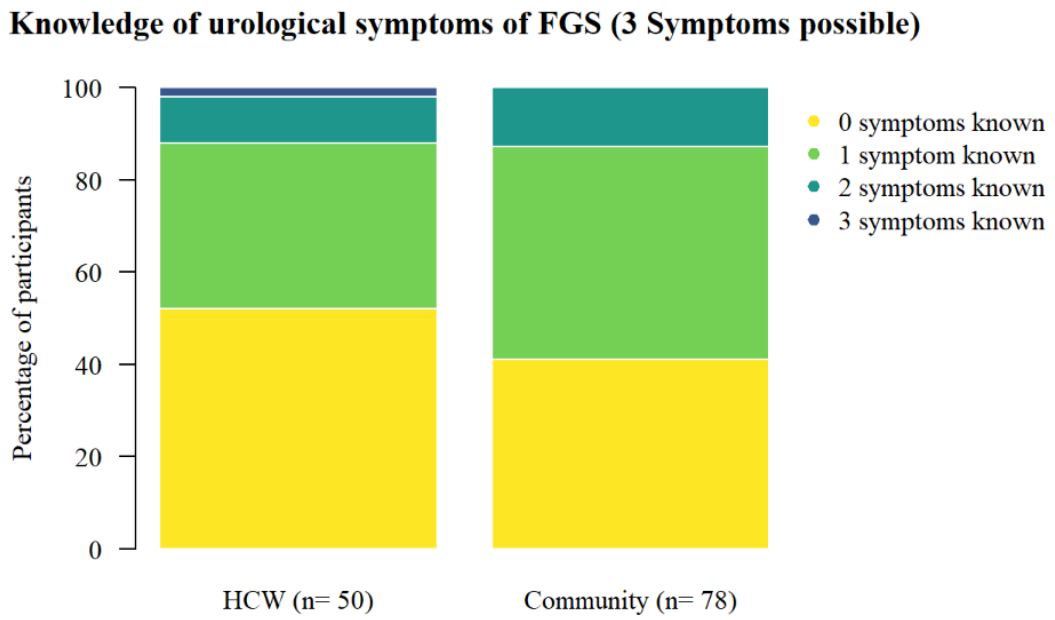


**Figure 11** **Comparison knowledge of urological symptoms**
Own visualization

The urological symptoms of FGS do include painful urination, frequent urination as well as blood in urine. In the direct comparison of the overall knowledge of urological symptoms of HCW and the women of the general population in figure 11, it is visible that proportionally more HCW are not knowledgeable of any urological FGS symptom in comparison to the women of the general population. Displayed in stacked bar charts are the proportions of urological symptoms that are known in both populations, derived from the multiple-choice symptoms shown in figure 10. The range of the amount known of symptoms in the group of the women is zero to two symptoms, while the population of the HCWs showed a range from zero to three urological symptoms that are known.

From the group of the aware HCW, 26 participants (52%) did not know of at least one urological symptom of FGS. Respectively, 32 participants (41%) from the general population that previously declared to have heard of FGS, were unaware of any urological FGS symptom. In depth knowledge where all three symptoms were known is not emerging in the group of the women and in one participant (2%) of the HCW.

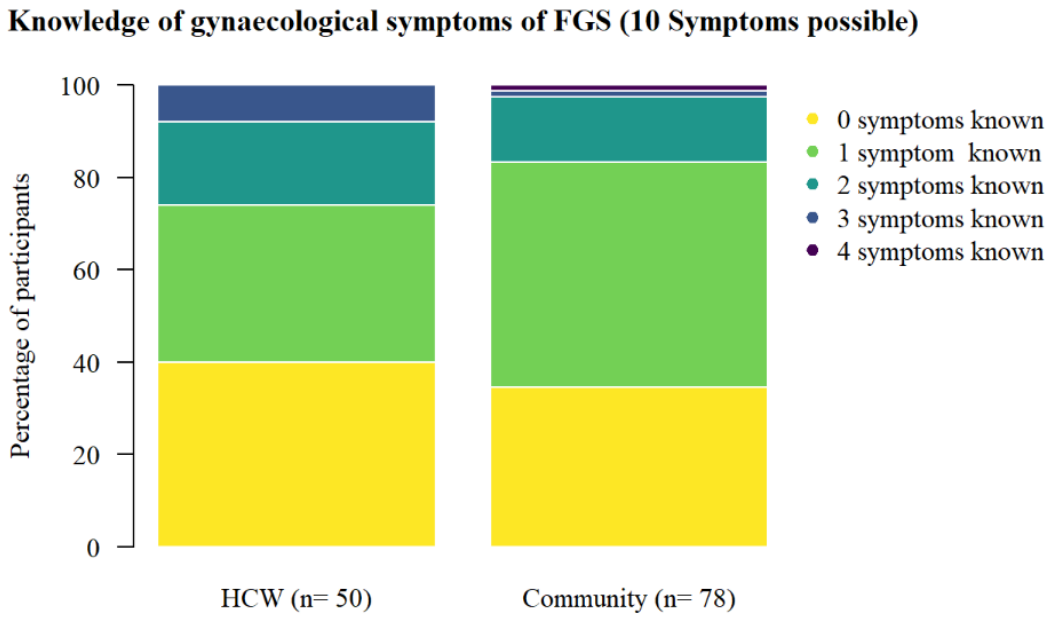


**Figure 12** **Comparison knowledge of gynecological symptoms of FGS**
Own visualization

The amount of known correct gynaecological symptoms of FGS are displayed in figure 12. The assessed gynaecological symptoms of FGS include bloody discharge, bleeding after sex or blood spots, burning sensation, pelvic pain, pain during or after sex, contact bleeding, intermenstrual bleeding, rash, or pruritus as well as infertility. In the direct comparison of the groups, it is apparent that like in the comparison of knowledge of urological symptoms, the proportional amount of HCW (40%) that are not aware of at least one symptom of FGS is again larger than the proportional number of the general population (34.6%) that are not aware of at least one gynaecological symptom of FGS.

Among the HCW 34 percent knew one symptom, while 48.7 percent of the general population were aware of overall one gynaecological symptom of FGS. In depth knowledge of 3 gynaecological symptoms is shown by 8 percent of the HCW and 1.3 percent of the community. Knowledge of 4 gynaecological symptoms was solely present in one participant from the community (1.3%).

*Consequences*

The last component of the FGS knowledge score are the suspected consequences of FGS as displayed in figure 13. The most chosen expression of a consequence of FGS for the HCW is infertility with 58 percent. The most selected answer among the women of the community is death because of FGS, this was only stated by 2 percent of the HCW, while 28.2 percent of the women also selected infertility among their choices. Increased risk of CC was named by 12 percent of the HCW and 11.5 percent of the community as a suspected consequence of FGS.

Among the four most named consequences, anaemia is named by 18 percent of the HCW and 5.1 percent of the community. Among the HCW 10 percent and the among the community 11.5 percent stated that they do not know a consequence of FGS. Among other items not named by neither HCW or community are the increased risks of infection with the human papilloma virus and HIV.

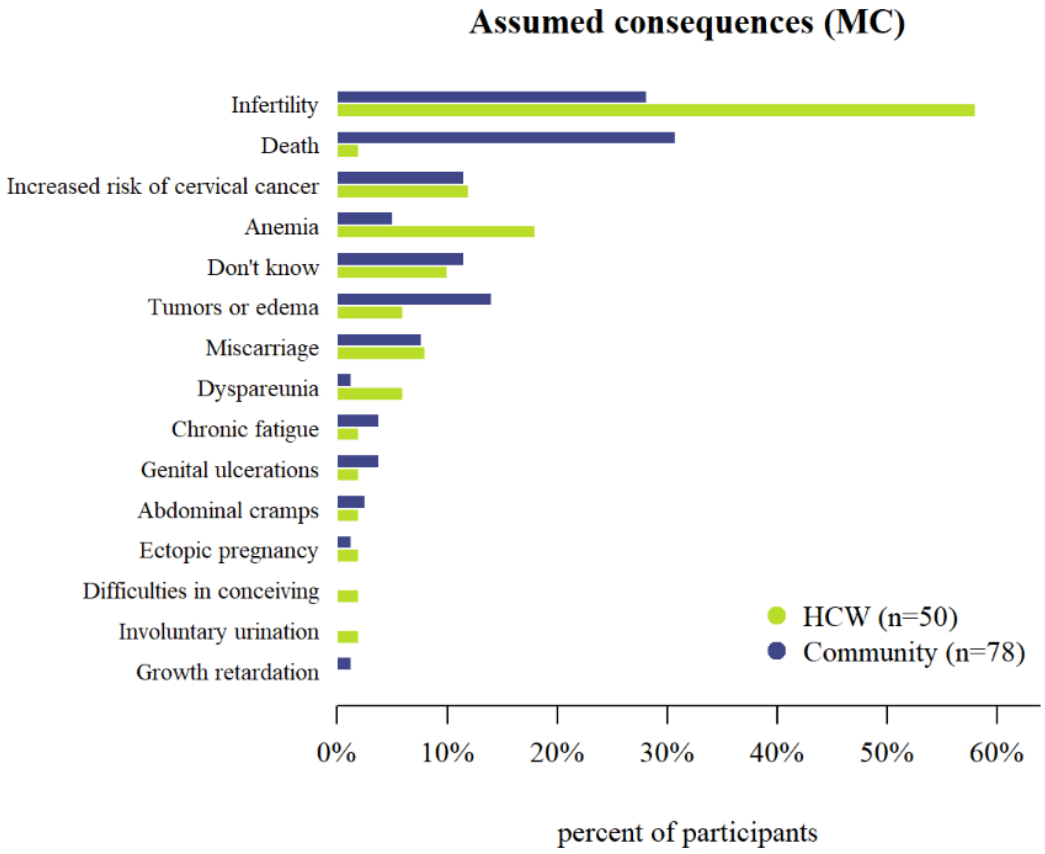


**Figure** *13* **Display multiple choice assumed consequences of FGS**
Own visualization

### 4.1.3 Female genital schistosomiasis knowledge score

Combining these previously displayed components into the knowledge score, the possible high score of the calculated knowledge score is 30 (contributing factors listed under point 3.4.1). Both groups present a minimum score of 0. While the HCW show a maximum score of 8, the maximum knowledge score in the general population is 9. Overall knowledge in both groups a low knowledge of FGS can be found, even though the participants stated to have previous knowledge of FGS. All participants of both groups were in the range of 0 to 9 points in the quality of knowledge score, considered as overall low knowledge, 10 to 19 points would be considered as moderate knowledge and 20+ points as good knowledge. Among this section of low knowledge, further grouping was conducted labelling 0-3 points as very low, 4-6 points as low and 7 and above as moderate to low quality of knowledge. HCW showed 16 (32%) very low, 28 (56%) low and 6 (12%) moderate to low quality of knowledge, displayed in figure 14. Confidence intervals are displayed embedded in the diagram.

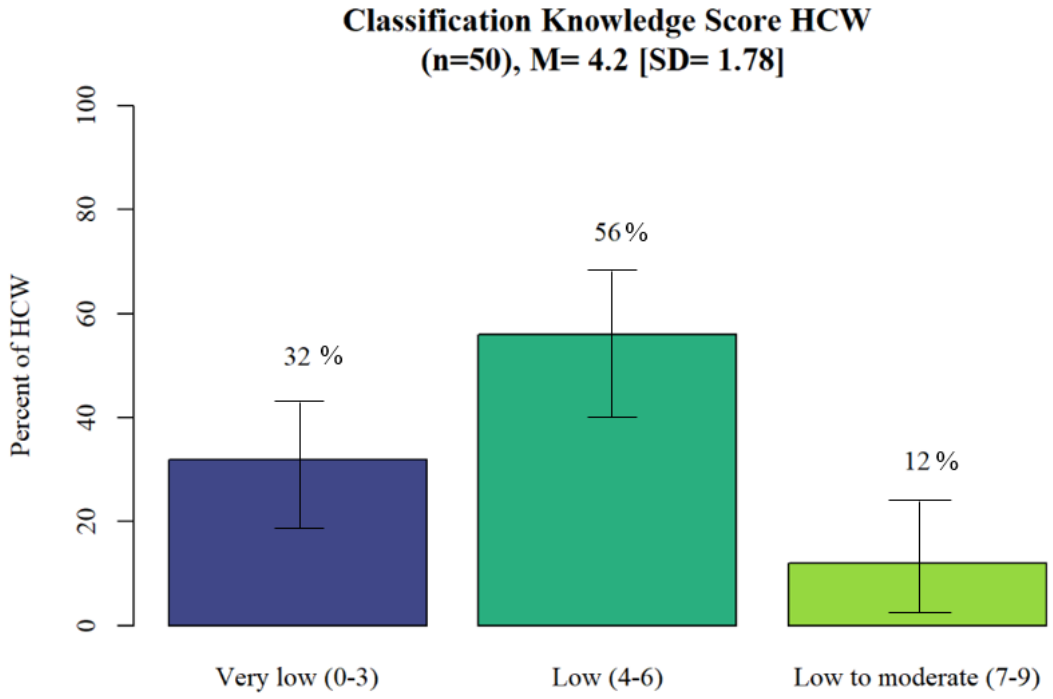


**Figure 14** **Classification knowledge score HCW**
Score classification displayed with 95% CI, Own visualization

Among the women, 28 (36%) showed very low-quality knowledge score, 39 (50%) presented a low score and 11 (14%) women were able to reach a low to moderate score as depicted in figure 15.

