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Exploring community perceptions of gender roles as a predisposing factor in schistosomiasis infection in southwestern Uganda

Faith Mugabi[a], Maxson Kenneth Anyolitho[a,b], Tine Huyse[c], Elizabeth Kemigisha[a] and Viola Nilah Nyakato[a]

[a]Department of Human Development and Relational Sciences, Mbarara University of Science and Technology, Uganda; [b]Department of Community Health, Faculty of Public Health, Lira University, Uganda; [c]Department of Biology, Royal Museum for Central Africa, Belgium

ABSTRACT

Schistosomiasis, a neglected tropical disease, affects people of all genders and ages. However, few studies have examined how communities in endemic areas perceive gender roles as factors influencing infection and control. This study explored the perceptions of farming (Kyaterekera) and fishing (Ndaiga) communities along Lake Albert in Uganda's Kagadi District regarding gender roles and their role in schistosomiasis infection. Using an ethnographic design, we conducted 10 key informant interviews and 18 focus group discussions with 150 participants. Data were analysed thematically. Participants from both settings recognised that gender roles influence infection risk differently for men and women. Societal expectations and gender stereotypes were seen as contributing factors. Farming men often perceived bilharzia as a lake-side issue. Drug side effects were a shared concern, but women in fishing communities preferred using herbs and prayers, while men favoured hospital visits. Gender roles and perceptions of schistosomiasis risk vary by gender and location. Common themes include societal expectations, stereotypes and concerns about treatment. Gender-specific interventions, such as gender-sensitive campaigns and inclusive decision-making, could help effectively control the disease.

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1. Introduction

Schistosomiasis (also known as bilharzia) is a neglected tropical disease (NTD) of public health importance, mostly affecting poor and rural communities, particularly agricultural and fishing populations. Globally, the disease is estimated to infect more than 240 million individuals, while 700 to 800 million people are at risk of infection (Adenowo et al., 2015; Munisi et al., 2017). It is the fourth leading parasitic disease globally in terms of burden of disease, with an estimated burden of 3.31 million disability-adjusted life years (DALYs) following leishmaniasis, intestinal nematodes and cryptosporidiosis (Pisarski, 2019). In terms of prevalence, schistosomiasis is the second most common parasitic disease to malaria, with over 95% of the global cases in Africa (Fatimah et al., 2015). In Uganda, intestinal schistosomiasis is the most common and widespread form of schistosomiasis, with over 20 million people in 73 districts at risk of infection (Stanton et al., 2017). An estimated 10 million people across 82 districts are reportedly infected with schistosomiasis (Exum et al., 2019). This disease is caused by schistosome flatworms that use freshwater snails as intermediate hosts (McManus et al., 2018). People become infected by swimming, bathing or doing chores in ponds, lakes or rivers containing infected snails (Colley et al., 2014).

The World Health Organization (WHO) recommends preventive chemotherapy through mass drug administration (MDA) of praziquantel (PZQ), snail control and behaviour change through water, sanitation, and hygiene (WASH), and health education and sensitisation (WHO, 2022). Despite these efforts, schistosomiasis is still endemic in Uganda, especially along lakes and rivers, even in areas where MDA has been implemented since 2003 (Exum et al., 2019). Several studies have attributed this problem to social and

CONTACT Maxson Kenneth Anyolitho manyolitho@lirauni.ac.ug Department of Community Health, Faculty of Public Health, Lira University, P.O. Box 1035, Lira, Uganda

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cultural factors, such as inadequate knowledge; negative attitudes; risky practices related to water, sanitation, hygiene and myths; and misconceptions (Ayabina et al., 2021; Exum et al., 2019; Rilkoff et al., 2013).

Emerging literature increasingly links schistosomiasis infection patterns and control efforts to prevailing gender roles, stereotypes and societal norms (Mugabi et al., 2024). These connections, however, yield mixed results and often neglect the perspectives of local communities regarding gendered expectations and responsibilities. For instance, a systematic review and meta-analysis assessing gender disparities in *Schistosoma* infection across Africa revealed notable variation in the prevalence of *S. mansoni* among males and females (Ayabina et al., 2021). This differential burden suggests that gender-specific roles—shaped by occupational, domestic and cultural factors—may influence exposure risk to schistosomiasis. However, the study does not examine how community perceptions of gender roles mediate these exposure patterns, which is a critical omission for fully understanding the sociocultural dynamics at play.

