

Faculty of Social Sciences

Community-led approaches to the prevention and control of schistosomiasis: a sociological analysis of the citizen science model among selected communities of western Uganda

PhD thesis submitted for the degree of Social Science: Sociology at the University of Antwerp to be defended by 2024

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Antwerp, 2024

DECLARATION

I declare that the work presented in this thesis is the result of my original research. Where I have used the works of other persons, I dully acknowledged them. No portion of this work has been submitted in support of an application for a degree or qualification to any other university or institute of higher learning. I present it without any reservations for external examination.

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APPROVAL

We the undersigned, declare that the research work culminating in this thesis was conducted by Mr. Anyolitho Maxson Kenneth under our guidance and supervision. The thesis is now ready for submission to the Directorate of Graduate Research and Training (DRGT) of Mbarara University of Science and Technology (MUST) for examination with our approval as his supervisors.

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DEDICATION

To Dad, Mr Kenneth Opion Anyolitho (RIP), « *wu wek awiya gikwan* » (You should ensure that my children acquire education), were your words to us through our uncles Joel and Champlain while at Karuma Falls, a few hours after which you breathed your last, became a signpost for my life's journey.

To Mum, Ms Hellen Acayo Anyolitho (RIP) « *Ka idok ungo i boarding School, amiyu iri ngo kony moko* » (if you don't go back to your boarding school, I will not provide you with any support). Your strong message stuck in my mind and has been willpower whenever I would want to give up.

To my wife, Kevin and children-Faith, Barbara, Jethro, Nathanael and Nicole.

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LIST OF ACRONYMS AND ABBREVIATIONS

ATRAP	Action Towards Reducing Aquatic snail borne Parasitic Diseases
CAO	Chief Administrative Officer
CDC	Center for Disease Control
CHEW	Community Health Extension Worker
CS	Citizen Science
DRC	Democratic Republic of Congo
FGD	Focus Group Discussion
IDI	In-Depth Interview
KAP	Knowledge Attitude and Practices
MDA	Mass Drug Administration
MWE	Ministry of Water and Environment
NTD	Neglected Tropical Disease
Praziquantel	PZQ
REC	Research Ethics Committee
SPSS	Statistics for Social Sciences
UNCST	Uganda National Council for Science and Technology
USAID	United States Agency for International Development
VHT	Village Health Team
WHO	World Health Organisation

LIST OF PUBLICATIONS AND CONFERENCES

Publications included in the thesis.

1. **Anyolitho, M.K.**, Nyakato, V.N., Huyse, T., Poels K. (2023): Health-seeking behaviour regarding schistosomiasis treatment in the absence of a mass drug administration (MDA) program: the case of endemic communities along Lake Albert in Western Uganda. *BMC Public Health* **23**, 1072 <https://doi.org/10.1186/s12889-023-16020-z>
2. **Anyolitho MK**, Poels K, Huyse T, Tumusiime J, Mugabi F, Tolo CU, Masquillier C, Nyakato N.V (2022): Knowledge, attitudes, and practices regarding schistosomiasis infection and prevention: A mixed-methods study among endemic communities of western Uganda. *PLoS Negl Trop Dis* 16(2): e0010190. <https://doi.org/10.1371/journal.pntd.0010190>
3. **Anyolitho, M.K.**, Huyse, T., Masquillier, C. *et al.* Empowering communities through citizen science and participatory action research: implementation of a schistosomiasis communication campaign in Uganda. *Humanit Soc Sci Commun* **11**, 227 (2024). <https://doi.org/10.1057/s41599-024-02714-1>

Conferences, symposia and seminars

4. **International Conference of Parasitologists Association (ICOPA2022)**- from August 21st to 26th 2022 in Denmark, Copenhagen. This was a one-week conference at the International Conference of Parasitologists Association. I made an oral presentation on a paper titled: “**Citizen scientists as communicators: community-led awareness campaigns for schistosomiasis prevention in Uganda**”; see link for details: <https://cslide.ctimeetingtech.com/icopa22/attendee/confcal/session/calendar/2022-08-26>
5. **European Citizen Science Association conference (ECSA2022)** from October 4th to 8th 2022. This was a four-day conference of citizen science experts across the world in Berlin, Germany. I made poster presentations for my research objective four titled: “**Citizen (Social) Science as a new Paradigm to Participatory Action Research in the Global South: A Case Study for schistosomiasis prevention in Uganda**”. <https://2022.ecsa-conference.eu/startseite.html>
6. Uganda Schistosomiasis Multidisciplinary Research Centre (U-SMRC)/ CHI in Africa: **Uganda Schistosomiasis Symposium I: schistosomiasis research and controlled human infection studies**

for helminth vaccine development in Africa: 27th February – 2nd March 2023 at Uganda Virus Research Institute, Entebbe Uganda: Title: Health-seeking behaviour regarding schistosomiasis treatment in the absence of a regular mass drug administration program among endemic communities along Lake Albert-Uganda. <https://pubmed.ncbi.nlm.nih.gov/37032215/>

7. Mbarara University of science and technology (MUST), Uganda: Annual Symposium, June 2022:

Community Engagement and Schistosomiasis Prevention. A sociological analysis of the citizen science model among selected communities of Western Uganda:

<https://www.must.ac.ug/event/the-6th-annual-must-phd-symposium-2022/>

8. Mbarara University of science and technology (MUST), Uganda: Annual Symposium, March 2023:

A Community Approach for Schistosomiasis Prevention through a Behavior Change Intervention. A sociological Analysis integrating a citizen science approach among selected communities of Western Uganda: <https://www.must.ac.ug/17ardcconcept/>

9. Mbarara University of Science and Technology (MUST), Uganda: Annual Scientific research dissemination conference, March 2023: (How) Can we implement behaviour change interventions for schistosomiasis prevention using Citizen Science and other participatory approaches?

<https://www.must.ac.ug/17ardcconcept/>

Summary

Schistosomiasis is a public health problem and a social challenge, affecting over 240 million people globally, the majority of whom live in sub-Saharan Africa. In Uganda, despite mass drug administration (MDA) of praziquantel (PZQ) and health education and sensitization interventions, (re) infections persist, possibly due to behavioural and implementation factors. This study examined the application of citizen science, a bottom-up community-led approach to behaviour change intervention in Kagadi and Ntoroko districts. A three-phase quasi-experimental approach was employed. In the baseline phase, a cross-sectional mixed methods survey assessed knowledge, attitudes and practices, qualitative studies of lived experience and health-seeking behaviour regarding the disease. In the second phase, citizen science and participatory action research approaches were utilised to co-design and implement contextualised behaviour change interventions. Finally, a participatory evaluation of the CS approach to behaviour change intervention was conducted in phase three. Using Kish and Leslie's formula and estimation, a sample size of 613 was used for the study. Systematic random sampling and purposive sampling techniques were employed to select participants. Semi-structured survey questionnaires, in-depth and key informant interviews, focus group discussions, data party, prioritisation and ranking, world café and storytelling were used to collect data. Quantitative data underwent descriptive statistical analysis and chi-square tests for associations, while thematic analysis was applied to qualitative data. From the data, almost everyone had heard of schistosomiasis, and the majority knew its signs and symptoms, diagnosis, transmission modes and prevention. A majority recognised the disease's severity and the importance of avoiding contact with contaminated water and open defecation. Misconceptions, limited access to safe water and latrines, open defecation, inadequate drugs, health workers' negative attitudes, and poor infrastructure led some to go to witch doctors, herbalists, and prayers for treatment were barriers reported. Also, stigma, isolation, loneliness, and domestic violence were challenges mentioned by individuals suffering from schistosomiasis. Door-to-door visits by community volunteers, community radios, dialogue meetings, drama, songs, and football were preferred channels mentioned by participants. Over 9000 individuals in 18 villages were directly reached by the CSs through awareness raising about the disease in just one week. CSs reported increased respect, trust, discipline, social status, and knowledge, attitudes, and practices regarding schistosomiasis. They were also able to effectively communicate and engage with communities and stakeholders. The CS approach was appreciated by the communities for being participatory, transparent, engaging, and appropriate. High expectations from the project by the communities, differences in priorities between community needs and project priority, and a slow response to the awareness messages by the communities posed a challenge to the approach. Conclusively, there is adequate knowledge, and positive attitudes towards schistosomiasis prevention, but limited access to safe water, open defecation, myths and misconceptions, inadequate drugs, and ineffective communication which inhibit prevention and control efforts. Engaging communities in identifying schistosomiasis problems and co-designing and implementing contextualised behaviour change intervention can yield sustainable outcomes. CS as a bottom-up approach, has the potential for fostering community empowerment, ownership, transparency, inclusivity, and local leadership. For better outcomes, there is a need to address communities' real needs and high expectations of WASH infrastructures and to ensure timely and in-depth community engagement and involvement. Government and development

partners should consider integrating CS and PAR as community-led approaches into preventive health programs for more impactful interventions.

Dutch Summary

Schistosomiasis is een probleem voor de volksgezondheid en een sociale uitdaging, die wereldwijd meer dan 240 miljoen mensen treft, van wie de meerderheid in Afrika ten zuiden van de Sahara woont. In Oeganda blijven (her)infecties bestaan, ondanks de massale toediening van praziquantel (PZQ) en gezondheidszorgvoorlichting en sensibilisatie-interventies, mogelijk als gevolg van gedrags- en implementatiefactoren. Deze studie onderzocht de toepassing van burgerwetenschap, een bottom-up, door de gemeenschap geleide benadering van gedragsveranderingsinterventie in de districten Kagadi en Ntoroko. Er werd gebruik gemaakt van een quasi-experimentele benadering in drie fasen. In de basisfase werden via een cross-sectioneel onderzoek met gemengde methoden kennis, attitudes en praktijken, kwalitatieve studies van geleefde ervaringen en gezondheidszoekend gedrag met betrekking tot de ziekte beoordeeld. In de tweede fase werden burgerwetenschappelijke en participatieve actieonderzoeksbenaderingen gebruikt om gecontextualiseerde gedragsveranderingsinterventies te ontwerpen en te implementeren. Ten slotte werd in fase drie een participatieve evaluatie van de CS-benadering van gedragsveranderingsinterventie uitgevoerd. Met behulp van de formule en schatting van Kish en Leslie werd voor het onderzoek een steekproefomvang van 613 personen gebruikt. Er werden systematische willekeurige steekproeven en doelgerichte steekproeven gebruikt om deelnemers te selecteren. Semi-gestructureerde vragenlijsten, diepgaande interviews en interviews met belangrijke informanten, focusgroepdiscussies, dataparty's, prioritering en rangschikking, wereldcafé en storytelling werden gebruikt om gegevens te verzamelen. Kwantitatieve gegevens ondergingen beschrijvende statistische analyses en chi-kwadraattoetsen voor associaties, terwijl thematische analyse werd toegepast op kwalitatieve gegevens. Uit de gegevens bleek dat bijna iedereen van schistosomiasis had gehoord, en de meerderheid kende de tekenen en symptomen, de diagnose, de overdrachtswijzen en de preventie ervan. Een meerderheid erkende de ernst van de ziekte en het belang van het vermijden van contact met besmet water en open ontlasting. Misvattingen, beperkte toegang tot veilig water en latrines, ontlasting in de open lucht, ontoereikende medicijnen, de negatieve houding van gezondheidswerkers en een slechte infrastructuur brachten sommigen ertoe naar toverdokters en kruidendokters te gaan, en gebeden voor behandeling waren barrières die werden gerapporteerd. Ook stigmatisering, isolatie, eenzaamheid en huiselijk geweld waren problemen die werden genoemd door personen die aan schistosomiasis leden. Huis-aan-huisbezoeken door vrijwilligers uit de gemeenschap, gemeenschapsradio's, dialoogbijeenkomsten, drama, liedjes en voetbal waren door de deelnemers genoemde voorkeurskanalen. Meer dan 9000 personen in 18 dorpen werden in slechts één week rechtstreeks bereikt door de CS's door middel van bewustmaking over de ziekte. CS's rapporteerden meer respect, vertrouwen, discipline, sociale status en kennis, attitudes en praktijken met betrekking tot schistosomiasis. Ze waren ook in staat om effectief te communiceren en betrokken te zijn bij gemeenschappen en belanghebbenden. De CS-aanpak werd door de gemeenschappen gewaardeerd omdat deze participatief, transparant, betrokken en passend was. Hoge verwachtingen van het project door de gemeenschappen, verschillen in prioriteiten tussen gemeenschapsbehoeften en projectprioriteit, en een trage reactie op de bewustmakingsboodschappen van de gemeenschappen vormden een uitdaging voor de aanpak. Concluderend is er voldoende kennis en een positieve houding ten aanzien van de preventie van schistosomiasis, maar beperkte toegang tot veilig water, ontlasting in de open lucht, mythen en

misvattingen, ontoereikende medicijnen en ineffectieve communicatie die de preventie- en controle-inspanningen belemmeren. Het betrekken van gemeenschappen bij het identificeren van schistosomiasisproblemen en het gezamenlijk ontwerpen en implementeren van gecontextualiseerde gedragsveranderingsinterventies kan duurzame resultaten opleveren. CS als een bottom-up benadering heeft het potentieel om de empowerment, het eigenaarschap, de transparantie, de inclusiviteit en het lokale leiderschap van de gemeenschap te bevorderen. Voor betere resultaten is het nodig om tegemoet te komen aan de werkelijke behoeften van gemeenschappen en de hoge verwachtingen van WASH-infrastructuren, en om tijdige en diepgaande betrokkenheid van de gemeenschap te garanderen. Overheids- en ontwikkelingspartners zouden moeten overwegen om CS en PAR te integreren als vanuit de gemeenschap geleide benaderingen in preventieve gezondheidsprogramma's voor interventies met meer impact.

CHAPTER ONE GENERAL INTRODUCTION

1.1 Introduction

Schistosomiasis presents a serious public health burden and a social challenge globally, with Africa being the most affected. The World Health Organisation (WHO) recommends three strategies for the prevention and control of schistosomiasis: preventive chemotherapy using mass drug administration (MDA), snail control and behaviour change using improvement in water, sanitation and hygiene (WASH), and health education and sensitisation (WHO, 2022). In Uganda, interventions for the prevention and control of the disease have mainly been through mass drug administration (MDA) of praziquantel (PZQ) drugs accompanied by health education and sensitisation (Adriko, Faust, et al., 2018). The programs are designed by the Ministry of Health with the support of development partners and delivered by village health teams (VHTs) at community levels with the help of district health teams (Muhumuza, Olsen, et al., 2013).

These interventions can be implemented either using top-down or bottom-up approaches but with different outcomes. A top-down approach to behaviour interventions is where programs are designed from the ministry and delivered down to the communities without their active involvement and participation in the design and implementation process (Onasanya et al., 2021). Meanwhile, bottom-up approach is where programs are developed and implemented in a collaborative and participatory manner by the local communities, government agencies and other stakeholders (Person et al, 2016).

Citizen science is one such bottom-up community-led participatory approach that involves collaboration between local communities as lay persons with researchers as scientists in conducting research. Citizen Science is defined as “the general public engagement in scientific research activities when citizens actively contribute to science either with their intellectual effort or surrounding knowledge or with their tools and resources” (Socientize, 2013). Simply put, CS is the partnership between scientists and the

community/citizens to conduct research (Toomey & Domroese, 2013). Using the CS model, scientists enter into a partnership with community members/citizens (citizen scientists) to conduct research (Toomey & Domroese, 2013).

Citizen science has enormous benefits such as stronger impact, promotion of in-depth understanding of the problem through data and information sharing, effective communication among different stakeholders, promotion of active community engagement, and harnessing complex local knowledge (Marrow & Volunteers, 2013). The application of citizen science in the global south, however, is still limited. Furthermore, although a bottom-up approach to behaviour change interventions like CS is said to produce successful and sustainable outcomes, it has not been exhaustively applied in the fight against schistosomiasis (Alexander, 2016).

It is against the above backdrop that in this PhD thesis, I examined the contribution of bottom-up community engagement interventions that employ citizen science and other participatory action research approaches to behaviour change regarding schistosomiasis among endemic communities in Western Uganda. The study adopted a multi-phase approach of largely qualitative mixed methods. The approach comprises a range of research designs such as a cross-sectional survey of equal status, qualitative phenomenological and ethnographic design, participatory action research (PAR), and participatory process evaluation designs. Utilising a sociological lens and methods, I interrogated the application of citizen science as a participatory research approach in addressing the social and cultural barriers to schistosomiasis disease prevention and control. By investigating the dynamics of community participation, knowledge exchange, and social mobilization, the research aimed to provide valuable insights for policymakers, healthcare practitioners, and community stakeholders involved in schistosomiasis prevention efforts.

The study was framed within a bigger project “Action Towards Reducing Aquatic Snail-borne Parasitic Diseases” (ATRAP). ATRAP was a five-year (2019-2023) citizen science-based collaboration between Mbarara University of Science and Technology (MUST) in Uganda, and the Royal Museum for Central Africa (RMCA) in Belgium. The project aimed to contribute towards promoting the health of the community along Lake Albert in Western Uganda, through a reduction in the prevalence of schistosomiasis and liver flukes. The project’s focus was on snail control, the geographical context of snail-borne disease, and the human social, cultural, and environmental aspects. The approach combines classical citizen science (CS) (collecting scientific data) with other participatory action research techniques as a bottom-up community-led project, to facilitate contextualized outreach activities that accommodate the many ecological, social and cultural factors that challenge the elimination of this disease. The project supported PhD and MSc students in the biological, social science, ecology and geographical disciplines. Using this approach, the students who are professional researchers, collaboratively work with the local communities as citizen scientists, to conduct research of different types. It is within this lens that I set out to evaluate the bottom-up approach to community engagement using citizen science to the prevention and control of the disease.

1.2 Background to the study

What is schistosomiasis?

Schistosomiasis or bilharzia is a snail-borne parasitic disease that is caused by trematode flukes of the genus *Schistosoma* (Colley, Bustinduy, Evan, et al., 2014). The disease infects humans when they come into contact with contaminated water. The parasite removes itself and enters the human body through the skin. It is one of the neglected tropical diseases (NTDs) that perpetuate the health of millions of communities, especially in Africa (Bah et al., 2006; Lo et al., 2022). Although it is a chronic disease, in some

cases it can become acute and fatal, resulting in the death of the infected person (Kaliyaperumal and Almalki, 2017).

What are the signs and symptoms of schistosomiasis?

Individuals with schistosomiasis present with common signs and symptoms such as swollen belly, blood in the faeces, skin rash, fever, head and body aches, diarrhoea and constipation, and general thinning of the body (Coulibaly, 2013; Reis et al., 2010; Ross et al., 2001). In advanced stages, liver fibrosis, intestinal ulcers, high blood pressure, stunted growth, cognitive impairment in children, and infertility in women are common but difficult to diagnose (A. G. P. Ross et al., 2001).

Risk factors of schistosomiasis

Sociocultural factors such as knowledge, attitude, and practices (KAP) and personal characteristics such as age, education, and economic and environmental factors are said to influence schistosomiasis infection and prevention (Bruun et al., 2008). Other personal factors include gender, marital status, and ethnicity (Adriko, Faust, et al., 2018; Angora et al., 2019; Trienekens et al., 2020).

At the individual level, there is a link between knowledge, attitude, and practices and schistosomiasis infection. Inadequate knowledge of the signs and symptoms means that people will be at risk of contracting the disease (Midzi et al., 2011). This is because the individuals will engage in risky practices without knowing the negative implications. Similarly, knowledge of the causes, prevention and treatment is crucial if prevention interventions are to be designed. Communities that have negative attitudes also tend to have poor health-seeking behaviours (Folefac et al., 2018). The differences in knowledge and attitudes affect not only the community's preventive practices but also their health-seeking behaviours and attitudes.

Furthermore, age, socio-economic status, gender, and educational levels are also associated with schistosomiasis infections (Adriko et al., 2018; Angora et al., 2019; Alencar et al., 2001; Trienekens et al.,

2020). For example, it is reported that poverty forces individuals to engage in risky practices, fail to access clean water and also fail to construct latrines (Atalabi & Adubi, 2019; Francisco et al., 2019; Nassiwa et al., 2020). Studies on gender seem to produce mixed findings. For instance in Uganda, although women were reported to be more engaged in water-related activities than men, no significant difference between the genders regarding re-infection rates (Trienekens et al., 2020). Meanwhile, in Nigeria, men were at more risk of infection than females (Dawaki et al., 2016).

Some studies have also reported a link between access to water and sanitation facilities and infection although this may not be absolute. That is, the absence or lack of access to clean water and proper latrines is associated with higher rates of schistosomiasis infection (Muhumuza, 2017). Studies show that communities that do not have access to clean water tend to have a high rate of infection compared to those that have (Musuva et al., 2014b). Engaging in risky water and sanitation practices such as defecating and urinating in water, swimming, bathing, washing utensils and clothes, and carrying out fishing activities pose a serious risk of infection with schistosomiasis (Gebreyohannis et al., 2018). Similarly, infections are bound to be higher in places where people do not have latrines, than in places where latrine coverage is high (Adriko, 2017b; Sanya et al., 2017a).

Community myths and misconceptions surrounding schistosomiasis disease, such as its meaning, beliefs regarding signs and symptoms and how it is prevented have also been found to inhibit prevention and control efforts (Rassi et al., 2019). For instance, in western Kenya, it is believed that schistosomiasis in children and young men is caused by witchcraft and it is a disease of those at the lake shores (Musuva et al., 2014b).

Studies on schistosomiasis further show that different people experience the same disease in different ways, thereby shaping their perceptions differently (Onyeneho et al., 2010). For instance, some people may develop fear and aversion to the disease, while others may look at it as an opportunity and potential

to change their livelihoods (Odhiambo et al., 2016). Most often, however, people who have suffered from an illness tend to develop different opinions afterwards and are often positive about preventive measures (Bah et al., 2006). Understanding the individuals' lived experiences of schistosomiasis and how such experiences shape their perceptions of the disease and their subsequent responses/actions is important in guiding effective and sustainable interventions.

Diagnosis and treatment of schistosomiasis

Diagnosis of schistosomiasis is normally done through the detection of schistosome eggs during microscopical urine and stool analysis (A. G. P. Ross et al., 2001; Tchuem Tchuente et al., 2017), although the majority of community members rely on observing the above signs and symptoms to confirm the disease presence or absence. Whereas most of the signs and symptoms regarding schistosomiasis show up at different stages after infection, some of them may trigger health-seeking by some members of the community. Studies on health-seeking regarding schistosomiasis show that people seek treatment from biomedical sources while others to go traditional healthcare sources or both for different reasons (Kirscht, 1981). These decisions and actions have different implications for schistosomiasis infection and control.

Prevention and Control

Schistosomiasis elimination has been at the centre of governments and development partners worldwide, but up to date, there is no confirmed cure or vaccine (Muheki, 2011). Historically, prevention and control have been at the forefront of global efforts to combat the disease. The control is through preventive chemotherapy (PC) using mass drug administration (MDA) of praziquantel (PZQ) and snail control, while prevention focuses on behavioural change strategies to encourage preventive practices (Ross et al., 2014). Of the three, PC through MDA of PZQ is the most commonly used strategy accompanied by behaviour change intervention (Envision, 2017). The WHO further recommends that PZQ be administered to school-

going age children (SAC) and adult individuals in endemic areas at least once every 2 years, once a year, and twice a year for low, moderate, and high-endemic areas respectively.

The socio-cultural construction of schistosomiasis

Schistosomiasis has a social and cultural construction in as much as the biomedical dimension. Different communities have different ways in which they perceive the disease including its name, meaning, signs and symptoms, and causes and treatment and prevention among others. The most common name is bilharzia. However, different communities have different local names with local meanings. In Nigeria, among the Imo community members, it is called ATOSIAJA relating it to water contact activities (Bolaji Os et al., 2014). In Uganda, names used for schistosomiasis include kidaada in Eastern Uganda associating it with witchcraft (Mujumbusi et al., 2023), empuuka in Bunyoro, and bilaja in Alur.

Regarding signs and symptoms, local interpretations vary from community to community, with some perceiving some of the signs and symptoms to be normal while others perceive it to be dangerous or a problem (Bruun et al., 2008). Furthermore, in Uganda just like in other countries schistosomiasis transmission and treatment are associated with perceptions like witchcraft, and misfortune (Muhumuza, 2017). Similarly, health-seeking is sought from different sources other than the conventional ones like herbalists and witch doctors. The above literature implies that schistosomiasis is an old-age disease that has a local meaning with local solutions.

Global situation of schistosomiasis

Schistosomiasis is a Neglected Tropical Disease (NTD), second to malaria in terms of prevalence with a public health burden and a social challenge globally, with Africa being the most affected (Gitaka et al., 2019). Firstly, it is referred to as a tropical disease because it largely affects populations that are in tropical

Africa, the Middle East, Central and South America, the Caribbean and the Far East (Kassa et al., 2005). Secondly, it is a neglected disease because it is one of the diseases that attract little or no public health attention for intervention and treatment/control (Vuoso, 2022). Globally, over 240 million people are infected by the disease, of whom over 90% are found in Africa, with 280,000 deaths, while 700 million and 800 million are at risk (French et al., 2018; Loewenberg, 2014). In terms of economic productivity, the sub-Saharan African region incurs an annual loss of about US dollars 3.5 billion to schistosomiasis and soil-transmitted helminthiasis alone (Tanser et al., 2018). The World Health Organisation (WHO) categorizes schistosomiasis infection endemic areas into three levels: low for areas below 10%; moderate for those between 10% to 49%; and high for areas from 50% and above (WHO, 2022). Uganda is one of the Sub-Saharan African countries considered highly endemic to schistosomiasis (Adenowo et al., 2015).

Schistosomiasis situation in Uganda

In Uganda, schistosomiasis is considered a serious public health problem (Melissa et al., 2012). The first cases of mansoni were reported in 1946 (Schwetz, 1951) and that of haematobium in 1967 (Bradley et al., 1967). By the 1990s, the whole country was considered to be at risk of the disease infection (Adriko, Tinkitina, et al., 2018; Stott, 1973). Since then, prevalence has been fluctuating, ranging from 2% to over 90% (Loewenberg, 2014). Most affected persons are those who live along those water bodies and who engage in water-related activities like fishing, fetching water, swimming, washing utensils, and bathing among others (Loewenberg, 2014). Although the disease affects groups of people, children below five years and those living along large water bodies like lakes, rivers and swamps are said to be the most affected (Muheki, 2011). Recent studies have further indicated that (re)infections have remained high, even in areas where MDA has been implemented (Exum et al., 2019).

The two common species of schistosomiasis in Uganda are haematobium (in the Lango sub-region) and s.mansoni mostly along large water bodies like lakes; Victoria, Albert, Kyoga and River Nile (Melissa et al., 2012). Schistosoma mansoni (intestinal schistosomiasis) is the most common of all the species and is endemic in most parts of the country followed by urogenital (urinal) schistosomiasis (Envision, 2017; Tuhebwe et al., 2015). In Uganda, the disease is one of those non-communicable diseases (NCDs) accounting for 54% of the total disease burden (Ministry of Health, 2010).

Prevalence has been fluctuating since the 1990s at 31.9%, with declines between 2003 and 2014, but a sharp rise in recent years as illustrated in the table below (Stott, 1973). Currently, at least 25.6% of adults and 36.1 % when children aged 2-4 years are included, are infected with the disease, with some areas having a prevalence as high as 92% (Exum et al., 2019). Exum and colleagues also report that surprisingly, prevalence is higher even in areas where MDA has been done compared to areas where it has not been conducted. Furthermore, over 122 districts in the country are affected by the problem of schistosomiasis with males, children, those with primary education, and the Western and Eastern parts being the most affected (Envision, 2017; Exum et al., 2019; PMA2020, 2017). More than half (55%) of the total Ugandan population is at risk of infection (Envision, 2017; Loewenberg, 2014).