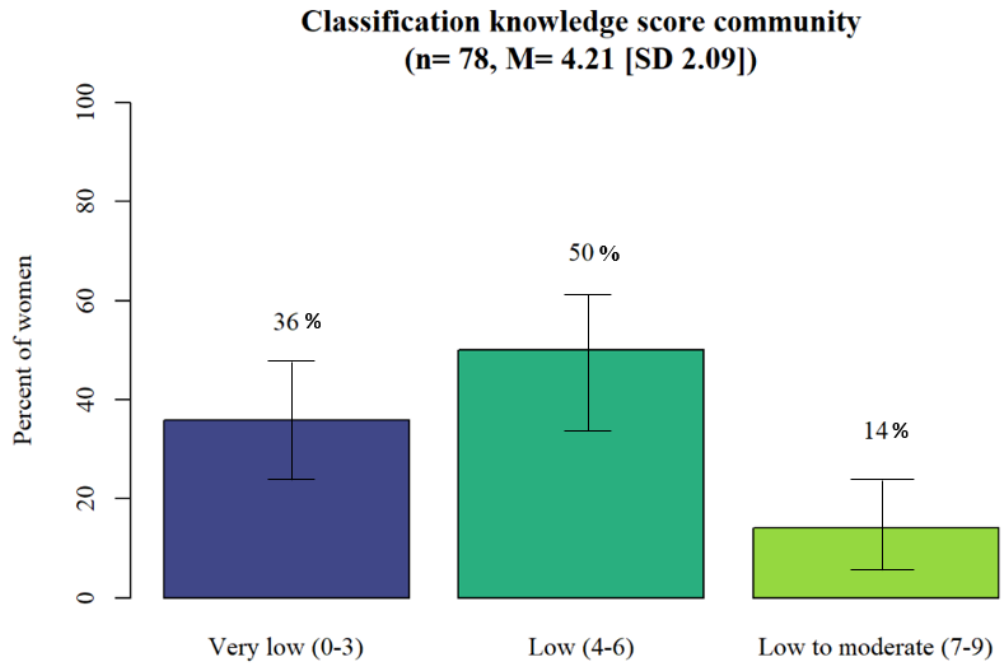


**Figure 15** **Classification knowledge score community**
Score classification displayed with 95% CI, Own visualization

After verifying a normal distribution through histograms (Annex B) and confirming homoscedasticity with the Levene-Test (p= 0.206), a two-sample t-test was performed to compare the quality of knowledge score among the general population and the HCW. No significant difference was seen in the means of the quality of knowledge score between the 50 observed HCWs (M=4.200 [SD= 1.78]) and the 78 women of the general population (M= 4.21 [SD= 2.09]), t(126)= -0.014, p= 0.989).

### 4.1.4 Access to care and treatment

Additional elements to consider next to the FGS knowledge score are insights on the attitude and behaviour towards the disease. These components inculde the FGS healthcare seeking behavior of the community, the source of the information on the disease and the knowledge of correct treatment and ways of diagnosis of the disease among the HCW.

*Source of information*

Among the HCW 17 (34%) stated that they did not talk about the topic of FGS in the last 6 months, as well as 21 (27%) of the community. Representing a low exposure to knowledge facilitation in both groups. The sources of information most used from the participants to know about the disease are displayed in figure 15.

The most often chosen information source differs between community and HCW. While the population of the HCW choose other HCW with 40 percent most often as the source of information, 33.3 percent of the participants from the community stated that the main source of information were friends and family showing quite different pathways of knowledge transmission for the general population and HCW. Radio and midwifes were a source of information for each 12 percent of the community, respectively. All other choices were selected by less than 10 percent of the participants each.

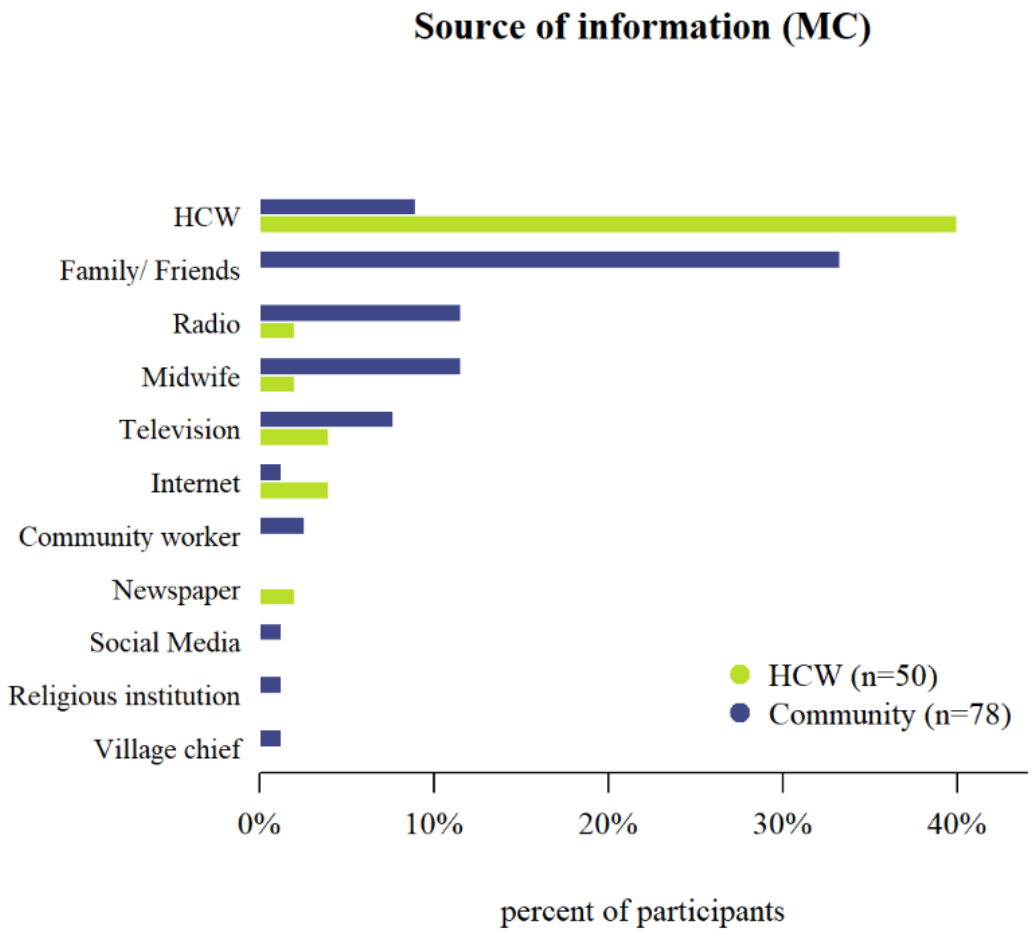


**Figure 16** **Display multiple choice source of information**
Own visualization

### *Treatment* and access

Out of the 50 HCW that previously had heard of FGS, 5 (10%, 95CI [3.3–21.8%]) ever treated a patient with FGS. Diagnosis was mainly done via a genital exam without colposcopy in 3 of the cases. One HCW used a colposcopy to diagnose and one HCW diagnosed with a urine sample. When asked for the choice of treatment administered, all 5 HCW, that have ever treated a patient with FGS, prescribed praziquantel. Unrelated to the previous treatment of a FGS patient, all HCW were asked in a multiple-choice format for the treatment of FGS, 45 out of the 50 HCW (90%) stated praziquantel as the appropriate treatment. Antibiotics were named from 5 (10%) HCWs as a treatment of FGS. Additional once named drugs do include for example antihistamines, albendazole or paracetamol.

From the women 76 (97.4%) would seek help if they would have gynaecological problems. Among these women, 44 (33.44%) would consult a CSB employee for treatment, representing the most chosen option when seeking for care. A midwife was chosen by 15 women (11.4%) as an element to seek care and 6 women (4.56%) would ask their husband for help.

Previously diagnosed with FGS were 11 (14.1%) of the women, out of them, no one was diagnosed via colposcopy, 2 (2.6%) respectively with a urine sample or a genital exam. In terms of medication each 2 (2.6%) women stated that they were treated with praziquantel or antibiotics. The other 7 (8.9%) of women of the general population did not remember the medication or took a different medication.

Overall, just a small proportion of participant previously had personal experience with FGS. Nevertheless, knowledge on treatment of FGS with praziquantel among HCW is good, with a smaller proportion of HCW also stating medication that is usually not used in FGS treatment, even though most of the surveyed HCWs had never seen a patient suffering from FGS in their professional life. Most of the women of the community are willing to search treatment for gynaecological problems, among them the CSB was determined as a focal point in seeking FGS care. Knowledge transmission in the region can be considered as rather low, with HCW mostly relying on other professionals and the general population sourcing knowledge through family and friends.

Concluding the quantitative analysis section, it is apparent that the previous knowledge in the general population is low, while in the population of the HCW the previous knowledge of FGS is more present. Quality of knowledge was overall low with no significant differences in the FGS knowledge score between the two groups. Nevertheless, the women did show a wider range in the quality of knowledge score.

## 4.2 Framework analysis

The following framework analysis aims to identify mechanisms through which awareness and related barriers and facilitators which can influence FGS treatment and diagnosis uptake among women of the general population in the Boeny region of Madagascar. Therefore, firstly the sample characteristics of the participants of the FGDs out of the women and HCWs were described. Afterwards, the contributors to the dimensions of awareness of FGS among the women, followed by the contributors to the dimensions of FGS awareness in the HCW are analysed. Thereafter, the acceptability of the FIRM-UP FGS campaign among the general population and HCW is displayed. Concluding this framework analysis is a comparison of HCW and women of the community.

### 4.2.1 Sample characteristics

In total, 53 respondents from the Boeny region of Madagascar participated in the focus group discussions. Out of the community 24 women participated in the FDGs at the primary health care centre of Marovoay (n=9), at the CSB in Antanambao Andranolava (n=6) and the CSB in Ankazomborona (n=9) (Table 5).

The overall age of the community women ranges from 18 to 46. In both, Marovoay and Ankazomborona the main occupation is trader, while in Antanambao Andranolava, the most rural setting, the main occupation is farmer and fisher. Overall 41.7 percent of the participants representing the community were traders and 33.3 percent farmer and fisher.

Three FGDs with 29 participants from the HCW were interviewed in the primary health care centres of Marovoay (n=12), the CSB of Antanambao Andranolava (n=7) and the CSB of Mahavoky Mahajanga (n=10) (Table 6).

The overall age of the HCW was ranging from 19–56 and the main occupation of the participants was student (58.6%) followed by midwife (20.7%) and nurse (10.3%).

**Table 5 Sample description FGD general population**

| Community (N=24) | CSB | | |
|---|---|---|---|
| | Marovoay | Antanambao Andranolava | Ankazomborona |
| | n (%) | n (%) | n (%) |
| **Total** | 9 (100) | 9 (100) | 6 (100) |
| **Age*** | 33.6 (18- 46) | 33.1 (19- 45) | 27.8 (20-45) |
| **Profession** | | | |
| Housekeeper | 0 (0) | 2 (22.2) | 1 (16.7) |
| Farmer & Fisher | 2 (22.2) | 5 (55.6) | 1 (16.7) |
| Student | 0 (0) | 1 (11.1) | 0 |
| Trader | 5 (55.6) | 1 (11.1) | 4 (66.6) |
| Community worker | 2 (22.2) | 0 (0) | 0 (0) |

Notes: * Mean (Range)

**Table 6 Sample description FGD HCW**

| HCW (N=29) | CSB | | |
|---|---|---|---|
| | Marovoay | Antanambao Andranolava | Mahavoky Mahajanga |
| | n (%) | n (%) | n (%) |
| **Total** | 12 (100) | 7 (100) | 10 (100) |
| **Age*** | 25.2 (19- 49) | 31.1 (21-56) | 26.6 (20-39) |
| **Profession** | | | |
| Midwife | 2 (16.7) | 2 (28.6) | 2 (20) |
| Service/ Support staff | 1 (8.3) | 0 (0) | 1 (10) |
| Student | 8 (66.7) | 4 (57.1) | 5 (50) |
| Nurse | 1 (8.3) | 0 (0) | 2 (20) |
| Community worker | 0 (0) | 1 (14.3) | 0 (0) |

Notes: * Mean (Range)

The discussion with the healthcare workers in Marovoay is partly influenced by the presence of an explanatory poster in the discussion room. Information that was clearly read from the poster are not being considered during this analysis. An extensive dialog about Schistosomiasis and FGS was cut short by the very scarce knowledge about the disease and treatment for adults in the discussion with the women out of the community in Antanambao Andranolava.

### 4.2.2 Dimensions of awareness among the general population

Following, the matrix charting thematizing awareness, test and treatment, access to information, socio-structural drivers, previous experience with FGS and the perceptions of a colposcopy screening were displayed (Table 7).