In Ethiopian communities, traditional gender norms typically constrain women and girls within the domestic sphere, while men predominantly occupy roles associated with economic provision and public decision-making (Wharton-Smith et al., 2019). This gendered division of labour often increases women's exposure to schistosomiasis through daily domestic activities, such as cooking, washing clothes, cleaning and agricultural work, all of which frequently involve contact with contaminated water sources (Donohue et al., 2017; Grimes et al., 2015).

Conversely, while men may have less routine contact with household water sources, specific livelihood practices—particularly fishing and riverine agriculture—are strongly associated with high-risk exposure environments (Rilkoff et al., 2013). These occupational roles contribute to the differential infection rates observed, yet little is known about how individuals perceive their own vulnerability in relation to their gendered roles, which is crucial for the design of targeted intervention strategies.

The broader gender frameworks in Uganda are fundamentally underpinned by entrenched patriarchal structures, which dictate not only domestic responsibilities but also access to power, resources and healthcare. According to Carol Watson (2020), Uganda's gender order is characterised by male dominance in household and community decision-making processes, with women often requiring male consent to access healthcare services. This dependency, coupled with limited financial autonomy, significantly impedes women's ability to seek timely and appropriate medical treatment. The consequences are particularly severe in the context of reproductive health, maternal care and preventative disease management, where delays in seeking care can lead to adverse outcomes.

These gendered inequalities are further reinforced by institutional and cultural systems. Tamale (2008) argues that the Ugandan state, through its legal and policy frameworks, sustains patriarchal values that subordinate women's roles in both private and public life. This structural imbalance begins in early childhood, with gender norms being transmitted through education, religion and media, perpetuating stereotypes that limit women's participation in health-seeking behaviours and civic engagement (Kyomuhendo & McIntosh, 2006).

The influence of gender on health outcomes extends to biological and epidemiological considerations. While Ayabina et al. (2021) reported higher schistosomiasis infection rates among males, they also noted a systemic underrepresentation of females in epidemiological studies, potentially leading to skewed interpretations of prevalence and risk. A complementary meta-analysis by Mbanefo et al. (2014) highlights that children and adult males exhibit higher reinfection rates within 6 to 12 months post-treatment with praziquantel. However, neither study addresses the critical psychosocial dimension: how individuals perceive their susceptibility to infection based on gender. Such perceptions likely shape behavioural practices, including risk avoidance and health service utilisation, thereby influencing reinfection dynamics.

Moreover, gendered behavioural norms affect health-seeking practices. Men are often socialised to embody ideals of stoicism and invulnerability, which can discourage the pursuit of preventative health services. Women, on the other hand, may delay seeking healthcare due to competing domestic priorities, caregiving roles and structural barriers, such as cost and transportation constraints exacerbated by the need for male approval or accompaniment (Mulumba et al., 2014). These intersecting factors result in differential health access and outcomes, with women disproportionately affected by conditions requiring early diagnosis and long-term management.

The Ugandan policy landscape has attempted to address gender inequalities in health through various frameworks, including the National Gender Policy (2007) and the Health Sector Gender Policy (2012). These documents acknowledge the necessity of integrating gender perspectives into health planning and service delivery. Nevertheless, evidence suggests that gender mainstreaming in health remains largely procedural, with limited transformative impact on institutional practices or community engagement. Implementation gaps persist due to resource constraints, limited training of health personnel in gender-sensitive service delivery, and the absence of accountability mechanisms.

The above studies present contradictory information regarding the impact of gender stereotypes and roles in schistosomiasis infection, warranting the need for more concrete evaluations. Moreover, most of the studies focused on risk factors by observing community members' behaviour and risky practices but not their perceptions of gender as a predisposing factor (Anyolitho et al., 2025; Trienekens et al., 2020). And yet, sometimes some people act or behave differently from what they think. However, there is hardly any literature on the individual and community perceptions of gender-specific differences in infection and reinfection risk. Understanding communities' views and perceptions of who they think is most at risk and how gender roles play to predispose infection is important to guide appropriate gender-sensitive interventions.