Table 1 Prevalence of Schistosomiasis between 1995 and 20

Year	Prevalence	Source
1995	31.9%	(Stott, 1973)
2003	20.4%	(Stott, 1973)
2010	15.9%	(Stott, 1973)
2014	11%	(Envision, 2017; Imran, 2014; Loewenberg, 2014)
2016	29.0	PMA2020, 2017
2019	25.6*	(Exum et al., 2019)

Prevention and control efforts in the country started as early as the 1990s when the disease was found to be a danger to the whole population (Kabatereine et al., 2014). However, a breakthrough in the efforts was made in 2002 when the mass drug administration of the praziquantel program was launched with the first round conducted in 2003 (Adriko, Tinkitina, et al., 2018). The program mainly targets school-going children where the prevalence is reported to be 75% and above, and adult community members in areas said to have a prevalence of 50% and above (Anguzu et al., 2007).

The PZQ drugs are procured with support from development partners such as the Schistosomiasis Control Initiative (SCI), ARISE and ASCEND, and are managed by the vector control division of the Ministry of Health and are then delivered to the districts (Muhumuza, Olsen, et al., 2013). From the district, the vector control officers together with the district health team distribute them to the communities for the VHTs to administer to adult community members and children of five years and above but not going to school, and for teachers to give to school-going children in schools (Tuhebwe et al., 2015).

Before the MDA is implemented, social mobilisation (SM) and health education and sensitisation are conducted by the Ministry of Health and the development partners (Envision, 2017). Social mobilisation refers to activities conducted to influence a large number of individuals to take certain actions for the benefit of the community as a whole (Rogers et al., 2018). In the context of MDA of PZQ, social mobilisation is those activities conducted by the district health team, VHTs, village chairpersons and the development partners, aimed at raising awareness and informing the target communities to participate in the program (Murphy, 2012). Other intervention measures include behaviour change comprising an improvement in water, sanitation and hygiene (WASH), health education and sensitisation (HES) (WHO, 2022) and snail control measures. WASH programs are implemented by the Ministry of Water and Environment (MWE) and are not directly linked to prevention and control measures. With the existing interventions, there has been

a steady increase in the uptake of PZQ over the years (Adriko, Faust, et al., 2018; Muhumuza, Olsen, et al., 2013).

1.3 Statement of the research problem

Uganda has been implementing the MDA of the drug praziquantel (PZQ) since 2003 (Adriko, 2017b; Adriko, Faust, et al., 2018; WHO, 2006), along with health education and sensitisations (Krauth et al., 2019). These efforts have led to marked improvements in PZQ uptake, increased awareness and improved preventive measures against the disease thereby reducing the morbidity of schistosomiasis (Adriko, Faust, et al., 2018). Despite the achievements, infections and re-infections remain high even in areas where MDA has been implemented, with some communities having a prevalence as high as 90% (Exum et al., 2019; Mupakeleni et al., 2017; Byagamy et al., 2019). Furthermore, MDA coverage is far below the WHO 75% coverage target for elimination (Adriko, Faust, et al., 2018) and risky WASH practices reportedly remain common especially the endemic in some communities, (Adriko, Tinkitina, et al., 2018; Exum et al., 2019; Muhumuza, 2017; Onasanya et al., 2021; Tuhebwe et al., 2015). In addition, some rural communities do not receive schistosomiasis messages, while others find it difficult to understand some of the messages despite the implementation of health education and sensitisation campaigns conducted by the MoH (Adriko, 2017a; Muhumuza, 2017).

Previous studies conducted especially along Lake Victoria in Uganda and elsewhere indicated that a limited understanding of schistosomiasis infection and prevention hinders the effectiveness of intervention strategies (Exum et al., 2019; Kabatereine et al., 2014; Kibira et al., 2019; Sanya et al., 2017a). Another study in other contexts also reported that community involvement and participation in promoting behaviour change interventions produces sustainable outcomes (Andrade, 2007; Estrada et al., 2018). Likewise, citizen science, a popular approach to community involvement in research that adopts

a bottom-up strategy (Crain et al., 2014) has been practised in the global south within the natural sciences but is not widely applied in the global south (Science Europe, 2018).

1.4 Purpose of study

This study aimed to investigate the application of behaviour change interventions that employ a community-led bottom-up approach using the citizen science approach in preventing schistosomiasis within endemic communities of western Uganda.

1.5 Objectives of the study

To achieve the overall aim of the thesis, five objectives were developed which include:

1. To determine the level of knowledge, attitude, and practice regarding schistosomiasis among communities of Western Uganda and understand their opinions and perspectives of the disease.
2. To gain insight into the lived experiences of schistosomiasis by individuals in Western Uganda, focusing on their symptoms, challenges, and coping mechanisms.
3. To explore health-seeking behaviour regarding schistosomiasis-related signs and symptoms by communities of Western Uganda.
4. To document the development and implementation of a citizen science-led communication intervention for the prevention of schistosomiasis among communities of Western Uganda.
5. To evaluate the citizen science approach of communicating schistosomiasis messages to communities of western Uganda and to explore the community's experience and perceptions of the approach.

1.6 Research questions

The following research questions were generated to address the research gaps identified in the statement of the problem above:

1. What is the level of knowledge, attitude, and practices regarding schistosomiasis by communities in western Uganda and what are their opinions and perspectives towards the disease?
2. What are the lived experiences of schistosomiasis by individuals of Western Uganda?
3. Where do communities in western Uganda seek treatment for schistosomiasis-related signs and symptoms especially when MDA is delayed and what factors influence their actions?
4. How can we use citizen science and other participatory action research approaches to implement behaviour change intervention for the prevention and control of schistosomiasis?
5. What are the changes, experiences and perceptions of the citizen science-led approach to implementing behaviour change regarding schistosomiasis?

1.7 Scope of the study

The scope of the study is explained in three key areas; that is the geographical scope, content scope, and time scope as illustrated below.

Geographical scope: In Uganda, schistosomiasis affects over 82 districts as per research conducted. Recent studies by Exum et al. (2019) revealed that both near the water source and distant communities have a similar risk of infections. In the case of this study, the area of focus was Western Uganda in the districts of Kagadi and Ntoroko. This is because both districts have been ranking high in prevalence, are located along the shores of Lake Albert and the terrains are difficult to access. These districts are therefore understudied, leading to the research gaps described above.

Although the ATRAP project operated in eight sub-counties, this particular study focused on only five of them namely Kanara Town Council in Ntoroko, Ndaiga, Kyateretera, Mpeefu and Bwikara in Kagadi. Two of the five sub-counties, Kanara and Ndaiga are along the lake shores, Kyaterekera and Mpeefu border Ndaiga while Bwikara is slightly detached from the lake. A total of 10 parishes, two from each of the five sub-counties were selected for the study from which 18 villages were again picked and formed the focus of the study area. Selection of the geographical scope was informed by information on socio-cultural factors and the availability of water contact points which also formed the framework of the ATRAP project objectives of snail monitoring.

Content scope: Schistosomiasis studies can take different dimensions and approaches. In this study, I looked at human behaviour from a sociological viewpoint. As presented in sections 1.3 and 1.4 above for the objectives and research questions respectively, the focus of this study was on the community's level of knowledge, attitudes and practices regarding schistosomiasis (objective 1), exploring their lived experiences of the disease (objective 2), exploring their health-seeking behaviours (objective 3). It also looked at community engagement using the citizen science and participatory action research approaches in developing and implementing behaviour change interventions (objective 4) and evaluating the application of the citizen science approach to behaviour change interventions (objective 5) respectively. The scope of this study was informed by the fact that top-down approaches to behaviour change interventions face various limitations to the achievement of WHO's target. Citizen science and participatory action research as bottom-up community-led approaches that have not been explored in the global south were conceptualised to provide potential solutions to the challenges.

Time scope: Uganda was the first to launch a mass drug administration program with the first implementation being in 2003 with support from the schistosomiasis control initiative (Kabatereine et al., 2014). Since then, the country has been implementing the program accompanied by health education and

sensitisation. In 2012, the WHO met and set 2020 as a target for the elimination of neglected tropical diseases (NTDs), schistosomiasis inclusive (World Health Organization & Savioli, 2012).

However, there have been some barriers to the implementation that have made it difficult to achieve the target of developing countries. A revised road map for the elimination target year of 2030 was developed in 2022 (WHO, 2022). Therefore, in this study, I look at the period between 2002 and 2019 when Uganda introduced the MDA as a time scope. This is because it is the period during which the country implemented various recommendations including a lot of research around the disease. The study was conducted between 2020 and 2022 during which the ATRAP project implemented its activities.

1.8 Significance of the study

Firstly, social and cultural factors are a major hindrance to the fight against schistosomiasis (Agbede, 2014; Nassiwa et al., 2020). Studies have indicated that some communities have limited knowledge of the disease, which influences their attitude and preventive practices (Exum et al., 2019). Also, communities hold certain beliefs and practices that make it difficult to take preventive measures (Adoka et al., 2014). Therefore, in addressing study objectives one and three of this study, the findings will contribute to the already existing knowledge about social-cultural barriers to schistosomiasis prevention and control by shedding more light on the knowledge gaps, attitudes and practices and existing myths and misconceptions concerning the disease. This is important in guiding the development and implementation of contextualised communication strategies that produce tangible outcomes for the community. The implementation of the behaviour change is expected to increase communities' knowledge about schistosomiasis and enable them to take appropriate preventive measures.

Secondly, studies on schistosomiasis prevention and control have focused on knowledge, attitude and practices including their health-seeking behaviours. Not much has been documented about the lived

experiences of those who suffer from the disease and how such experiences shape their perceptions and subsequent preventive actions. The only lived experience study of schistosomiasis in Kenya looked at the experiences of the community health extension workers' implementation of MDA and not the disease experience itself (Odhiambo et al., 2016). Failure to understand what individuals go through and how such experiences shape their perceptions of the disease and its subsequent impact on their health-seeking and preventive measures inhibits efforts to combat the disease.

In addressing this gap, which is framed in research objective two, this study makes a significant contribution to the knowledge base about the different experiences that individuals in communities go through and how such experiences shape their perceptions of the disease. More specifically, findings from this study will help create awareness among the communities on the different negative consequences of schistosomiasis not only to the individuals that go through the illness but also to their significant others such as spouses, children relatives and friends. Therefore, the finding will have the potential to inform the design of behaviour change interventions holistically.

Furthermore, this study provides insights into how communities can be involved in identifying and appreciating the problems of schistosomiasis that affect them, and how they can be engaged to take actions aimed at addressing the identified problems. Previous interventions on schistosomiasis especially on MDA programs have mainly looked at communities either as study participants who provide information regarding the research topic or who receive the PZQ drugs and messages provided to them by the government (Muhumuza et al., 2017; Onasanya et al., 2021). However, in this study, I demonstrate how communities can actively get involved in the research process, especially through snail sampling, community awareness and stakeholder engagements for awareness raising. I highlight that engaging local communities in behaviour change activities can facilitate community ownership of the intervention and empower them to take charge of their affairs.

In addition to the above, at an institutional level, the study is significant in that its recommendations will help to guide what steps and actions can be taken by the government of Uganda's Ministry of Health, other agencies and development partners, to address the problem of schistosomiasis. The district local government leaderships of the two districts-Kagadi and Kanara, for instance, will also benefit by incorporating some of the key recommendations into their planning and implementation systems and strategies.

Methodologically, the study adopted a multifaceted approach to provide answers to the different research questions stated above. In this study, I employed bottom-up citizen science and other participatory action research approaches in the research process to design and implement behaviour change intervention regarding the disease. In the global south, not many studies have used citizen science as a bottom-up approach to community engagement for communication intervention regarding disease prevention and more so, on the subject of schistosomiasis (Onasanya et al., 2021). Moreover, in Uganda, health education interventions regarding schistosomiasis have been implemented using the conventional top-down approach (Adriko, 2017a).

Therefore, the application of the CS and other PAR, a relatively new approach to community engagement, is likely to be a game changer in ensuring that the government of Uganda and its development partners embrace the CS bottom-up approach and integrate it into their programming and implementation. The findings could also provide key policy recommendations to the government in reviewing the current preventive strategy from a centralised approach to a totally community-led and not just community-based.

1.9 Justification of the study

Firstly, previous studies have demonstrated that socio-cultural factors such as limited knowledge and awareness, coupled with negative attitudes toward prevention hinder the fight against the disease (Sacolo et al., 2018). Moreover, these factors affect different communities and populations differently (Yirenya-Tawiah et al., 2011). Failure to understand these social and cultural factors could jeopardise efforts to prevent and control. In the case of communities along Lake Albert in western Uganda, there was hardly any literature linking the high prevalence of the disease (Exum et al., 2019). This study was justified because it necessitated understanding such barriers to prevention and control to inform the design of contextualised interventions.

Furthermore, schistosomiasis signs and symptoms take a long time to manifest (Melissa et al., 2012). When it finally does manifest, the infected person is in a stage of potentially irreversible damage. Early detection is not common due to a lack of early diagnosis and poor health-seeking behaviours among others (Ginossar & Nelson, 2010). This makes it very difficult to control and sometimes too late to treat. Although Uganda has been implementing the MDA of PZQ, its implementation is reported to be characterised by delays, irregular and inadequate supplies of the drugs as well as poor health-seeking behaviour by some communities (Adriko, Faust, et al., 2018; Tuhebwe et al., 2015). It is not clear what happens to such communities when there is no MDA program. As indicated in my study objective three above, this study was justified because of the need to understand where individuals in endemic communities go for treatment of schistosomiasis-related signs and symptoms in the absence or situations of delayed PZQ.

Also, despite the implementation of MDA with PZQ, health education and sensitisation programs, with marked improvement in uptake, there is evidence suggesting that infections and re-infections remain high in certain communities, with prevalence rates reaching as high as 90% (Exum et al., 2019). Additionally, some communities continue to engage in risky WASH practices, despite health education and sensitisation

but it was not clear why (Muhumuza, 2017). With these risky practices, some individuals end up getting infected. It was not however clearly documented what such individuals go through, and such illnesses shape their perception and health-seeking. There was a need to investigate the lived experiences of individuals who fall sick with the disease.

Lastly, this study was justified because the implementation of health education and sensitisation had some limitations related to reach, coverage and language barriers (Muhumuza, 2017). Although studies elsewhere have demonstrated the effectiveness of community involvement and participation in behaviour change interventions, such approaches have not been applied in the case of schistosomiasis prevention and control and Uganda in particular (Onasanya et al., 2021).

Also, citizen science, a complementary approach to community engagement has demonstrated highly engaged, rigorous and impactful outcomes (Domi Asingizwe, 2020). However, the approach is still not much appreciated within the social sciences and in the global south. Conducting this study was crucial since it was hoped to provide valuable insights into how government and other partners can design and implement interventions with communities taking a lead and owning such interventions that are pro-people, effective and sustainable.

1.10 Conceptual framework

The conceptual framework was developed and adapted from two models of health intervention programs. The socio-ecological model constituting the independent variables, was used for studying objectives one and two focusing on individual, interpersonal, institutional, community and societal factors that influence schistosomiasis infection (Bronfenbrenner, 1979). Kroeger's model of health-seeking underpinned objective three to complement the health-seeking factors under independent variables. This module helped to explain the actions that people take for health-seeking regarding schistosomiasis and

the reasons behind their actions (Kroeger, 1983). These are the socio-ecological model and Kroeger's model as explained below.

1. The social-ecological model regarding schistosomiasis

Developed by Urie Bronfenbrenner in 1979, the model states that human behaviour is situated in social, institutional, and physical environments (Bronfenbrenner, 1979). It depicts the notion that human behaviour is influenced by factors such as individual, interpersonal, institutional, community and societal (Environment, 1988; Golden & Earp, 2012). The model demonstrates the interrelationships between individual (intrapersonal) factors, interpersonal connections, primary groups, institutional factors, community influences, and public policy.

Individual factors related to people's knowledge of the phenomena, their attitudes, practices, perceptions, and personal aspects such as age, gender, socio-economic status, education and marital status (Huang & Manderson, 1992). Other factors directly attributable to a single individual include age, sex, education, and socio-economic status (Huang & Manderson, 1992). Interpersonal personal factors look at the interactions between members of couples, families, and networks of friends.

The organizational factors include formal and informal groupings of individuals around interests, including workplaces and social institutions. The community-level factors comprise relationships between organizations and the physical environment. Finally, policy factors include legislation at the local, national, or international level. Elder et al., (2007), borrowing from Urie, identify only four levels by combining interpersonal and institutional factors and call them relationship, community and societal factors.

The interaction between the individual and environmental factors influences a person's health and well-being (Priscilla, 2016). Based on this understanding, it can be argued that disease infections are caused by a range of factors going beyond the individual. Consequently, intervention should also focus on a person and an environment-oriented approach (Stokols, 1996). The model was chosen because of its

appropriateness in explaining the knowledge, attitude, and practices regarding schistosomiasis infection and control as well as individuals' lived experiences of the disease.

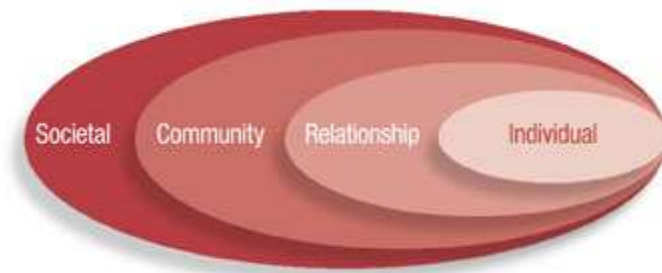


Figure 1.2. The Social-Ecological Model: A Framework for Prevention

Figure 1 Conceptual framework adopted from Elder et al, 2007

2. Kroeger's model of health-seeking behaviour

To complement the socio-ecological model, Kroeger's (modified) theoretical model of health health-seeking behaviour was used for objective three. The model states that when faced with morbidities of different kinds, individuals will often decide to seek healthcare services from different sources (Kroeger, 1983). The sources include (a) traditional sources (herbalists, witch doctors, and bone setters); (b) modern health services (government hospitals at different levels); (c) private facilities (for-profit or not-for-profit); (d) pharmacies or drug shops; (e) self-medications; and (f) not taking any action at all (Kroeger, 1983). According to Kroeger, health-seeking behaviour is determined by three sets of factors. First, predisposing factors include age, sex/gender, marital status, household size, education level, social networks and socioeconomic status, and ethnicity, among others (Tomison, 2013).

Second, the disorder and the perception that signs and symptoms are chronic or acute, severe or trivial, cause and types, and expected benefits and satisfaction from treatment (Pokhrel & Sauerborn, 2004).

Third, enabling factors are accessibility and acceptability, communication between the physician and patient, quality of care, and cost of medication (Pushpalata & Chandrika, 2017). The model was chosen

because it enabled the researcher to holistically examine, analyse and interpret health-seeking actions regarding the treatment of schistosomiasis-related signs and symptoms and the determinants of such actions (Shaikh et al., 2008). As can be seen from the above explanations, the two models are relevant to understanding the factors associated with schistosomiasis that can guide the development of interventions. However, they do not tell which kind of interventions should be designed and the appropriate strategies for the interventions. These limitations led me to design a pragmatic participatory model of behaviour change intervention as illustrated below.

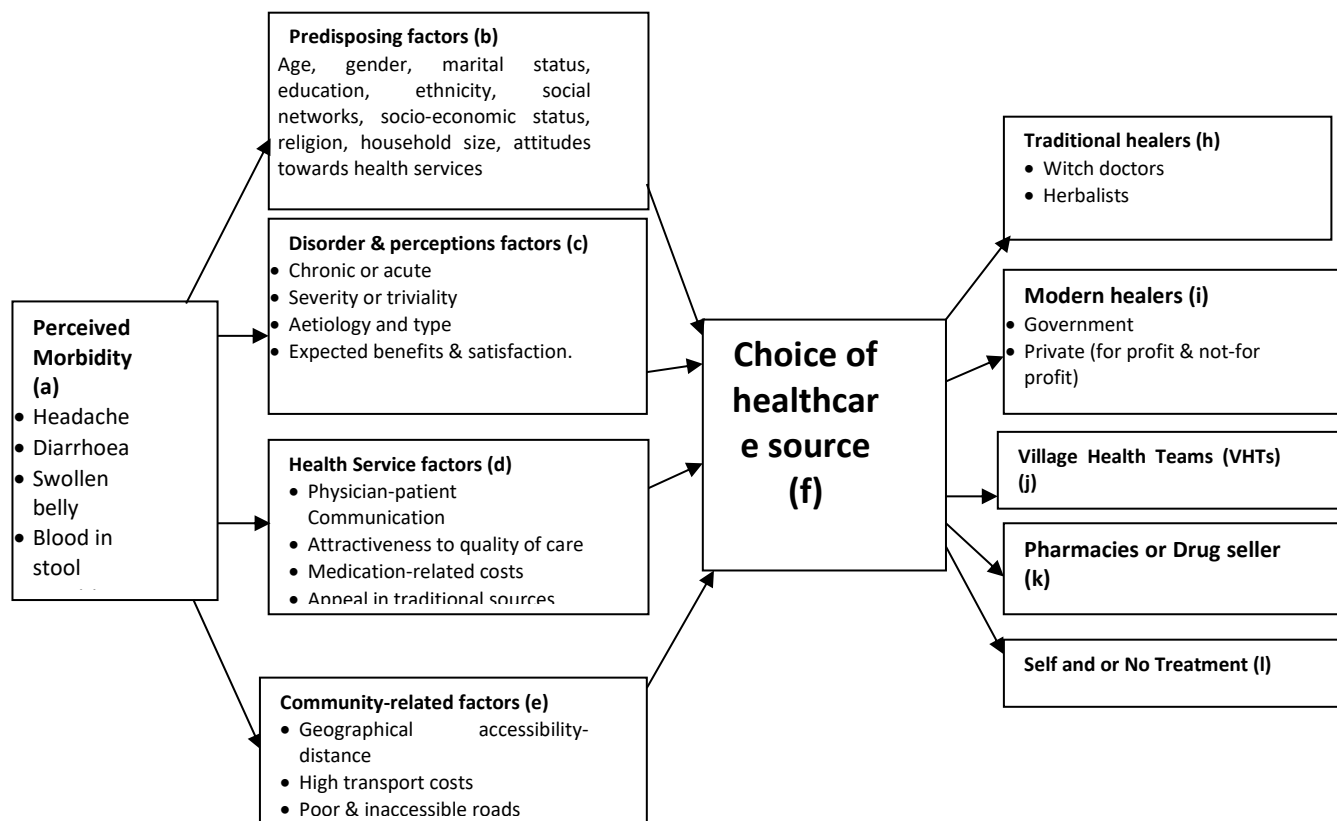


Figure 2 Axel Kroeger's modified Model of health-seeking behaviour (1983)

3. Unified conceptual framework

This conceptual framework illustrates the relationships between social and cultural factors that influence schistosomiasis infection as the independent variables, communication campaign interventions that can

be implemented, and the citizen science-led strategy for the prevention and control of schistosomiasis as the moderating and intervening variables respectively, and the outcomes of the interventions which are the improved behaviour to prevention as the dependent variable.

The framework postulated that social and cultural factors have a significant influence on schistosomiasis infection. Adopting the social-ecological model of human behaviour, such factors are categorised into individual (knowledge attitudes and practices, lived experience and health-seeking behaviours), interpersonal (family, friends, groups, and networks), institutional (policies, rules, programs and systems), and community/societal (norms, values, beliefs, services and infrastructures).

The framework further postulated that addressing such barriers requires a bottom-up participatory approach to the design and implementation of contextualised behaviour change communications intervention to achieve tangible and sustainable outcomes. The assumption here is that previous conventionally designed and implemented interventions have not been effective in reaching out to the rural endemic setting. The bottom-up strategy that is conceptualised in this study includes citizen science and participatory action research. The approaches are assumed to facilitate community ownership, empowerment and participation through the selection and training of volunteers, their involvement in data collection, dissemination of study findings, design and implementation of communication strategy as well as participation in evaluating the approach.

The study also conceptualised that the local channels of passing schistosomiasis messages such as door-to-door, community meetings and dialogues, drama, songs and tournaments and stakeholder engagement are appropriate for reaching out to the communities. Also, the use of community volunteers who are known and trusted by the community could be preferred over bringing people from the ministry or district. These assumptions were based on the understanding that previous health communication programs designed by the government do not reach the rural communities and are complex using

languages and channels that local communities do not understand. Finally, the framework assumes that employing local communities in behaviour change communication interventions should lead to improved health and a reduction in schistosomiasis prevalence through improved knowledge and awareness of the disease, change in attitude and perceptions and improved preventive practices.

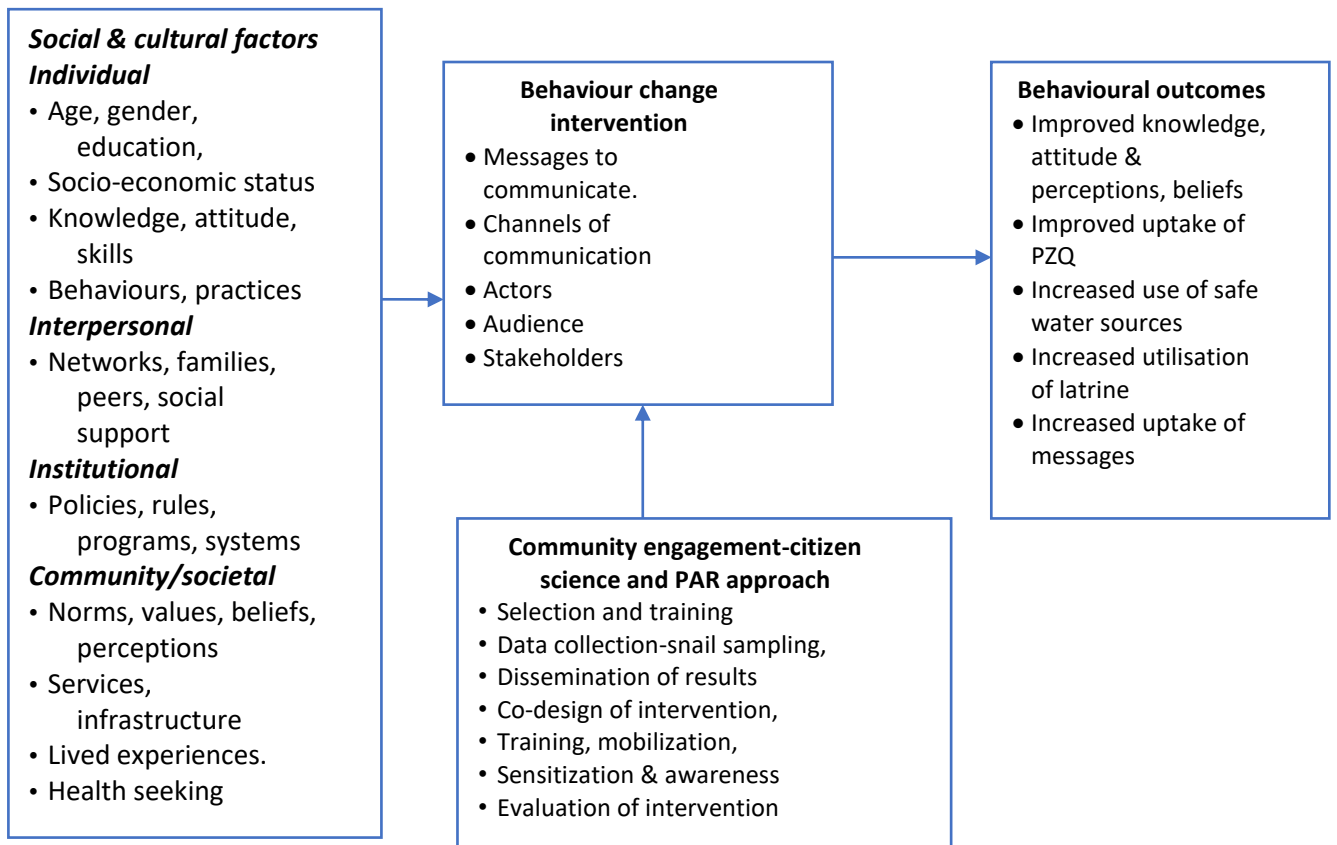


Figure 3 Unified conceptual framework in the context of schistosomiasis prevention developed by the researcher adapted and modified from the socio-ecological model and Kroeger's model of health-seeking behaviour.