**Table 7 Matrix framework dimensions of awareness comunity**

| **Community (n= 24)** | **Number of participants** | **Example Quotes** |
|---|---|---|
| Themes | **n** | |
| **Awareness** | | |
| Aware of schistosomiasis: Knows of symptoms | 7 | Before, we always heard of bilharzia on the human body, i.e. blood in the urine (1-MK-F1, Focus group discussion Ankazomborona) |
| Aware of schistosomiasis: Knows infection source | 1 | Bathing at the water's edge (1-MK-F1, Focus group discussion Ankazomborona) |
| Aware of Female Genital Schistosomiasis | 2 | There is a bad smell, I spoke to the community worker who told me it is bilharzia because there is also pruritus (5-MK-F1, Focus group discussion Ankazomborona) |
| **Test & Treatment** | | |
| Treatment just for children | 1 | All children aged 5-15 years are given bilharzia pills, but women are not. (3-MT-F1, Focus group discussion Antanambao Andranolava ) |
| Treatment received without a diagnosis | 3 | There has never been a test here before, that's the truth. But there is distribution of bilharzia pills. (5-MV-F1, Focus group discussion Marovoay) |

| | | |
|---|---|---|
| Opting for alternative treatment strategies | 1 | I had bought at the pharmacy, there is something long like this that you put in the vagina, and when I took it, it disappeared. (4-MK-F1, Focus group discussion Ankazomborona) |
| Treatment costs | 1 | There is genital itch, and the doctor advised me to buy this. And it disappeared until now. It costs too much. (4-MK-F1, Focus group discussion Ankazomborona) |
| **Access to information** | | |
| Lack of information prior to campaign | 6 | We've already heard about bilharzia. But we never heard about FGS until you raised awareness. (5-MV-F1, Focus group discussion Marovoay) |
| Source of information: Community health worker | 2 | I spoke to the community worker who told me it is bilharzia (5-MK-F1, Focus group discussion Ankazomborona) |
| **Socio-structural drivers** | | |
| Not feeling affected by FGS | 1 | It doesn't matter for my health if I have it or not. So I wonder if I have this FGS? There's no [problem] with that. (2-MT-F1, Focus group discussion Antanambao Andranolava) |
| Rice farming is main income: Contact with water is not a6voidable | 4 | But going to the rice field is already a means of income for people, what can we do to avoid it? (3-MK-F1, Focus group discussion Ankazomborona) |
| Insufficient water and sanitation structure | 4 | There are even some who have toilets but are used to defecating in the open. (3-MK-F1, Focus group discussion Ankazomborona) |
| **Previous experience with FGS** | | |
| Suffering from FGS-Symptoms | 5 | I have pain here already, but I am still treating myself but about my uterus, most of the time I have miscarriage at 2 months of pregnancy, and I have abdominal pain. Even when I had my period, I have so much pain. (9-MV-F1, Focus group discussion Marovoay) |
| Suffering from general schistosomiasis symptoms | 3 | It hurts so much when I urinate, it hurts like it's burning, so that's probably schistosomiasis. (7-MV-F1, Focus group discussion Marovoay) |
| No previous experience | 3 | have not heard until this moment, (1-MK-F1, Focus group discussion Ankazomborona) |
| **Perceptions of Screening** | | |
| Positive attitude toward screening | 4 | Doing the screening is not a problem for me. (9-MT-F1, Focus group discussion Antanambao Andranolava) |
| Screening free of charge is good | 3 | So I was very happy when the community worker told me about free testing for women, I seem to like it (8-MT-F1, Focus group discussion Antanambao Andranolava) |

| | | |
|---|---|---|
| Screening is good for my health | 9 | Personally, for me, it's not a problem because it's being healthy that we are looking for. (7-MV-F1, Focus group discussion Marovoay) |

*Knowledge of schistosomiasis and female genital schistosomiasis*

Overall knowledge on schistosomiasis among the participants of the women from the community is incomplete. While a few women knew some symptoms of schistosomiasis, most seemed to know the disease in detail. One woman (1-MK-F1, focus group discussion Ankazomborona) showed more in-depth knowledge of schistosomiasis in describing the transmission pathway by contact to water and therefore was aware of the risk factors for contracting schistosomiasis. The women responding in the discussion of Antanambao Andranolava. did shortly touch on the effect and knowledge of the disease schistosomiasis itself for children, perceiving the schistosomiasis as a disease that primarily affects children and not adults.

*"In the past, for every child aged 5 to 15, we have heard"*

- 3-MT-F1, Focus group discussion Antanambao Andranolava

Knowledge of female genital schistosomiasis is particularly limited and an absolute lack of awareness of the disease can be observed. Several women especially mentioned that they never heard about female genital schistosomiasis before. When asked about the disease the women remained silent or stated that they do not have any knowledge of the disease. Only two women out of the 24 participants showed basic knowledge of FGS:

*"We did not know and there has not been any awareness here yet that it constitutes infertility. We did not know that it is [schistosomiasis] with haematuria that has consequences on the reproductive system until there is awareness like this."*

- 5-MV-F1, Focus group discussion Marovoay

The women are not aware that schistosomiasis can affect the reproductive system as well and therefore never considered it as a possible source of symptoms and consequences such as infertility.

*Access to information*

The main overarching theme in this category is the lack of access to information stated by the women prior to the FIRM-UP campaign. As the women 5-MV-F1 from the focus group discussion in Marovoay, who works as a community worker, stated:

*"We've already heard about bilharzia. But we never heard about FGS until you raised awareness."*

- 5-MV-F1, Focus group discussion Marovoay

This woman was showing in depth knowledge of the symptoms and consequences of schistosomiasis previously, yet she had no access to information about FGS prior to the campaign and therefore no knowledge nor awareness of the disease. This woman is representative of the main body of the interviewed women. One woman reported to be told about schistosomiasis in general by a community worker as she was treated by the community worker. Another woman reported to gained knowledge about FGS from a community worker as she was suffering from genital symptoms, these two were the only ones having a set source of information about schistosomiasis or FGS prior to the campaign.

*"I spoke to the community worker who told me it is bilharzia"*

- *5-MK-F1,* Focus group discussion Ankazomborona

*Previous experience with schistosomiasis*

The previous experiences of the study group can mainly be clustered under the experience of symptoms of either FGS or general schistosomiasis symptoms. Several of the women are suffering from gynaecological symptoms that can be caused by FGS or different gynaecological diseases. The women are reporting a range of symptoms from miscarriages over pain during sex or spot bleedings. These reports of symptoms are suggestive of FGS and can be found in all three focus group discussions.

*"I have pain here already, but I am still treating myself but about my uterus, most of the time I have miscarriage at 2 months of pregnancy, and I have abdominal pain. Even when I had my period, I have so much pain."*

- 9-MV-F1, Focus group discussion Marovoay

Other women are suffering from more general schistosomiasis symptoms, that are not specific for FGS. These women are mainly reporting fatigue or pain during urination. The reports of the general schistosomiasis symptoms are all found in the focus group discussion in Marovoay.

*It hurts so much when I urinate, it hurts like it's burning, so that's probably biliousness.*

- 7-MV-F1, Focus group discussion Marovoay

Among the women, three stated that they did not have had any previous experience with schistosomiasis or FGS. After stating this, some of the women said that this changed after the implementation of the FIRM-UP campaign.

*Test and treatment*

The women, responding that they were treated for schistosomiasis, mentioned that the treatment that they received or have given in the function as community worker was done without a previous diagnostic test. Overall, none of the respondents specifically mentioned the name of the medication for schistosomiasis, praziquantel. There seemed to be a general lack of awareness that one gets tested for schistosomiasis. Overall, none of the respondents specifically mentioned the name of the medication for schistosomiasis: praziquantel. The women were mostly talking about treatment in terms of mass drug administration, rather than individual treatment:

Treatment in form of mass drug administrations is not distributed by HCW but rather by community worker such as 5-MV-F1 from the focus group discussion in Antanambao Andranolava:

*"Regarding the distribution period [e.g. Mass drug administration] of the bilharzia pill, we distribute. It is at this time of distribution that the participants are [counted] and receive the pill. They ask us to treat them. They get a three-day treatment and that's it. Then, the next time it's time to take the pill, there will always be an announcement that there will be another one. But there hasn't been a test yet."*

- 5-MV-F1, Focus group discussion Marovoay

The same women that previously stated that she only knew about schistosomiasis in children, did mention that only children are treated for schistosomiasis in her area but no women. Women are mostly neglected in the mass drug administration procedures that are often performed in school aged children, even though women do suffer from schistosomiasis and particular chronic expressions of the disease as well. Therefore, a gap in the access to treatment can be observed due to misconceptions of the disease and focus of treatment administration policies on children:

*"All children aged 5-15 years are given bilharzia pills, but women are not."*

- 3-MT-F1, Focus group discussion Antanambao Andranolava

Another factor in relation to treatment was mentioned by one woman (4-MK-F1, Focus group discussion Ankazomborona).

*Socio-structural drivers*

Among the women, two main socio-structural driver were identified. When women were made aware of risk factors for FGS transmission, such as open defecation and contact to freshwater bodies such as rice fields, they situate the risk within competing concerns, such as the economic necessity of working the rice fields or the lack of clean water and sanitation. This concern was an ever-emerging theme in all three focus group discussions over the different cities:

*"But going to the rice field is already a means of income for people, what can we do to avoid it?"*

- 3-MK-F1, Focus group discussion Ankazomborona

Some of the women included in this study showed insecurities, if they will reinfect at work after the treatment or if an infection is even avoidable if they work in a rice field.

*"Is there a recurrence of the disease or not for those who go to work?"*

- 4-MT-F1, Focus group discussion Antanambao Andranolava

The participants discussed the habits and the missing risk perception of persons that even have the possibility to use sanitation infrastructure. Additionally, the participants stated that they are in a lot of contact with water in their daily life in the region. According to the FGD discussants some people in the region do not seem to be aware that open defecation might be a health hazard or are influenced by behavioural convenience not to use toilettes even if available:

*"There are even some who have toilets but are used to defecating in the open"*

- 3-MK-F1 Focus group discussion Ankazomborona

Rice farming is an economic necessity for the people living in this rural region, whether they are farmers themselves or traders who sell the produce on the markets of rather urban cities in the region. Elevated by the ever-present lack of clean water and partly insufficient sanitation structure, this dilemma might lead to resignation among the women, accepting a chronic infection as 'necessary evil'. Such a resignation can be observed in a woman showing a rather fatalistic outlook on the infection:

*"It doesn't matter for my health if I have it or not."*

- 2-MT-F1, Focus group discussion Antanambao Andranolava

*Perception of screening*

All women showed very accepting towards the screening procedure and were openly talking directly about their perceptions of a genital screening method. The common message from the general population towards the acceptance of the colposcopy screening itself is that there is no problem with the screening itself as it is about their health. Another factor that the women pointed out is that the screening is free of costs.

*So I was very happy when the community worker told me about free testing for women, I seem to like it.*

*8-MT-F1, Focus Group discussion* Antanambao Andranolava

The implementation of a screening procedure was therefore experiencing a good willingness of participation among the women. The important factors for the women, that need to be pointed out in the construction of possible campaigns, seem to be the health promoting aspect of a screening as well as the clarification of possible costs or the complete coverage of costs.

### 4.2.3 Awareness and influences among health care workers

Within the focus group discussions with the health care professionals, three very lively discussions were held. The discussion with the healthcare workers in Marovoay is partly influenced by the presence of an explanatory poster in the discussion room. Information that was clearly derived from the poster are not being considered during this analysis. The matrix framework of the dimensions of FGS among HCW is displayed in table 8.

**Table 8 Matrix framework dimensions of awareness HCW**

| **HCW (n= 29)** | **Number of participants** | **Example Quotes** |
|---|---|---|
| Themes | **n** | |
| **Awareness** | | |
| Aware of schistosomiasis: Knows of symptoms | 1 | In the past, we have heard that urine with blood, but in the genital area we have not heard, it is only the one with terminal hematuria at the end (7-MT-T1, Focus group discussion HCW Antanambao Andranolava) |
| Aware of schistosomiasis: Knows infection source | 4 | For example, in the countryside, going to the water's edge, to the rice field, bathing (3-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |
| Aware of Female Genital Schistosomiasis | 6 | There may be pruritus, there may be discharge, As 2-TT-T1 said there may be bleeding. (3-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |

| | | |
|---|---|---|
| **Test & Treatment** | | |
| Nonstandard of care Treatment | 3 | For example Benzanthine (7-MV-T1, Focus group discussion HCW Marovoay) |
| Treatment should be received by a professional | 4 | Go to the CSB, consult a doctor. (7-MV-T1, Focus group discussion HCW Marovoay) |
| Uncertainty around treatment | 2 | This disease looks like an STI (3-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |
| **Access to information** | | |
| From affected | 1 | I have heard this before from a victim. (2-MT-T1, Focus group discussion HCW Antanambao Andranolava) |
| Lack of information prior to campaign | 8 | We never heard until you informed her here (7-MV-T1, Focus group discussion HCW Marovoay) |
| **Socio-structural drivers** | | |
| Only men are affected by schistosomiasis | 1 | Most often, we know it when the man has haematuria. But for women, even if they have haematuria, they think they don't have it because it's always men who are affected. And it's always the men who have it. (9-MV-T1, Focus group discussion HCW Marovoay ) |
| Rice farming is main income: Contact with water is not avoidable | 3 | If you talk about this, they think you are going to destroy the means to feed their families by talking about the rice field. They say that the rice field, which is our means of feeding the family, causes disease. (9-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |
| Insufficient water and sanitation structure | 2 | The water here is dirty (6-MT-T1, Focus group discussion HCW Antanambao Andranolava ) |
| **Previous Experience with FGS** | | |
| Treated patients with FGS | 1 | I have heard this before from a victim. (2-MT-T1, Focus group discussion HCW Antanambao Andranolava) |
| No previous experience | 2 | Never heard (3-MV-T1, Focus group discussion HCW Marovoay) |

*Knowledge of schistosomiasis and female genital schistosomiasis*

In the participant group of the HCW, some participants do show knowledge of FGS. Women that are aware of the disease are giving insight into symptoms and consequences of the disease. Nevertheless, around 80 percent of the surveyed women seem not to be aware of the disease FGS as they did not give any response regarding symptoms or consequences of the disease. The participants that knew about FGS are from the focus group discussions among the HCW in Mahavoky Sud and Antanambao Andranolava. Women from the FGD in Marovoay did not contextualize FGS and stated that there is no knowledge about the disease before the campaign and then continued reading the symptoms off a display in front of the group. Among the symptoms and consequences thematized by the HCWs were for example miscarriages, bleeding, pruritus, as well as infertility of the women. Considering only the HCW aware of the disease, the knowledge of symptoms and consequences can be categorized as rather good, being able to name both mode of transmission and symptoms or consequences.