To fully understand and effectively address schistosomiasis and similar endemic diseases in Uganda, it is imperative to adopt a multidimensional approach that integrates sociocultural, epidemiological and behavioural perspectives. Gender paradigms not only influence exposure and infection but also determine patterns of reinfection, responsiveness to treatment and engagement with public health interventions. Interventions must, therefore, go beyond biomedical models to incorporate gender-sensitive strategies informed by the lived experiences, roles and perceptions of affected populations. We, therefore, explored how community perceptions of gender roles are a predisposing factor in schistosomiasis infection and control among endemic communities along Lake Albert, Western Uganda.

2. Materials and methods

2.1. Study area and setting

The study was conducted in Kagadi district in two communities. Ndaiga sub-county (considered highly endemic with schistosomiasis) is located along the Lake Albert shores, and Kyaterekera sub-county (considered moderately endemic with schistosomiasis transmission) is located further away from the upland. Both communities have been receiving PZQ under the MDA programs. Four of the eight fishing villages in Ndaiga sub-county and three of the eighteen farming villages in Kyaterekera sub-county were purposively selected. Population density, the nature of economic activities and proximity to the lake were the criteria used for the selection of study sites. The lakeside community is more densely populated than the farming communities. Also, both sites have different economic activities, with fishing identified near the lake, while farming is further away. This study postulated that the two sites would have different perceptions of gender roles and their influence on schistosomiasis infection and control, with Ndaiga sub-county near the lake having positive perceptions compared to those further away from the lake.

2.2. Study design

We employed a qualitative approach using the ethnographic study design to explore the community's perception of gender roles as predisposing factors to bilharzia infection and control. The qualitative study approach explores and understands complex phenomena through groups or individuals' in-depth perspectives, behaviour and experiences (Hamilton & Finley, 2019). Also, the approach seeks to obtain a richer and more dynamic data pool concerning different topics under consideration, such as the community's perception of gender roles with bilharzia infection, for this study. The ethnographic study design was used so that the researchers could immerse themselves in the community being studied to obtain a holistic understanding of the community's way of life (Andreassen et al., 2020). Our study was guided by the principles and methodologies of ethnography, where we spent 12 months in the two communities and engaged the community members to obtain a deep understanding of the research topic.

2.3. Sample size estimation and participants' selection

A total sample size of 215 was estimated, comprising 200 participants for 20 focus group discussions and 15 participants for key informant interviews. However, a total of 161 participants were finally selected for the study. This consisted of 11 participants for the key informant interviews and 150 adult community members for 18 focus group discussion sessions. The principle of the saturation method was used to determine the actual sample size, that is, the point at which no new information was obtained from participants (Guest et al., 2006). For KIIs, the study participants included local government workers, key public health officers, district health inspectors and health assistants. The village health team (VHT) members are individuals in communities trained to conduct mobilisation and provide basic health services at the household level voluntarily. Meanwhile, for the FGDs, adult men and women, household members aged 18 years and above were considered in the sample.

Purposive sampling was used to select the participants for the study. Purposive sampling involves study-participant selection based on the researchers' knowledge about the topic (Berndt, 2020). Only those local community members who had lived in Kyaterekera and Ndaiga sub-countries for at least a year and above were selected. This period was considered long enough for a person to have an idea about the disease and, therefore, be able to comment on it. Additionally, key informants were included in the study based on their experience concerning health promotion at our study sites and their interface with MDA programs implemented by local healthcare departments. Focus group discussion participants were purposively sampled according to specific traits or qualities. The common trait was that those who have suffered from the disease share their lived experience. The person must have lived in the communities for more than a year because the communities are multilingual and have many people who come and leave the area due to the nature of the communities being land sites and close to Congo. Also, someone who has lived in the community for more than a year knows the area and has seen mass drug administration administered.

2.4. Data collection

Key informant interviews (KIIs), focus group discussions (FGDs) and observation were employed for collecting data. KII involves one-on-one in-depth interviews with participants who have expert knowledge about the topic, as guided by the researcher (Cossham & Johanson, 2019). KII was used because it provided much more detailed information than what was available through other data collection methods that were used (Cossham & Johanson, 2019). Also, it was justifiably used because it was believed that these people are trained in carrying out mass drug administration and know the subject matter under study, so they have more detailed information. KII guides were used to obtain data from the key informants. They contained lists of questions upon which an interview was conducted. Interview guides were used because they helped to eliminate response errors since it was the researcher who controlled the interview process.