1.11 Operational definitions

Attitude- Can be defined as “a state in which man moves to act or do in social activities with certain feelings in response to a situation or condition of the objects in the surrounding environment as well as providing readiness posture to respond to the positive or negative nature of the object or situation” (N.,

2013). In the context of schistosomiasis, I used the term to find out the feelings and opinions people have towards the disease that make them act or behave in certain ways.

Citizen science: This term refers to the involvement and engagement of citizens as lay persons in the research process either collaboratively with professional researchers in the relevant field or as locals themselves (Pettibone et al., 2016). It can take place at different phases of research and can be of different levels of participation.

Citizen social science: A form of citizen science in which the locals are involved in the conduct of social research (Albert, Balint, et al., 2021). In simple terms, citizen social science adopts all the principles of citizen science but is tailored to addressing social problems.

Community engagement-According to the Center for Disease Control and Prevention (CDC) refers to “the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people” (Walker, 2011:1)

Health-seeking behaviour: According to David Mechanic, health-seeking (or illness behaviour) refers to ways in which given symptoms may be differently perceived, evaluated and acted upon by different kinds of persons (Mechanic, 1961:1).

Knowledge- This is referred to as a “justified true belief” (Oeberst et al., 2016). In my study, I looked at it as encompassing awareness and understanding of a particular thing, object, item or any problem. In this case, the term knowledge was used to refer to justified true belief in what schistosomiasis is, its signs and symptoms, transmission modes, causes, diagnosis, treatment and preventive ways.

Lived experiences- Scannel defines lived experience as “an element of our humanly created world that offers a critical vantage point from which to examine the meaning of contemporary living” (Poyntz & Lesage, 2016). Looking at the above definition, lived experience may also mean our everyday encounter

with social reality or a given phenomenon. People's experiences are influenced by the social, political, cultural and historical contexts in which they find themselves.

Participatory action research: This is a type of research in which those who are affected by the problem are the primary source of information and the primary actors in generating, validating and using the knowledge for action (Pyrch, 2018). In this study, I used the term to refer to the active involvement and participation of locals in almost all the research processes. This is because, in the conduct of my study, I involved the communities in selecting the study site, discussing and harmonising the problem of schistosomiasis, participating in the dissemination of findings, and designing, implementing and evaluating the intervention.

Perceptions- Sandrock refers to perception as "the process of organizing and interpreting sensory information to give meaning." (Ekanem, 2004). Sensory here therefore could mean opinions and beliefs about something. In my view, it remains a belief, a thought about something. In this study, I used perception to imply the thoughts and views people have concerning schistosomiasis.

Practice- Practice is defined in four different ways "(1) phenomena or processes which occur in the individual when an act is repeated;(2) it may refer to a certain kind of consciousness;(3) it may mean the act of repeating when repetition is accompanied by a gain in efficiency, or (4) it may mean mere repetition whether or not accompanied by improvement" (Gates, 1922). I used the term this study to refer to activities that communities engage in that either predispose them to or protect them from the risk of schistosomiasis infection. Such activities may include coming into contact with water sources of different types, fishing, farming, and defecation among others.

CHAPTER TWO: REVIEW OF RELEVANT THEORY AND LITERATURE

2.1 Introduction

This chapter provides a review of relevant theories and literature on the topic of schistosomiasis and its related aspects. The chapter aims to establish a philosophical foundation and empirical understanding of the research problem. The chapter begins by exploring key research paradigms that were employed to underpin the study. Next, the chapter delves into a review of previous studies conducted on the disease about knowledge, attitudes and practices, lived experiences, and health-seeking behaviours. Knowledge aspects which are a focus of this study include the meaning, its signs and symptoms, diagnosis, and preventive measures among others. The chapter also delves into a critical examination of studies conducted on different community engagement for behaviour change, while not forgetting the application of the citizen science approach. The chapter concludes with highlights of the existing gaps, inconsistencies, contradictions and emerging issues in both theory and practice that this study set out to fill.

2.2 Philosophical underpinnings

To begin with, in this study, I used the concepts of philosophy, worldview, paradigm, perspective, approach, and lens interchangeably. A worldview refers to a set of beliefs held by people that inform their actions and behaviours (Creswell, 2014). This study adopted two philosophical research paradigms which are interpretivism and critical realism.

2.2.1 Interpretivism

Interpretivism is a philosophy that originated as a response to the limitations of positivism. Positivism assumes that we can use natural science laws of objectivism, observation, measurement and generalisation to explain social phenomena (Bryman, 2012). However, interpretivism argues that it is impossible to use natural science abstract laws and rules to study social phenomena (Wagner et al., 2012). This is because human behaviour is complex, unique, dynamic and unpredictable thereby making it difficult to reduce to laws (Neuman, 2014). As such, there are multiple accounts of looking at social phenomena that cannot be studied using abstract laws objectively (Ulin et al., 2005). Instead, what researchers can do is understand (*verstehen*) and interpret such phenomena in their natural settings (Neuman, 2014).

Philosophically, interpretivism seeks to explore the meanings, beliefs, and experiences of individuals and groups, recognising the influence of cultural and social contexts on human behaviour (Neuman, 2014). Newman (2014), extensively describes interpretivism and I intend to sight the ten assumptions here: reality is created in the process of human interactions; the purpose of research is to understand and describe meaningful social actions; humans are social beings who create meaning and constantly make sense of their worlds; humans have free will power and freedom to make choices and act towards them without any limits. According to Neuman, common sense guides everyday human actions and not any form of theorising; the use of description of how a group's meaning is generated and sustained. Furthermore, truth is only that which those being studied hold; the evidence is embedded in social interactions; knowledge is obtained through practical orientation i.e. everyday lived experience and finally, values are part of social life and cannot be delineated from those being studied (Neuman, 2014). Taking the symbolic explanations of interpretivism by scholars George Herbert Mead, Charles Horton Cooley, W.I. Thomas, Herbert Blumer, and Erving Goffman, interpretivism's three key assumptions are

laid down. The first is that human beings act toward things based on the meanings that they attach to those things. Secondly, the meanings are derived from or arise out of social interaction with others. Finally, these meanings may change or be modified in the process of interaction and interpretation (Abrahamson, 2012). Blumer argued that human beings are dynamic in that they keep changing depending on the situation. That is, humans are not mere objects that should be constrained or influenced by the structures of society. Rather, they are beings that have the sense, capacity, and ability to interpret the world and act accordingly (Ritzer, 2011).

To Blummer, symbols may include words, language, sounds, objects, colours, and events that represent something other than themselves and are critical for understanding social interaction. Language, therefore, is very important in that through it, human beings create words of shared meanings for communication. Language according to Mead, enables us to become knowledgeable of ourselves and we begin to see ourselves in the way others would see us (Giddens, 2009). The perspective was used in this study largely to understand the meanings rural communities attach to symbols such as water, fishing, defecation, well-being or livelihoods, signs and symptoms of schistosomiasis, causes, cure, prevention, and control as they interact among themselves. This dimension of interpretivism however is limited to a micro approach to phenomena and focuses only on meaning alone (Ritzer, 2011; Weiss & Lonquist, 2015). Yet phenomena are broader than meaning to include interactions, processes and effects. To address this gap, there is a need to use other dimensions of interpretivism.

The social constructionist interpretivism advanced by Peter L. Berger and Luckmann Thomas in 1966 is adopted to explain social interaction (Ryan T. Cragun, 2010). This dimension of interpretivism assumes that individuals and groups create their own perceived reality and reproduce it in a dynamic process of interaction (Ritzer, 2011). Interaction is, therefore, the centre of the explanation of human social phenomena. Once the reality is created, it becomes habituation i.e. individuals begin to act according to

the reality that is so created (Burr, 2015). That is, it is people who have the will and capacity to determine what is internal and external to them through interpretation (Berger, 1991). Accordingly, all our representations of the natural and social world are arbitrary and could have been interpreted differently, if the forces that made them occur had been different (Abrahamson, 2012). That is, our characterization of the social world depends not on the inevitably determined nature of things, but on how we continually construct them. Reality, therefore, is not just an objective world, but both objective, subjective, and intersubjective (Berger, 1991; Ritzer & Smart, 2003; Ryan, 2010). However, meanings, interpretations and interactions alone are insufficient in explaining everyday lived experiences. In response to this paradigmatic pitfall, a phenomenological interpretivism approach was adopted to explain phenomena from a human social experience dimension.

Alfred Schutz in his response to and reaction to Talcott Parsons' structural-functionalist theory developed the concept of phenomenology (White, 2002). This dimension of interpretivism states that certain everyday phenomena can only best be understood by analysing the insider or neat grit of the individual consciousness (Scott, 2006). That is people's lived experiences rather than the external outside world should be the subject of any research. Schutz uses concepts of the "lifeworld", or the world of everyday life" to explain human experience (Ritzer, 2011). To Schutz, individuals in their day-to-day lives not only create their social reality but are also restricted by the social and cultural forces that have been established earlier on. Therefore, unpacking the details of these social experiences is crucial, rather than assuming the obvious of the often taken-for-granted common sense (Abrahamson, 2012). Methodologically, the interpretivist paradigm employs qualitative research approaches to data collection and analysis. Methods such as participant observation, in-depth interviews, key informant interviews, focus group discussions and discourse analysis among others are used.

Interpretive paradigm was justified in this study because it allowed me to explain how communities perceive and socially construct schistosomiasis, what they think of it, that is, its meaning, signs and symptoms, transmission modes, diagnosis and preventive ways, their everyday experience of the disease and risky practices. It also involves the actions they take for treatment and the reasons behind their actions. The paradigm was useful in explaining the qualitative research methods in the baseline KAPs survey and health-seeking regarding schistosomiasis.

It was also vital in this study because it helped put into perspective, the lived experiences of the communities of western Uganda regarding schistosomiasis, how they negotiate their lives with the people they relate with, and other complexities that shape their perception of the disease. This is critical to developing sustainable solutions to the problem of schistosomiasis, especially by taking into consideration people's lived experiences and how they can be involved in prevention and control efforts. In this study, I used interpretivism to explain how rural communities socially construct their knowledge of schistosomiasis, its signs, and symptoms, and how it shapes their attitudes and perceptions of the disease and health-seeking decisions and actions. David Mechanic used this understanding to develop the concept of health-seeking behaviours. He gives explanations why a person may decide to seek help if he/she perceives and or interprets the symptoms to be serious, or cannot tolerate them, or based on the availability and accessibility of health care services (Weiss & Lonquist, 2015).

In conclusion, the interpretivist paradigm was influential in this study in explaining how we understand human phenomena. However, interpretivism was insufficient in explaining the causal mechanisms of the knowledge, attitudes and practices regarding schistosomiasis. For instance, it could not explain the extent of and the relationship between their knowledge, attitudes and practices towards the disease and their socio-demographics such as age, education, marital status, socio-economic status and gender. Secondly, the paradigm could not explain what collective practical actions the communities can take to address the

problems of schistosomiasis. It also, could not explain fully, the structural factors that underly human social behaviour. Lastly, the approach does not explain what happens when we understand and interpret reality. To address the above philosophical gaps, I adopted a critical realist paradigm.

2.2.2 Critical realism

Critical realism is a philosophy that agrees with the positivists that reality exists independently of us, but the critical realists argue that this reality is socially constructed through subjective experiences, cultural beliefs and social interactions as explained by the interpretivists (Bryman, 2012; Neuman, 2014). Reality to the critical realists, is not independent of us as posited by the positivists. Neuman adds that critical realists object to the illusions created by positivists as well as the false consciousness premised by interpretivism.

Critical realism, therefore, posits that the purpose of research should be not just to understand and interpret reality as postured by the interpretivists (Burr, 2015). Rather it should be with the ultimate goal of changing the social world through creating a form of knowledge that those being studied “see light” (emphasis mine), by identifying the structures at work that generate those events and discourses (Bryman, 2012). These structures are not only physical but also immaterial which can be understood through both observations and questioning the those being studied (Wagner et al., 2012).

Neuman enumerates the following assumptions: social reality has multiple facets (empirical, real and actual); the purpose of research should be to reveal hidden facts, dismantle myths about reality and empower individuals to challenge their status quo and effect change (Neuman, 2014). To critical realists, people have potential but are only misled by reification, social life is relational; there is free will but within certain boundaries; science is not absolute though it helps to fight false consciousness (common sense), as such both should be considered (Neuman, 2014). Additionally, the explanation of reality should be

through both deduction and induction, that is, abduction (Bryman, 2012). According to this thinking, what works to unearth reality and influence change in a practical sense is the more relevant (or the praxis for that matter). Also, knowledge should be used for transformation and not just for the status quo and finally, social reality is ebbed in moral political contexts that create unequal existentialists (Neuman, 2014).

Methodologically, the paradigm employs both quantitative, qualitative, and mixed methods approaches to data collection and analysis (Bryman, 2012; Wagner et al., 2012). From a transformative viewpoint, it also considers the active involvement and participation of those being studied. That is, participants actively get involved in the whole or part of the research process such as identifying the research problem, designing the study, data collection, analysis, interpreting, dissemination of findings and using the findings to design and implement interventions (Wagner et al., 2012). Herein, therefore, participatory action research is handy.

Critical realism was justified in this study because it allowed me to describe the level of knowledge, attitude, and practices as well as the association with different socio-demographic characteristics regarding schistosomiasis. Using this philosophical underpinning I adopted a mixed methods cross-sectional survey design to determine the associations between KAPs and socio-demographics such as income, age, gender, geographical distance, education and marriage. It also enabled me to interrogate the reasons behind such causations. Additionally, the paradigm was important in demonstrating the collective actions of endemic communities in western Uganda to address their problems. Finally, the paradigm allowed the explanation of community participation in evaluating their involvement in intervention. In the next section, I delve into a presentation of empirical review.

2.3 Empirical review

2.3.1 Knowledge, attitude, and practice regarding schistosomiasis

Social and cultural factors such as knowledge, attitude and practices regarding schistosomiasis have been widely researched. Various studies have demonstrated the relationships between knowledge, attitudes, and practices and infection and control. Inadequate knowledge of the signs and symptoms, for instance, means that people will be at risk of contracting the disease (Midzi et al., 2011). Similarly, knowledge of the causes and prevention and treatment is crucial if prevention interventions are to be designed. Communities that have negative attitudes also tend to have poor health-seeking behaviours (Folefac et al., 2018). The differences in knowledge and attitudes affect not only the community practices but also their health-seeking behaviours and attitudes as well. The issue of attitude can also lead to stigma and discrimination by the community.

Limited knowledge of transmission modes, signs and symptoms, diagnosis, and prevention, also affects efforts to control schistosomiasis (Midzi et al., 2011). A recent nationally based survey conducted in Uganda revealed that only 61.8% of respondents had ever heard of schistosomiasis, a factor associated with the high prevalence of infection (Exum et al., 2019). Relatedly, a study on the islands of Lake Victoria in Uganda, showed that although 92.3% of the biomedical staff, 84.3% of pupils, 80.4% of teachers, and 87.3% of household heads had knowledge and awareness of the disease, limited knowledge of transmission mode was reported to be a major challenge (Kabatereine et al., 2014). These findings imply that variations exist in the knowledge and awareness of schistosomiasis among different geographical locations and different population groups, which could influence prevention efforts.

Studies also show that community attitudes toward schistosomiasis differ from place to place. A cross-sectional study conducted on the Lake Victoria islands of Uganda found positive attitudes toward efforts

to control schistosomiasis (Kabatereine et al., 2014). On the contrary, a systematic review of KAPs regarding schistosomiasis in Uganda revealed negative attitudes toward preventive measures (Muhumuza, 2017). These findings imply that different communities have different attitudes towards schistosomiasis and its prevention.

Community myths and misconceptions surrounding the disease such as its meaning, beliefs regarding signs and symptoms, and how it is prevented have been found to influence prevention and control efforts (Rassi et al., 2019). For instance, some communities believe that schistosomiasis is caused by witchcraft, still, others think it is a disease of young ones and men only, and yet others think it is too costly to treat it (Musuva et al., 2014b).

Engaging in risky water and sanitation practices such as defecating and urinating in water, swimming, bathing, washing utensils and clothes, and carrying out fishing activities also pose a serious risk of infection (Gebreyohanns et al., 2018). Individuals who engage in risky water practices tend to have a higher risk of being infected with the disease compared to those who have fewer frequencies of engaging in water-related activities.

Good WASH practices are important for the prevention of schistosomiasis. The absence or lack of access to clean and safe water forces communities to use contaminated sources of water, while the absence of a proper latrine encourages open defecation (Muhumuza, 2017; Musuva et al., 2014b; Sanya et al., 2017b). Some scholars have also reported that a low level of knowledge and negative attitudes tend to influence risky practices such as defecation and urination in water, swimming, bathing, washing utensils, and clothes, and fishing (Gebreyohanns et al., 2018).

There is a difference between practice and having access to the facility. The absence or lack of access to clean water and proper latrines is associated with schistosomiasis infection (Muhumuza, 2017). Studies show that communities that do not have access to clean water tend to have a high rate of infection

compared to those that have (Musuva et al., 2014b). Similarly, infections are bound to be higher in places where people do not have latrines, than in places where latrine coverage is high (Adriko, 2017b; Sanya et al., 2017a).

Regarding other social factors such as poverty, previous research revealed that some individuals engage in risky practices due to difficulties in accessing clean water and constructing latrines (Francisco et al., 2019). Meanwhile regarding gender, a study regarding the impact of host gender on the risk of schistosomiasis infection in the Mayuge district of Uganda found that both boys and girls had similar amounts of contact with water, with no significant differences between genders in infection and re-infection (Trienekens et al., 2020). Although the above study did not find any difference between gender in children regarding water practices, there is a need to look at the implications of gender variations in knowledge, attitudes, and practices regarding schistosomiasis and not just on infection and treatment alone.

2.3.2 Lived experiences and perceptions regarding schistosomiasis.

Studies on social and cultural factors regarding schistosomiasis have mainly focused on factors such as knowledge, attitude practices and behaviours of the community. The studies, however, do not mirror the victims' views. Few studies on lived experiences of the disease have looked at the individuals' pre-experience perceptions, but not actual experiences.

For instance, a study on the lived experience found that those who suffer from symptoms related to schistosomiasis signs and symptoms may also present symptoms of other diseases such as dysuria, pelvic pain and blood in the stool, squamous, cell carcinoma, and renal disease (Nwabueze, 2013). Similarly, a study on urinary schistosomiasis found that the communities perceived it to be a male and children thing but not for other categories of people (Onyeneho et al., 2010).

Another study on experiences and perceptions of community health workers on treatment interventions regarding schistosomiasis in Kenya looked at health workers' experiences but not the communities' lived experience of the disease (Odhiambo et al., 2016). The same study found inadequate incentives for health workers, fear of side effects by the community, misconceptions about treatment, mistrust, difficulties working in unsanitary conditions, insecurity, and inadequate time as some of the challenges. These challenges, however, are not directly related to those faced by individuals suffering from schistosomiasis. As can be seen from the findings above, firstly the findings seem to suggest that those who suffer from diseases have different experiences which also shape their perceptions differently. Secondly, the studies looked at different topics and study populations but not the lived experience of the disease itself. The few studies on individual lived experiences have not explored in detail, the symptom experience, challenges, and coping mechanisms. It is therefore imperative that further studies are done by looking at the perspectives of the individuals who suffer from the disease themselves.

2.3.3 Health-seeking behaviour towards schistosomiasis

Health-seeking behaviour refers to "any activity undertaken by individuals who perceive themselves to have a health problem or to be ill, to find an appropriate remedy" (Ward et al., 1997). Studies on health-seeking regarding schistosomiasis treatment with PZQ have equally been conducted showing varied findings. Some of the studies have suggested that people seek treatment from either biomedical or traditional healthcare sources or both (Kirscht, 1981). In Southwest Ethiopia, for instance, most of the urban communities (80.7%) sought health services from modern sources in contrast to rural areas at 48.1% (Pokhrel & Sauerborn, 2004).

In the Kiri community of Adamawa state- Nigeria, findings showed that a significant proportion of the participants usually bought drugs from the pharmacy or drug shops for schistosomiasis-related signs and

symptoms, whereas some got medication from herbalists and the majority never sought medication at all (Tidi, S.K. and Jummai, 2015). Likewise in Tanzania, some participants sought medication for schistosomiasis treatment from both traditional and modern healthcare sources, although modern medicine was taken to be the most effective (Angelo et al., 2019). The above findings suggest that different populations seek medication for certain illness conditions from various sources, but it is not clear whether this is the same for schistosomiasis-related signs and symptoms.

Determinants of health-seeking also vary across space, time, and different population groups (Pushpalata & Chandrika, 2017). Factors such as age, sex, education level, marital status, socioeconomic status, social networks, ethnic beliefs, and attitudes among others, have been found to influence the decisions to seek treatment from different sources (Pokhrel & Sauerborn, 2004). In Ethiopia, a study on health-seeking for different NTDs showed that gender disparities in healthcare access and utilization were attributed to inequalities and power dynamics between men and women regarding the decision to seek treatment and its financing (Wharton-Smith et al., 2019).

Disease-related factors, such as cause and type of illness, acute or chronic illness, and severe or trivial, also influence individuals' health-seeking behaviour (Jean et al., 2013). People with biomedical knowledge of transmission and who perceive the symptoms as severe and acute, tend to seek treatment from modern sources (Cronin et al., 2013; A. Danso-Appiah et al., 2004). Lack of health workers and limited drug supplies have also been found to hinder the communities along Lake Victoria in Eastern Uganda from seeking treatment for schistosomiasis-related signs and symptoms from a health facility (Kabatereine et al., 2014).

Findings from studies in Eastern Uganda and Zanzibar, also showed that some participants did not receive PZQ drug treatment because either they were absent or unaware of the MDA program, were busy, feared

side effects, or were pregnant (Adriko, Faust, et al., 2018; Knopp et al., 2016). These findings were similar to studies in Brazil, the Philippines, and Nigeria where communities reported long distances from the nearest health facility, transport costs, poor road networks, and lack of health information as barriers to seeking treatment from health facilities (Miguel & Sur, 2021; Reis et al., 2010; Van et al., 2020).

2.3.4 Prevention and control of schistosomiasis

Prevention and control of schistosomiasis have majorly been on four key strategies: preventive chemotherapy through mass administration of praziquantel drug, snail control, improvement in water, sanitation and hygiene, and health education and sensitisation. These are global strategies recommended by the WHO.

The MDA program targets high-risk communities such as those around lakes and treats infected and non-infected children aged between 5 and 12 years (Adriko, 2017b; Adriko, Tinkitina, et al., 2018; Kibira et al., 2019). PZQ drugs are procured with support from development partners such as the schistosomiasis control initiative (SCI), ARISE and ASCEND, and are managed by the vector control division of the Ministry of Health and delivered to the districts (Muhumuza, Olsen, et al., 2013). From the district, the vector control officers together with the district health team distribute them to the communities for VHTs to administer to adult community members and children of five years and above but not going to school, and for teachers to give to school-going children in schools (Tuhebwe et al., 2015).

Although it is hoped that MDA interventions can facilitate the achievement of the WHO's target of 75% MDA coverage by 2030, in Uganda's case, this is far from attainment. This is evidenced by low uptake among school-going children of 28.2% in 2011 to 48.9% in 2012 and among adult communities of 48.8% in 2016 (Adriko, Faust, et al., 2018; Muhumuza, Katahoire, et al., 2013). A significant proportion of the

population does not get the drug (Adriko, Faust, et al., 2018), while those who are given the drug usually present low cure rates (Woldegerima et al., 2019). The low uptake is attributed to inadequate drugs, distance from treatment centres, and logistical challenges. There are also complaints about the negative side effects which further increases the problem (Mcmanus et al., 2018).

Besides, children, especially those of preschool age groups below five years, are discriminated against since they are not part of the targeted population (Exum et al., 2019). For Uganda specifically, the top-down approach to interventions, the overburdened healthcare system, challenges in using the VHTs for drug distribution, and limited knowledge regarding schistosomiasis and its prevention are some of the programmatic shortfalls (Muhumuza, 2017). To ensure optimum outcomes and sustainability of PZQ uptake, there is a need to improve the MDA implementation strategy to realize increased drug uptake (Anthony Danso-Appiah et al., 2010).

Snail control is another strategy that is used to prevent schistosomiasis. It was introduced and recommended by the WHO in 2017 (Li et al., 2019). Snails harbour the schistos as they move from humans through defecation and or urination, and are washed into water bodies (Stothard et al., 2017). Killing the snails either by use of chemicals or any other method will interrupt the life cycles of schistos, thereby eliminating them or reducing their populations (Evan Secor, 2014). However, it is difficult to control snail populations not only because they are mobile and seek shelter, but also because, the use of chemicals may end up destroying other aquatic organisms like fish (Sanya et al., 2017a). Snail control alone is, therefore, not sustainable.

In recent years, interventions have been extended to the provision of clean water and increasing latrine and toilet coverage and education to keep children away from water sources (Loewenberg, 2014; French et al., 2018). There have been massive investments in extending piped water and boreholes, including protected springs to rural areas to increase accessibility to clean and safe drinking water. Also, there are

comprehensive campaigns aimed at increasing toilet coverage to eliminate open defecation. Despite these efforts, infections and re-infections have continued to occur, while in some areas, the risks are increasingly alarming (Lund et al., 2019).

The use of conventional channels such as national television, radio, newspapers, billboards, magazines and posters for health education and sensitisation has been reported by various studies but with mixed results. For instance, some studies have highlighted the importance of using mass media channels as a form of social mobilisation for better uptake of health information (Grilli et al., 2002). Social mobilisation refers to activities conducted to influence a large number of individuals to take certain actions for the benefit of the community as a whole (Rogers et al., 2018). In the context of MDA of PZQ, social mobilisation is those activities conducted by the district health team, VHTs, village chairpersons and the development partners, aimed at raising awareness and informing the target communities to participate in the program (Murphy, 2012).

In Uganda, social mobilisation (SM) and health education and sensitization are conducted by the Ministry of Health and donors, that is the development partners before the MDA is implemented (Envision, 2017). Consequently, the health education and sensitisation interventions have registered tremendous success such as an increase in praziquantel (PZQ) uptake and improvement in knowledge, attitude and practices regarding schistosomiasis (Adriko, Faust, et al., 2018; Muhumuza, Olsen, et al., 2013).