> *The mode of transmission is working in the rice field for example. The complication can be infertility.*
>
> - 2-MT-T1, Focus group discussion HCW Antanambao Andranolava

*Test and treatment*

While some of the respondents showed good knowledge of FGS transmission pathways and symptoms of FGS, the discussion of FGS treatment by the HCW revealed a lot of uncertainty around the choice of medication. One woman (3-TT-T1, Mahavoky Mahajanga) stated that the disease looks like a sexual transmitted infection (STI) the HCW explained that it is always assumed that it is automatically a STI if there are certain symptoms, and the treatment regime is following this assumed diagnosis.

Rather than FGS STIs seem to be more commonly considered when treating patients on a day-to-day basis:

> *When I used to work, because I used to work in the big hospital, most of the time you look at it and there is a sore, so you always think it's STI. Even the treatment is not for schistosomiasis.*

- 7-MV-T1, Focus group discussion HCW Marovoay

When women present with FGS-related symptoms of FGS these are usually treated as if they were indicative of an STI. Consequently, the treatment administered commonly involves antibiotics, such as nystatin, ceftriaxone, doxycline [..*doxi*] (2-TT-T1, Mahavoky Mahajanga), benzanthine or metronidazole. Praziquantel was not named by the HCW as a choice of medication for FGS or symptoms that might lead to a suspected FGS diagnosis, even though at least one nurse was aware that the treatment with antibiotics is not the standard of care treatment for schistosomiasis.

All three focus group discussions had in common that the treatment should be given at a health care centre or by a doctor, while only in the discussion of Marovoay it was said that women suspecting to be ill with FGS should go to the local CSB. Primary level of care such as the CSB is scarcely seen by the HCW as the level of care for FGS, rather seeing the treatment and diagnosis at secondary or even tertiary level of care, which would represent harder access to appropriate care for especially for rural populations.

*Access to information*

All but one HCW, stated that they had no access to information about FGS prior to FIRM-UP awareness campaign.

*We never heard until you informed here*

-7-MV-T1, Focus group discussion HCW Marovoay

The one exception was a HCW (2-MT-T1, Antanambao Andranolava) who had gained knowledge of the disease from an affected patient directly. No other HCW neither midwifes nor nurses in our study had ever worked with an FGS patient before.

*Socio-structural factors*

The discussion of the HCW thematized the risk perception of the disease by their patients and is dominated by the conflict that the HCWs are seeing for the rural population between the necessary contact to water to provide for the family's income and the view of these water sources such as rice fields as sources and risk of infection. This conflict of interest is the main concern of the HCWs when talking about risk perception and communication of the infection risk as well as the interest of patients in receiving treatment.

> *If you talk about this in the countryside, they won't be interested. If you talk about this, they think you are going to destroy the means to feed their families by talking about the rice field. They say that the rice field, which is our means of feeding the family, causes disease*
>
> -9-TT-T1, Focus group discussion HCW Mahavoky Mahajanga

The same HCW further expressed the direct concern of the connection from rice field and disease in the active awareness raising and that it might lead to a disapproving the campaign and leads to a lowering of the acceptability. This concern was stated as well by 4-MT-T1 from the focus group discussion of Antanambao Andranolava.

> *And if I raise awareness about schistosomiasis, they will say that this nurse has gone crazy because the rice field causes a disease. So no one will be convinced.*
>
> -*9-TT-T1,* Focus group discussion HCW Mahavoky Mahajanga

To reduce this conflict potential 9-TT-T1 and 5-TT-T1 suggest putting more emphasis on the perception of the disease as a facilitator for infertility than on the rice field as a possible path of transmission. Additional to this conflict between income provision and infection source, one HCW is mentioning that the general population often only perceives a risk of schistosomiasis in men and not in the female part of the population.

*Most often, we know it when the man has haematuria. But for women, even if they have haematuria, they think they don't have it because it's always men who are affected.*

-9-MV-T1, Focus group discussion HCW Marovoay

Concluding the risk perception of the HCWs, another factor that is perceived as a risk for infection by the HCWs is the dirty water in the region.

### 4.2.4 Acceptability of FIRM-UP campaign among rural women

Overall, the campaign was very well received by the general population. Some suggestions were made and are displayed in the following as well as key facilitators in the uptake of the campaign. The framework matrix for the acceptability of an awareness campaign on the example of the FIRM-UP project is displayed in table 9.

The women made recommendations towards the logo of the campaign. The display with the women's head in the centre is looking rather like a disease that is affecting the brain, than a reproductive tract disease. The women suggested to add a logo referring directly to the female genitalia. There was no problem with this rather direct imaging of a genital in a logo. Furthermore, the interpretation of the FIRM-UP logo displaying a women's head with a *Schistosome* lead to misinterpretation. Participants were thinking the logo was about AIDS, headaches or that the disease mainly was affecting a set ethnicity due to its dark colour.

The women are suggesting proceeding with the testing and to implement a test-based screening programs for men and children as well. This might indicate a high willingness to further participate in screening and treatment campaigns for all members of the community.

**Table 9 Campaign acceptability community**

| **Women of the general population (n= 24)** | **Number of participants** | **Example Quotes** |
|---|---|---|
| Themes | **n** | |
| **Campaign acceptability** | | |
| Women responded overall positively to the campaign | 8 | Yes. The FIRM-UP project is perfect for us living in the countryside. We live on it every day. (2-MT-F1, Focus group discussion Antanambao Andranolava,) |
| **Campaign feedback** | | |
| Logo is misleading | 7 | We are in a meeting and we can understand because you explain it to us, but if it is posted on a wall, people don't understand it, it is a person with a headache or what? (3-MK-F1, Focus group discussion Ankazomborona) |
| Campaign should be continued | 1 | It's O.K. but what I like, the test should always be continued. It's like we're doing this in January or February, and it should continue. Because we in Marovoay, we are really immersed in water, we soak in water (5-MV-F1, Focus group discussion Marovoay) |
| Campaign should be for males/ children as well | 1 | For men and for children too, because children are also wriggling around there, we don't know anymore. We're asking you for the screening for men and children please. (5-MV-F1, Focus group discussion Marovoay) |

### 4.2.5 Acceptability of FIRM-UP campaign among healthcare workers

The discussions with the HCW mainly focused on the providers view of the screening and contextualizes the setting of the screening as well as the cultural considerations specifically for Madagascar to be taken when implementing the screening and the community-based awareness campaign in the region. The framework matrix for the campaign acceptability is displayed in table 10.

**Table 10 Campaign acceptibilty HCW**

| HCW (n= 29) | Number of participants | Example Quotes |
|---|---|---|
| Themes | n | |
| **Perceptions of Screening** | | |
| Being screened by a Male person can be problematic | 5 | If it's a woman looking at it, it's okay. But if it's a man, it looks weird. If it's you, it's okay because you are a woman like her. If it's a man, it can be embarrassing. (7-MV-T1, Focus group discussion HCW Marovoay) |
| Colposcopy is rarely used | 1 | This is rarely used (1-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |
| Many people in the room can be problematic | 1 | There are so many frustrations when so many people watch it. (2-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |
| A local person should do screening | 1 | Yes, it is true. Once if it is a man, she becomes shy. If possible, a Malagasy man should be present. (7-MT-T1, Focus group discussion HCW Antanambao Andranolava) |
| **Campaign acceptability** | | |
| Women responded overall positively to the campaign | 3 | It's okay. (1-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |
| Not sure if campaign is right | 1 | Personally, I don't know if it's right what you're doing (3-MT-T1, Focus group discussion HCW Antanambao Andranolava) |
| **Campaign improvement** | | |
| Logo is misleading | 3 | About this logo, I think it's in Africa because the picture is too black (7-MV-T1, Focus group discussion HCW Marovoay) |
| Intervention sites should be different | 4 | So as soon as you talk about this in the hospital, they just pass by, you will not get them because going to the hospital will waste their time. If you talk about this at the CSB […] you raise awareness about schistosomiasis […] (9-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) |

One HCW (1-TT-T1, Focus group discussion HCW Mahavoky Mahajanga) stated that colposcopy is rarely used in her practice as a midwife. This states the need for specifically designed trainings, as done in FIRM-UP, for the use of colposcopy for the HCW before implementing the colposcopy screening. A perceived barrier for the screening from the HCWs is the presence of male doctors or study personal during the screening process. The women also recommended that at a local person should do the screening as well as the limitation of number of people being in the room to avoid dropouts during the study process.

> *If it's a woman looking at it, it's okay. But if it's a man, it looks weird. If it's you, it's okay because you are a woman like her. If it's a man, it can be embarrassing.*
>
> -7-MV-T1, Focus group discussion HCW Marovoay

The logo of the campaign was discussed by HCW as a bit misleading and hard to interpret. One women pointed out that the logo was targeted at the wrong ethnicity so that it seems like the disease is only present in [mainland] Africa due to the colour of the logo. This might lead to problems in the realisation that the campaign is targeted at Malagasy women and create a barrier in raising interest in the campaign among the target population. The HCW suggested to a logo with a uterus on it, to make the purpose of the screening clear on first sight.

A discussion about the campaign language was held among the HCWs, some have the opinion that the campaign text on Facebook for example, should be in Malagasy first and then in French. Others advocated for French as the primary campaign language for HCWs as some specific terms medical terms do not have an adequate Malagasy translation. On the other side, HCWs augmented that not every person is able to read French properly.

One HCW shows hesitant if the campaign structure is as fitting as it is carried out. She suggests involving the village presidents as they know the people and can announce the campaign among them.

## 4.3 Triangulation awareness survey and framework analysis

On the basis of the quantitative and qualitative findings of the thesis, four key dimensions were identified, which interlink with the level of FGS awareness in the Boeny region of Madagascar (Figure 17). The dimensions identified are (1) delivery of information, (2) the socio-structural factors, (3) personal health behavior, and (4) local infrastructure. Further, awareness facilitates the willingness for uptake of diagnostic services in the community that might lead to adequate diagnosis and treatment of the disease by HCW, and is hypothesised to influence future adherance to treatment by the community.

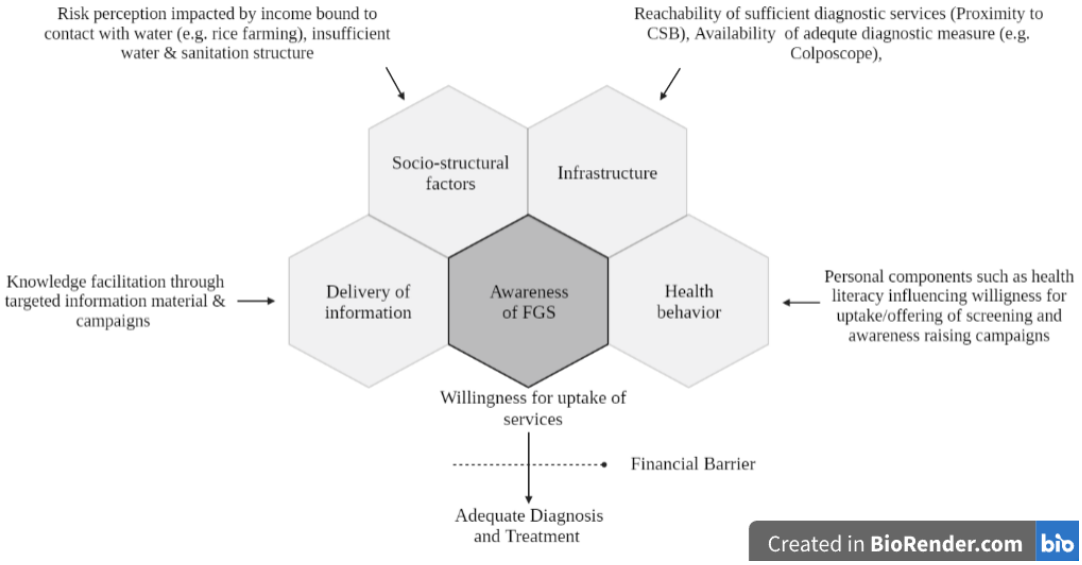


**Figure 17** **Dimensions of awareness of FGS in the Boeny region of Madagascar**
Displayed are the interrelated dimensions of FGS awareness and selected examples of barriers or facilitators.. Clockwise the dimensions are delivery of information, socio-structural factors, infrastructure and health behavior. Awareness is influencing the willignes for uptake of services, impacted by an external financial barrier. Considering the dimensions of awareness and its influncing factors in the provision of diagnostic services is a facilitator for adequate diagnosis and treatment of FGS in the region

# 5 Discussion

FGS is a highly neglected disease, causing physical as well as psychological consequences due to stigma and infertility. Adequate access to FGS diagnostic and care in primary health care settings is not established in Madagascar. Additionally, reliable data on the awareness of FGS were not available. Therefore, this thesis evaluated the dimensions of awareness in the Boeny region of Madagascar among women from the community and HCW using a mixed-method approach to determine barriers and facilitators of the dimensions of awareness. Knowledge of FGS and access to treatment and care were assessed using a quantitative approach. In a second analysis, data collected through FGDs with the general population and HCW enriched the baseline assessment, portraying barriers and facilitators on access to care and successful diagnosis and treatment in the region. In a concluding step, the dimensions of awareness, specifically delivery of information, socio-structural factors, infrastructure, and health behaviour, with the associated barriers and facilitators were elaborated.