Meanwhile, FGD encompasses group conversations between the researcher and a group of participants, with specialised knowledge related to the research topic. FGD participants range from approximately five to ten participants. The technique was used to get an in-depth understanding of the roles performed by men and women in the community and how they perceive their gender differences to predispose them to schistosomiasis infection. FGD guides were used in this study to gather participants' views regarding the topic. The guide contained open-ended questions aimed at stimulating informal discussions with participants to understand their perceptions regarding schistosomiasis infection and control. A total of 18 focus group discussions were conducted, 11 in Ndaiga and 7 in Kyaterekera sub-county with male, female, and mixed-gender participants, respectively. A total of nine FGDs were with women, eight with men and one was mixed, that is, both men and women. This was done to obtain the views of different genders and compare their perceptions accordingly. Also, the men and women were separated to allow them to express themselves openly and freely since some of the topics to be discussed were gender sensitive. The one unique FGD with mixed genders was done to assess how power dynamics and other gender parameters shape the discussion, though this did not come out explicitly.

The FGD sessions were guided by the first author as the moderator, who introduced topics for discussion and engaged participants in lively discussion amongst themselves. Probing was used by the facilitator to further investigate and understand the topics under discussion. Each focus group session comprised between 8 and 10 participants. Discussions lasted about an hour on average. Data were collected in the

Table 1. Total number of FGDs and KIIs conducted in the communities.

Data collection method	Number	Gender	Sub-county
Focus group discussions	9 FGDs	Female	5 In Ndaiga 4 In Kyaterekera
	8 FGDs	Male	5 In Ndaiga 3 In Kyaterekera
	1FGD	Mixed-4 males and 6 females	1 in Ndaiga
TOTAL		**18 FGDS**	
Key informant Interviews	1 Vector control officer	1 Male	Kagadi District
	1 Health inspector	1 Male	Kagadi District
	3 Health assistants	2 Males, 1 Female	2 Ndaiga, 1 Kyaterekera
	5LCs	5 Male	3 Ndaiga, 2 Kyaterekera
TOTAL		10 Individual In-depth Interviews	

home and community settings and within the community settings. For privacy purposes, the researcher chose quiet places such as church buildings, schools or tree shades in isolated locations. The information from the participants was recorded using a digital voice recorder and later transferred to laptops for safety purposes.

Finally, the observation method was utilised to observe key features that describe the practices of the communities. A list of observable items, such as the availability of water bodies, such as ponds, streams, lakes, rivers, and swamps, and their closeness to people's households, was physically observed by the researcher and recorded or captured using cameras. Additionally, risky practices, such as defecating in lake waters and bushes, swimming or playing in waters, and many others, were observed and recorded. The methods complemented each other to provide an in-depth understanding of the community's perception of gender roles and their predisposition to bilharzia infection (Odhiambo et al., 2014).

2.5. Data analysis and management

Thematic analytic method was used to analyse the data. Firstly, the audio recordings from the KIIs and FGDs were transcribed and translated into English. Later, the transcripts were uploaded into Dedoose software version 9.0.46 for data management. Afterwards, coding frames were developed from one FGD and one KII transcript. To ensure the credibility of the data, two research assistants concurrently read the transcripts and made corrections and clarifications accordingly. The coding frame was then used to code the data by the first author. Next, the first author identified and generated themes from the coded data and then organised them into categories. Themes and subthemes that were similar were grouped, while those that differed were put separately, a process that was repeated for the whole data set. Finally, the findings were presented based on the different perceptions of the participants as per the research objectives. The findings were supported with quotes from transcripts representing participants' views.

2.6. Ethical considerations

We received ethical approval from the Mbarara University of Science and Technology (MUST) Research Ethical Committee (REC), reference number MUST-2021-59. We also received clearance from the district health authority and community local leaders before conducting the data collection. Written informed consent was obtained from all study participants using the ethical consent process. Participants' confidentiality was ensured by concealing participants' identities, conducting interviews in private and quiet places, and refraining from asking personal information that would compromise participants' privacy.

3. Results

3.1. Participants' response rate

A total of 160 out of 161 participated in the study. Only one participant from the KII did not turn up for the study due to personal commitments, while no study participant refused to engage in the FGD session. Additionally, all the participants who turned up for the study fully participated up to the end. No one in the FGD sessions dropped out during the study (Table 1).