Despite the increased awareness and drug uptake, some rural communities do not receive the messages, while others find it difficult to understand some of the messages (Muhumuza, 2017). Studies have reported that the use of conventional channels such as national television, national radio and national newspapers, billboards, magazines and posters do not reach some rural communities but not conclusively (Muhumuza, 2017; Natifu, 2006; Onasanya et al., 2021; Person et al, 2016). These findings call for the need to take into consideration geographical, social and cultural variations when designing behaviour

change interventions so that they are implemented in a contextualised manner (Kauppi, 2015; Ngigi & Busolo, 2018).

2.3.5 Community engagement approach to health education and sensitisation

Community engagement refers to the process of working collaboratively with, and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting their well-being (McCloskey et al., 2013). Members of the community are mobilized to participate in activities that aim at addressing their problems. In research, community engagement is a process that starts right from problem identification through action planning and budgeting, activity implementation including data collection and analysis up to report dissemination and evaluation (Bergold & Thomas, 2012).

Key principles of community engagement/participation include social justice, self-determination, collaboration, teamwork, sustainability, participation, reflective practice, ethics, and trust among others (Mazzurco & Jesiek, 2015; Randles & Harmon, 2014; Sarno, 2012). Arnstein's ladder of participation gives eight levels along which participation takes place (Arnstein, 1969). They include manipulation and therapy at the bottom, tokenism, consultation, and placation in the middle, and finally, citizen power involving partnership, delegation, and control at the extreme level where there is full participation by the community (Arnstein, 1969; Wilcox, 1994). However, it is not possible to find all these principles and ladders being followed by all actors. Participatory action research is one such approach that is a community engaged in nature.

Participatory Action Research (PAR) refers to collaborative research in which researchers and a group of community members actively engage in identifying and addressing particular problems that affect them (Pain et al., 2011). PAR facilitates a proper understanding of the problems and situates such initiatives in

their social and cultural context (Jallad et al., 2021). Although PAR has been used in the social sciences for a long time, it is limited in geographical scope, audience appeal, the volume of data collected and scientific rigour (Legrand & Chlous, 2016).

Citizen science could accommodate this limitation of PAR since it allows the achievement of broad research outcomes such as increased knowledge, awareness, skills, attitudes, and behaviours towards a particular topic (Legrand & Chlous, 2016; Marrow & Volunteers, 2013). CS also harnesses complex local knowledge and facilitates community engagement and information sharing with different audiences such as scientists, policymakers, and the wider community (Roetman and Daniels, 2018; Asingizwe *et al.*, 2019). Furthermore, CS facilitates the collection of large quantities of data from a diverse section of the population at minimum costs and using local human resources (Ordóñez Vela et al., 2016; Wildevuur & United, 2020).

Active community involvement in behaviour change interventions could facilitate the development of the right message, packaged to the right audience, using the right channels and taking into consideration social and cultural diversities (Estrada et al., 2018). Other studies on behaviour change interventions have also highlighted the need to integrate community involvement in the planning, design and implementation, including infrastructure provision for sustainable outcomes (Onasanya et al., 2021; Person et al., 2016; Torres-Vitolas et al., 2023). A lack of community involvement and participation in the design and implementation of behaviour change messages have been reported to hinder their acceptability, uptake and ownership, thereby inhibiting the achievement of the intended goals of the interventions (Andrade, 2007).

2.3.6 Participatory evaluation

Understanding the impacts of behaviour change interventions is important not only because of the substantial amount of time, finance, labour, skills and commitment involved (Kobori et al., 2016) but also, to inform future interventions. Evaluations take different forms and strategies including experimental (randomised controlled trials), quasi-experimental (case comparison designs) and pre and post-interventional designs among others (Shae, 2021). For instance, an evaluation of the impact of the obulamu program of topic-specific messages on the adoption of health behaviours found a significant increase in knowledge, attitudes, practices and intentions to use HIV, tuberculosis and maternal and child health services by Ugandan communities (Burke et al., 2021). Similarly, in Tanzania, a study to evaluate the impact of health education on the incidence, knowledge and practices regarding schistosomiasis among US Peace Corps volunteers (PCV) found that infection incidence had greatly reduced and people's knowledge and practice had increased (Outwater & Mpangala, 2005).

Also, a mixed methods study to evaluate the impact of integrated preventive chemotherapy for malaria, schistosomiasis and soil helminths (STH) among communities along Lake Victoria in Kenya demonstrated improved knowledge of the disease but the persistent risky practice of bathing (Gitaka et al., 2019). Despite their significant contributions, most evaluations have focused on impact and not how intervention processes are done, and neither do such evaluations involve the beneficiaries as active participants in the evaluation process.

Some studies have highlighted the importance of evaluating the processes that lead to intervention outcomes and impacts rather than evaluating the outcomes and impacts themselves. Process evaluation refers to “the evaluation of “individual, collective or management perceptions and actions in implementing any intervention and their influence on the overall result of the intervention (Nytrø et al., 2000). Evaluations of this nature look at the causal mechanisms, that lead to ultimate change in behaviour

such as fidelity and quality of intervention implementation, acceptability, appropriateness, reach and coverage and experiences and perceptions among others (Moore et al., 2014). For instance, a process evaluation of the communication for healthy adolescents in Uganda revealed that the program activities were successfully implemented collaboratively, with the messages reaching the intended audience, and adolescents empowered to make informed decisions (Nalukwago et al., 2020). In Peru, findings from a process evaluation of an intervention revealed that the identification of intervention components helped to guide successful implementations (Lazo-porras et al., 2023).

There is also an increasing concern that understanding the actors' perspectives of the processes involved in the intervention could equally be beneficial for its subsequent implementation (Albert, Balint, et al., 2021). That is, involving the citizens right at the start of the project in setting expectations, objectives and intended goals facilitates successful implementation (Kieslinger et al., 2020). Participatory process evaluation (PPE) is one of the evaluation techniques, that "uses methods that seek to get to grips with the life of an intervention as it is lived and perceived and experienced by different kinds of people, including programme or project personnel" (Cornwall, 2014:5). PPE has potential benefits such as citizens' involvement and active participation in addressing challenges that affect them, empowerment, changes in attitude, norms and values, improving coherence, community building, social capital, social learning and trust among others (Den Broeder et al., 2018).

Citizen Science (CS) is one of the participatory action research approaches that has gained prominence in many disciplines in the recent past (Elliott & Rosenberg, 2019). Evaluation of citizen science projects as a growing sub-discipline within citizen science (CS) has also received wide recognition. For instance, findings from a study to co-design a citizen science program for Malaria prevention in Rwanda demonstrated the contribution of community ideas in decisions on what and how to collect data, tools to use, species to focus on and the incidence of malaria among others (Domina Asingizwe et al., 2019). An evaluation of the

role of citizen science in human-wildlife conflict management in Colorado State of the United States of America also found that volunteer participation had positive effects on the way they related and thought about the project, enhanced knowledge, empowered the volunteers and communities to take action, changed their attitudes, beliefs and behaviours (Adams, 2014).

Relatedly, an observational study evaluating the participation of citizen science volunteer observers of begging in the UK, found that different circumstances force different people to do begging in different locations and at different times (Purdam, 2014). However, except for the study in Rwanda, most of the studies have focused on CS projects in the global north and have not involved citizen scientists in the evaluation process.

2.4 Summary of literature review

This chapter reviewed the literature on the philosophical underpinning to support the study, as well as an empirical review of previous studies around the objectives. Regarding the theoretical review, I pointed out the two key research paradigms that were relevant to the study. These are interpretivism as the dominant paradigm and critical realism as the supporting one. In the literature, I defined the paradigms and highlighted their major assumptions, applications and critical limitations as well.

The empirical literature reviewed showed a link between knowledge, attitude and practices and schistosomiasis. According to the literature, good knowledge of the disease enhances a positive attitude which in turn promotes good preventive practices. Good knowledge, can also, directly contribute to positive behavioural practices. The literature reviewed also demonstrated that sometimes, good knowledge may not lead to a change in attitude and neither does it translate to good practice. Limited knowledge impedes prevention and control efforts. Moreover, KAPs differ for different geographical populations, age, gender, education, income and other individual factors. Linked to KAPs are also

community belief systems surrounding the disease which also vary from society to society or ethnic group to another. Arising from these variations and complexities, it is only important that KAPs for a particular geographical area be ascertained to guide the implementation of contextualised interventions.

I also observed from previous research that other behavioural factors like health-seeking for the PZQ still pose a big challenge. The issue of drug shortage, concerns about drug side effects, and disease and health service-related factors together with predisposing and community factors were highlighted by different studies according to the literature. What came out from the literature also, is that different studies produced different findings on health-seeking. Furthermore, no studies had documented communities' health-seeking in situations when there is no MDA. This was critical to informing policy measures.

In addition, while understanding lived experiences of schistosomiasis is important for developing holistic approaches, I found out from the literature reviewed, that there was hardly any literature about this. The literature available albeit scant includes the experience of community health extension workers' participation in the distribution of PZQ conducted in an outside setting. This presented a problem that needed to be researched since the people who suffer from the disease, their voices need to be directly captured in designing any prevention strategy. This failure to identify critical aspects of disease experience could partly be the reason why the disease has continued to persist.

The chapter further revealed from the literature that while health education and sensitisation have been conducted in some parts of the country, there were some flaws in the strategy and implementation, which negatively affected the outcomes. For instance, literature by Muhumuza showed that materials were inadequate, and the language used was not well understood by some sections of the community. As a result, some of the communities continue to register a high prevalence of the disease. This and other studies elsewhere showed a potential problem with the approach. The studies also showed a lack of community involvement in the process. Finally, the literature showed that most evaluations were impact-

based, mostly quantitative in nature, with little to no consideration of the local communities as beneficiaries. All these plus other challenges meant that possibly, a different approach to schistosomiasis prevention and control could be explored, culminating in this PhD research project.

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter presents information on the methodology that was employed to answer the research questions focusing on the study area, setting, study population and general research design. Furthermore, the chapter presents information on the designs of each objective, sample size determination, sampling procedure as well as participants' eligibility, data collection methods and instruments, and data analysis methods and instruments. The chapter concludes with a section on the ethical considerations undertaken to conduct the study, all of which are presented below.

3.2 Study area and setting

The study was conducted in Kagadi and Ntoroko districts along the Lake Albert shores. The two districts were selected from the six districts that border Lake Albert from the Ugandan side. They are bordered by Lake Albert to the west, Kikuube district to the north, Bundibugyo to the south and Kabarole, Kyenjojo, Kibaale and Kakumiro districts to the east respectively. The other four districts are Pakwach (formerly Nebbi district), Buliisa, Hoima and Kikuube. The two districts were selected because they are located along Lake Albert, considered highly endemic with prevalence reported to be over 50% (Adriko, 2017a), although no specific study was conducted for the area. Also, they were selected because of the need to have tangible project outcomes using the available funding.

Five sub-counties, one from Ntoroko district (Kanara Town council), and four from Kagadi district (Ndaiga, Kyaterekera, Mpeefu, and Bwikara) respectively were considered in the study (See Figure 4 below for more information). A total of 10 parishes, two from each of the sub-counties were picked for the study. A

total of 18 villages were randomly chosen from the five selected sub-counties above. Of the 18 villages, four were from Kanara, Kyaterekera, Mpeefu and Bwikara each, and two were from Ndaiga respectively. The selection of the sub-counties was based on reported cases of schistosomiasis by the district health authority, closeness to Lake Albert, availability of other water sources such as rivers, ponds, springs, and wells, the presence of health facilities, transport networks, and human activities such as fishing, farming, and cattle rearing. Furthermore, being a participatory action research, meetings were held with the district and local leaders of the proposed sub-counties from where endorsement was obtained. The literature reviewed also revealed that the areas experience poor health service accessibility, low levels of literacy, inadequate water sanitation and hygiene infrastructure, and high poverty situation among other challenges as explained below.

Health services and infrastructures: There are inadequate healthcare facilities in the area (NPHC, 2017; Statistics, 2017). This causes the problem of accessibility to health care services. For instance, in Butungama (99.2%), Karugutu (98.8%), Kibuuku TC (73.7%), and Kagadi (60%) households live 5km or more from the nearest health facility (NPHC, 2017; Partnership, 2018; Statistics, 2017). Also, despite the government's policy of having at least health centre III and II per every sub-county and parish respectively, Ndaiga sub-county in Kagadi district does not have HC III, while those that have health centre III serve more than the recommended number of people. With this situation, there is bound to be a problem of access to health information and healthcare services.

The area also experiences frequent outbreaks of cholera, malaria, dysentery, yellow fever, Congo Crimean fever and Ebola, with some reported cases of bilharzia especially along the lake (Birungi et al., 2018; Mbonye & Sekamatte, 2018; Mdrug, 2018). HIV/AIDS prevalence is also reported to be a major problem, especially among fishing communities. For instance, by 2014, between 4.2% and 5.9% were reported to

be infected, although it was below the national figure of 6.9% (NPHC, 2017; Partnership, 2018; Statistics, 2017).

Water sanitation and hygiene: A lack of access to safe water and toilet facilities in both districts has been documented by reports. For instance, by 2014, Kanara (81.3%), Butungama (69.3%), Karugutu (60.9%), Bweramule (56.2%), Kibuuku TC (55.3%) and Rwebisengo (41.9%) in Ntoroko district did not have safe water, while (Butungama SC, 35.7%; Kanara SC, 32.4%; Kibuuku TC, 20.5%; and Rwebisengo SC, 12.5%) did not have any toilet facility. Similarly, in Ndaiga (83.2%), Mpeefu (67.5%), Kyaterekera (50%) and Bwikara (40%) in Kagadi district did not have access to safe water, while Ndaiga SC, at least 32.9% of the households did not have toilet facilities (NPHC, 2017; Partnership, 2018; Statistics, 2017). Lack of access to clean water and toilet facilities means the community might force the communities to use unsafe sources of water. This could put their lives at high risk of contracting diseases such as cholera, diarrhoea, dysentery, schistosomiasis and other related water diseases.

Education: The study area has a high level of illiteracy as a significant number of children are unable to attend school. For instance, a census report indicated that by 2014, at least 30.2% of children aged 6-12 years in Butungama SC, Ndaiga (27.1%), Kyaterekera (25.7%) and Mpeefu (23.8%) were not in school. While 17.5% & 16.5% of children in Ndaiga and Muhorro respectively, were not in secondary school (NPHC, 2017; Statistics, 2017).

Gender inequality and teenage pregnancy: Gender inequality and teenage pregnancy are also reported to be common in the area. Women are particularly disadvantaged in access to education and employment opportunities, access to, control over and ownership of land. Besides, teenage pregnancy (7.1%) and early marriage (8.1%) are still a common problem (NPHC, 2017; Statistics, 2017).

Economic activities: Despite the good climate, fertile soil and productive economic activities in the area, a significant proportion of households are still very poor. According to the 2014 census data, Kanara TC

(14.1%), Kanara SC (12.8) and Bweramule (15%), and Kagadi district (24%) were living on less than one US dollar a day (NPHC, 2017; Partnership, 2018; Statistics, 2017).

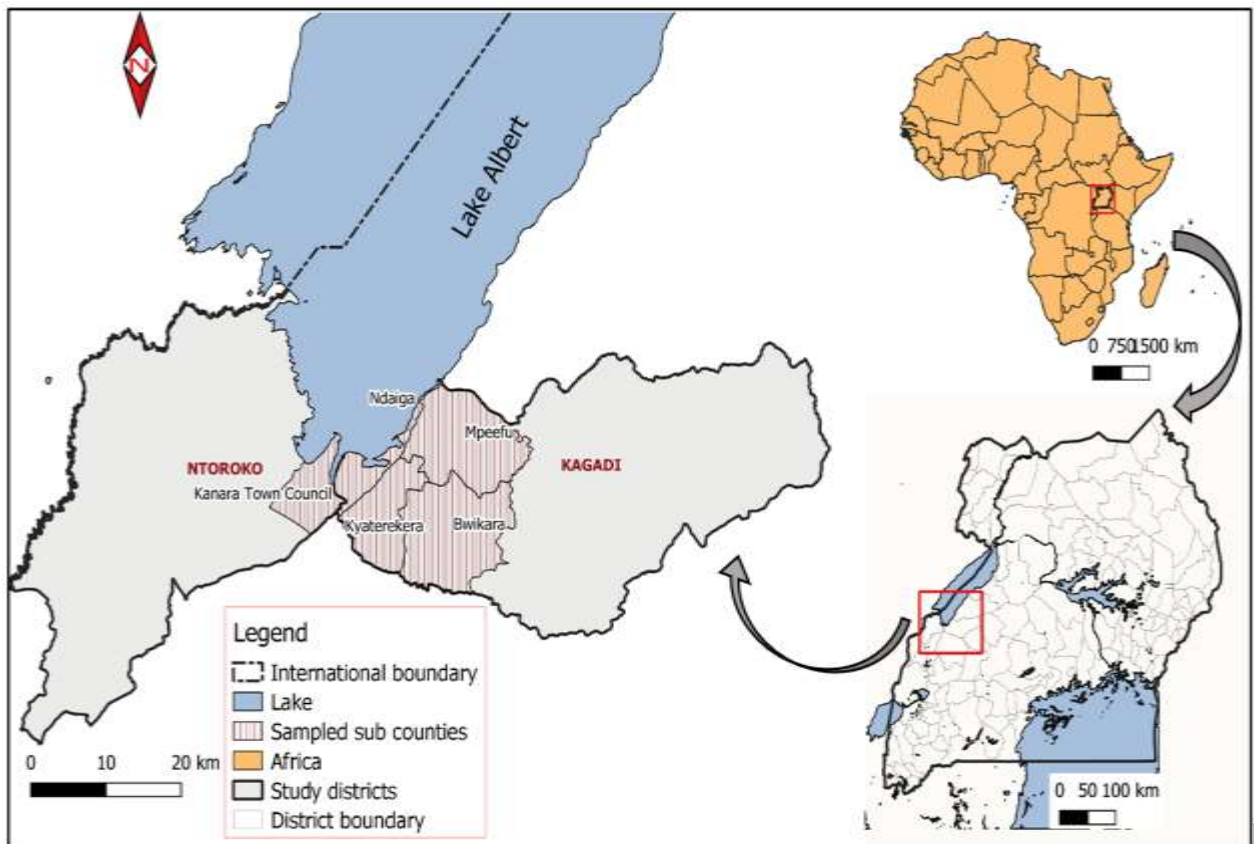


Figure 4 Study area showing districts and sub-counties in southern Lake Albert, Uganda.

Source: Uganda Bureau of Statistics (UBOS) (2018):

<https://ubos.maps.arcgis.com/home/webmap/viewer.html?layers=4e92034071494dff6239a219449fd2c1> (Accessed on February 4th)

3.3 Study population

According to the Uganda national population and housing census of 2014, the two districts of Ntoroko district had 67,005 while Kagadi had 351,033 people (NPHC, 2017; Statistics, 2017). The census report further revealed that over 80% of the population was very young (i.e., aged 0 to 39 years) with slightly over half being males. The main ethnic groups in the study include the Batuku, Bakonjo, Batooro, Banyoro, Banyarwanda, Bamba, Bakiga, Bafumbira, Alur, Baganda and Bagungu among others hailing either from

Uganda or the Democratic Republic of Congo (DRC) or both, with Lutoro, Lukonjo, Lukiga and Lunyoro as the common languages spoken (Baligira, 1996; Ssentongo, 2016).

For this study, the population comprised the following categories of participants: a) Adult household heads or any adult member of the household; b) District and sub-county local government workers; c) Local leaders; d) Village Health Teams members (VHTs); e) individuals who had ever suffered from schistosomiasis, and finally; g) The citizen scientists (CS) as community volunteers in the research project.

a) Adult household heads or any adult member of the household

The individual adult household members were community members from the five selected sub-counties. They were mainly categorised as coming from the lake shores or the uphill side. Those from the lake shores mostly are engaged in fishing and fishmongering. Furthermore, those from the uphill side are mostly farmers engaged in different kinds of farming such as cultivation/crop growing and agribusiness as well.

Those from the lakeshores were mainly Alur, Bakonzo, Batoro and other tribes, of whom the Alur and Bakonzo were from both Uganda and DRC. Moreover, the Banyoro, Bakiga, Bakonzo and a few other tribes are almost equally spread across the uphill side. The adult community members not only participated in baseline studies but also actively attended and participated in the awareness campaigns. The adult individuals were considered in the study because they would provide the necessary information regarding schistosomiasis.

b) District and sub-county local government workers

The district and sub-county local government staff comprised both political and technical departments. The district-level participants included the district health team such as the health educator, health inspector, surveillance officer, and vector control officer from the technical wing. The political department included the chairperson and speaker.

At sub-county levels, the study population included the local council chairpersons and a selection of their councillors, the sub-county senior assistant secretary, health assistants, community development officers, and parish chiefs. During the study, these categories of individuals provided qualitative data for the baseline information. Meanwhile, several of them also participated in community mobilisation for the behaviour change intervention, attended different workshops and engaged with different stakeholders including their participation in the process evaluation of the intervention. The inclusion of district and sub-county workers in the study was important because they were deemed to possess in-depth information regarding schistosomiasis.

c) Local community leaders

At the village/community level, the individuals that constituted the study population included village chairpersons, traditional healers, herbalists, and religious and cultural leaders. These categories of individuals were spread across the five sub-counties. Usually, they are known by the community to be active and committed to local community activities. Different communities had different kinds of leaders with some very active while others less active. Despite the variations, each sub-county had at least some calibre of leaders the community believed in and trusted. The inclusion of local community leaders was important as they have ever participated in some of the schistosomiasis programs and were, therefore, deemed to possess experience in the program.

d) Village health team members

Next to the local leaders were the VHT members drawn from all five sub-counties. In this study, VHTs were instrumental in providing information of various kinds. First, the VHT members participated in baseline studies by providing qualitative data for the KAPs and health-seeking regarding the disease. They also participated in different workshops to disseminate baseline study findings. Lastly, they actively did community mobilisation for awareness raising, while others participated in the awareness campaigns by

joining the citizen scientists. Furthermore, the VHTs participated in the evaluation of the citizen science approach by appraising the most significant stories and sharing their experiences and perceptions of the citizen science approach to behaviour change intervention. VHTs were included in this study since they were the ones who participated in social mobilisation and subsequent distribution of the praziquantel drug.

e) Individuals who have ever suffered from bilharzia.

Individuals who have suffered from schistosomiasis were part of the study population. Firstly, they were included in the study because were able to share their lived experiences with the disease and how it had shaped their perception of preventive measures. The information they provided was useful in informing the kind of messages to be developed and delivered to the communities on top of what other participants had already provided. Furthermore, some of them actively participated in workshops for the dissemination of study results and co-design of intervention. A few others also participated in the awareness-raising activities.

f) Citizen scientists

Lastly, the citizen scientists formed part of the study population. These are a group of community members who were selected and trained to volunteer and participate in the research process. Their selection was with the help of community leaders and recommended by the local community members themselves. The citizen scientists were instrumental in this study as they took the lead in conducting community mobilisation for community workshops and participated in the dissemination of baseline results and co-design of interventions. They also led the awareness-raising campaigns regarding schistosomiasis from their various villages and parishes. Furthermore, the citizen scientists participated in providing stories of the most significant changes that had happened to them because of their

involvement and participation in the intervention. Such participation formed one of the bedrock of the research process.

3.4 Research design

1. General research design

This PhD research adopted a quasi-experimental multi-phased mixed methods design of a sequential dominant status (Leech & Onwuegbuzie, 2009). Creswell defines multi-phase mixed methods design as that type where mixing of the approaches is done severally, sometimes employing only quantitative or qualitative studies in a longitudinal study by focusing on a common objective and with emphasis either on an equal approach or one dominating the other (Creswell, 2014: 293). A quasi-experimental mixed methods design was selected because of its suitability for intervention and evaluation studies, allowing for a longitudinal examination of the research problem (Creswell, 2014). Furthermore, the use of different designs across the three phases provided a comprehensive and holistic approach to addressing the research problem by enhancing its outcomes (Bryman, 2012). Also, combining quantitative and qualitative methods, along with participatory approaches, enabled a deeper understanding of the topic and facilitated the development of contextually appropriate interventions.

The qualitative approach was dominant since it was applied across all three phases with only the survey employed in the KAPs baseline phase (see Figure 7 below). A cross-sectional survey of mixed methods equal status employing both quantitative and qualitative approaches was used for the KAPs baseline

study. Meanwhile, a qualitative approach was used for the lived experience and health-seeking behaviour, as well as for assessing the community's preferred sources of receiving information regarding the disease, also in phase one. In phase two, citizen science and other PAR design another qualitative approach was employed to disseminate baseline study findings, co-design and implement a contextualised communication strategy. Finally, in the third phase, qualitative participatory design was used to evaluate the application of the citizen science approach. Details of these sub-designs and the respective methods are explained below:

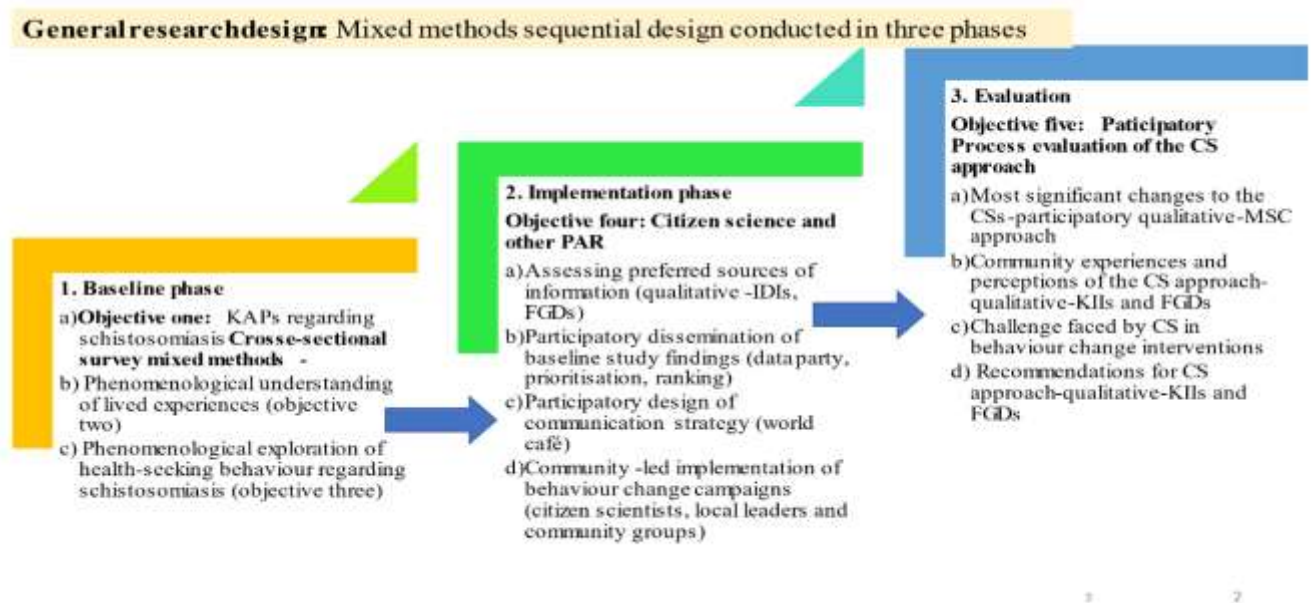


Figure 5 Research design

2. Cross-sectional design

The design was employed for a study of knowledge, attitude, and practices regarding schistosomiasis in phase one. A cross-sectional mixed methods survey design of a concurrent equal status is an approach to research in which both quantitative and qualitative methods are employed while giving equal weight throughout the research processes (Leech & Onwuegbuzie, 2009). The design was chosen because it

provided an in-depth understanding of the research question by triangulating different research methods including sampling, data collection, analysis, and discussions (Bryman, 2012).