While both HCWs and general population have knowledge regarding general infections with *S. haematobium*, knowledge on FGS is lacking, especially for the general population, even though multiple women are suffering from possible FGS symptoms. While both study groups showed similar in depth-knowledge among the participants that previously heard of FGS, HCW presented better knowledge of FGS in the FGDs. Among the knowledgeable, the most common information sources for HCWs were other HCWs and for the women family or friends were the main source of information. Both correct (Contact with water) and incorrect (oral pathways such as drinking water or sexual pathways) routes of transmission were named. Misconceptions about sexual transmission and possible symptoms of FGS mistaken for those of an STD are facilitating psychological strain on the diseased. While colposcopy is not often used by the HCW as a diagnostic mechanism in their daily life, women from the community are not hesitating to accept colposcopy screening. The free colposcopy exam is perceived among the women as a facilitator of health.

The results showed an elevated need for a target group specific improvement of awareness, considering all four determined dimensions of awareness such as delivery of information, socio-structural factors, infrastructure, and health behaviour.

Similar results from the rural, peri urban and urban areas might suggest that the findings of this thesis can be transferred to different contexts in Madagascar. We can speculate that increased awareness among HCW and community can lead to improvement of treatment uptake, diagnosis of the disease and adequate treatment.

## 5.1 Discussion of triangulation

The first dimension of FGS awareness in the Boeny region of Madagascar among HCW and women from the community is the delivery of information for the disease. While general schistosomiasis knowledge is presenting well, knowledge especially on FGS is lacking among the general population. HCW do show overall greater knowledge of the disease. In depth knowledge among the participants that have heard of FGS before presents low among both the HCW and the community. Therefore, targeted information facilitation presents vital to raise awareness of the disease. Diverse information sources such as radio, flyer and campaign staff provide a multi-channel approach of reaching the target population, facilitating the transfer of knowledge. Another contributing factor of information facilitation is the training of diagnostics and knowledge of treatment, whereas sustainability of information needs to be considered (e.g. train the trainer). Barriers in the information facilitation were found in the language of the campaign material and misunderstandings of the logo of the awareness campaign.

The second dimension, describing the context of FGS awareness is the consideration of the living environment as the socio-structural determinants. To ensure targeted tailoring of awareness messages, the individual setting needs to be considered. The Boeny region is heavily influenced by activities of daily life that require contact with possible infection sources of schistosomiasis such as rice farming. Susceptibility for awareness raising measures that target rice farming may be impacted by the indispensable relation of the income to this possible transmission pathway, presenting a barrier for the awareness of FGS in the region. On the other hand, the living environment can facilitate the awareness of the disease as well. Participants can directly identify possible infection sources such as rivers or insufficient water and sanitation structure in their direct surrounding and daily living patterns. This might elevate risk perception of the disease and the willingness to participate in knowledge building interventions.

The third dimension related to FGS awareness refers to the infrastructure of the health facilities and the region. The point of first contact when seeking health care is an important component in the analysis of the infrastructure in the region. Considering important infrastructural points of daily life such as markets or hospitals in the design and targeting of awareness raising measures can facilitate a good outreach of the measures. The CSB is mainly named by women as the point of health care seeking for gynaecological diseases, availability of diagnostic measures and consideration of this infrastructural point that these primary health care centres represent can lead to a reduced barrier to participate in screenings and to build awareness of the disease.

The final dimension influencing awareness of FGS in the Boeny region of Madagascar is the individual health behaviour, including individual health literacy or perceived susceptibility and severity of the disease as an important component of health behaviour. These four components can influence the decision and willingness of a person to participate in awareness raising measures. An approach considering health behaviour and the associated health literacy as well as the status of susceptibility of an individual and the individual rating of the severity of the disease can be a promotor of the uptake of awareness raising measures.

Among the HCW in the Boeny region, high functional health literacy, such as reading, and writing can be observed. The women of the general population have a higher number of participants that just received primary or less education, what might indicate a lower functional health literacy in this group. Adapted information material for each level of individual health behaviour can facilitate awareness of FGS. Interactive health literacy as an influence among the participants was seen for the HCW mostly among other HCWs, while the community mainly discussed the disease among friends and family. High perceived severity among the women can be observed, due to death as a suspected consequence of FGS.

Overall, the willingness of the general population to participate in screenings for diseases was very positive. Screenings are perceived as important for health and therefore, women are happy to participate in the colposcopy screening.

### 5.1.1 Influence of awareness on diagnosis and treatment

The previously named dimensions do influence the overall awareness of FGS in the Boeny region of Madagascar among HCWs and general population. Awareness as the by Saurman (2015) adapted 6th dimension of the framework of access to health care services by Penchansky & Thomas (1981) represents a direct influence on the correct diagnosis and treatment of FGS, as well as the uptake of the service by the women of the community. Similar outcomes in different diseases with a positive influence of awareness-based health promotion activities on the uptake of breast cancer diagnostic measures were observed through a systematic review (81).

Awareness in the region is shaped by external dimensions, such as knowledge facilitation and the context in the region, including its socio-structural characteristics and the infrastructure, as well as the internal dimension, including individual factors such as health behaviour. As awareness in the community for the disease is currently lacking, diagnosis with adequate diagnostic mechanisms present challenges due to insufficient training as well as the availability of colposcopy in primary health care settings within the region. Low awareness of FGS presents a barrier to both equitable access to FGS care and providence of the services through HCW and facilitate misconception about the disease. Consequences of low awareness are the observed underreporting and undertreatment of FGS observed not only in the region but worldwide, contributing to the status as a highly neglected disease.

This thesis furthermore determined a possible financial barrier beyond the awareness that might influence the uptake of diagnostic measures among the community. The determined awareness influencing dimensions each contribute to the overall awareness of the disease, enabling the knowledge of the disease to be elevated. Resignation in the willingness to build knowledge through socio-structural factors such as the inevitability of water during work activities is preventable if awareness raising activities do address their points in a targeted and sensitive way. Improved awareness of the disease and its correct diagnosis and treatment can prevent misdiagnosis of FGS as an STI, followed by unnecessary treatment with antibiotics as well as associated stigma of the disease.

## 5.2 Comparison of findings with current literature

Several findings of this thesis are in line with the recent literature results such as Kukula et. al. (2019), describing the misunderstanding of FGS as an STD and related mistreatment with antibiotics (9). In the baseline awareness survey, among the knowledgeable most HCWs rightly identified PZQ as the medication of choice for FGS, though some suggested non-standard of care treatments such as antibiotics. While through quantitative data collection the right treatment was described, when digging with FDG it was found that there was no description of the right treatment of the disease. This could be associated both to an unclear knowledge of the diseases but also linked to methodological weaknesses such as recall bias. All medications listed by the HCWs for treatment of FGS belonged to the group of antibiotics and therefore a non-standard of care treatment. Regarding the treatment a common theme among FGDs and baseline study was that most HCW have never seen a patient with FGS before, showing a low experience with the disease in the daily clinical life.

Similar results were seen in Mazigo et. al. (2022), where HCW did not consider FGS in the initial diagnosis process and systematically first treated for STDs before considering FGS as a possible diagnosis. In line with the association with the disease as an STD, sexual transmission was named in the results of this thesis as a possible transmission pathway by both HCW and general population next to the actual pathways. This is a common misconception of the transmission pathways of the disease not only found in Madagascar, but also in the study conducted in Tanzania by Mazigo et. al. (2022) (60).

While FGS infection and transmission pathways were perceived as sexually related by both HCW and community, no knowledge on the relation of FGS and HIV or HPV infection was present in the sample. Even though the association of the risk between FGS and HIV and HPV is named in the clinical atlas of FGS for HCW by the WHO published in 2018, no HCW in the baseline awareness assessment selected increased risk of HIV or HPV infection as a possible consequence of FGS (13). In comparison to this the study conducted by Mazigo et. al. was able to show knowledge of the relation between HIV/HPV and FGS within their smaller, solely qualitative sample in Tanzania. Differences in the information facilitation between Madagascar and Tanzania could be compared to evaluate differences in the availability of information resources such as the clinical atlas.

More research in this field is needed to establish valid comparisons of the status of FGS co-infection knowledge with other countries and cultural settings. Nevertheless, it might be hypothesized that the HCWs in the Boeny region are lacking specific in-depth knowledge of FGS that is already present in other countries.

Surprisingly, the women are showed a high willingness to take part in screening measures and mostly display a positive attitude towards colposcopy. The literature was suggestive of barriers for the screening of FGS regarding the sensible nature of genital screening measures and of fear of accessing health care services due to stigmatization generating concerns for the successful conduct of the study (9,61). These concerns were found not present within the sample. Many women were interested in taking up the screening package that was offered to them, identifying the screening as important for their health. So far, women were mainly not tested before being treated for FGS or schistosomiasis and only targeted during MDAs. The willingness to participate in screenings was very high among the women, projecting a good uptake if diagnostic services in the region will be offered.

Additionally, the women named death as a suspected consequence of FGS, showing a high perceived severity of the disease among the women in the Boeny region of Madagascar. Death was not displayed among the multiple-choice options in the questionnaire but was added by the women under the available free text option for other mentions. A high perceived severity has been previously determined as a component of schistosomiasis related health seeking behaviour in a study in Ghana. Danso-Appiah et. al. (2010) stated perceived severity as the most important determinant in visiting a health facility for schistosomiasis (82).

As a disease of poverty, schistosomiasis represents a big strain on already impoverished and marginalized population. Madagascar has a poverty headcount of over 70 percent in mainly the rural areas of the country. Therefore, awareness facilitating campaigns considering socio-structural components and the infrastructure of the target population is vital to prevent rejection of the campaign among the population.

Within this study, one of the main reported barriers in the dimension of the socio-structural factors is the main income source of the community representing an infection risk. This makes the conveyance of the transmission pathway a sensitive topic, which might not be a factor in differently structured populations and settings. Emphasizing rice farming in the first point of contact with the campaign to capture interest might create disapproval of the awareness raising activities. Instead, the participants recommended to focus on consequences of the disease such as infertility when first contacting the community to improve the adherence to the campaign and reduce the potential of conflict. This factor was not yet seen in one of the studies that previously examined the awareness of FGS.

As a barrier to the access to diagnosis and treatment of FGS not influenced by the awareness financial barriers were named. The offered free diagnosis package was perceived very positively. This barrier is also described the existing literature on access to FGS treatment and care, such as in Masong et. al (2021), defining socioeconomic challenges as an influencing factor for the uptake of diagnostic and treatment services.

## 5.3 Mixed method designs in awareness research

While there are plenty of publication on general schistosomiasis in Madagascar, previous studies assessing FGS in Madagascar were published more than 20 years ago and only assessing prevalence and clinical presentation of the disease (83). Considering this, no comparable studies are published assessing the awareness of FGS in Madagascar currently. The few assessments of the awareness of FGS that are comparable to this thesis were conducted in different cultural and geographical settings such as Tanzania, Ghana, Cameroon or Egypt (9,46,59–63). These studies were performed through qualitative methods and targeted HCW, general population or both. One study conducted in Cameroon combined a clinical assessment and questionnaire of clinical history with interviews and an observational approach in form of a ethnographic participant observation (46).

In this thesis, the study design based on a mixed-method approach gave the advantage of assessing the overall knowledge of FGS in a lager sample and to portrait the proportions of knowledge distributions within this population as well as gaining first insights on the barriers and facilitators of awareness. The applied mixed method design combined both inductive and deductive logic of thinking, strengthening the results.

Through the FGDs, a different view on the levels of awareness and an in-depth assessment of the dimensions that influence awareness was provided. Subsequently, through triangulating these two methodological approaches a multidimensional visualisation of awareness and its influence on willingness, uptake and diagnosis of FGS was provided.

Nevertheless, through the application of this research design focus moved from a one-dimensional knowledge assessment to the investigation of facilitators and barriers of awareness in the region and to further explore the mechanism of diagnostic and treatment uptake. The combination of the results from both sections allowed to build a more dimensional picture of the influencing factors of awareness for FGS in the region. Therefore, the choice of a mixed method approach presents a strength of this thesis and enriches the results in comparison to previous studies.

# 6 Limitations

While this study offered a selection of interesting findings and defined the dimensions of awareness in the Boeny region of Madagascar, three main limitations need to be acknowledged when discussing the results.

Firstly, data collection was heavily influenced by the SARS-CoV-2 pandemic due to the timeframe of the data collection from 2020-2021. To ensure the safety of all participants and study personal, the FGDs were moved from initially being planned simultaneously with the baseline knowledge assessment in September 2020 to November 2020 for the women. The FGDs with the HCW were moved to August 2021. Awareness raising activities were already going on in the region when these discussions were held, therefore most women are stating that they did not know of FGS before the campaign. Additionally, several months in between the assessments of the women of the community and the FGDs with the HCW could have an impact on the results presented in this thesis.