3.2. Participants' socio-demographic characteristics

From the socio-demographic data analysed, more than half of the participants (53.33%: 80/150) were females, and most study participants (80%: 120/150) were married. On the other hand, more than half of the participants (56.67%: 85/150) were between 30 and 49 years old, implying that most participants were young adults. Furthermore, more than three-quarters of the participants (73.33%: 110/150) were either at the primary level or below, with slightly more than half of the participants (50.67%: 76/150) being fishmongers, as shown in Table 2 below.

3.3. The community perception of gender roles as a predisposing factor to schistosomiasis infection

The participant responses are summarised in Table 3.

a. Perception of gender roles and schistosomiasis infection

The overall perception reported by participants is that men think they are more exposed to schistosomiasis infection compared with females. This view is mostly held by those in the fishing and not the farming community because of their fishing activities in Lake Albert. The male participants argued that men spend much of their time in the water, which increases their risk of infection. One of them had this to say:

> *'I can even spend a full month on Lake Albert fishing, there are no toilets or bathrooms, and I defecate in the lake and even drink this water'* **Male FGD, Kitebere Village, Ndaiga sub-county.**

On the other hand, a few female participants from the fishing community also argued that they are at greater risk of infection due to their roles. These roles, according to the participants, put them in greater contact with the infested water of Lake Albert. Some of the roles mentioned include cooking, fetching water from swamps, and washing clothes and utensils. Some female participants reported:

> *'I have been selling fish ever since I started living here at the lake; I always wash the fish from the lake; I clean the fish at the shoreline where the lake water can easily wash away the scales and intestines from the fish back to the*

Table 2. Participants' socio-demographic characteristics.

Sex	Frequency	Percent
Male	70	46.67
Female	80	53.33
Total	**150**	**100.00**
Marital status		
Single	25	16.67
Married	120	80.00
Divorced	5	3.33
Total	**150**	**100.00**
Age in years		
18–29	26	17.33
30–39	40	26.67
40–49	45	30.00
50–59	35	23.33
60–69	4	2.67
Total	**150**	**100.00**
Education level		
Primary	110	73.33
Secondary	25	16.67
Tertiary	15	10.00
Total	**150**	**100.00**
Occupation		
Fishmongers	76	50.67
Farmer	48	32.00
Social worker	10	6.67
Fishermen	10	6.67
Public servant	6	4.00
Total	**150**	**100.00**

Source: data from participants, 2021.

Table 3. Participants' perception of gender as a predisposing factor to schistosomiasis from both the fishing and farming communities.

SN	Themes	Views from fishing communities	Views from farming communities
A	Gender roles as a risk factor	Men said they are more exposed to Schistosomiasis because they carry out fishing on Lake Albert. Women stated that they are most exposed, due to their roles like fetching water for domestic use, cleaning fish, washing clothes from the lake, which expose them to contaminated water.	Men said women are more at risk due to socially constructed roles. Women also said they are most at risk due to the roles that expose them to contaminated water.
B	Societal cultural norms	Women think they are at a higher risk of acquiring the infection due to societal expectations of their roles, like fetching water, bathing children, washing clothes and utensils.	Women are vulnerable due to societal expectations of social roles like fetching water and cooking food. Society also expects men to do activities such as fishing and swimming increase their risk of bilharzia infection.
C	Stereotypes of signs and symptoms	Both men and women associate swollen belly and vomiting in women with pregnancy.	Both men and women associate a swollen belly in men with being rich.
D	Myths and misconceptions	Bilharzia is a disease of the lake only and is a sign that an individual misbehaves in the lake.	Signs attached to HIV; Some Symptoms attributed to alcohol. Some signs and symptoms attributed to witchcraft
E	Medicine side effects	Both men and women in fishing communities have a negative view of the medicine, experienced severe Side effects from using the medicine, such as diarrhoea, vomiting and general body weakness	Both males and females in the farming community get side effects from the drug, such as headache, vomiting

lake, once am done cleaning the fish I am starting walking around the village selling it and then fry the remaining that people would not have bought that day' **Female FGD, Ndaiga Village, Ndaiga sub-county.**

The above finding was also supported by views from the farming community, who perceive that a higher risk of infection arises due to their roles. A key informant had this to say:

'……. now like most women arethe ones who go to fetch water they are the ones that go to wash, they spend much time in water……' **Male FGD, Kyaterekera A village, Kyaterekera sub-county.**

From the above findings, there exist different perceptions among men and women regarding gender roles as a predisposing factor for infection and spread. That is, both men and women perceive themselves to be more exposed than the other gender due to their different roles. Although this view is more strongly held by the men from the fishing community than the females from the same communities and both the men and women from the farming communities.