The quantitative method assessed the community knowledge, attitude and practices related to schistosomiasis and its associated factors, while the qualitative method delved into the underlying reasons and motivation behind these factors. The concurrent use of both methods allowed for a broader study population coverage and a more in-depth exploration of the research problem, which would not be possible with a single method (Creswell, 2014).

3. Phenomenological Research Design

The study design was utilised for objective two, which aimed at gaining insights into the lived experiences of schistosomiasis by individuals in western Uganda, focusing on their symptoms, challenges, and coping mechanisms. Phenomenology is “an approach to the study of social life that focuses on the discovery of implicit, usually unspoken assumptions and agreements of social phenomena and often involves the intentional breaking of agreements as a way of revealing their existence” (Babbie, 2011).

Drawing from the phenomenological theory, the study uncovers the profound stories and unveils the hidden narratives of these communities’ subjective experiences of schistosomiasis-related signs and symptoms, reactions of significant others, coping mechanisms, actions taken to seek treatment and challenges faced while experiencing the different signs and symptoms (Braun & Clarke, 2013; Bryman, 2012; Leavy, 2017). The design was chosen for this study because it allowed for an in-depth exploration of the lived experiences of the community members affected by schistosomiasis. Using the phenomenological design, the study aimed to capture the subjective experiences, actions, and reasons of the participants in their natural settings.

4. Ethnographic design.

This design was employed to explore the health-seeking behaviours regarding schistosomiasis by communities in western Uganda, especially in the absence of a mass drug administration program. Ethnography is a qualitative approach to research that refers to a description of people or their culture, that is, digging deeper than the outside or the explicit appearance to understand given phenomena (Neuman, 2014). The design was justified in this study because it enabled me to dig deeper into the views and perspectives of the community on what actions they take whenever they present with signs and symptoms of schistosomiasis and what factors inform their actions. This emic perspective allowed for a proper understanding of the problems of schistosomiasis control from the point of view of the sufferers rather than from the implementors.

5. Participatory Action Research and Citizen Science.

This design was employed for study objective four in phase two. On the one hand, participatory research approaches comprise the active involvement of the general public in the research process, recognising their knowledge experiences and creativity as valuable resources (Alexander, 2016; Wiggins & Wilbanks, 2019). On the other hand, citizen science is a participatory approach that ensures scientific rigour in the research process.

The design was chosen because it offered significant advantages in jointly developing community-owned behavioural interventions that effectively interrupt schistosomiasis transmission. Moreover, it ensures sustainability and cost-effectiveness, aligning with the financial and methodological considerations (Person et al, 2016). Building on the above evidence, the design allows for the production of knowledge and active community engagement in addressing issues of schistosomiasis that directly impact them (Balazs & Morello-Frosch, 2013). The design was relevant in allowing community participation in

dissemination of baseline study findings, co-designing intervention as well as its implementation and evaluation.

6. Participatory Process Evaluation

The design was adopted to evaluate the process of the intervention implementation in phase three. Participatory process evaluation (PPE) “uses methods that seek to get to grips with the life of an intervention as it is lived and perceived and experienced by different kinds of people, including programme or project personnel” (Cornwall, 2014). The design was chosen because it facilitates a comprehensive understanding of the intervention’s implementation and the actors’ engagement. Furthermore, it allows for capturing of the lived experiences and perceptions of project personnel, including community members and the exploration of intervention’s impact on various aspects such as empowerment, changes in attitudes, norms, and values, coherence, community building, social capital, social learning and trust among (Den Broeder et al., 2018).

In this study, the design helped to explore and document the changes that had happened to the citizen scientists because of their involvement in the intervention, and the experiences and perceptions of the community members and leaders regarding the intervention approach. The choice of the design was driven by the need to document the intervention’s processes and changes from the actors’ perspectives, rather than solely focusing on the impact. The design facilitated a deeper exploration of the citizen scientists’ involvement and active participation in the intervention, providing valuable insights into their experiences and perceptions (Onasanya et al., 2021). By adopting this design, the study aimed to amplify the voices and perspectives of the citizen scientists and other stakeholders involved, capturing their lived realities and contributions throughout the intervention process (Albert, Social, et al., 2021).

The role of citizen scientists in all the phases: The CSs played a pivotal role in each of the different study phases, two and three, except in phase one when they had not yet been recruited. In phase two during the dissemination of study findings, co-design and implementation of the intervention, the CSs worked together with local leaders and the researcher to identify and mobilise study participants, organise workshop venues, translate languages, lead discussions during workshops and present group work among others. Meanwhile, in phase three, they identified and organised community groups in their respective sub-counties to participate in drama, songs, and football tournaments. They also mobilised community members and local leaders and organised venues for community meetings. Finally, in the evaluation phase, the CSs participated in storytelling to highlight the most significant changes that took place in their lives because of their participation and involvement in the intervention.

3.5 Sample size determination

A total sample of 613 was utilised for the whole study, of which 372 were utilised for the KAPs study, 40 for lived experiences, 35 for health-seeking behaviour, 115 for co-design and implementation and lastly, 51 for the evaluation as presented in Table 2. Details of the breakdown of sample sizes for the different studies are presented below.

Table 2: Summary of sample size

SN	Category of participants	Sample size	sampling	Data collection methods
01	<i>Assessing the level of knowledge attitudes and practices regarding schistosomiasis by the communities and understanding their perspectives and opinions of the same</i>			
A	Adult household individuals	337	Systematic random	Survey
B	Adult household individuals	20	Purposive	Focus group discussion
C	Village chairpersons	5	Purposive	In-depth interview
D	Village health team members	5	Purposive	In-depth interview
E	Sub-county health assistants	3	Purposive	In-depth interview

F	District health team	2	Purposive	In-depth interview
	Subtotal objective one	372		
02	<i>Understanding the lived experience of schistosomiasis by endemic communities in western Uganda</i>			
A	Adults who have ever suffered from schistosomiasis	30	Purposive	Focus group discussion
B	Adults who have ever suffered from schistosomiasis	10	Purposive	Key informant interview
	Subtotal objective two	40		
03	<i>Exploring health-seeking behaviours and information sources regarding schistosomiasis treatment by communities in western Uganda</i>			
A	Adult household individuals	20	Purposive	Focus group discussion
B	Village chairpersons	5	Purposive	In-depth interview
C	Village health team members	5	Purposive	In-depth interview
D	Sub-county health assistants	3	Purposive	In-depth interview
E	District health team	2	Purposive	In-depth interview
	Subtotal	35		
04	<i>Document co-design & implementation of communication campaign intervention</i>			
A	Citizen scientists	18	Purposive	Workshop
B	Local council one leaders	11	Purposive	Workshop
C	Local council 3 leaders	5	Purposive	Workshop
D	Technical leaders	18	Purposive	Workshop
E	Cultural & religious leaders and traditional health practitioners	27	Purposive	Workshop
F	Village health teams	11	Purposive	Workshop
G	Victims of schistosomiasis	22	Purposive	Workshop
H	District Health Team	3	Purposive	Workshop
	Subtotal	115		
05	<i>Participatory evaluation of citizen science approach</i>			
A	Citizen scientists	18	Purposive	Storytelling
B	Local council one leaders	4	Purposive	Key informant interviews
C	Local council 3 leaders	2	Purposive	Storytelling and interviews
D	Technical leaders	2	Purposive	Key informant interviews
E	Village health teams	1	Purposive	Key informant interviews

F	District Health Team	1	Purposive	Key informant interviews
G	Adult community members	12	Purposive	Focus group discussion
	Subtotal	40		
	TOTAL	613		

1. Sample size for baseline KAP study

For the baseline study of KAPs, a sample size of 372 comprising 337 households, 20 groups of adult participants (160 individuals) and 15 community leaders respectively, were employed. The sample size was chosen because it was considered highly representative since it was scientifically determined. Kish's formula was used for the quantitative study of adult populations within households aged 18 years and above. It relied on the national prevalence of schistosomiasis reported at 25.6% (Exum et al., 2019). The formula used for sample size determination is:

$$n = \frac{Z^2QP}{E^2}$$

Where:

n represents the sample population

Z is the confidence level given by the Z score value of 1.96 at a 95% confidence level

Q is the proportion of individuals infected with schistosomiasis

P is the proportion of individuals not infected with schistosomiasis given as 1-Q

E is the level of precision, also known as the standard error set at 5% for this study

By substituting the values into the formula, a sample size of 293 was obtained. Considering a 15% allowance for non-response, the total sample size was determined at 337.

For the qualitative data, a total of 15 community leaders comprising local government workers, local council chairpersons, and village health teams (VHTs) were utilised. Also, a total of 20 FGDs comprising 160 adult community members were proposed. VHTs are individuals selected and trained to mobilise communities and provide basic health services at the household level voluntarily. However, the final sample size for both the community leaders and adult members of the communities was determined based on the saturation principle.

Table 3: Proposed sample size for KAPs baseline and health-seeking behaviours

Probability-based sampling					
S	Sub counties	Parish	Village	No of Household	sample size
1	Kanara	Ntoroko	Kisenyi A	186	16
			Kisenyi B	176	15
		Kanyansi	Ntoroko Central A	97	16
			Ntoroko East B	142	16
2	Ndaiga	Nyamasoga	Nyamasoga	150	45
		Kitebere	Kitebere	300	46
3	Mpeefu	Rubirizi	Nyakatoj	220	20
			Mutuule	93	20
		Nyamukara	Kanyamunguse	457	20
			Kayera	200	20
4	Bwikara	Kisuura	Kaiha	158	15
			Kisuura A	212	16
		Nyakarongo	Magusuuru	300	16
			Nyamarembo	22	16
5	Kyaterekera	Buswaka	Lyanda	300	10
			Katerera	546	10
		Kyaterekera	Kyaterekera	499	10
			Town council	Central	
				Kyaterekera East B	600
Total				4,658	337
Non-probability-based sampling					
Study population				Population	Sample size
Estimated population (based on av. of five per household)				23,290	20

Village chairpersons (based on no. of villages)	18	5
Village health teams (est; two per village)	36	5
Sub-county Health workers	5	3
District health team	8	2
Total	23,357	35
Grand total	28,015	372

Source: Data from respondents, 2020

2. Sample size for baseline lived experience study

For objective two of the lived experience study, a sample size of 40 was estimated, 30 for individual interviews and 10 for group interviews comprising 80 adult community members. This was based on the research objectives, available resources, and the nature of the research design. The final sample size was arrived at upon achieving data saturation. Data saturation is the point at which no new information and no new themes emerge from discussions (Leavy, 2017; Neuman, 2014; Ploeg, 1999). Study participants included adult community members, health workers, community leaders, and individuals with extensive knowledge of the disease and its impact on the community.

3. Sample size for baseline study of health-seeking behaviour

For study objective three on health-seeking behaviour, I used a sample size of 35 that was utilised in the KAPs study, consisting of 20 groups (160 adult community members) and 15 community leaders comprising health workers, VHTs, and local council chairpersons. The technique was chosen because it enables the identification of participants who possess the characteristics essential for answering the research inquiries (Bryman, 2012; Johnman, 2010).

4. Sample size for co-design and implementation study

A total sample size of 115 was utilised in phase two of the co-design and implementation of the intervention. These consisted of adult individuals, citizen scientists, community leaders, health workers, religious and cultural leaders, traditional health practitioners, and those who had ever suffered from schistosomiasis as summarised in Table 4 below. The sample size was determined based on the scope of the study, available resources, and the need to ensure a diverse representation of the target population. More details concerning the category of participants, specific sample size, and the different activities are presented in the table below.

Table 4. Study participants category

Category	Sub-counties					Total
	Kanara	Ndaiga	Kyateker	Mpeefu	Bwika	
Citizen scientists	2	4	3	4	5	18
Local council one leaders	3	2	2	2	2	11
Local council 3 leaders	1	1	1	1	1	5
Technical leaders	3	4	3	5	3	18
Cultural and religious leaders and traditional health practitioners	7	6	5	6	3	27
Village health teams	2	2	2	3	2	11
Victims of schistosomiasis	5	7	8	2	0	22
District Health Team	0	0	0	0	0	3
Sub-total	21	22	21	19	11	97
Total	105	82	76	58	54	115

5. Sample size for the participatory evaluation

For the participatory evaluation of the CS approach, I employed a total sample size of 51 comprising 18 storytelling processes 21 in KII and 12 in FGD. Individuals included citizen scientists, district vector control

officers, sub-county health workers, community development officers, village health teams, local council three (LC III) chairpersons, and local council leaders as well as adult community members.

3.6 Sampling procedures

Both multistage area sampling probability and non-probability purposive sampling techniques were employed in this study. Probability sampling technique was employed to select the parishes, villages and households, while non-probability sampling was employed to select the sub-counties, and participants for the qualitative data collection as explained below.

3.6.1 Probability sampling techniques

In this section, I employed multi-stage area sampling and systematic random sampling. The techniques were utilised to study objective one of the KAPs baseline study in phase one. Probability sampling techniques were chosen because they allowed representation of the study population thereby enhancing generalisation of the study findings. To allocate the sample size for each parish and village, disproportionate stratification was utilised. Afterwards, simple random sampling using bowl methods by replacement was used to select parishes and villages. Lastly, systematic random sampling was employed to select the households from each of the disproportionately selected villages. These procedures are explained in detail in the sections below.

1. Multi-stage area sampling.

This technique was utilised to select parishes and villages. At the sub-county level, for each of the sub-counties, I obtained the list of the parishes, and then I wrote numbers equivalent to the parishes on pieces of paper. Afterwards, I shook for a while, then I picked a piece of paper, opened it, and recorded the name

of the selected parish. I then placed back the paper in the bowl after rolling it. I shook and did the same for the rest until I picked two parishes for each of the five sub-counties. Furthermore, 18 villages were included in the study, two from Ndaiga sub-county, and four from Kanara, Kyaterekera, and Mpeefu respectively. Similarly, I employed the same methods in selecting the parishes above, for the villages as well.

2. Systematic sampling technique.

This approach was employed to select households within the chosen villages. A list of households was obtained for each of the selected villages. Next, a sample interval was obtained by dividing the total number of households in a village by the desired sample size for each village (see table below). A simple random sampling technique using the fishbowl method was utilised to select the first household to be included in the study. Subsequent households were then chosen at fixed intervals to ensure a systematic and unbiased selection process (Leavy, 2017). The selection of respondents involved identifying households where any consenting adult member would be available to answer the questions from the questionnaire.

3.6.2 Non-probability sampling techniques

Non-probability sampling techniques, specifically purposive, were utilised to select the districts, sub-counties, and study participants for the qualitative data collection. The districts and sub-counties were selected using participatory community engagement approaches. The number of sub-counties was agreed upon after engagement meetings with district and sub-county leaders as the stakeholders. This approach ensured diverse representation and enabled the capturing of a range of perspectives and experiences related to schistosomiasis within the study population.

The selection of the sub-counties was informed by previous information provided by the district health offices. The leaders indicated that the said sub-counties were known to have commonly reported cases of schistosomiasis. Additionally, the district and sub-county leaders during the project inception stakeholders' engagement also recommended the same sub-counties for consideration as they were known to be having a significant burden of the disease. The leaders' suggestions were important because they were deemed to be familiar with the local context.

For the participants in the individual interviews, purposive sampling technique was justified because it ensured the selection of individuals with knowledge, information and expertise on the subject but not so much for generalisability purposes (Bryman, 2012). The selection was based on their age (18 years and above), gender, place of residence, involvement or expertise in schistosomiasis-related activities and willingness to participate in the study (Bryman, 2012; Decrop, 2004). For the community leaders, the selection was based on criteria such as possessing adequate information about schistosomiasis and having experience in dealing with the community. For the citizen scientists, criteria such as commitment, a good track record in project work, working in the specific sub-county area of operation, gender and proficiency in English (both reading and speaking) were considered. The inclusion of citizen scientists and local leaders in the selection process further enhanced community engagement and fostered a participatory approach to research.

Similarly, for group interviews, a purposive sampling technique was used to select adult community members who represented a diverse range of perspectives and experiences related to schistosomiasis. Factors such as previous experience with the disease, age, gender, occupation, and residence were considered to facilitate a comprehensive understanding of the lived experience of schistosomiasis within the community. The selection process involved collaborating with local community leaders and health

workers to identify and invite eligible participants. By selecting a diverse range of participants, the study aimed to capture a wide range of perspectives and experiences, enhancing the validity and richness of the findings. A summary of the sample size and sampling procedure is presented in the table below.

3.7 Study procedure

Setting up the citizen science network and its operationalisation

Before embarking on implementation, the students made about four field visits to different communities of Kikuube, Kagadi and Ntoroko districts in 2019. The visits aimed at mapping out the different water sources and those that harbour snails and the socio-demographic characteristics of the communities. The students also held informal interactions with selected community leaders about the problem of schistosomiasis including whether there were common cases. Observation of human-related activities such as open defecation, and water-related activities such as bathing, swimming, washing, fishing, etc were also made. Information gathered from the visits helped to identify water contact points and to make suggestions on the potential study sites.

Equipped with the above information, the students went back to the communities and held community engagement entry meetings and workshops with the district and community leaders in which the project received endorsement. Thereafter, a network of citizen scientists (CSs) was set up in early 2020, between January and February. This was done through participatory approaches of community engagement meetings with community leaders. The selection was based on criteria agreed together with the communities (Brees et al., 2021). A total of 75 volunteer candidates were recommended by community leaders out of whom 25 were successful after going through basic validation questions.

The successful volunteers were then invited for a two-day training and induction about the project and what they would be expected to do. Training contents included the problem of schistosomiasis i.e., what

it is, signs and symptoms, transmission modes, diagnosis, treatment, and preventive measures. It also looked at the different types of snails and their possible hot spots at the water sites. Included in the training content also, was, the use of smartphones for data collection and reporting. The training was concluded by practical sessions in one of the nearby selected water contact points.

After the training and induction, the volunteers were assigned different contact sites from which they would conduct snail sampling and reporting. They were also provided with different gadgets such as scoop nets, phones, t-shirts, bags, thermometers, stripes, and others. They were also briefed on their other roles of community mobilisation, health education and sensitisation and community engagement generally. Periodic training was also conducted every year to refresh the CSs' knowledge and skills and share feedback on the progress of their work.

The CSs were then deployed to the communities to start their work in March 2020. Each citizen scientist was to conduct weekly snail sampling and reporting for the different water contact points allocated to them. Data on snails, water parameters and human-related activities were fed onto a smartphone and remitted to one of the PhD students. The student validated the data and feedback was given accordingly. However, the COVID-19 world pandemic disrupted CSs' work from March until October of the same year 2020, when they resumed their work after the government lifted some of the restrictions. The CSs then resumed snail sampling activities from October 2020 up to February 2023 when their contracts came to an end.

Between August and October of 2022, the citizen scientists participated in workshops for the dissemination of findings from the baseline study and in the co-design of behaviour change communication intervention. The workshops helped the communities to come up with socially diverse problems associated with schistosomiasis and their most pressing ones, contextualised communication tools, community action points and supervisory committees. They were also trained in skills and

knowledge of communication generally, and on how to communicate schistosomiasis information using the developed tools. Afterwards, the CSs conducted awareness about the disease for one week from November 5th to 10th of 2021. The exercise drew the participation of local leaders, community groups and youth. With the baseline studies that were already conducted before the intervention, there was a need to evaluate the CS project.

3.8 Data collection methods and instruments

Both quantitative and qualitative data collection methods and instruments were employed for the different studies. The survey method was used for collecting quantitative data. For the qualitative data, in-depth interviews (IDI), key informant interviews (KII), focus group discussions (FGD), participatory techniques such as data party, prioritisation and ranking, and world café, and storytelling were utilised. The different methods are explained in detail below.

3.8.1 Quantitative data collection methods and instruments.

1. Survey.

This method involves the development of a structured set of questions designed to gather quantitative data from respondents around the research topic. The method was considered suitable because it enabled obtaining information on attitudes, beliefs, opinions, perceptions, and experiences related to a specific phenomenon (Neuman, 2014). In the present study, a survey was utilised in phase one to gather baseline data on socio-demographic characteristics, knowledge, attitudes, and practice regarding schistosomiasis infection and prevention.

An interviewer-administered questionnaire was developed by the researcher and administered to the respondents by trained research assistants (RAs). The RAs possessed a background in social sciences background and had prior experience in research. Additionally, they were familiar with the local language and community context. The RAs visited the selected households and approached either the household head or an adult member who expressed willingness to participate in the study. After introducing themselves, the RAs obtained written informed consent from the respondents and proceeded to administer the questionnaires in the language preferred by the respondents. The RAs asked the survey questions, including the accompanying response categories, and recorded respondents' responses directly in the questionnaire. The questionnaire allowed respondents to give responses from the answer categories provided.

3.8.2 Qualitative data collection methods and instruments.

1. In-depth interviews.

The method involves informal and open-ended conversations between the researcher or interviewer and the interviewee, to gather rich qualitative information on a specific research topic (Neuman, 2014). In-depth interview was utilised for the collection of qualitative data on KAPs, health-seeking behaviour, and preferred sources of information. The use of in-depth interviews was justified in this study as it allowed the collection of detailed information from the participants' perspectives, shedding light on their perceptions related to schistosomiasis.

To ensure a systematic approach, well-developed in-depth interview guides were used to steer the conversation process. The guides covered major themes and sub-themes regarding the study objectives such as knowledge, attitude, practices, and perception, as well as myths and misconceptions regarding

the disease. Also, information on the sources of health-seeking, and factors for health-seeking, together with preferred sources of schistosomiasis information were considered.

2. Key Informant Interviews

Key informant interview is used for collecting data from participants who possess knowledge and expertise about the research problem and are well-suited to provide valuable data (Decrop, 2004). Key informant interview (KII) was used to gather comprehensive and diverse insights into the research problem. The utilisation of KIIs was justified because it enabled the collection of rich, varied, and nuanced data from informed individuals and community members who knew the subject of schistosomiasis. The method was particularly appropriate as it facilitated the acquisition of information from participants who had direct experience and understanding of the disease thereby ensuring a comprehensive exploration of the research question. KII guides were employed for collecting the qualitative data from participants.

In study objective two of lived experiences, KII conversations revolved around participants' pre-experience perceptions, their encounters with the various signs and symptoms associated with the disease, as well as their personal feelings and opinions on these symptoms. Other themes are the reactions of significant others towards the participants, actions taken in response to the signs and symptoms, the challenges encountered, coping mechanisms employed, and post-experience perceptions, among other relevant aspects. Significant others in the context of this study include parents, children, siblings, friends, relatives, and colleagues among others.

In the case of study objective five of phase three on participatory evaluation of the CS approach, the KII was utilised to triangulate the views of the citizen scientists regarding the changes that occurred. The interviews aimed to capture the experiences of local leaders involved in the intervention and their

perceptions of the citizen science approach. KIIs provided valuable insights into the implementation process, challenges faced, and the overall effectiveness of the citizen science approach. The interviews were conducted using a semi-structured interview guide tailored to elicit in-depth responses from the key informants. The interviews were audio-recorded with the participant's consent and later transcribed for analysis.

3. Focus group discussions (FGDs).

Focus group discussion was utilised for the collection of qualitative data on four of the five objectives. These include 28 FGDs for objective one on KAPs, 10 FGDs for objective two on lived experience, another 28 FGDs for objective three on health-seeking behaviour, and 12 FGDs for objective three on participatory evaluation study. FGDs involve bringing together a group of individuals to engage in a facilitated discussion about a specific topic (Creswell, 2014; Neuman, 2014). FGDs were valuable in this study because they allowed participants to freely express their opinions and interact with one another, which might not be possible in individual interviews. FGD was also chosen due to its ability to capture diverse perspectives from participants with different socio-cultural and geographical backgrounds (Angelo et al., 2019).

FGD groups can either be homogenous or heterogeneous, depending on the nature of the research question. Homogeneity addresses aspects of specialised knowledge and experience about a particular topic, while heterogeneity is about obtaining information of a diverse nature (Gravlee, 2011). In these studies, adult males and females from different ethnic backgrounds residing in the selected villages were invited to participate in the sessions. The rationale for the choice of the composition was to get diverse views from males and females and different geographical areas-sub-county.

Each FGD session consisted of an average of 8 participants with each session lasting between one hour and one and a half hours. At least two sessions were conducted in each village, with one session dedicated to males and another to females, ensuring gender diversity and allowing for comprehensive

insights. The discussions were focused on key themes and sub-themes that were developed based on the research objectives.

4. Data Party

The data party technique was adapted for this study for objective four on participatory design and implementation of behaviour change intervention. It is a participatory method in which participants are engaged in data collection, analysis and interpretation of results (Bird & Lewis, 2021; Franz & Franz, 2013). This method was chosen because it ensured the active involvement and participation of community laypersons, in appreciating and understanding the problems related to schistosomiasis identified during the dissemination phase. Participants in this phase included citizen scientists, district, sub-county, and community leaders, as well as those who had ever suffered from schistosomiasis.

The technique involved presenting the baseline study findings to participants during workshops. A tool with five guiding questions was used to facilitate participants' understanding of the data. Two additional questions were included in the tool. The first additional question was on what participants thought were the socio-cultural problems associated with schistosomiasis infection. The second one asked them to identify the three most pressing problems regarding schistosomiasis infections that require immediate attention.

To implement the data party technique, a total of five community engagement workshops one, for each of the five sub-counties consisting of Kanara, Ndaiga, Kyaterekera, Mpeefu and Bwikara, were conducted. The workshops began with the presentation of baseline study findings by the researcher. Presentations were made in English and translated into local languages by the citizen scientists (CSs). Copies of the presentations were provided to participants to follow along and guide their discussions. Participants were divided into groups based on different categorisations.

Guided by the data party tool, I took the role of a facilitator and, asked groups to interpret the findings, reflect on them, and discuss whether the results were true. Participants were expected to identify key socio-cultural problems associated with schistosomiasis infections from the findings presented. Participants were encouraged to add any problems they felt were not captured in the findings. Each group was then tasked with selecting at least three key problems they considered to be the most pressing. Following the group discussions, participants reconvened in a plenary session. Each group presented their work, highlighting the identified problems and three most pressing issues they had selected. After all the presentations, participants engaged in a thorough discussion to clarify and generate consensus on the identified problems. This process resulted in the development of a single, consolidated list of problems for each sub-county.

5. Prioritisation and ranking.

This is another participatory technique that was utilised in the study to select the most pressing problems of schistosomiasis affecting the communities. After coming up with a list of the problems as explained during the data party exercise, participants proceeded to prioritise, rank and score the identified problems. Prioritisation was conducted through voting by show of hands in the cases of Kanara, Kyaterekera, Mpeefu and Bwikara sub-counties. However, in the case of Ndaiga sub-county, individuals preferred to vote by tallying. Each participant was required to tally at least three pressing problems from the list. Afterwards, the three problems with the highest scores were agreed upon by participants as the most pressing socio-cultural problems associated with schistosomiasis infection for that sub-county. This process was repeated for all five sub-counties.