Secondly, the chosen region was selected based on the expected high prevalence of *S. haematobium* as indicated by first prevalence assessments of schistosomiasis in the region. At the moment there is no published prevalence of FGS in the Boeny region of Madagascar available. Nevertheless, with the upcoming publication of colposcopy-based prevalence data from the FIRM-UP project, this limitation will be revoked.

Thirdly, the main limitation of the presented data is the restricted variety of gender. While urogenital schistosomiasis does not solely infect women, male genital schistosomiasis is a highly neglected disease as well. Due to the selection of the target group, only women were surveyed and the dimensions and status of awareness of male genital schistosomiasis in the region were not explored.

Recognizing these limitations, the results of this study provided an in-depth view on awareness of FGS and its determining dimensions with associated facilitators and barriers among women and HCW in the rural Boeny region of Madagascar. Additionally, the impact of awareness on the access, diagnosis and treatment was displayed.

## 6.1 Methodological limitations

Additional to these three main limitations of the study, methodological limitations need to be considered and mitigated. In a mixed-method design, breadth and depth of understanding are enriched through balancing out strengths and weaknesses of both investigational approaches (73). While the quantitative section of this thesis gave limited information on the influencing factors of absence of FGS knowledge through a restrictive branching logic and closed question, clear results with minimal influence of the interviewers were produced. To capture community-specific items like the additional mentioning of death as a suspected consequence of a disease it is recommended to design closed question with an additional option to add free text, but also train the interviewers accordingly, that information that correspond with one of the available closed answers are not entered in the free text option.

Interviewer bias needs to be considered when discussing the qualitative analysis section. Measures to minimize the influence of the interviewer on the results were taken through detailed interview guidelines and statements in the topic guide. Additionally, not all passages from the FGDs were possible to transcribe due to multiple persons speaking at the same time of the recording. The interview transcripts were translated twice, from Malagasy into French and then into English. It might be possible that certain sentiments are different in the translated versions and therefore a translation bias cannot be excluded. This effect was mitigated by a native speaker cross checking the translations for plausibility. Personal interpretation and influence of the analyst was documented in the familiarization reports to ensure transparency in the individual understanding of the transcripts.

During the first day of data collection from the baseline awareness assessment, no occupation of the HCW were entered into the database, generating n=54 systematically missing values. Missing values in more than half of the participants hindered a previously planned comparison of knowledge between the occupational groups. To detect systematically missing values like this earlier, a check-up of the collected data after the first ten participants could improve the recognition of patterns in missing data early in the study process.

Through the non-randomized sampling applied in the awareness survey it was possible to generate enough participants, nevertheless it needs to be considered that this sample is likely to be influenced by a certain degree of sampling bias. More participants were sampled in the community than in CSBs and hospitals. While women with no knowledge of FGS were most likely found in community spaces such as markets or the participants home (n= 605 [83.2%]), women from the community that heard from FGS before were most often sampled at the hospital (n= 76 [81.7%]). A more balanced sampling approach with equal sized groups from CSBs, hospitals and markets could improve the external validity of the sampling approach.

The sampling of the FGDs was based on the selection of potential information rich cases, picked among a list of available participants. While the distribution of occupations among the general population showed more diversity, the discussions with the HCWs were sampled with at least half of each discussion group being students. As the students were not able to participate a lot in the discussions due to scarce knowledge, an adapted sampling is recommended to further enrich the results of the FGDs, opening more potential to identify additional facilitators and barriers of the dimensions of awareness. To optimize the qualitative data collection process, the topic guides pre-interview section should be adapted to ensure the check-up of the interview room before starting the FGD, due to the HCW in Marovoay being influenced by the presence of a campaign poster in the room during the discussion.

# 7 Recommendation for action

Results show low levels of FGS awareness in a sample of women and HCW in Madagascar. Findings align with existing literature describing underreporting and undertreatment of FGS as a result of the influence of awareness on access to health care (9,60,61). Identifying gaps in FGS awareness and determining the influencing dimensions can inform the design of targeted FGS awareness campaigns to improve the health of women affected in Madagascar. Based on this research, future awareness raising activities in the Boeny region could consider the determined dimensions of awareness and the facilitators and barriers found in this thesis to design expanded, target population centered awareness campaigns. These campaigns can fill the existing gap in knowledge for the general population as well as for health care workers. Through a sensitive and target population adapted awareness building approach, uptake, and correct diagnosis as well as treatment of the disease could be improved, and existing barriers could be minimized.

Knowledge promoting activities are needed to improve the scarce knowledge of FGS among women and HCW in the region while considering the unique influencing factors of this setting. Approaches that combine the consideration the socio-economic status, and the living context of the participants are needed. Joint efforts in the areas of agriculture and disease awareness might offer a solution for the inevitable contact to water in the rice fields of the region and break down barriers for the access to knowledge building efforts. Improved knowledge on one hand will help to eliminate unnecessary treatment with antibiotics and on the other hand inform the community about the consequences of the disease, supporting marginalized women struggling with gynecological symptoms or infertility.

The overall very positive perception of colposcopy screening among the women represents a promising starting point for the introduction and uptake of routine colposcopy screenings implemented in a primary care setting in the region as proposed by the additional work packages included in the FIRM-UP study. Additionally, the positive perceptions of a gynecological screening are not only applicable in the context of FGS but could furthermore represent an advantage in view of planning integrated programs which include screening for multiple gynecological disorders including cervical cancer.

In addition to these measures proposed for women, perceptions and influencing factors of the male citizens of the Boeny region could be portrait under the addition of male genital schistosomiasis in the frame of a follow up study. Furthermore, additional research could explore the transferability of the determined dimensions found in this thesis in a low prevalence setting and the transferability to different cultural and geographical contexts. Future research regarding FGS, including assessment of the prevalence and strategies to raise awareness in different settings as well as framing policies for a routine implementation of FGS screening are needed to tackle this highly neglected disease.

The study FIRM-UP was conducted by the BNITM from Hamburg, Germany, and the University of Antananarivo, Madagascar. The results of this thesis are bound to be compared to a quantitative and qualitative post-assessment of the awareness of FGS in the region at the end of the FIRM-UP study to evaluate changes in FGS awareness, acceptability, and uptake among the target population and HCWs. Additionally, the results can contribute to inform future awareness raising activities conducted by the FIRM-UP study team in the Boeny region of Madagascar.

Furthermore, the results of this thesis will help to assess the feasibility of a FGS community-based intervention and the implementation of colposcopy in a primary health care setting. Future awareness campaigns can build on the determined dimensions of this thesis to formulate a target group specific approach for the improvement of FGS awareness.

# 8 Conclusion

This thesis described the status of FGS awareness in the Boeny region of Madagascar in combination with an assessment of the awareness related barriers and facilitators in the region among the general population and the HCW for the first time. Triangulating qualitative and quantitative results, the dimensions of awareness in the region were defined and influencing mechanisms of barriers and facilitators on the uptake and correct treatment and diagnosis of FGS were evaluated and visualized.

As key results, four determined dimensions with an influence on the uptake and offer of adequate diagnosis and treatment of FGS were proposed. The dimension of information delivery was defined by the low baseline knowledge of FGS, while good knowledge on general schistosomiasis is present in the community. Similar effects were seen in the population of the HCW. While proportionally a higher number of knowledgeable persons were observed, the quality of the knowledge was similar as in the community. Uncertainty around treatment and misconceptions with STI due to the lack of proper information facilitation were observed among the HCW. The determined dimensions of socio-structural and infrastructure described the influence of the context on awareness. The main source of income in the region is rice farming, which presents a barrier to awareness due to the inevitability of this potential source of infection and might lead to resignation. Another contributing factor of the context is available infrastructure in the region and the first point of contact of information and health care. Lastly, internal components of the health behavior such as health literacy and perceived severity are influencing the willingness of participant to take up awareness building measures. The results of this thesis showed a high perceived severity of FGS among the women, influencing the willingness to uptake health care in a positive way.

Awareness as a component of access to healthcare is determined by multi-dimensional influences, considering these specific factors can promote the facilitation of awareness and influence the uptake of treatment and diagnosis among the general population as well as the offer of adequate treatment through HCW in the region.

The findings suggest that the identified knowledge gaps and dimensions of FGS awareness can inform the design of targeted FGS awareness campaigns to improve the health of women and improve the uptake and quality of diagnosis and treatment of this highly neglected disease in Madagascar.

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# Declaration of academic honesty

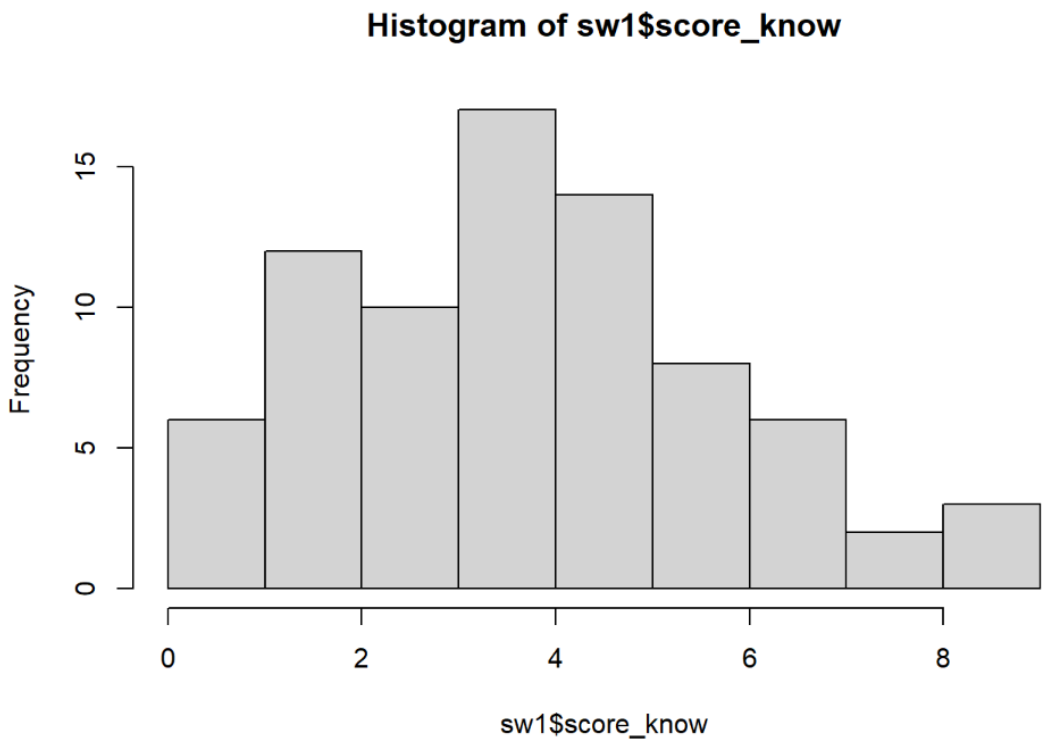
Hereby, I declare that I have composed the presented thesis independently on my own and without any other resources than the ones indicated. All thoughts taken directly or indirectly from external sources are properly denoted as such. This thesis was not presented to another examination office before the submission today.

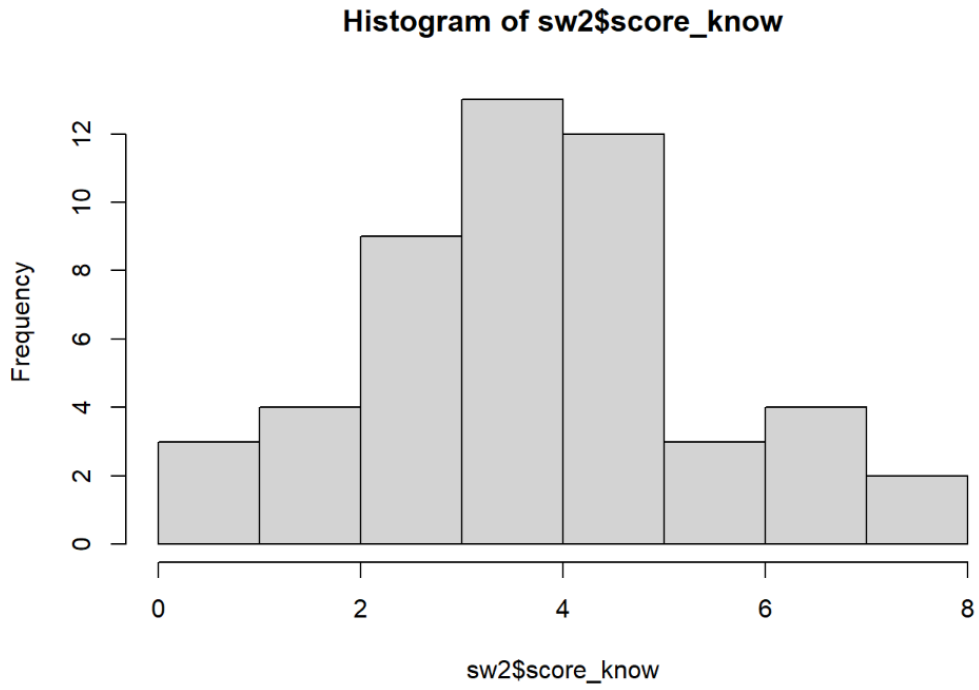
Hamburg, 20.10.2022

Pia Rausche

# Annex

## Annex A Histograms knowledge score



## Annex B Familiarization reports

Discussion of health workers at CSB Marovoay

Duration of the interview: 33 min 0 sec

Date of the interview: 18.08.2021

**No Knowledge of FGS before the campaign, symptoms are treated as an STI**

The participants do not have any knowledge of FGS before the campaign. There is only knowledge of urinary schistosomiasis with blood in the urine and terminal hematuria in the end. During the interview they are sitting right next to a display of the FIRM-UP campaign, so they read the symptoms of it. Named as symptoms of FGS are abdominal pain, vaginal discharge, genital pruritus, and infertility. The mode of transmission over swimming in water over the larvae that came into the water by someone urinating in it is known. If someone is suspecting to have FGS they should go to the CSB or doctor. Some of the participants know the speculum, one does not. The speculum is used often at the maternity hospital for abortion/miscarriage exam or IUD removal or insertion. For STDs the speculum can be used to look at the condition of the cervix. When there is a sore the personal in a big hospital always thinks about and STI and treats it therefore with for example Benzathine. They never had a patient with FGS. For the screening one participant says it always should be a woman, another one says if it's a man, there should be a conversation with the patient beforehand and the patient can refuse or accept. Several people have already signed up for the screening. Most often it's the men who have hematuria, the women often don't think they are affected. The logo of the FIRM-UP campaign lets the participants think that the screening is in (central) Africa because its so black and it looks a bit like the disease goes to the head. The display needs to be a bit enlarged and substituted with more information on screening and disease. The flyer for the health care workers is only in French, it should be in Malagasy as well. There is a need to raise awareness in the rural areas by maybe going door to door. The dates of the screenings are a bit unclear for the participants.