b. Societal cultural norms and susceptibility to infection

Findings from the data reveal that female participants thought that women are at a higher exposure risk to bilharzia due to societal cultural practices, such as fetching water and norms like cooking food. For instance, the women are expected to fetch water, wash utensils, bathe children and wash clothes, among others. The male participants also supported the female participants' views, saying that they too, perceive the women as highly exposed to schistosomiasis infection due to cultural expectations of the women's roles, such as washing clothes along the lake shore. One male participant from Soborwa village in an FGD reported:

'…..……...I think women because women go to water sources a lot, they fetch water, wash clothes wash utensils and then children go with their mothers to the water sources this exposes the children too……' **Male FGD, Kyaterekera B village, Kyaterekera sub-county.**

Data from participants also revealed that culturally, society expects males in the farming community to fend for household needs. The participants perceived this to be the reason why men frequent the lake for business purposes, such as fishing and transporting food products. Some take their agricultural produce, such as matooke (green bananas), beans, Irish potatoes, and sweet potatoes, for sale, while others go to the lake to fish or buy fish. A participant reported:

'I am a farmer who grows matooke; when it is ready, I cut some and take it to the lake for sale……. that is how I get school fees for my children' **Male FGD, Nyantonzi Villages, Kyaterekera sub-county.**

c. Gender stereotypes of bilharzia signs and symptoms

Both the male and female participants reported commonly known signs and symptoms, such as weight loss, swollen stomach, body weakness, stomach ache, vomiting, yellow urine, swollen stomach and pale skin. Other symptoms and signs reported include red eyes and diarrhoea that manifest among those infected with Bilharzia.

3.3.1. Confusing signs and symptoms

However, female participants reported that signs might be confusing as they are often stereotyped by society. For example, women's swollen stomachs and vomiting are sometimes interpreted as a pregnancy. For men, there is a belief that if a man's stomach grows big, it could be because he has a lot of money. In an interview, one of the women in Kamina village said:

> *'……. the women also suffer, but it is difficult to realize they have bilharzia, but children, you can easily tell……..'* **Individual In-depth Interview, Kamina Village, Ndaiga sub-county.**

3.3.2. Difficulties in noticing signs and symptoms

This gender stereotype is further reinforced by scientific explanation that such signs and symptoms take long to manifest, thereby making it difficult for the community to notice. Participants noted that bilharzia could stay in the bodies of both men and women for a long time before signs begin to manifest. People, therefore, tend to neglect it before it worsens as the signs manifest. In an interview, a key informant said:

> *'……you know bilharzia can be in your body for a very long time before the signs manifest outside……'* **Key Informant Interview, Kagadi District Health Authority.**

d. Gendered myths and misconceptions

The study findings revealed gender differences in the misperception regarding the place of residence and risk of schistosomiasis infection. Male participants from the farming communities thought of bilharzia as a disease only affecting people who live at the lake, men who carry out fishing from the lake. The participants also perceived it to be for women who spend long hours performing house chores in the lake water. They referred to it as 'a disease of the lake'. A participant expressed himself and said:

> *'We do not have people suffering from bilharzia in this village; if you want to see people suffering from bilharzia, go to the lake; many people have swollen bellies. That disease is very common at the lake. I cannot lie that I have seen or heard anyone die from bilharzia in this village'* **Male FGD, Kyaterekera B Village, Kyaterekera sub county**.

In the fishing community, men and women attributed the disease to witchcraft for example, some of them believe that when a person gets a swollen belly, he or she might have misbehaved at the lake by stealing the Congolese fish nets, he or she is bewitched, whereas others said it is related to HIV, as the signs of bilharzia are almost similar to those of HIV/AIDS, whereas others believed that the signs and symptoms were for alcoholism.

e. Perceptions of gender aspects in the side effects of bilharzia medicine

The study's findings indicate that whereas people use PZQ as the prescribed and Mass Drug Administered medication to treat schistosomiasis, its side effects are perceived to be similarly experienced by both men and women and in both farming and fishing communities. The side effects were perceived as more severe than the disease itself. Both men and women believed that the side effects were because of the infection, which also showed that the treatment was effective. Also, in both the fishing and farming community, men and women participants reported diarrhoea, dizziness, vomiting and fatigue or general body weakness as common side effects after taking the medicine. For example, in a focus group discussion, participants expressed themselves and said:

> *'……. I know there is bilharzia medicine which they give us, and after you have swallowed them, you get diarrhoea……..'* **Female FGD Kyaterekera A village, Kyaterekera sub-county.**

The fear of the bilharzia drug side effects is why some people resort to other methods, including herbal medicines and prayers in churches. In both communities, it was perceived that more women sought herbal medicine for bilharzia treatment than men. A female FGD participant from Kitebere Village reported:

> *'…….I quickly thought about going to look for herbal medicine. I went and sought herbal medicine. And they helped me better than the bilharzia tablets.* **Female FGD participant in Kitebere Village.**

4. Discussion

Although some studies have been conducted on gender as a predisposing factor to schistosomiasis infection, the perceptions of men and women in endemic communities regarding gender roles as a potential predisposition have not received adequate attention. We conducted a qualitative study to understand the perception of gender roles and how these roles predispose communities along Lake Albert in Uganda to schistosomiasis infection. The main findings from the data analysed include community perceptions of gender roles as risk factors for infection, gendered cultural norms, gendered stereotypes about bilharzia signs and symptoms and gendered myths and misconceptions, among others. This section presents a discussion of the study findings below.

4.1. Community perceptions of gender roles as a risk for infection

First, regarding the community's perception of gender roles as a risk factor, both males and females are perceived to be at risk of infection due to the roles they differently play. However, among the fishing community, participants perceived men to be at a higher risk of infection than women. The participants attributed this to the longer time the men spent at the lake while fishing. This is likely attributed to the societal role of men being providers and family heads. As a result, they are forced to go to the lake for fishing, and sometimes they take a long time, which certainly cannot be avoided, as explained by the community. While on the lake, they must defecate in the lake and drink the lake water, as they do not have any other options. Sometimes they even jump into the lake to organise the fishing nets. The findings from this study differ from Munisi et al. (2017), who demonstrated no significant difference in schistosomiasis infection between men and women. Therefore, this study provides significant insights into not only actual infection but also the different male and female perceived roles that predispose the communities to infection.

On the other hand, women are also believed to be at risk of being exposed to bilharzia due to their household roles, such as washing utensils and clothes, bathing children and cooking, among others. When these household roles, such as washing clothes and utensils, are performed in groups, it transforms their mundane tasks into a time for socialisation and increasing time spent in the infested water. However, the women still believe men spend more time in infested lake water than them. The explanation for why women would be less at risk goes back to the amount time spent in the water, where they believe that these household roles do not require them to spend that much time in the infested water compared to men, who even spend weeks on the lake fishing. The findings from our current study agree with a study conducted at Lake Victoria on perceptions about interventions to control schistosomiasis (Sanya et al., 2017). Similarly, Trienekens et al. (2020) found that for children, the type of activity, duration, frequency, level of submersion and site of water activities showed only a few behavioural differences between men and women.

In the farming community, respondents believe women's susceptibility to bilharzia exposure is established by norms, cultural and social practices that require women to perform roles, such as fetching water, cooking and washing, compared to men. Women are perceived to be always exposed because of continuous water contact, as they are fetching from contaminated sources. These roles, according to participants, make women to be more vulnerable to schistosomiasis infection. Furthermore, participants perceived that the women who farm near infested swampy areas may require water from these sources for a constant water supply, thereby increasing their risk of infection.

Overall, however, both men and women in the farming community are perceived to have a lower risk of contact with infected water than their fishing community counterparts and this is in accordance with their lower prevalence. The women from farming communities usually fetch water from dams and streams that may be infested, for household use, such as washing utensils, cooking and washing clothes. Those men's and women's farming community who frequent the lake for business purposes are perceived to be at a higher risk of exposure. It was also noted that men from the farming communities are more engaged in doing business at the lake shore than women, thereby increasing their infection risk. This could be because they step in the water directly from the lake when they reach it. Moreover, a study by Chala and Torben (2018) also reported that some women scooping water at a river in Ethiopia keep their hands dry to prevent contact. However, they demonstrated that contact with water carried home from the river might increase their infection risk. These findings provide insight into the communities' perception of gender roles as infection risk among different genders using the time factor. Targeted sensitisation programmes on gender roles and risk factors in endemic areas, such as boiling water for drinking, must be prioritised.