6. World café participatory technique.

The World café is yet another participatory action research technique that was utilised in the co-design of the behaviour change intervention strategy. It is a technique organised in a workshop setting that

follows a café environment, where small groups of five to eight participants come together to brainstorm on topics of specific interest (Brown, 2002).

The technique incorporates seven key principles: setting the context, creating a hospitable space, generating meaningful and important questions for discussion, encouraging contributions from all participants, connecting diverse perspectives, promoting collective listening and fostering information sharing (Terry et al., 2015). The choice of the method was due to its ability to elicit participants' views and opinions around a particular topic. Based on ideas generated from the dissemination phase, world café workshops were then held to co-design the intervention. The activity took place soon after the participatory dissemination of the baseline study findings.

Similarly, another five workshop sessions were conducted in the same five sub-counties between August and September 2021. The same number and category of participants that participated in the dissemination phase were used in this phase. However, this time round, it was for a different purpose, that is for the co-design of a behaviour change intervention strategy. The main topic of discussion during the workshops was the development of a communication tool aimed at addressing the socio-cultural problems identified during the dissemination of baseline studies. Major themes including goal setting, objective development, generation of the preferred messages, identification of the target audience, establishment of key actors, and selection of appropriate and relevant channels and strategies were explored.

Using the World café tool as a guide, participants were divided into three to four groups, each consisting of five to eight participants. Within each group, a secretary was selected to act as the session's host. The secretary facilitated the discussion, took notes, and provided a summary of previous discussions to new participants joining the group. The new participants then engaged in discussions on the same questions for approximately 20 to 30 minutes before rotating to another group, leaving only the host/secretary

behind. This process continued until all participants had rotated through all groups, ensuring comprehensive discussion and exploration of the topics. After the group discussions, participants gathered in a plenary session where the secretaries presented the findings from their respective groups. Guided by the researcher, participants worked together to harmonise the findings and develop a single communication tool specific to their sub-county.

7. Storytelling using the Most Significant Change Technique.

Adopting a storytelling approach, the MSC technique was employed to collect qualitative data on objective five phase three regarding the participatory evaluation of the citizen science approach. Storytelling is a collection of stories of changes both expected and unexpected, resulting from project implementation (Akaturkwa et al., 2023). The MSC technique is used to obtain information from the project beneficiaries regarding the most significant changes that have occurred to them as a result of their involvement and participation in the intervention (Davies & Dart, 2005). MSC is a qualitative participatory monitoring and evaluation technique that is used by most projects and programmes and allows the involvement and participation of beneficiaries in the process (Pramanik et al., 2012). In this study, a total of nine CSs selected from across the five sub-counties participated in the storytelling.

Criteria for the selection of the sub-counties are explained in the sampling procedure section above. The MSC technique was adapted to align with this research design in two ways. First, three levels of selection and ranking were utilised. The first two levels involved the parallel selection and ranking processes conducted by the CSs and community leaders. In the third level, the researcher used a matrix of ranking and scores for each of the four selected stories (further details are provided in the analysis section). The second adaptation was that the CSs were asked to share the challenges they faced and propose recommendations for improving the approach.

The key domains of change identified and used in the study included the ability to sample and report on snails, the ability to communicate schistosomiasis information, increased knowledge, skills and a change in attitude, as well as increased respect, trust, social networks, and change in social status. Furthermore, four key pathways of change were conceptualized: 1) citizen scientists' selection and training, 2) snail sampling and reporting 3) Community awareness and 4) Community engagement.

Facilitated by the researcher and a master's student, the MSC story collection guide was used to guide the verbal storytelling by the CSs. Participants were free to use their preferred language. In cases where local languages were used, the facilitators transcribed the stories after validation. The facilitators probed and prompted participants to ensure all the aspects of the domains, levels and pathways were captured. The typed stories were then read back to the citizen scientists for proofing, and final versions were saved for selection. Proofing was done by seeking comments and clarifications from the citizen scientists as to the correctness, clarity, and facts about their experiences.

8. Community engagement approach to intervention implementation.

The implementation of a contextualised behaviour change intervention adopted a community engagement participatory approach led by the 18 citizen scientists (CSs) with guidance from the researcher. The techniques included door-to-door visits, community meetings, drama and songs, football infotainment and stakeholder dialogues. The techniques are discussed in detail below.

a. Door-to-door visits and community meetings: The CSs visited households within the communities to engage residents in one-on-one conversations. They provided information about schistosomiasis, debunked existing myths and misconceptions, and discussed the importance of adopting prevention behaviours such as the use of clean and safe water and defecating in latrines. Additionally, community

meetings were held to address larger gatherings and promote community-wide awareness and engagement.

b. Drama, song, and dialogue meetings: CSs organised drama performances and music presentations to captivate and engage the community members. These performances conveyed key messages related to schistosomiasis prevention and addressed the identified problems. Dialogue meetings were also conducted, providing a platform for community members to share their thoughts, concerns, and questions related to the disease. Additionally, CSs identified hot spot areas within the communities where schistosomiasis prevalence was high or where specific risk factors were prominent. Signposts were strategically placed in these areas to raise awareness and provide educational messages to passersby.

c. Football Tournament and Radio Talk Show: A football tournament was organised as a community event to attract a large audience. CSs utilised this opportunity to disseminate schistosomiasis-related information, especially during breaks and half-time. Additionally, a radio talk show was conducted, reaching a wider audience, and allowing for in-depth discussion of schistosomiasis-related issues.

d. Stakeholder Dialogue Workshop: A stakeholder dialogue workshop was held with different stakeholders at both community, district and ministry levels. Participants included community leaders, health workers, educators, representatives of non-governmental organisations working in WASH areas, and local and central government authorities. The workshop provided a platform for in-depth discussions, exchange of ideas, and collaborative planning for sustained schistosomiasis prevention efforts beyond the intervention period.

3.9 Data analysis methods and instruments

Both quantitative and qualitative methods of data analysis were employed in the study. The quantitative method was utilised for the baseline KAPs study of phase one, while qualitative data analysis was employed for all the study objectives of the three phases.

3.9.1 Quantitative Data Analysis

Analysis of quantitative data was done using the Statistical Package for Social Sciences (SPSS v.25) software. The software enabled the calculation of frequencies and percentages, as well as the performance of chi-square tests to examine the associations between socio-demographic characteristics and knowledge, attitudes, and practices (KAPs) related to schistosomiasis. A significance level of $p < 0.05$ was set to determine statistically significant associations.

To further understand the strength and direction of these associations, crammer's phi (ϕ), and gamma (γ) tests were employed. These tests are extended measures of chi-square and provided values ranging from -1 to +1. A phi or gamma value below 0.1 was considered weak, a value between 0.1 but below 0.3 was considered moderate, a value between 0.3 and 0.6 was considered moderately strong, and a value of 0.6 or above was considered very strong (Mehta & Patel, 1996).

3.9.2 Qualitative Data Analysis

For the analysis of qualitative data, three techniques, that is, thematic analysis, selection and ranking and matrix of score were utilised. The thematic analysis approach was utilised for the analysis of qualitative data in all the study objectives, while the latter techniques were employed for analysis of the most significant change stories in phase three objective five.

a. Thematic analysis

The data analysis process using the thematic analysis method followed a step-by-step approach (Braun & Clarke, 2006, 2013). In the first step for thematic analysis, all qualitative data collected were transcribed verbatim by the researcher with the assistance of a master's student. Transcriptions were then uploaded to Nvivo 12 software for further analysis. Also, it involved reading through the transcripts to become familiar with the data. This process helped the researcher to gain a comprehensive understanding of the content, context and nuances present in the data.

Next was coding frame development which was done abductively. This is where the coding frame is developed with information from both the data collection tools and data from participants. For the initial coding frame, I selected a sample of transcripts from the IDI, KII, FGD and MSC story transcripts, along with the respective guides. I then carefully read through these documents to identify phrases and words that held specific meanings related to the study objectives. These identified phrases and words served as the initial codes for the analysis. Using the developed coding frame, I then systematically coded the data by going through each transcript individually. This process involved assigning relevant codes to specific sections or excerpts of the data, ensuring that all data were appropriately categorised.

In the fourth step, themes and sub-themes were developed based on the coded data. Codes with similar meanings were grouped to form broader themes, aligning with the study objectives. Additionally, codes that did not align with any specific themes were considered stand-alone themes but also interconnected with other relevant themes. Throughout this phase, the themes and sub-themes were continuously reviewed, refined, and modified to accurately reflect the underlying data.

For the baseline studies of KAPs, lived experiences and health-seeking behaviour regarding schistosomiasis, the themes and sub-themes related to the level of knowledge, attitude and practices as well as opinions and perspectives of schistosomiasis. Also, pre-experience perceptions, symptoms

experienced by individuals, actions taken, as well as challenges and coping mechanisms as well as factors for health-seeking were identified. Meanwhile for the phase two study on the dissemination of baseline study findings, co-design and implementation of the intervention, a list of socio-cultural risk factors associated with the disease in the study area was identified. Furthermore, the messages and channels used to disseminate schistosomiasis information to the communities formed some of the themes and sub-themes.

For study objective five on participatory evaluation of the CS approach, the identified themes and sub-themes related to the community's experiences with the intervention, perceptions of the community-led approach to behaviour change before the project, citizen scientists' selection and training, views on snail sampling and reporting, awareness-raising campaigns, and participation in training and community engagement. Additionally, themes and sub-themes regarding community experiences and perceptions of the CS approach included fidelity acceptability, appropriateness, reach and coverage, recruitment, and participation, as well as perceptions of barriers and challenges.

In the fifth step, themes were defined and analysed clearly and concisely, aligning them with the study objectives. I examined the relationships between different themes, ensuring that they formed coherent narratives that encapsulated the broader meaning of the study. Finally, I wrote the results section, incorporating verbatim quotes from the data to support and substantiate the findings. Following this systematic approach, allowed for a rigorous and comprehensive exploration of the data, resulting in meaningful themes and sub-themes that addressed the different research objectives.

In the case of the KAP study in phase one, the findings from the quantitative and qualitative data analysis were presented and discussed concurrently to complement each other. The integration of both types of data allowed for a comprehensive exploration of the research topic and enhanced the understanding of schistosomiasis-related knowledge, attitudes, and practices. This approach facilitated a detailed

interpretation of the results, providing a nuanced understanding of the research problem and its implications.

b. Selection and ranking

Using this method, the first level consisted of the selection and ranking of MSC stories by the first set of nine CSs and community leaders (Serdar, 2019). The first selection and ranking were conducted by 18 citizen scientists who participated in the exercise. A total of nine MSC stories were collected from the CSs, type-written by the researcher, and validated by the CSs themselves for accuracy, authenticity, and clarity. Subsequently, the stories were presented to 9 other CSs and 11 local leaders who had participated in the interventions for selection and ranking (Pramanik et al., 2012).

After giving the CSs the stories, the CSs were asked to read through and afterwards, select four stories that stood out according to their experiences and that of the community (Mathison, 2013). Before beginning the exercise, the researcher shared the domains of change with the CSs. They were then guided to identify stories that stood out most from the domains of change (Serdar, 2019). To make the exercise more interactive and participatory, the researcher divided the participants into four groups of two participants each, with the fourth group having three participants. After going through the stories and using the domains of change, each group selected four stories from the nine, that stood out the most (Sango & Dube, 2014).

All the groups recorded and presented their findings on a flip chat. A list of stories with the MSC from all the groups was compiled. Participants then went through the stories and ranked them according to the scores each one got. Participants were also asked to state reasons for the choice of the stories with the MSC. Using the scores, the first four stories with the highest number of scores for the MSC were picked (Change & Report, 2020).

The same exercise was repeated for community leaders the next day (Dahmen-Adkins & Peterson, 2019; The Challenge Initiative, 2019). All participants individually first read through the same stories. Afterwards, they went through the stories again, but this time with a participant reading through a particular paragraph to identify domains of change that in their opinion, stood most. Then they were asked to select by secret ballot, four stories they felt stood out most. Later, all stories selected by all participants were listed. The exercises concluded with the community leaders (CL) picking four stories that had the highest scores as stories that stood out most.

c. Matrix of scores.

A matrix of scores was the second phase in the selection of the MSC stories (Ho et al., 2015; Pramanik et al., 2012). Using the matrix of scores I identified two stories with the MSC (IFAD, 2002; Kitamura et al., 2020). To do this, I brought all the stories together, four from the CSs and another four from the local leaders giving eight stories. However, two of the four stories selected in each of the groups were the same, resulting in a total of six MSC stories at the first level.

To arrive at the two stories, a matrix of scores comprising five columns and eight rows was created (Serdar, 2019). Scores were used to aid in ranking and selection of stories that stood out most (Koroma et al., 2016). The first column was for MSC stories, the second and third were for CSs, and CLs, fourth and fifth were for total scores and ranks respectively. Meanwhile, seven rows were created; the first row was for MSC story number one, followed by the second row for selected MSC story number two in that order until the last row, with the seventh row being for totals (**Table below**).

Next, I assigned scores to each of the stories (Koroma et al., 2016). The highest score 4 was given to the story that stood out most by either the CSs or the CLs. The lowest score 1 was assigned to the story that ranked last by each of the two groups with a score of zero being assigned to a story that was not selected

by one of the groups. Adding up scores from both stories, the story that scored highest was ranked number 1, followed by the second highest until the last in that order (Brenner, 2010; Care, 2014). Based on the rankings of the scores, two stories that had the highest scores were selected (IFAD, 2002).

Table 5: Ranking of stories of MSC by the CS and CL

MSC stories	Scores by CS	Scores by CL	Total Score	Rank
1	4	0	4	3 rd
2	3	2	5	1 st
3	1	0	1	5 th
4	0	4	4	4 th
5	2	3	5	2 nd
8	0	1	1	6 th
TOTAL	10	10	20	

3.10 Ethical considerations

This study underwent three approval processes. Firstly, it was presented before the higher degree committees of the faculty of interdisciplinary studies (FIS) of MUST. Next, ethical approval was received from Mbarara University of Science and Technology (MUST) Research Ethical Committee (REC), reference number MUREC 1/7. Afterwards, the study was registered with the Uganda National Council for Science and Technology (UNCST) under reference number SS836ES. Clearance was also obtained from the district health officers of the two districts of Kagadi and Ntoroko. Before the start of the study, the project was

introduced to the sub-county and village leaders in the respective sub-counties and villages who later introduced the project team and the researchers to the community members.

In addition, written informed consent was obtained from study participants after following an informed consent process. For both the IDIs and the FGDs, the researcher obtained participants' both written and verbal consent for audio and video recording and photo taking. Participants' confidentiality was ensured by concealing their identities using serial numbers in place of names to act as identifiers during data collection. Interviews were conducted in private and quiet places within the comfort of participants' home settings, respecting their private matters and properties, assets, and materials. These included church buildings, schools and hospitals as well as tree shades far away from homes.

To conclude, this chapter looked at the methodology that was employed for conducting my PhD research project. Firstly, I presented the study area and setting, I later demonstrated the general research design with a vast array of designs for the different studies. I then highlighted the sample size and sampling procedure, data collection and analysis respectively. Finally, I demonstrated how the ethical approval processes were followed. The next chapter presents the analysis, presentation, results and discussion of the three baseline studies of KAP, lived experience and health-seeking behaviour regarding schistosomiasis.

CHAPTER FOUR: RESULTS AND DISCUSSION OF THE BASELINE STUDIES FOR KAPs, LIVED EXPERIENCE AND HEALTH-SEEKING BEHAVIOUR REGARDING SCHISTOSOMIASIS

4.1 Introduction

This chapter presents information on the analysis, presentation, and findings of the baseline studies. The results are structured into four major sections with section one focusing on the introduction to the chapter, followed by section two on findings and discussion of the KAPs regarding schistosomiasis. Section three of the chapter looks at findings and discussion on lived experience regarding schistosomiasis after which results and discussion on health-seeking regarding the disease are laid down in section four.

4.2. Assessing knowledge, attitude, and practices regarding schistosomiasis

4.2.1 Introduction

The main objective of this study was to determine the level of knowledge, attitude, and practices (KAPs) regarding schistosomiasis among endemic communities of western Uganda along Lake Albert and to understand the communities' views and perspectives regarding the disease. A mixed methods survey design employing both quantitative and qualitative approaches was employed across the whole research process. Quantitative data collected was analysed descriptively and inferentially using SPSS V.25 software. The thematic analytic method was used to analyse qualitative data (Braun & Clarke, 2006). Details of the findings are presented in the sections below.

4.2.2 Results

1. Socio-demographic characteristics of Respondents

In terms of the socio-demographics of the respondents, a total of 337 questionnaires were administered to respondents. The questionnaires were disproportionately divided into 18 villages, 10 parishes and five

sub-counties accordingly. However, nine questionnaires were removed from the total, of which two were not fully completed by respondents, while the other seven had inconsistencies and inaccuracies. This implies that only 326 fully completed were considered for analysis, resulting in a response rate of 96.7%.

The table below presents information on respondents' demographic characteristics.

According to the data, respondents were predominantly from Ndaiga (27.3%) and Mpeefu (23.9%) sub-counties. There was a slightly higher representation of females (52.1%) compared to males (47.9%). The age distribution showed that most of the respondents (47.5%) were in the category of 18-35 years old, while 42.9% were in the 36-55 years category. Regarding marital status, most respondents (58.6%) reported being in a monogamous marriage. In terms of education, 55.2% had attained a primary level of education. Additionally, more than half of the respondents had monthly incomes less than Ug. 100,000/= (equivalent to about USD 27.17)

Table 6: Sociodemographic characteristics of the respondents.

	Description	Frequency (N=326)	Percentage (%)
1	Sub-county of residence		
	Ndaiga	89	27.3
	Mpeefu	78	23.9
	Bwikara	61	18.7
	Kanara	61	18.7
	Kyaterekera	37	11.3
2	Sex		
	Female	170	52.1
	Male	156	47.9
3	Age		
	18-35	155	47.5
	36-55	140	42.9
	56-75	28	8.6
	76 and above	3	0.9
4	Marital status		
	Married (one partner)	191	58.6
	Single (not married)	60	18.4
	Married (> one partner)	44	13.5
	Separated	13	4.0

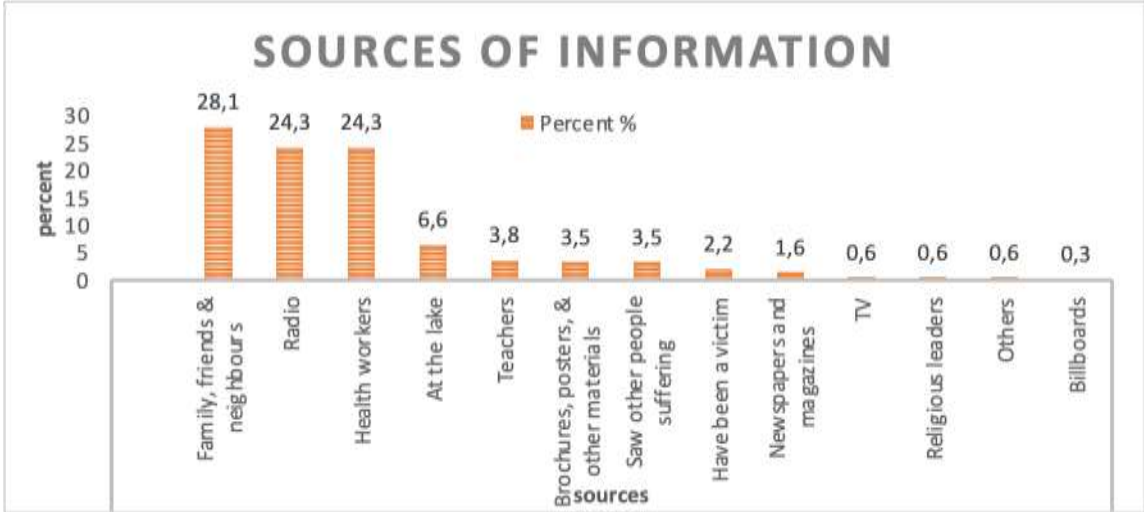
	Widowed	12	3.7
	Divorced	6	1.8
5	Household size		
	1-5	166	50.9
	6-10	130	39.9
	11-15	30	9.2
6	Educational level		
	Primary level	180	55.2
	Secondary level	77	23.6
	No formal education	60	18.4
	Tertiary level	6	1.8
	Post-graduate	3	0.9
7	Income levels		
	Less than 100,000	164	50.3
	100,000-199,999	54	16.6
	200,000-299,000	48	14.7
	300,000-399,000	25	7.7
	400,000-499,000	10	3.1
	500,000-599,000	9	2.8
	600,000 and above	16	4.9

Key: UGX-Uganda Shillings (1\$ = Ugx 3685/=); Source: Data from respondents, 2020

2. Knowledge regarding schistosomiasis

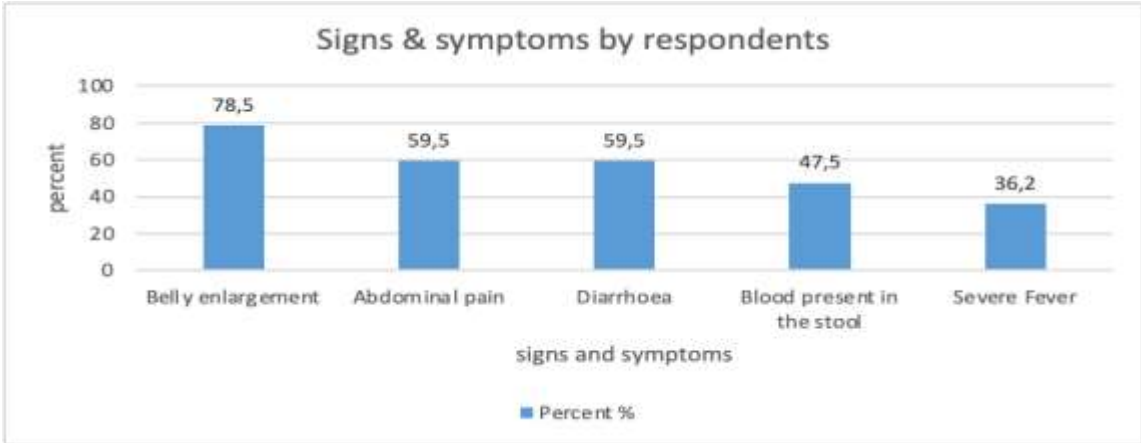
The finding revealed a high level of familiarity with schistosomiasis among respondents, with an overwhelming majority (98.5%) reporting having ever heard about the disease. Also, the graph below shows that the primary sources of information about schistosomiasis were identified as family, friends, and neighbours accounting for 28.1%. This suggests that informal networks play a significant role in disseminating information about the disease within the community.

Sources of information regarding schistosomiasis mentioned by respondents.



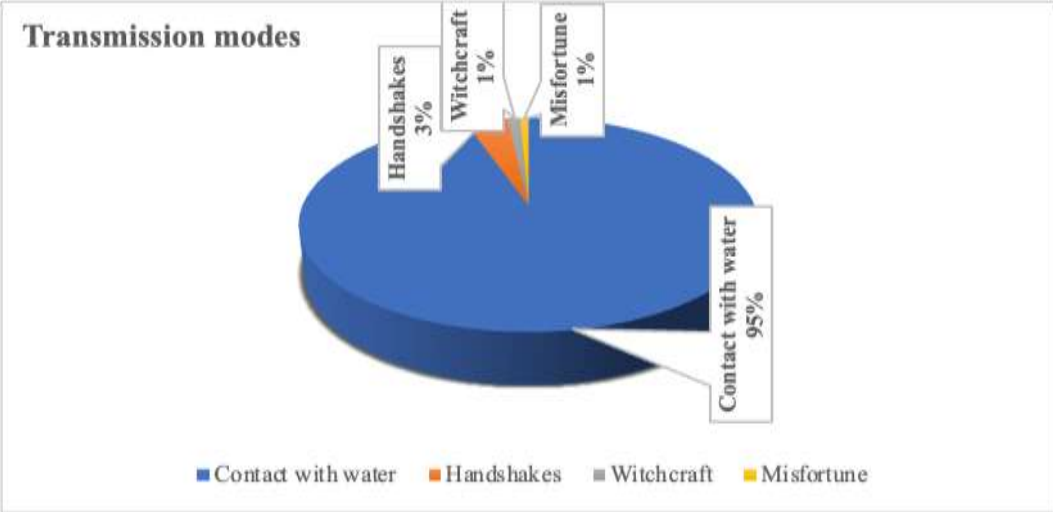
Source: Data from respondents, 2020

Signs and symptoms mentioned by respondents: When asked about the signs and symptoms associated with schistosomiasis. The most mentioned was belly enlargement (78.5%), followed by abdominal pain and diarrhoea both at 59.5%, suggesting that abdominal distention is perceived as a prominent manifestation of the disease within the community. Other signs such as blood in stool and severe fever were not as mentioned as the others.



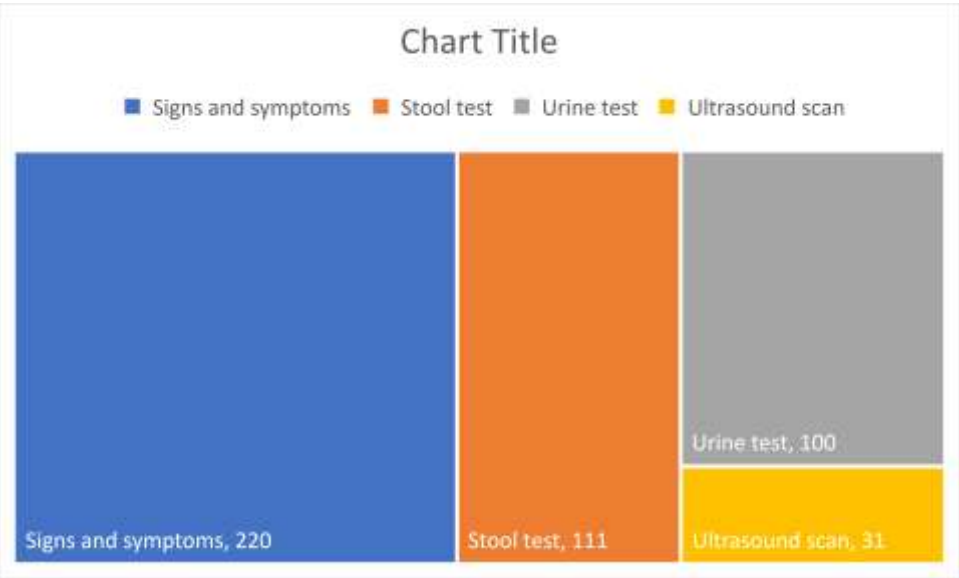
Source: Data from respondents, 2020

Transmission modes: Regarding transmission modes, a substantial majority of respondents (81.3%), identified contact with water as the primary mode. This highlights the recognition of waterborne transmission as a key factor in the spread of the disease among the respondents.



Source: Data from respondents, 2020

Diagnosis of schistosomiasis: Furthermore, 67.5% of the respondents believed that observing signs and symptoms was the easiest way to determine whether a person has schistosomiasis or not, implying reliance on visible indications to identify potential cases.



Source: Data from respondents, 2022

Preventive measures: Finally, in terms of preventive measures, the majority of respondents (75.8%), emphasized the importance of avoiding contact with contaminated water as the most mentioned strategy against schistosomiasis. This was followed by avoiding open defecation (51.2%) and open urination (48.8%). These results underscore the recognition of unsafe water as the primary source of infection, thereby highlighting the need to promote hygienic practices to reduce transmission. The findings also imply that observing good sanitation and personal hygiene is critical to preventing schistosomiasis.