*Memo: The placement of the interview setting next to the FIRM-UP display is a bit complicated, the participants are just reading of the poster for major parts of the interview. It is not really their own status of knowledge.*

| Person & Backstory | Core Content | Topics |
|---|---|---|
| 1-MV-T1<br>Student, Age 20<br>Itandrava | - Everything regarding the exam in case a man does it has already been said | - Barriers and facilitators |
| 2-MV-T1<br>Student, Age 19 | - FGS can cause infertility in women | - Awareness |

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| Itandrava | | |
| 3-MV-T1<br><br>Midwife, Age 26<br><br>Ambovomavo | - Never heard of FGS<br><br>- Symptoms include genital pruritus<br><br>- The mode of transmission is when a infected person swims in water, the microbe spreads in the water and when another person swims in it afterwards they get infected<br><br>- The speculum is used for abortion/miscarriage exam<br><br>- Never had a patient with FGS<br><br>- The logo looks like the disease goes to the head<br><br>- Suggests Door to door awareness raising per district | - Awareness<br>- Attitudes and perceptions, acceptability, needs assesment<br>- Barriers and Facilitators<br><br>- Feedback on campaign materials and effectiveness<br>- Relevance and recommendations |
| 4-MT-T1<br><br>Student, Age 22<br><br>Tsimahajao | - There can be complications from FGS<br><br>- A speculum can be used for cervix exams with STDs<br><br>- If the exam is done by a men, the information should be done in detail<br><br>- The display needs to be a bit more precise about the screening method | - Awareness<br>- Barriers and facilitators<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness<br>- Relevance and recommendations |

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| | - The dates for the screening are not clear | |
| 5-MT-T1<br><br>Student, Age 19<br><br>Itandrava | - One symptom is vaginal discharge | - Awareness |
| 6-MT-T1<br><br>Student, Age 19<br><br>Soaniadanana | - Image should be in the sidebar | - Feedback on campaign materials and effectiveness |
| 7-MT-T1<br><br>Nurse, Age 40<br><br>Tsimahajao | - Never heard of FGS before the awareness campaign<br><br>- Reads from the display that one of the symptoms are abdominal pain<br><br>- When someone urinates in water the larvae come out and when another person soaks in it gets into the skin<br><br>- If someone suspects to have FGS they should go to the CSB and consult a doctor<br><br>- Speculum is used often at the maternity hospital for IUD insertion/ removal<br><br>- When a person with FGS symptoms present at a big hospital it is seen and treated as an STI with for example Benzathine<br><br>- A woman making the exam is ok a men can be embarrassing | - Awareness<br>- Barriers and facilitators<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness |

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| | - The logo looks like it's in Africa because the picture is too black<br>- The display needs to be enlarged | |
| 8-MV-T1<br>Support Staff, Age 49<br>Tsimahajao | - Agrees with the discussion before the screening if a man does it | - Barriers and facilitators |
| 9-MV-T1<br>Student, Age 23<br>Morafeno | - Never heard of FGS<br>- Never used a speculum<br>- If a man does the exam there should be a conversation beforehand explaining and the women can accept or refuse<br>- Men are most often affected by hematuria, women even if they are affected by it often don't think of being affected by it and its always the men that are affected | - Awareness<br>- Attitudes and perceptions, acceptability needs assesment<br>- Barriers and facilitators<br>- Equity |
| 10-MV-T1<br>Student, Age 22<br>Tsimahajao | - One should consult a doctor if suspected to be sick<br>- The display for the health care professionals should be available in Malagasy as well<br>- There is need for awareness raining in the rural districts | - Attitudes and perception, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness<br>- Relevance and recommendations |
| 11-MV-T1<br>Midwife, Age 22<br>Ambovomavo | **Does not say anything** | |

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| 12-MV-T1<br><br>Student, Age 21<br><br>Fihaonana | - Agrees with the demonstration of the speculum | |

Womens group discussion in Ankazomborona

Duration of the discussion: 43 min 49 sec

Date of the discussion: 27.11.2020

**Participants are suffering from symptoms of FGS and STIs, prevention of diseases transmission is important**

Two participants did not hear of FGS before the distribution of the flyers, they only knew Urinary schistosomiasis of which they know symptoms and mode of transmission. They are able to name symptoms of FGS like pruritus and difficulty in conceiving One of the participants noticed symptom of FGS by herself and went to the community worker which gave her medication. The symptoms are reoccurring. Another participant noticed symptoms and the doctor gave her a treatment to put into her vagina and the symptoms vanished but now returned. This treatment is expensive the participant said. Colposcopy is fine because it considers the health. The participants are concerned if they will receive the results of the screening and if a disease is found if they will receive treatment as well. There is a discussion about if the screening procedure hurts and a bit of arguing on that. Another worry that the participants have if the disposable speculums are enough for every person. The display is received well, but the logo is interpreted as a disease in the head or about mental health and the subject of the campaign should be mentioned in the logo as well. The participants do not have Facebook. Another concern is that the work in the rice field talked about in the radio spot is unavoidable to provide income for the family and that even if they get treated, they will reinfect with the disease. They point out that eliminating the defecation will stop the spread of the disease.

*Memo: The discussion itself is very lively, the participants ask a lot of questions and seem very interested in the topic. Interviewer talked about the Interview in Antanambao Andranolava and said that someone said it is difficult here to make latrines because people are used to defecating in the open. This was not recorded in the initial interview from Antanambao Andranolava (went back and checked it). Just the interviewer talked about the defecation of people in the open in that interview. Question is if this is just stigma by the interviewer or they talked later after the recorded discussion was finished again.*

| Person & Backstory | Core Content | Themes |
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| 1-MK-F1<br><br>Trader, Age 24 | - Not heard of FGS before the distribution of the flyers, has | - Awareness<br>- Feedback on campaign materials and effectiveness |

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| Tanambao | knowledge on schistosomiasis<br>- One route of transmission is bathing on the water's edge or from running water<br>- Symptoms can include difficulty in conceiving<br>- The meaning of the picture is hard to understand<br>- Can the results of the screening be received immediately?<br>- Concerned if the screening does induce pain<br>- Are there enough disposable speculums even for many people?<br>- The picture is ok but the people will not understand the project, the subject of the project should be mentioned in the picture<br>- Female genitalia in the logo would be better<br>- The distribution of the flyer was received and clear and understandable, understood it is a screening for FGS<br>- Main income source in Marovoay is rice farming, even if they get treated | - Questions and concerns<br>- Relevance and recommendations |

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| | schistosomiasis will still be around them<br><br>- People must be made aware of the need to use a toilette as no (open) defecation means no schistosomiasis | |
| 2-MK-F1<br><br>Grower, Age 20<br><br>Tanambao | - Screening with colposcopy is fine because it is about health<br><br>- The display needs to be changed<br><br>- The logo looks like a disease that's in the brain<br><br>- Open defecation is a problem for example at the market<br><br>- The project is excellent | - Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness<br>- Relevance and recommendations |
| 3-MK-F1<br><br>Trader, Age 21<br><br>Tanambao | - The only disease seen by the testing is Schistosomiasis (If there is no schistosomiasis it is not seen under a microscope)<br><br>- Also write an explanation so people understand the display better as there are some people who can read but also don't understand the image<br><br>- The logo looks like it is about mental health<br><br>- Cannot avoid to go to the rice field as it is a mean of income<br><br>- Some people have toilettes but are used | - Feedback on campaign materials and effectiveness<br>- Relevance and recommendations |

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| | to defecate in the open | |
| 4-MK-F1<br><br>Housekeeper, Age 45<br><br>Tanambao<br><br>Had symptoms like smell and genital itch | - Got an intra vaginal treatment from the doctor, bought it at the pharmacy and symptoms disappeared.<br><br>- Treatment is very expensive<br><br>- Introducing the speculum is not painful<br><br>- It is health that is needed, only the ones that don't want to be healthy are going to say bad things about the project | - Background<br>- Barriers and facilitators<br>- Attitudes and perceptions, acceptability, needs assessment |
| 5-MK-F1<br><br>Trader, Age 35<br><br>Tanambao<br><br>Has diagnosis of FGS by a community worker with symptoms like smell and pruritus on the genitalia. | - Symptom of Schistosomiasis is blood in the urine<br><br>- Symptoms are going on for a long time, spoke to community health worker who told its Schistosomiasis and gave treatment<br><br>- Treatment did not work, reoccurrence yellowish with pruritus | - Awareness<br>- Background<br>- Attitudes and perceptions, acceptability, needs assessment |
| 6-MK-F1<br><br>Trader, Age 22<br><br>Tanambao | - Gained knowledge on FGS from the flyer<br><br>- The display for illiterates is clear, adjust the sentence of explanation | - Awareness<br>- Feedback on campaign materials and effectiveness |

Focus group discussion of health workers in Antanambao Andranolava

Duration of discussion: 51 min 16 sec

Date of the interview: 17.08.2021

**Knowledge about FGS comes from the awareness campaign**

The knowledge about FGS is good, the participants say they have their knowledge from the awareness campaign. Symptoms and mode of disease transmission are known. Screening at a health care centre is recommended by the participants if a patient suspects to have FGS. Speculums are not used very often (5 to 8 times a month), if they are used, they are used for IUD insertion/ removal or leucorrhoea diagnostic. Examination should be performed by a woman and a Malagasy person should always be present. To convince people of screening and treatment one should explain the disease. A bit of confusion about the terms of BFG and FGS in the French and Malagasy version of the flyer is happening in the participants. The flyer might be a bit difficult to understand for someone who is not able to read. On Facebook are some French terms in the Malagasy version, another participant argues that the translation of the technical terms intro Malagasy would make understanding more complicated. As people's main income source is the work in rice fields, they should be tested more frequent (every 6 to 8 months). More coordinated work is needed to achieve the goal of FIRM-UP, participants recommend working with the president of fokontany to enhance the ability of the project to get people to understand better.

*Memo: Some answers seem to be missing in the transcript, sometimes it looks like the interviewer is answering questions from the participant group, but the questions are not transcribed (but indicated by timestamps). Refers to a college that said might cause difficulties in conceiving or infertility; this is not mentioned in the interview before. A lot of these not transcribed passages can be found in the transcript. In some key passages like as 3-MT-T1 critics the campaign, there is also transcript missing, disabling further information there*

| Person & Background | Core Content | Topic |
|---|---|---|
| 1-MT-T1<br><br>Community Agent, Age 56<br><br>Antanambao | - Heard of the awareness campaign and therefore of FGS in the Radio<br><br>- Genital pruritus is a symptom of FGS<br><br>- Screening is a method to check for FGS<br><br>- To convince people of the screening you need to explain the disease | - Awareness<br>- Relevance and recommendations |
| 2-MT-T1 | - Knows FGS through someone who had it | - Awareness |

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| Paramedical student, Age 31<br><br>Antanambao | - Mode of transmission is working in the rice field<br><br>- French first on Facebook, then Malagasy | - Feedback on campaign material and effectiveness |
| 3-MT-T1<br><br>Paramedical student, Age 27<br><br>Antanambao | - FGS might lead to bleeding while sexual intercourse as well as pain<br><br>- One should go to the health centre if FGS is suspected<br><br>- The logo of the campaign looks a bit like the disease is in the head<br><br>- The images are hard to interpret<br><br>- Not sure if the campaign is the right thing<br><br>- Suggests working together with the president of fokontany<br><br>- People in the countryside need a lot of persuasion | - Awareness<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness<br>- Relevance and recommendations<br>- Barriers and facilitators |
| 4-MT-T1<br><br>Paramedical student, Age 21<br><br>Antanambao | - Knows about FGS from the awareness raising<br><br>- Speculum is used for leucorrhoea detection<br><br>- Malagasy first on Facebook would be best<br><br>- The radio spot is well done as it targets a lot of people that might be infected and they | - Awareness<br>- Feedback on campaign materials and effectiveness<br>- Barriers and facilitators |