4.2. Gendered stereotypes of bilharzia signs and symptoms

Findings from this study revealed that the commonly known stereotypes about bilharzia signs and symptoms include weight loss, swollen stomach and body weakness. Other stereotypes of symptoms include stomachache, vomiting, yellow urine, swollen stomach, pale skin, red eyes and diarrhoea. Also, the stereotype in men is that a swollen belly is a sign of having a lot of money, while women may be considered pregnant, as confirmed in a previous study (Anyolitho et al., 2022). This could explain why some individuals delay seeking medications for such signs and symptoms. Although the study by Mujumbusi et al. (2023) agrees that bilharzia presents with symptoms, such as abdominal pain, abdominal swelling and anaemia, the study does not tell whether these signs and symptoms are also stereotyped. There is a need for more gender-awareness raising to clarify such stereotypes among communities.

4.3. Perception of gender factor in side effects of bilharzia medicine

This current study found that both males and females from both study settings perceive the medication prescribed to treat bilharzia to be effective. This could explain that some factors like transportation costs, non-availability of the drug in government hospitals, and poor inaccessible roads, which are important in the limited drug uptake reported in a previous study of health-seeking behaviour in the same community (Anyolitho et al., 2023).

Additionally, both male and female participants in both communities thought that men, especially fishermen and farmers, were usually hesitant to take bilharzia medicine. This could be attributed to fear of the side effects, which require them to stay home until they are fine. Moreover, they believe that they could use this time to continue doing their daily activities like fishing and attending to their gardens. Furthermore, the female study participants from the fishing communities reported using herbal medicine, perceived to provide relief compared with conventional medication. Our findings agree with those of Ayesiga et al. (2022), who reported that various individuals from western Uganda perceived more treatment benefits with herbal medicine usage. Also, women wait for their husbands to decide when and where they should seek treatment. Men being the breadwinners of their families, provide money for transport and treatment. After the man has provided money, he will still decide if they should go to a government facility, buy the drugs from a drug shop or go to the herbalist (Anyolitho et al., 2023). Therefore, more sensitisation concerning bilharzia management must be intensified for better outcomes.

In this study, some male participants argued that even when they followed advice from health workers, the advice did not work, as they still experienced drug side effects. Advice given included things like eating food before swallowing the drug to reduce the side effects. The participants described the side effects as ‘worse than the disease itself.’ Some participants suggested that there should be a vaccine to replace the current drugs, which can also be given to pregnant women. Furthermore, other studies have shown that Ugandan fishing communities are willing to participate in vaccine trials to fight bilharzia (Sanya et al., 2017). Therefore, mass sensitisation concerning drug reception must be prioritised for better health outcomes in both communities, though with emphasis on the fishing communities.

While this study provides interesting insights into the perceptions of gender roles as a predisposing factor in schistosomiasis infection and control in endemic communities, it is difficult to generalise the findings to the overall population due to the small sample size and biased data collection methods. Furthermore, the fact that few gendered parameters were considered in this study makes it difficult to draw an overall conclusion about the perceptions of gender roles. Other parameters, such as gender identities, power dynamics, vulnerability, empowerment and intersectionality, among others, could also have an influence.

5. Conclusions and recommendations

Understanding the community's perceived social and cultural gender roles is important in schistosomiasis prevention and control efforts. This study concludes that there exist perceptions towards schistosomiasis infection and control. That is, whereas both men and women from both fishing and farming communities think that their different gender roles put them at higher risk of infection than their counterparts, the men perceive themselves to be at greater risk due to engaging in fishing activities in the lake. On the contrary, the females in farming communities think that their domestic house chores, like fetching water, washing utensils and clothes and others, predispose them to a greater risk of infection than the males. A comprehensive gendered approach to the design and implementation of awareness campaigns that take into consideration the perceived differences in gender roles is critical to attaining equitable outcomes. Lastly, there is a need to conduct a quantitative study to elucidate the views of the communities regarding the perceptions of gender roles as a predisposing factor for schistosomiasis infection and control.

Author contributions

CRediT: **Faith Mugabi:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration; **Maxson Kenneth Anyolitho:** Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing; **Tine Huyse:** Funding acquisition, Writing – review & editing; **Elizabeth Kemigisha:** Supervision; **Viola Nilah Nyakato:** Investigation, Supervision, Writing – review & editing.

Disclosure statement

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Data availability statement

Transcripts and other field data content for this study are available from the corresponding author on request.

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