Table 7: Respondents' knowledge of schistosomiasis preventive ways

Description	Frequency	Percent %
Prevention methods		
Avoid contact with water.	247	75.8
Avoid open defecation.	167	51.2
Avoid open urination.	159	48.8
Medication.	151	46.3
Avoid eating unwashed vegetables.	103	31.6

Source: Data from respondents, 2020

3. Socio-cultural factors associated with knowledge regarding schistosomiasis.

As illustrated in the table below, I used the Pearson Phi coefficient to test for the strength of association. Knowledge of signs and symptoms ($\phi=0.348$, $p=0.006$) and preventive ways ($\phi=0.529$, $p<0.001$) were found to be significantly associated with respondents' place of residence. Furthermore, education and knowledge of signs and symptoms ($\phi=0.553$, $p=0.004$) had significant associations. Finally, respondents' age and diagnosis ($\phi=0.357$, $p= 0.024$), and income and prevention ($\phi= 0.603$, $p= 0.005$) were also significantly associated.

Table 8: Association between respondents' socio-demographics and knowledge of schistosomiasis

Description	ϕ	p-value	ϕ	p-value	ϕ	p-value
	Residence		Gender		Age	
Signs and symptoms	.348	.006*	.113	.577	.21	.398
Transmission	.232	.398	.133	.187	.14	.601
Diagnosis	.256	.217	.093	.633	.35	.024*
Prevention	.529	.001*	.149	.723	.32	.191
					Income	
Signs and symptoms	.280	.432	.553	.004*	.41	.017*
Transmission	.171	.863	.230	.214	.21	.813
Diagnosis	.278	.272	.201	.580	.33	.104
Prevention	.336	.638	.298	.498	.60	.005*

Key * chi-square phi (ϕ) test of association was significant at $p < 0.05$.

Source: Data from respondents, 2020

Findings from both the quantitative and qualitative data regarding the sources of information about schistosomiasis agreed. Other sources of information regarding the disease mentioned by some of the FGD participants include schools, hospitals, and VHTs, as well as from the local council chairpersons, or physically seeing those with the signs and symptoms. However, some male and female FGD participants, especially those farther away from the lake, expressed ignorance of the disease, saying it was their first-time hearing about the disease. The participants noted:

"[Me] I had never heard about it. Today was my first time to hear of it. That's why I kept quiet because I thought you had come to teach us about it." **(Female FGD, Nyakatoj, Mpeefu Sub-County)**

"[As for me] I am a new resident in this area. Where I came from in Rwanda, I had never heard about bilharzia. I have spent 10 years in Uganda so far and this was my first time hearing it." **(Male FGD, Nyamarembo, Bwikara Sub-County)**

Others stated that they did not know the signs and symptoms of the disease, even though they saw people with such conditions. A male FGD participant from Songarao, Ndaiga, said:

"I had not yet known it well, I am just learning now but I have seen people with the symptoms mentioned by the people above." **Male FGD Songarao, Ndaiga Sub-County**

Local perspectives regarding schistosomiasis: Data from participants also revealed some local explanations regarding the signs and symptoms of schistosomiasis. The participants described a person with a swollen belly as a balloon or a swollen part of a guitar.

"They get swollen stomach and it becomes like a balloon; swollen cheeks; severe stomach; vomiting; swollen feet; when they are urinating, they urinate urine with blood" **Female FGD, Kayera village, Mpeefu Sub-county.**

According to the participants, a person with a swollen belly looks like a rich person even though they are not. Others said that due to a thin body, the person may look like someone suffering from HIV/AIDS.

"...hands become so thin as if they have HIV/AIDs, cracked lips, and legs." **IDI-VHT Nyamasoga village-Ndaiga Sub-county.**

Some people associate swollen bellies with being healthy and doing well economically, but in this context, being rich has a negative connotation. Similarly, in Uganda, some of the persons living with HIV/AIDS present with a thin body and rashes all over their skin, both of which are signs of schistosomiasis.

4. Attitudes Toward Schistosomiasis Prevention

From the table below, nearly all respondents in the sample (96.6%) agreed that schistosomiasis was a dangerous disease, and 94.2% stated that it is necessary to prevent the disease. 94.8% said that they would take personal responsibility to prevent it. Almost all respondents (98.4%) agreed that defecation in a latrine was very important for their health. About three-quarters of respondents (73.4%) also acknowledged that it was important to avoid risky contact with water.

Table 9 Respondents' attitudes regarding schistosomiasis

Responses	SD F %	MD F %	DA F %	NS F %	A F %	MA F %	SA F %	Total %
Bilharzia is a very dangerous disease.	1 (0.3%)	0 (0.0%)	2 (0.6%)	8 (2.5%)	28 (8.6%)	21 (6.5%)	265 (81.5%)	325 (100.0%)
It is necessary to prevent infection from bilharzia.	3 (0.9%)	0 (0.0%)	4 (1.2%)	12 (3.7%)	81 (24.9%)	22 (6.8%)	203 (62.5%)	325 (100.0%)
It is my responsibility to prevent infection from bilharzia.	3 (0.9%)	0 (0.0%)	1 (0.3%)	13 (4.0%)	95 (29.3%)	19 (5.9%)	193 (59.6%)	324 (100.0%)
It is important to avoid contact with water.	42 (13.0%)	4 (1.2%)	20 (6.2%)	20 (6.2%)	71 (21.9%)	11 (3.4%)	156 (48.1%)	324 (100.0%)
Defecating in the latrine is important for my health.	0 (0.0%)	0 (0.0%)	2 (0.6%)	3 (0.9%)	62 (19.1%)	17 (5.2%)	240 (74.1%)	324 (100.0%)

Key: SD-Strongly Disagree; MD-Moderately Disagree; DA-Disagree; NS-Not Sure; A-Agree; MA-Moderately Agree & SA-Strongly Agree, F-Frequency

Source: Data from respondents, 2020

5. Socio-cultural factors associated with attitudes toward schistosomiasis

The table below presents findings from the analysis that was done using the gamma coefficient (γ), to measure the strength and direction of association between socio-demographic variables and attributes of attitude. I found a significantly weak negative association between the age ($\gamma = -0.153$; $p=0.046$) of respondents and the perceived necessity of avoiding contact with water, but a strong negative association

between income ($\gamma = -0.308$; $p < 0.001$) of respondents, and the perceived necessity of avoiding contact with water as shown in. Place of residence, marital status, education, and gender did not show any significant association.

Table 10: Association between respondents' sociodemographic characteristics and attitude regarding schistosomiasis

Description	γ	p.val ue	γ	p.val ue	γ	p.val ue
	Residence		Gender		Age	
Schistosomiasis is a dangerous disease.	.054	.696	.054	.696	-.085	.477
It is necessary to prevent schistosomiasis.	-.054	.602	-.054	.600	-.097	.288
It is my responsibility to prevent schistosomiasis.	-.023	.824	-.023	.823	-.060	.508
It is necessary to avoid contact with water.	.077	.367	.077	.370	.153	.046*
Defecation in a latrine is important for prevention.	-.025	.829	-.025	.834	.023	.831
	Marital status		Education		Income	
Schistosomiasis is a dangerous disease.	-.057	.620	-.069	.539	-.173	.095
It is necessary to prevent schistosomiasis.	.134	.125	.068	.179	.077	.333
It is my responsibility to prevent schistosomiasis.	.162	.060	-.010	.907	.077	.339
It is important to avoid contact with water.	.075	.317	-.029	.687	.308	.001*
Defecation in a latrine is important for prevention.	.002	.983	.042	.682	.076	.117

Key * Chi-square gamma (γ) test of association was significant at $p < 0.05$

Source: Data from respondents, 2020

Normalizing the abnormal of schistosomiasis: Whereas there was no significant association between perceived severity and any socio-demographics, participants from the qualitative side had mixed views, with some agreeing that schistosomiasis is a dangerous disease, while others did not. Those in favour reasoned that the disease is dangerous because it kills, has no cure, and is also stigmatizing. For example, one FGD participant said:

“Yes, it is a dangerous disease because it kills. Once you get it, you can never get healed. It’s like having HIV. Most people who have suffered from it don’t live for long. Even people and friends run away from you once you have bilharzia, so madam, this disease is very dangerous.” **Male FGD,**

Nyamarengo Village - Bwika Sub County

Meanwhile, those who felt that it is not as dangerous as other diseases, such as Ebola or HIV/AIDS, argued that it can be prevented, it is curable, and if infected, one can live with it for a long time. They said other diseases can be treated in the hospital setting, thus indicating some knowledge of and trust in biomedical health care.

“At least bilharzia because it is a curable disease in the area, but Ebola, and AIDS are curable diseases in the area, but it is only when you get the treatment from the government.” **IDI LCI**

Kitebere Village - Ndaiga Sub County

Interestingly, both those who felt that schistosomiasis is dangerous and those who disagreed had similar reasons such as “kill” and “not kill,” “cure” and “no cure,” and liken it to having HIV/AIDS and not having. Furthermore, those who said it was dangerous still felt it was something they could live with because there was nothing they could do about it.

Water is our life; we cannot avoid it: Although quantitative findings revealed that avoiding contact with water is important, the qualitative side seems to suggest otherwise. For instance, some FGD participants

reasoned that water is everything to them and that it is the resource from which they derive their livelihoods, including fishing and fish mongering, drinking, bathing, swimming, washing items, and other activities. This view was held by men and women, especially from the lake communities as seen in the submissions by these FGD participants below:

“It is very difficult to prevent ourselves from entering into the water, yet that is the only way through which we do survive in the area.” **Male FGD, Nyamasoga Village - Ndaiga Sub County**

“No, I don’t think it is possible to stop going to the water. All of us here are fishmongers; if you tell me to stop going to the lake, then I wouldn’t have what to eat the next day. We can try other measures, like not drinking the lake water and maybe defecating there, but we depend on the lake.” **Male FGD, Ntoroko East B Village - Kanara Town Council**

In addition, whereas quantitative data revealed that defecating in a latrine is important for schistosomiasis prevention, qualitative data showed that avoiding open defecation is difficult. The male participants especially justified defecating in the lake arguing that they spend most of their time on the lake when fishing—sometimes even for a month—and therefore cannot come on land so they have to defecate in the lake. Some, however, prefer to defecate outside in an open space.

R4: “Most of the men in this community are fishmongers. They can spend close to even a month on [the] water. The lake has no latrine.” **Female FGD, Nyamasoga Village - Ndaiga Sub County**

6. Water, sanitation, and hygiene practices (WASH) Involving Schistosomiasis

The majority of the respondents used lake (46.3%) or pond (23.1%) water for various purposes, including drinking (85.3%) and washing clothes (79.1%). More than one-third (34.6%) of the respondents visit water sources either twice, ten times or more in a day, whereas 22.3% come into contact with water at least

three times a day. At least 44 (13.6%) of the respondents do not have latrine facilities and thus choose to defecate in bushes, in open places, or near the water (**Table**).

Table 11: Respondents' practices regarding schistosomiasis

Description	Frequency	Percent (%)
Common sources of water (255)		
Lake	118	46.3
Pond	59	23.1
River	34	13.3
Stream	27	10.6
A developed well	17	6.7
Common uses of water (N=1221)		
Drinking	278	85.3
Washing clothes	258	79.1
Bathing	174	53.3
Washing utensils and dishes	129	39.6
Taking animals to drink	109	33.4
Fishing	98	30.1
Swimming	90	27.6
Washing vegetables	85	26.1
Frequency of contact with water (323)		
Thrice a day	72	22.3
Twice a day	56	17.3
10+ times/ uncountable	56	17.3

Five times a day	40	12.4
Four times a day	30	9.3
Not sure	28	8.7
Once a day	24	7.4
6-9 times	15	4.6
Do not get into contact with water.	2	0.6
Presence of latrine facility (N=323)		
No	44	13.6
Yes	279	86.4
Open defecation (N=64)		
In the bush	40	62.5
I don't remember.	11	17.2
In an open place	6	9.4
In the water	5	7.8
Near the water	2	3.1

Source: Data from respondents, 2020

7. Socio-cultural factors associated with risky WASH practices regarding schistosomiasis

According to the table below, findings from the bivariate analysis, using the Pearsons phi coefficient test, revealed a significant positive association between place of residence and the commonly used sources of water ($\phi=1.111$; $p<0.001$), frequency in the use of water ($\phi =.578$; $p<0.001$), and open defecation (ϕ

=.644; $p < 0.001$) respectively. Marital status also showed a significant positive association with commonly used sources of water ($\phi = .432$; $p = 0.012$) and frequency of the use of water ($\phi = .451$; $p = 0.021$). Finally, this study found a significant association between education and common water-related activities ($\phi = .505$, $p = 0.012$) and between income and common water-related activities ($\phi = .439$; $p = 0.012$) respectively. Gender and age did not show any significant association with the practices regarding WASH.

Table 12: Association between respondents' socio-demographics and practices regarding schistosomiasis

Description	ϕ	p.value	ϕ	p.value	ϕ	p.value
	Residence		Gender		Age	
Commonly used source of water	1.11	.001*	.098	.876	.248	.486
Common water-related activities	.267	.085	.118	.365	.160	.510
Frequency of use of water	.578	.001*	.189	.164	.196	.976
Open defecation types	.644	.001*	.337	.108	.414	.508
	Marital status		Education		Income	
Commonly used source of water	.432	.012*	.253	.790	.375	.308
Common water-related activities	.312	.171	.505	.012*	.439	.012*
Frequency of use of water	.451	.021*	.359	.125	.372	.577
Open defecation types	.613	.262	.511	.392	.623	.227

Key * Chi-square Phi (ϕ) test of association was significant at $p < 0.05$.

Source: Data from respondents, 2020

Data from both the quantitative and qualitative methods seemed to produce similar findings regarding risky water practices. For instance, the women especially from the lakeside complained that they do not have access to safe and clean water, which forces them to resort to the use of water from the lake. Meanwhile, those further away from the lake, said they mostly use boreholes and ponds as their sources

of water. Regarding gender and usage, some FGD participants said that the men mostly use lake water for fishing purposes, whereas the women mostly use it for domestic-related purposes as seen below:

R1: "This lake that you see here is the only source of water we have." R2: "We used to have a borehole, but [it] got spoilt, so we all go to the lake." R3: "I see men fishing, others buying fish from the fishermen." R4: "Me, I wash from the lake." R5: "Me, I bathe from the lake, aaarh, no we bath[e] at night when it's dark and there are no people." R1: "I have seen other people washing their clothes and utensils from the lake." **Female FGD, Nyamasoga Village - Ndaiga Sub County**

R1: "Men do fish in the lake." R2: "Women sell fish." R3: "Women wash clothes and utensils from the lake." R4: "Men bathe and swim in the lake." R5: "Women fetch water to use at home." R5: "Women collect firewood near the lake." R6: "Women sell alcohol." **Female FGD, Songarao Village - Ndaiga Sub County**

Furthermore, although 86.4% of respondents who answered the questionnaire reported having latrines, most participants from the qualitative side especially those around the lake, explained that the lack of latrines is a major problem they face. As a result, they resorted to defecating in the lake, bushes, or open spaces.

R5: "But even for women, they defecate in the bush, but the faeces end up in the lake. Even when some are bathing in the lake, they defecate in the lake." R6: "Others defecate in polythene 'kavera' (polythene bags) and throw it behind people's houses or compounds. We are doing badly, madam."

Female FGD, Nyamasoga Village - Ndaiga Sub County

Other reasons for open defecation mentioned by the participants include a lack of space for construction due to a dense population, difficulties with constructing latrines due to poor soil (mostly the clay soil type is at the lakeside), and a high water table as the following participants mentioned:

“As you can see, we live close to the lake, so if you dig a latrine, the water comes from deep below and break[s] it down; that’s why we have latrines far from the homes.” **Male FGD, Ntoroko East B**

- Kanara Town Council

Other participants also said that;

“We have some people who are just renting the place, and they find it difficult to construct the latrine. You find some other people who came from the top of the hills; they came to do fishing for two to three days and move out, and they do not see any reason [why] constructing the latrine is difficult.” **Male FGD, Nyamasoga Village - Ndaiga Sub County**

8. Myths and misconceptions regarding schistosomiasis

As illustrated in the table below, findings from the qualitative data revealed some myths and misconceptions of knowledge, attitudes, and practices regarding schistosomiasis as presented below.

Table 13 Summary of myths and misconceptions surrounding schistosomiasis in western Uganda.

Themes	Sub-themes	Myths and misconceptions
Knowledge	Transmission/cause	<ul style="list-style-type: none"> • Being dirty causes infection. • Eating cold and contaminated food can cause infection. • Not washing hands when eating food can cause a person to get the disease. • Gassing from the inside of the water can cause a person to become infected.
Practices	Contact with water	<ul style="list-style-type: none"> • Have used the lake water for a long time without any health problems. • Water from deep inside the lake is clean and safe from diseases. • Water in the very early morning has no germs. • Lake water tastes sweeter than water from either a borehole or water purifier (water guard).
	Open defecation	<ul style="list-style-type: none"> • Good for catching a larger number of fish. • Latrine defecation compromises fish caught. • Used to defecate in a bush than in a latrine

Participants noted that being dirty, gassing in the water, eating cold and contaminated food, and not washing one's hands were some of the ways that can transmit the parasite according to some respondents. Similarly, some FGD participants also seem to agree as one of them said:

"When you play in the water and gas in it, you can get bilarlivos (schistosomiasis)." **Female FGD, Ntoroko East B - Kanara Town Council**

A few male FGD participants, especially those along the lakeshore, also argued that they had used lake water for a long time without having any problems and therefore saw no reason to stop using it. One FGD participant had this to say:

"For us, we stay next to the lake we have used water from the lake for a long time. We use the water for bathing, and drinking if we go fishing so we have no problem. If you have the money you buy if not you take the un-boiled one. "Polo pe dhano weng otiye malaika" (literally meaning, we should not expect everybody to use clean water)" **(Male FGD, Songarao Village - Ndaiga Sub County)**

Moreover, some of the men and women explained that fetching water from the middle of the lake or very early in the morning is okay because no germs are present in that spot or during those hours of the day, respectively. A few other participants reasoned that the lake water tasted sweeter and better than water from other sources, like a borehole or water guard (purifier). One of the male participants from Songarao said:

"But you know when you are staying in the water and you fetch the water directly in the middle of the water. The reason why some of us do not even boil water and you find that the faeces are being carried away by the running water directly into the Lakes." **(Male FGD, Songarao Village - Ndaiga Sub County)**

Participants also said they prefer to defecate in the water because the faeces act as bait for catching large numbers of fish. To them, defecating in a latrine will compromise their fish catch, and this is why they do not want to use a latrine:

“The fishermen here believe that if you go to the latrine you don’t catch a lot of fish. You would rather defecate in the lake. Defecating in the lake helps them get a lot of fish.” **Female FGD,**

Kitebere Village - Ndaiga Sub County

The above myths and misconceptions were mostly held among those who stay along the shore of the lake compared with those from the hillside. Similarly, both men and women hold a similar view, although mostly the men view faeces as acting as bait.

4.2.3 Discussion

In this section, I present a discussion of results from baseline studies on knowledge, attitude, and practices, regarding schistosomiasis. The main objective of the KAP study was to determine the level of KAPs regarding schistosomiasis and to explore the community's views and perspectives regarding the same. The findings of this study together with those from lived experiences and health-seeking behaviour were then used to guide the development and implementation of contextualised behaviour change interventions to try and bring down prevalence by changing the communities’ behaviour.

1. Knowledge regarding schistosomiasis

Community knowledge of a particular disease is critical to taking up preventive measures. Persistent infections and re-infections have been linked to limited knowledge of the disease. I, therefore, set out to ascertain the community’s level of knowledge. My conceptualisation of knowledge was whether: individuals had heard of the disease, their sources of information, and their understanding of it, including their knowledge of the signs and symptoms, transmission modes, diagnosis and preventions. A higher

percentage of respondents' answers to this in the affirmative would mean that the respondents know about schistosomiasis, while the reverse would be true for a lower percentage.

Findings from the data analysed reveal that most respondents had heard of schistosomiasis, and knew of the signs and symptoms, its transmission modes and preventive measures. The study further reveals that respondents from the lakeshore had higher levels of knowledge of signs and symptoms and preventive ways than those farther away. The adequate knowledge of the disease could also be attributed to the recent countrywide health education campaigns by the Ministry of Health, Uganda between 2017 and 2018 (Adriko, 2017a).

However, it is not clear why findings from the current study contrast with those of Exum and colleagues which revealed that only about two-thirds (61.8%) of respondents had heard of schistosomiasis (Exum et al., 2019). Furthermore, findings from the current study differ from the one conducted along Lake Victoria on the Ugandan side, which showed limited knowledge of transmission routes (Kabatereine et al., 2014). A higher knowledge level of the disease especially among respondents from the lake sides could be attributed to the fact the study area at the lakeside has a significant prevalence and morbidity of schistosomiasis leading the community to pay greater attention to the disease.

In addition, the results from the current study show that respondents with higher income levels were more knowledgeable about the signs/symptoms and prevention compared with those with lower incomes. Furthermore, educated respondents had more knowledge of the signs and symptoms than the less educated ones. Lastly, my study revealed more adequate knowledge of the diagnosis of the disease among older respondents than among the younger ones. The knowledge variation attributed to income is probably because, with more income, a person is likely to have more access to different sources of information regarding schistosomiasis. The aspect of education might be partly explained by the fact that people with higher education can better read communication messages that are prepared and passed in

English. Regarding age, it might be that with increasing age, the chances increase that people or their close relatives have experienced the disease itself, so they can tell through the signs and symptoms.

The current study also provides an interesting insight into the community's local perspectives regarding signs and symptoms. For instance, when a person presents with a swollen belly, people disguise it under names such as "balloon" and "guitar." The person is also labelled as being "rich" because the swollen belly makes the person look like a rich person and yet, in a real sense, they are not. Failure to understand these local descriptions may lead to the stigmatisation and discrimination of the victims, thereby impeding prevention and control efforts. In addition, it may create a knowledge gap regarding the disease. These findings provide an interesting insight regarding the disease, which is crucial for the effective implementation of any intervention.

2. Attitudes regarding schistosomiasis prevention

People's attitudes can be influenced by how much knowledge they have of the subject which in turn can influence their actions and behaviours. Similarly, a person's knowledge of schistosomiasis can influence their attitudes towards the disease and preventive measures as well as actual preventive practices. That is why in this study, I set out to find out the community's attitudes regarding the disease. The attitude was measured in terms of participants' views of the disease as dangerous, whether they think it is important to take preventive measures, and whose responsibility it is for prevention.

Also, it is important and necessary to avoid contact with contaminated water, open defecation and open urination among others. A seven-point Likert scale measure was used to determine respondents' attitudes. A positive attitude was ascertained if respondents scored at least more than half of the positive

sides, while below would imply a negative attitude. Meanwhile, from the qualitative side, participants were asked to share their views and opinions on the same with reasons behind their thoughts.

Findings from both the quantitative and qualitative sides revealed that generally, schistosomiasis is perceived to be a dangerous disease. The main reasons for the disease severity are long-lasting negative effects and stigma. Indeed, studies have shown that chronic schistosomiasis may induce stunting and impair cognitive development, in addition to anaemia liver complications, and other negative effects (Gryseels et al., 2006). Similarly, in other studies, like in Cameroon, Kenya, and some parts of Uganda, they found that the community perceived schistosomiasis to be a dangerous disease (Folefac et al., 2018; Kibira et al., 2019; Musuva et al., 2014b). However, qualitative data from the current study also revealed that some people think it is not as dangerous as other diseases such as HIV/AIDS and Ebola. It is possible that those who have not had any experience of schistosomiasis or stay far away from where it is highly prevalent, tend not to bother much about it. The variations in perceptions about disease severity could also explain differences in views, opinions, and behaviours of the community regarding preventive measures. It could explain some of the myths and misconceptions regarding the disease and their behaviours as well. For example, some people who experience the disease are normalizing it, they accept it as a fact because they see no way of avoiding it, as they depend on the water.

This study also established that although generally, the communities acknowledged that avoiding contact with contaminated water is considered to be an important preventive measure, participants, especially from the lakeside, argued that it was difficult to do so. The study further revealed that the older a person is, the less likely they will think it is necessary to avoid contact with lake water and vice versa. Likewise, respondents with higher incomes were less likely to think that it is necessary to avoid contact with lake water compared to those with low incomes. This could be because the lake is where these participants obtain their living from. Furthermore, it could be that older people have had various experiences with the

disease and therefore may tend to normalize the abnormality of the disease as they feel there is nothing to do about it. But it could also be that lack of access to clean and safe water sources, coupled with low income and less education, forces these participants to rely on unclean ones such as lakes, rivers, ponds, and streams. These are some of the issues that are likely to impede any prevention effort.

Additionally, the study found that although it is important to defecate in latrines, participants said it is not possible to avoid defecating in the water because they spend most of their time on the lake. A KAP study along the Lake Victoria region of Uganda (Kabatereine et al., 2014) and a systematic review of KAP regarding schistosomiasis in Uganda (Muhumuza, 2017), also found that it was not possible to avoid contact with the water since it is linked to the community's livelihoods. Providing clean and safe water sources and increasing latrine coverage to the community would therefore be important interventions.

3. Water, sanitation, and hygiene (WASH) practices involving schistosomiasis

Risky practices regarding water, sanitation and hygiene have been found to significantly influence schistosomiasis infection (Sacolo et al., 2018). Communities especially those along lakes, rivers and ponds are susceptible to disease infection due to their constant contact with such water sources. Also, open defecation, attributed to low latrine coverage or its lack, has been reported by other studies to be an influencing factor for disease infection (Sacolo-Gwebu et al., 2019). Similarly, this study reported the use of water from the lake and ponds for different purposes coupled with open defecation.

The study found that those who reside along the lake mostly use lake water as their main source, as frequently as possible in a day and they practice open defecation more than those living farther away. The use of lake water was justified due to the lack of clean and safe sources of water. In addition, the failure to boil lake water was said to be due to a lack of wood fuel (scarce firewood). The continuous use of unclean water is likely to increase the risk of infection, thereby inhibiting prevention efforts. Findings

from this study confirm other studies done in western Tigray-Ethiopia, Brazil and Namibia which also found that water-related activities, such as swimming, bathing, washing, and fishing, are common community practices that pose a serious risk of schistosomiasis infection (Calasans et al., 2018; Gebreyohannis et al., 2018; Mupakeleni et al., 2017).

The current study also found that those with high incomes tend to use less lake water for drinking and washing purposes compared to those who have low incomes. This could be because, with more income, they can avoid contact with the lake and use clean water from taps or boreholes, buy protective gear such as gumboots and gloves, and water purifiers and also be able to construct latrines. Equally, respondents with a higher level of education were less likely to use lake water for drinking and washing purposes than those with no or low levels of education. This could be because those with higher levels know the benefits of taking preventive measures. Indeed, previous studies have also indicated that the higher one's income the less likely one will engage in risky water practices. Likewise, those with a higher level of education tend to practice good preventive measures (Calasans et al., 2018).