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| | visit a hospital often, but the source of income for the people is the work in rice fields | |
| 5-MT-T1<br><br>Paramedical student, Age 31 | - People in the region are swimming in water, so Schistosomiasis is common in the area<br><br>- Pictures should not be to direct<br><br>- In the Malagasy part of the Facebook posts are a few French words, but sometime to translate a technical term into Malagasy can make the understanding more difficult | - Awareness<br>- Feedback on campaign materials and effectiveness |
| 6-MT-T1<br><br>Midwife, Age 24<br><br>Antanambao | - Heard of FGS on television and radio<br><br>- Speculum is not used very often<br><br>- As the main source of income is working in a rice field, there should be regular testing every 6 or 8 month to interrupt transmission | - Awareness<br>- Relevance and recommendations<br>- Barriers and facilitators |
| 7-MT-T1<br><br>Midwife, Age 28<br><br>Antanambao | - Schistosomiasis can transmit via defecation outside<br><br>- Speculum is used for IUD insertion<br><br>- Speculum is used 5 to 8 times a month<br><br>- A woman examining is better than a men | - Awareness<br>- Barriers and facilitators<br>- Relevance and recommendations<br>- Feedback on campaign materials and effectiveness |

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| | - A Malagasy person should be present at all times<br>- Some problems with the mix up of the terms BGF and FGS<br>- Explanation in Malagasy is missing on the flyer for the HCWs<br>- Interested in the timeframe of the FIRM-UP campaign | |

Group discussion for women in marovoay

Duration of the discussion: 38 min 19 sec

Date of discussion: 25.11.2020

**Good Knowledge of Schistosomiasis but not of FGS, more testing is needed**

The participants did not know of Female genital schistosomiasis before the awareness campaign, only of the existence of schistosomiasis itself, even though they are able to see symptoms of urogenital schistosomiasis in their bodies. One participant reports trouble of conceiving and miscarriages as well as abdominal pain. The participants have been treated against schistosomiasis by community workers twice a year, but they don't know with which product and there were no tests beforehand. As long as it considers the health, a colposcopy and inspection if the genitals are accepted. The flyers are seen informative and inspirational. The testing should be continued and to implement a screening for men and children.

| Person & Backstory | Core Content | Themes |
|---|---|---|
| 1-MV-F1:<br><br>Trader, Age 38<br><br>Ambovomavo<br><br>Problems urinating | - Had problems urinating in the last eight years, gained knowledge of schistosomiasis through this problem<br>- seems a bit concerned about sample taking<br>- thinks the awareness campaign flyer | - Background<br>- Awareness<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness |

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| | looks a bit like an AIDS campaign<br><br>- radio spot is clear | |
| 2-MV-F1:<br><br>Trader, Age 32<br><br>Ambovomavo | - Knows of abdominal pain and problems urinating<br><br>- The symptoms do not go away after treatment<br><br>- Colposcopy is fine because it concerns the health<br><br>- Flyer looks fine | - Awareness<br>- Background<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness |
| 3-MV-F1:<br><br>Fishermen, Age 26, Ambovomavo | - Schistosomiasis causes urinary problems and makes tired | - Awareness<br>- Feedback on campaign materials and effectiveness |
| 4-MV-F1:<br><br>Trader/Breeder, Age 25<br><br>Ambovomavo | - Visualisation of mode of transmission in the awareness flyer is ok | |
| 5-MV-F1:<br><br>Community Health Care Worker, Age 33<br><br>Ambovomavo | - Knowledge of schistosomiasis, but not of FGS until the awareness campaign<br><br>- patients ask for treatment and get a three-day treatment and an announcement when the next pill is to take (twice a year), no testing is done<br><br>- No previous knowledge that FGS can have consequences on the reproductive system before the awareness campaign | - Awareness<br>- Barriers and facilitators<br>- Feedback on campaign materials and effectiveness |

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| | - interpretation of the visualisation of the campaign is good<br>- hears spot on the radio every day | |
| 6-MV-F1:<br>Grower, Age 40<br>Ambovomavo | - Accepts screening because it's about health<br>- material of the awareness campaign is inspiring<br>- wants screening for children and men as well | - Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on materials and effectiveness<br>- Relevance and recommendations |
| 7-MV-F1:<br>Trader, Age 46<br>Ambovomavo<br>Experiences sharp pain while urinating | - Husband told to go to the doctor and get treatment for a long time<br>- got pills from the Community health care worker but no test<br>- Colposcopy is fine because it is regarding the health<br>- visualisation of the flyer is wonderful | - Barriers and facilitators<br>- Background<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness |
| 8-MV-F1:<br>Trader, Age 18<br>Ambovomavo | - Screening is ok | - Attitudes and perceptions, acceptability, needs assessment |
| 9-MV-F1:<br>Community health care worker, Age 44<br>Morafeno<br>Experiences miscarriages at 2 months of pregnancy and abdominal pain as well as | - Knows of schistosomiasis consequences of haematuria but no knowledge of FGS<br>- Is interested in Colposcopy<br>- Flyer is ok | - Background<br>- Awareness<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Feedback on campaign materials and effectiveness<br>- Relevance and recommendations |

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| pain during sex and light period | - | People in Marovoay are in a lot of contact with water, therefore tests for men and children would be good as well and continuing the screenings for all | |

Group discussion with women at CSB Antanambao Andranolava

Duration of the discussion: 36 min 37 sec

Date of the discussion: 26.11.2020

**Children are treated for Schistosomiasis, women not**

Knowledge on FGS is not existing, only on schistosomiasis regarding children. In the past children from 5 to age 15 were treated but no women. One participant is unsure about the need of the screening. The other participants do not know if they are affected by FGS or not so the majority is willing to participate in the screening. Some symptoms are shown by participants, but they are unsure if it is FGS or not. The description of the disease via the visualisation is well understood by the participants. Some confusion is happening about the different species of Schistosoma.

*Comments on the discussion by analyst: Overall discussion of the participants on the topic is not that intensive, includes a lot of simple "Yes" answers.*

| Person & Backstory | Core Content | Themes |
|---|---|---|
| 1-MT-F1:<br>Housekeeper, Age 32<br>Antanambao | - Screening is uncomfortable, but doesn't mind colposcopy<br>- treatment is good | - Attitudes and perceptions, acceptability, needs assessment |
| 2-MT-F1:<br>Housekeeper, Age 26<br>Antanambao | - Does not really feel affected by FGS, no effect on the health | - Attitudes and perceptions, acceptability, needs assessment |
| 3-MT-F1:<br>Grower, Age 40<br>Betaolo | - No knowledge of FGS, only heard of schistosomiasis for children aged 5-15 and treatment of these | - Awareness |

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| 4-MT-F1:<br><br>Grower, Age 45<br><br>Antanambao | - Would like to participate in the screening | - Attitudes and perceptions, acceptability, needs assessment |
| 5-MT-F1:<br><br>Grower, Age 20<br><br>Antanambao<br><br>Pain during sex | - Health is happiness<br><br>- Will participate in a screening, because doesn't know if affected or not by FGS<br><br>- Some symptoms are there but not all | - Attitudes and perceptions, acceptability, needs assessment<br>- Background |
| 6-MT-F1:<br><br>Grower, Age 43<br><br>Antanambao | - Fine with the screening | - Attitudes and perceptions, acceptability, needs assessment |
| 7-MT-F1:<br><br>Student, Age 19<br><br>Antanambao | - Does not mind screening as it is about health | - Attitudes and perceptions, acceptability, needs assessment |
| 8-MT-F1:<br><br>Grower, Age 35<br><br>Antanambao<br><br>Has problems with brown (vaginal) loss and unregular periods | - Concerned because of the symptoms shown (brown loss)<br><br>- Very happy when community workers told her about the free testing<br><br>- Does not have other symptoms like itchiness or pain during sex | - Background<br>- Attitudes and perceptions, acceptability, needs assessment |
| 9-MT-F1:<br><br>Trader, Age 38<br><br>Antanambao | - No knowledge of FGS<br><br>- Screening is free that it very good<br><br>- Participation in free screenings, no problem with that | - Awareness<br>- Attitudes and perceptions, acceptability, needs assessment |

Group discussion at CSB Mahavoky Mahajanga

Duration of the discussion: 53 min 7 sec

Date of the discussion: 24.11.2020

**FGS is know but treated like an STI; Carefully choose the topic when raising awareness based on the population**

Good knowledge about the mode of disease transmission and symptoms of FGS with an exemption about the transmission of Schistosomiases in rice fields. The consequences such as miscarriage or infertility are known as well to the participants. The knowledge on correct treatment is lacking administered medication is lacking, no Praziquantel is mentioned when asked for medication for the disease, only antibiotics were named. A speculum is rarely used at the CSB, mainly for IUD removals or vaginitis/ STI diagnosis. Many people watching the screening procedure could be a reason for frustration. The display at the pharmacy did not reach the health care professionals yet. The results of the colposcopy should be presented in pictures to the patient so that they see they have the disease. Facebook page is seen by all the participants, the posts should be in Malagasy first and then in French for a better and fast understanding. An emphasis when doing awareness raising should be put on the benefits of treatment and consequences of the disease. When talking about the transmission in rice fields extensively, the interest and trust in the HCW in the project could go down because it is the way to feed the family. Same with the placement of the campaign, a location of the campaign at the CSB would be best.

*Memo: Lively discussion, Interviewer seems to give in some sarcastic like comments. Interviewer tries to direct the direction of the discussion a bit too much. The analyst is not entirely Shure if the question about the medication was understood 100% by the participants or if they thought they need to list the treatment for STIs*

| Person & Backstory | Core Content | Themes |
|---|---|---|
| 1-TT-T1<br><br>Midwife, Age 39<br><br>Majunga Be<br><br><br>Does not read | - Complications of FGS can be infertility ot miscarriage<br><br>- If someone shows symptoms, they should go to the health care centre<br><br>- Ceftriaxone IV or Metronidazole as treatment<br><br>- Speculum is rarely used, when it's used | - Background<br>- Awareness<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Barriers and facilitators<br>- Feedback on campaign material and effectiveness |

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| | its used for IUD insertion/ removal or leucorrhoea diagnosis<br>- Good explanation is needed when the speculum is used for diagnosis<br>- Patients might be uncomfortable if men do the screening<br>- Did not look at the FIRM-UP logo at the entrance of the treatment room<br>- Every symptom displayed in the flyer should be displayed by a picture, pictures need to be sensitive and not to exposed<br>- Video would be a good way to transport the message of FIRM-UP | |
| 2-TT-T2<br>Service Major, Age 38<br>Mahavoky South | - Symptoms of FGS are known (pruritus, loss)<br>- Nystatin/Doxi as treatment<br>- Speculum I s used for STI or vaginitis diagnosis<br>- There can be a problem when many people watch the screening (embarrassment) | - Awareness<br>- Attitudes and perceptions, acceptability, needs assessment<br>- Barriers and facilitators |
| 3-TT-T1<br>Midwife, Age 26<br>Mahavoky North | - Knows only Schistosomiasis and its transmission mode not FGS | - Awareness<br>- Barriers and facilitators |

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| | - Symptoms of FGS are pruritus, discharge and there may be bleeding (looks like an STI)<br>- The pharmacy is far away | |
| 4-TT-T1<br>Paramedic student, Age 20<br>Ambohimandamina | | |
| 5-TT-T1<br>Paramedic student, Age 22<br>Mahavoky North | - Malagasy first on Facebook would attract more people<br>- Many people don't know the cause of infertility, a campaign like this can give them help to solve the problem | - Feedback in campaign materials and effectiveness<br>- Relevance and recommendations |
| 6-TT-T1<br>Paramedic student, Age 23<br>Mahavoky North | - Speculum is used for IUD removals | - Attitudes and perceptions, acceptability, needs assessment |
| 7-TT-T1<br>Paramedic student, Age 20<br>Tsararano Amabny<br>First year student | | - Background |
| 8-TT-T1<br>Paramedic student, Age 22<br>Mangarivotra | **Did not say anything** | |
| 9-TT-T1<br>Nurse, Age 28<br>Abattoir | - Results of the colposcopy should be displayed in pictures so that the patient can see that they have the disease | - Feedback on campaign materials and effectiveness<br>- Relevance and recommendations |

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|---|---|---|
| | - The radio spot itself is good, but there is a need for sensitive formulation as the rice fields are the way to feed the family and the trust in the HCW and the success of the campaign can be hindered when putting too much emphasis on the rice fields<br><br>- CSB is the best place to raise awareness, village and hospital are not that good<br><br>- When raising awareness there should be an explanation of the consequences of the disease and the benefits of treatment | |
| 10-TT-T1<br><br>Nurse, Age 28<br><br>Mahovoky North | - Facebook page is clear but some of them do not speak French, Malagasy version is not seen at first sight | - Barriers and facilitators<br>- Feedback on campaign materials and effectiveness |

# Digital Annex

All digital annex is strictly confidential and available only upon request at the author of this thesis (Pia Rausche, pia.rausche@bnitm.de) and is attached to the print version of this thesis for grading purposes with an USB stick.

Digital Annex A CRF awareness survey FIRM-UP

Digital Annex B Dataset awareness survey

Digital Annex C Data dictionary awareness survey
Open with libre office

Digital Annex D R script awareness survey

Digital Annex E Topic guide FIRM-UP

Digital Annex F Original interview transcripts (French)

Digital Annex G MAXQDA Analysis
Open with MAXQDA reader

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