Furthermore, just like the findings on knowledge and attitude, this study did not find any difference in gender and risky WASH practices. That is, both male and female participants mentioned similar activities that take place at different water sources. Qualitatively, however, participants said that the women mostly fetch water for drinking, and they also use it for cleaning fish, washing clothes and utensils, and bathing. Meanwhile, the men use it for fishing, bathing, and swimming, among other tasks. This again highlights the added value of including qualitative approaches in KAP surveys. More attention will be paid to the follow-up study to understand these conflicting results. My findings do agree though, with another mixed-methods study conducted in Mayuge district in eastern Uganda that also showed that although quantitatively, there was no significant difference between the genders in infection, qualitatively, the adult women did most of the water contact compared to their male counterparts (Trienekens et al., 2020).

A deliberate effort to provide clean and safe water sources coupled with a comprehensive community sensitization that takes into consideration variations in gender, marital status, income, and education could go a long way in yielding positive outcomes.

The study also established that although quantitatively most of the respondents (86.4%) reported having adequate latrine coverage, qualitative findings seemed to suggest otherwise. It is not clear how this difference comes about, but possibly it may be that the FGD participants might have reinforced each other. But it should also be noted that having a latrine does not necessarily mean using it. The FGD participants, especially from the lakeside, also expressed that the lack of latrine facilities remains one of the biggest challenges they face. This could explain why open defecation, especially along the lake, is still a common practice. An intervention that is specifically aimed at addressing the problem of a lack of latrines, as well as problems with space and construction materials especially at the lakeside, would yield more tangible results. The findings confirm the common practices that have been reported in other studies conducted along Lake Victoria—from the Ugandan, Kenyan, and Tanzanian sides, as well as other parts of Africa (Dawaki et al., 2015; Exum et al., 2019; Munisi et al., 2017; Takeuchi et al., 2019).

4. Myths and misconceptions regarding schistosomiasis

Certain beliefs held by people about a disease whether its signs and symptoms, transmission modes or diagnosis and prevention can negatively impact their attitudes and subsequent preventive actions. Risky practices related to water and sanitation as well as negative attitudes toward preventive measures for schistosomiasis prevention and control are sometimes driven by community myths and misconceptions (Maseko et al., 2018). Equally in this study, myths and misconceptions that the community holds, such as a belief in witchcraft, shaking hands (touching the hands of a person suffering from schistosomiasis), misfortune, eating cold food, houseflies, and gassing in waters as causes of infection, were reported.

Additionally, the use of lake waters, especially among communities along the lakeshore, and defecating in the water to produce bait for catching more fish are some of the misconceptions reported. The finding is supported by a previous study in Uganda on the Lake Victoria islands which also revealed some misconceptions, although they did not specify them (Kabatereine et al., 2014). Meanwhile, in the Kano state of Nigeria, it was established that eating salty or sour foods and sharing latrines are said to be the cause of schistosomiasis (Dawaki et al., 2015). As can be seen from the above, myths and misconceptions differ from place to place, and their explanations also vary. Therefore, there is a need to understand the different myths and misconceptions, as well as to design programs aimed at unpacking and debunking them in their contexts for any tangible outcomes.

4.2.3. Conclusion

To conclude, the above findings have demonstrated that the communities had sufficient knowledge and a positive attitude towards schistosomiasis. In particular, the study demonstrated the community's strong knowledge of signs and symptoms, transmission modes and preventive ways, with a slightly moderate knowledge of the diagnosis. Furthermore, the findings indicated that generally, the community perceives the disease as dangerous, especially those along the lake shores, even though they had no means of avoiding contact with the lake. That is, the will is there, but the means are not there.

Also, open defecation seems to be attributed to the challenge of construction, coupled with migration, and myths surrounding defecation in the lake. Lastly, the lack of access to clean and safe water seems to be a license for the community to continue engaging with the lake, even though they could try and do something about it. The feeling that they cannot do anything about their situation even worsens the already debilitating scenario. Some studies have also demonstrated that adequate knowledge and a

positive attitude alone may not necessarily translate into good practice. This means that a holistic approach to addressing WASH factors is key to finding lasting solutions.

4.3 Gaining insight into the lived experiences of schistosomiasis by individuals in western Uganda.

4.3.1 Introduction

This part of the PhD research investigated the lived experiences of schistosomiasis focusing on its signs and symptoms, challenges, and coping mechanisms by individuals of Kagadi and Ntoroko districts of western Uganda along Lake Albert. The main aim of the study was to try and dig deep into what people think before getting schistosomiasis, how they experience and perceive the signs and symptoms, and the reactions and perceptions of people around them, including challenges, actions taken and coping mechanisms. It also looked at the perceptions of such individuals after having suffered from the disease. This was important because it allowed me to ascertain what goes around in the everyday lives of the people infected, and how such are perceived and reacted upon by communities. The findings helped to unpack a broad range of the problems of schistosomiasis that had not been adequately documented by previous research.

4.3.2 Results

Findings relate to participants' socio-demographics and key themes that include schistosomiasis pre-experience perceptions, signs and symptoms experienced and the participants' feelings and opinions of the same. Other themes presented were the reaction of significant others, challenges faced, and coping mechanisms as well as the perceptions after the illness experience.

1. Socio-demographics of participants

A total of 77 out of 110 individuals all of whom had experienced the disease, responded to the study giving a 70% response rate. The main reasons for the other individuals not participating in the study included being in the garden and the lake carrying out fishing. Nearly 60% (46) of the participants were males, and over half of 42 (54.5%) were aged between 20 and 40 years. The majority 54 (70.1%) were married whereas most of them 36 (46.8%) were engaged in fishing and fish mongering, 15 (19.5%) were casual labourers also at the lending sites and 12 (15.6%) were farmers.

2. Pre-experience perceptions and experience of signs and symptoms regarding schistosomiasis

From the data analysed, three sub-themes emerged; those who take the disease as serious, those who do not take it to be serious and are therefore, not bothered about it, and lastly, those who are scared and worried about the disease, even though it is not clear if they take it to be serious. People who have not suffered from schistosomiasis have different perceptions of the disease. A significant portion of participants believed that bilharzia is a serious disease. This view was more strongly held by male participants in the individual interviews than the FGDs. This perceived seriousness was mainly based on observation and information from significant others, although they do not know much about it. Such participants noted that:

"...yes, I used to know it was serious because your stomach would swell and if you spend a long time with a swollen stomach it bursts" (Male IDI-6, Mpeefu Sub-County).

"R; Of course, I knew it was serious because I had seen people suffering from it" Male IDI-11 Ndaiga Sub-County).

Other categories of participants not only took it to be serious, but they were scared and worried about the disease as well. This was especially from what they heard about the disease and what they saw their fellow community members going through. Worry and scare were mainly attributed to swollen bellies, one of the signs and symptoms that appear to the individuals. Some of the participants who were both male and females stated that,

“I used to get scared and think it was a serious disease because people’s stomachs were big and they expressed difficulty in breathing” (Male IDI-5, Mpeefu Sub-County).

“I was scared of the disease; I would see people’s stomachs grow very big. Sometimes I would think it wasn’t a serious disease and that was why I didn’t swallow tablets when they were given to me by the government” (Female IDI-21, Kanara Town Council).

Still, a few other participants thought it was not a dangerous disease even after being advised by their relatives more than once. Not hearing about the disease or hearing from certain sources contributed to the perceived lack of seriousness by such participants. The participants, who were both males and females and from both study sites, also did not bother about it even when they saw or heard that some people died of it. Some of the participants shared:

“I had seen people who had it at the lake but I never thought it was that serious. It, however, started killing the young kids that didn’t get treatment” (Male IDI-2, Kyaterekera Sub-County).

“R; I didn’t think it was a serious disease because I had never seen anyone suffering from it but only heard stories from my parents and peers (Female IDI-17 Kanara Town Council).

3. Signs and symptoms experienced, and feelings, opinions and reactions by significant others

Signs and symptoms experienced. The participants reported experiencing a wide range of symptoms related to Schistosomiasis these included headaches, fever, loss in weight, diarrhoea, stomach grumbling,

loss of appetite, skin rashes, loss of hair, passing blood in stool, stomach pain, swollen belly and feet. For example, one participant described his experience as follows:

"I started experiencing stomach pain, my legs started swelling, I lost weight, became weak and could no longer do any work. What made me know it was bilharzia was when I failed to walk and my joints were not working well" (Mixed gender FGD-2 Kanara Town Council).

Another participant shared:

"I had a swollen stomach, passing blood in the stool, body weakness, pain in the leg and eating little yet the stomach was increasing. So, what made me conclude was the continuous stomach grumbling, then I rushed to the toilet and had diarrhoea and also body weakness. One time they gave me the PZQ is when I knew I had it, because of the reactions that were exactly the way we were taught" (Mixed gender FGD-2 Kanara Town Council).

4. Feelings and opinions about symptom experience and reactions of significant others

Regarding feelings and opinions about signs and symptoms experienced, three sub-themes emerged, which are, linking signs and symptoms directly to the disease, associating it with other diseases that present with similar signs and symptoms, and thirdly worries and denials.

Schistosomiasis-related feelings and opinions: A significant proportion of participants thought that the signs and symptoms they were experiencing were related to schistosomiasis. The participants' experience of symptoms like a swollen belly or passing blood in stool, made them suspect to be suffering from bilharzia. Confirmation from hospital tests and the effectiveness of prescribed medication further solidified these perceptions.

"When I was defecating blood, I suspected it could be bilharzia, then I went to Mr Kaseru's hospital, he tested it and found bilharzia, he gave me the drug and I took, after some three months, I again got the ones distributed by VHT I also took" (IDI-26, Ndaiga Sub-county)

"R5. What made me conclude that it's bilharzia was the stomach pain and swelling because they used to tell me about it. R6. I came to know it is bilharzia because of the loose stool" (Mixed gender FGD-7 Ndaiga Sub-county)

Non-schistosomiasis-related feelings and opinions: The majority of the participants initially thought they were suffering from a different disease like malaria or worms. Some even considered the possibility of having HIV or being bewitched, indicating a lack of awareness about the symptoms of schistosomiasis.

"I first thought I had worms but when the symptoms persisted and increased then I knew it was something different" (IDI-13, Ndaiga Sub-county).

Also, one other participant said,

"R1. I first thought it was malaria so I quickly thought of buying malaria tablets because it all started with fever in the evenings" (Male FGD-1, Kanara Town Council)

Worries and denials: Fear and worry, particularly about dying, were common feelings among participants due to the severe and persistent nature of the symptoms. Some participants refused to believe they had bilharzia, often because of preconceptions that the disease is common in children or that they were too old to contract it. Denial was solidified by the misconception that schistosomiasis only affects children and so, some adults do not accept they can get it.

"I had the worry that I would die, but when I got the drugs, I got some changes and I regained my confidence" (IDI-25, Kyaterekera Sub-county).

“People said I had bilharzia but I refused to believe it. I never thought I would get such a disease as it commonly affects children, but not old people like me” (IDI-1 Bwikara Sub-county)

Reactions by significant others: From the data analysed, different people perceived those who experience schistosomiasis signs and symptoms differently and therefore, reacted to them differently depending on various factors. Some people expressed emotional and social support, others negatively labelled the sufferers, while others experienced domestic violence from their spouses.

Social and emotional support. A significant portion of participants said they received social and emotional support in various ways. Support from significant others ranged from providing physical help, such as taking the participants to the hospital and preparing their meals, to offering emotional support and encouragement. This included advising them to take prescribed medication and not to worry about what others might say.

“R; I got a good friend who encouraged me and told me not to mind what people say and accept the results we get from the hospital. He even escorted my mum to the hospital for my treatment” (IDI-10, Ndaida Sub-county).

Ways in which the significant others provided social support include;

“R1. My children, brothers and sisters used to take care of me and provide for me, they took me to the hospital, counselled me, and gave me drinks and food as well” (Female FGD-3, Kanara Town Council)

Still, other respondents indicated receiving sympathy and empathy from close relatives and friends as well as parents and spouses. On empathy, the participants reported that their families, friends, and communities generally felt pity for them due to their suffering and inability to work or attend school.

“Many people felt pity for me because I wasn’t going to school and constantly came home to visit me” (IDI-7, Mpeefu Sub-county).

Sympathy and empathy were accompanied by phrases like;

“R6; my relatives felt sorry for me and wished me a quick recovery” (Male FGD-1 Kanara Town Council)

Labelling: Despite the support of some people, there were instances of negative labelling by other members of the community. Some participants were suspected to have HIV/AIDS or to have been bewitched, while others were ridiculed or teased. This resulted in some participants feeling stigmatized and avoiding people.

“People said a lot of things. Some said I had bilharzia, others said I was suffering from HIV” (IDI-12, Ndaiga Sub-county).

Also, different people have different labels against those who present with signs and symptoms as indicated by one of the participants below,

“Some people said I was suffering from HIV/AIDS, others said I had been bewitched, others said maybe it’s the poverty situation we are living in. My friends and family felt pity for me” (IDI-11, Ndaiga Sub-county).

Overall, however, HIV was the common disease that the community associates schistosomiasis signs and symptoms with.

“R4. Other people around me and my wife told me to check for HIV/AIDs because I looked so bad, I could be having HIV/AIDS and I went and did so” (Mixed gender FGD-4, Kyaterekera Sub-county).

Domestic and gender-based violence: Domestic violence increased in families, with the husband running away. The experiences of some participants depict instances where spouses blamed each other,

particularly husbands, who were quick to assign blame, often accusing their partners of having HIV. This accusation was typically driven by the persistence of symptoms, such as prolonged diarrhoea. The blame game not only increased emotional distress for the afflicted individual but also complicated their health-seeking journey. The accusations often led to heightened tensions within the household and a delay in obtaining the appropriate diagnosis and treatment.

“When I got schistosomiasis, my sister sent me ARV straight away to take. She said she heard that I had been suffering from HIV for a long time now. Then my husband came and told me to first go for testing. Everyone said I had HIV, including my husband. He is the one who called my sister that your sister has HIV because her diarrhoea has refused to go.” (Mixed gender FGD-5, Ndaiga Sub-county).

5. Challenges and coping mechanisms

Challenges faced: The findings reveal a significant level of social, psychological, and economic challenges experienced by individuals suffering from Bilharzia. This is primarily due to the stigma associated with the disease, often leading to isolation, loss of social networks, and other socio-economic impacts.

Stigma, self-pity, isolation and loneliness: Participants experienced significant stigma due to their disease condition. Misconceptions, such as associating Bilharzia with HIV/AIDs, were common, leading to social exclusion and abandonment. For instance, IDI-10 from Ndaiga Sub-County expressed,

"My Dad denied me and left me with my mum claiming that I had HIV/AIDs. Stress was too much for me. All my friends and neighbours said I had HIV AIDs and people would tease me about the thinning body weight and concluded that my neighbours had bewitched me."

In the same vein, participants from Kanara Town Council had this to say;

"My neighbours ran away from me and started saying I would infect their children. My wife also left me and went to the neighbouring district with my children. She found the perfect excuse to leave me"(IDI-15, Kanara Town Council)

In the same vein, some participants experienced internalised stigma expressed in the form of self-hatred and the wish to die. This form of stigma was mainly experienced by those who had reached an advanced stage of illness experience whereby they had big swollen bellies and passed blood in stool. As IDI-2 from Kyaterekera Sub-county stated,

"I hated myself so much that I wished I could die because I was too good for nothing and couldn't do anything for myself."

The stigma and misconceptions around Bilharzia often led to isolation and loneliness. As indicated by IDI-22 from Kanara Town Council, family members and relatives failed to offer support, thereby exacerbating feelings of isolation. The participant said:

"The problem with me is that I didn't grow up with my parents and they didn't take care of me, yet even up to now they are present. My relatives would also not bother. My father is well off and stays in Kagadi at Kyaterekera and my mother is in Fort Portal. So, I became lonely" (IDI-22, Kanara Town Council)

Relatedly, the loss of the workforce and dissipation by loved ones furthered the situations of loneliness. Also, the fear and stigma associated with Bilharzia led friends and acquaintances to distance themselves from the infected individuals. This was apparent in both the lake shores and the uphill side stated as below:

"I couldn't work because I was very weak; my wife left me and felt dizzy and dehydrated." (IDI-15, Kanara Town Council).

Loss of potency: Still other participants said the disease also impacted their sexual health and performance, leading to additional stress and strain. It appears though that the loss of libido could have been attributed to too much stress occasioned by the loss of business and not the disease itself. For instance, IDI-2 from Kyaterekera Sub-county reported a loss of libido due to Bilharzia and goes ahead to mention other challenges. In his own words, he said in the quote below.

“I lost libido and couldn’t perform in bed. I also lost my business because like that season I didn't sell or plant anything, my wife also fell sick so I lacked someone to care for me, I lost many friends, and I became poor to even afford to buy the drugs” (IDI-2 Kyaterekera Sub-county)

Loss of household labour: Due to the debilitating symptoms of Bilharzia, participants were unable to engage in their normal work routines, leading to economic hardship. IDI-3 from Kyaterekera Sub-county stated,

“During that time when I was sick, I was so weak that I couldn’t even work. My business died; all the planting season passed when I hadn’t planted a thing because I was sick.” (IDI-3, Kyaterekera Sub-county)

Some participants experienced job loss due to their inability to work full-time as a result of their illness. These were mainly from lakeshore participants like Ndaiga Sub- County who expressed that, reduced working hours in the lake led to decreased income.

Coping mechanisms: This theme looks at how participants dealt with their circumstances, spanning from symptoms experienced, reactions from significant others, and challenges faced. Sub-themes under this include taking action for treatment from different sources (extensively addressed by objective three), adopting preventive measures, seeking social support, and finding solace by engaging in different

activities and interacting with different people. This section presents findings on the last two, as the first sub-theme of actions taken is covered in detail in 5.3 under objective three in the subsequent section.

Adopting preventive measures: A few participants said they adopted various preventive measures to cope with their situation. These included avoiding using lake water, switching to tap or borehole water, and adopting healthier eating habits, such as consuming more vitamins. Participants attributed their actions to listening to the messages from their close relatives and friends. A participant said,

“I left drinking lake water and resorted only to taking tap or borehole water. I started eating only vitamins now, and that is why I feel fine, though am not sure if I have it or not.” (IDI-22, Kanara Town Council).

“I also followed rules of not going to the water, following the right ways of eating.” (IDI-24, Kanara Town Council).

Finding solace: Some participants had a strong view about seeking solace in certain activities such as drinking alcohol, watching TV and listening to the radio. Some participants turned to alcohol, specifically 'waragi', to cope with stomach upset.

“When I got the stomach, I was encouraged to drink ‘waragi’ (alcohol) to reduce the stomach upset” (IDI-6, Mpeefu Sub-county).

Some participants used leisure activities such as listening to music on the radio, watching football, or talking to friends to distract themselves and cope with their situation.

“I listened to music on my radio, watched football and even talked to my friends” (IDI-11, Ndaiga Sub-county).

6. Post-experience perceptions regarding schistosomiasis

This theme focuses on the perceptions and attitudes of individuals who have experienced bilharzia. After their experiences with the disease, their views vary, with some showing a positive shift towards better health behaviours while others continue to lack the proper knowledge, showing mixed or negative perceptions.

Positive perceptions: The majority of the individuals who have suffered from bilharzia tend to view it as a serious disease, leading them to adopt preventive measures and debunk myths after being told by those around them of the importance of taking preventive measures. They expressed awareness of the link between lake activities and the spread of the disease, and some even indicated behaviour changes such as boiling water before drinking and avoiding direct contact with lake water.

"I fear the lake so much, I make sure I drink boiled water and I bathe borehole water...I don't go to the lake to fish anymore am just a casual labourer now"(IDI-15, Kanara Town Council).

"I had to construct all the necessary things to prevent infection like a toilet, bathroom, drying rags and using boiled water. Up to now, I only feel slight stomach pain. For me, I feel bad about it and I would want to kill it straight away" (IDI-26, Ndaiga Sub-county)

Negative perceptions: Some individuals continue to engage in high-risk behaviours, such as drinking unboiled lake water, due to resource constraints or disregard for health advice. Other participants held the misconception that lake water when added to a water purifier does not taste good.

"I don't boil drinking water I just drink straight from the lake. You see us here it's a struggle to get firewood and the charcoal is very expensive that's why I drink water from the lake." (IDI-14, Ndaiga Sub-county)

“R6. For me, I know the disease is bad but I just drink lake water, I don’t like water guards. R1. Let us say the truth, some people don’t like water guards, they say it is not nice for them.” (Mixed gender FGD-5, Ndaiga Sub-county)

4.3.3 Discussion

This section discusses these findings given key themes such as the schistosomiasis pre-experience perception, experiences of schistosomiasis-related signs and symptoms and individuals’ feelings and opinions towards the signs and symptoms, the reaction by significant others, challenges faced, coping mechanisms and post-experience perceptions as presented below.

1. Pre-experience perceptions

Regarding pre-experience perceptions, my current finding reveals that some individuals are usually worried, scared, sad/ and fearful about the disease. Such emotional expressions were tied to observing others going through it or hearing it from social networks. It appears therefore that individuals carry such expressions to construct their lived experiences of the disease when it strikes them because of the way they perceive it. The finding of this study aligns with the Common Sense Model (CSM) of illness representations which suggests that individuals form emotional representations of illness that can significantly affect their health behaviour (Leventhal, 1984) and the subsequent actions required (Susan, 2008).

The emotional distress associated with schistosomiasis highlights the need for psychological support in managing the disease. Healthcare service provision should therefore go beyond simply giving praziquantel drugs to include addressing these emotional responses in treatment plans and focusing not only on treating physical symptoms but also on mitigating the psychological distress associated with the disease (Folkman & Greer, 2000).

Directly opposite to the above finding is the fact that some people are not bothered with certain diseases if they haven't experienced them even if they hear about or observe others going through the illness. This was revealed in this current study whereby, some participants did not perceive schistosomiasis as a serious illness, which could be due to a lack of exposure to severe cases or misinformation. This kind of perception is concerning as it may lead to delayed treatment seeking by such individuals and potential complications as reported by another study (Ruege, 2019). This calls for the need to dispel myths and misconceptions about the disease through awareness-raising campaigns. My finding resonates well with the emphasis on prioritising improving health literacy as an important determinant of health behaviour and outcomes in health interventions (Nutbeam, 2000).

2. Symptom experience and the subsequent feelings and opinions about them

Concerning symptom experience, my current study found that participants described various signs and symptoms they experienced due to schistosomiasis. These included but were not limited to abdominal pain, diarrhoea, blood in stool or urine, general malaise, and fatigue. The experience of these symptoms directly impacts individuals' quality of life, contributing to the physical and emotional burden of the disease. This underlines the need for early detection and treatment to manage symptoms and prevent complications. This symptom profile is consistent with the literature on schistosomiasis (Colley, Bustinduy, Secor, et al., 2014).

The study further revealed a significant gap in understanding and interpreting these symptoms among participants, pointing to the need for health education to ensure that individuals can recognize symptoms and seek appropriate care promptly. Importantly, it also suggests that interventions should go beyond merely treating the disease to managing symptoms and improving the quality of life of individuals. The findings are in line with the World Health Organization's (WHO) recommendation that interventions

should focus on people-centred care, which emphasizes understanding and addressing the needs and experiences of the affected communities (World Health Organisation, 2015).

Schistosomiasis-related and non-symptom-related feelings and opinions were expressed by a significant portion of participants in this study which demonstrated a varying degree of understanding about schistosomiasis, its causes, and its implications. The majority especially from the lake shores, attributed their symptoms to schistosomiasis, reflecting a degree of knowledge about the disease, consistent with prior research conducted in schistosomiasis-endemic areas (Anyolitho et al., 2022; Exum et al., 2019).

However, the disconnect between knowledge level and appropriate health-seeking behaviour was also observed, which could be because schistosomiasis treatment does not follow the healthcare service delivery system. The previous study of health-seeking among endemic communities in western Uganda also revealed challenges of delayed drugs, poor health system and other factors forcing individuals to seek medication from sources other than modern (Anyolitho et al., 2023).

In this study, I also found that some participants attributed their symptoms to causes other than schistosomiasis, reflecting possible misconceptions or lack of awareness about the disease. These findings echo another study that revealed that individuals often associate their symptoms with more commonly known diseases or non-medical factors (Mazigo et al., 2010). This underscores the importance of targeted health education to correct misconceptions and enhance understanding of schistosomiasis.

Other feelings reported in this study were worries, fears and denials by participants related to their symptoms and the potential long-term impacts of the disease. Such fears and anxieties are not uncommon among individuals suffering from chronic and neglected tropical diseases as reported by other studies (Molyneux et al., 2005). Molyneux and colleagues further note that such worries might also act as barriers to seeking help and adhering to treatment probably due to their stigmatising nature, suggesting the need for psychological support and counselling as part of disease management strategies.

Furthermore, denial or downplaying of symptoms was another theme that emerged from the interviews. This could be due to fear, stigma, or lack of understanding of the seriousness of the disease. It aligns with the findings of a study assessing community knowledge, attitude and practices regarding schistosomiasis in Kenya which also showed that denial is a common coping mechanism in the early stages of illness but can lead to delays in seeking treatment (Musuva et al., 2014a). This further calls for the need for constant health education to ensure that individuals not only understand the importance of early diagnosis and treatment but also do not stigmatise those who suffer from the disease.

3. Reactions by significant others

My current study reveals that individuals who experience schistosomiasis-related signs and symptoms receive social and emotional support of different kinds from different people. Mostly, however, it was extended to the participants by their families, friends, and communities are critical aspects of disease management. Under emotional support were also sympathy and empathy from significant others as mentioned by some study participants, reflecting the essential role emotional support plays in coping with illnesses. It's widely acknowledged in the literature that such support can enhance patients' psychological well-being and motivate them to engage in health-promoting behaviours, thereby potentially improving their health outcomes (Uchino, 2006).

Similarly, previous studies have shown that the presence of empathy and sympathy can contribute positively to health outcomes by reducing stress and promoting adherence to treatment plans (Holt-Lunstad et al., 2010). These findings further highlight the need for interventions to look at schistosomiasis not only as a medical problem requiring medical solutions. Rather a broader solution taking into consideration psycho-social and cultural factors could go a long way in addressing the problem.

This current study also found that labelling as a negative reaction was experienced by some participants. This is most likely due to knowledge gaps by such individuals, but it could also be due to social and cultural constructions of the disease according to existing societal norms. Some people tend to give negative labels to certain signs and symptoms thereby stigmatising such illnesses. This concept of labelling was explained by Goffman, one of the sociologists who argued that labelling could lead to individuals being defined by their condition, contributing to their isolation and the development of a spoiled identity (Goffman, 1963).

This is even worse if such labels are negative as in the case of schistosomiasis-related signs and symptoms. For example, a study in the Philippines indicated that schistosomiasis was considered to be shameful (Susan, 2008). Such experiences further underline the need for community awareness programs to combat stigma, labelling and discrimination against individuals suffering from schistosomiasis.

Finally, domestic and gender-based violence perpetuated against some individuals who experience such signs and symptoms was also reported by some participants in this study as one other negative reaction. The experiences of such individuals further demonstrate the dire social consequences of schistosomiasis disparaging the already adverse women's positions in society. The experiences reflect broader societal norms and attitudes towards people who go through such illness with the women and girls being particularly affected.

The above finding resonates with various studies on NTDs that linked gender-based violence to factors such as unequal power relations, failure to perform certain gender roles and gender inequality generally (Dijkstra et al., 2017; Tsegay et al., 2018; Wharton-Smith et al., 2019). Any control efforts should therefore put into consideration the social consequence of schistosomiasis on gender with a focus on women and girls as the most affected category.

4. Challenges faced and coping mechanisms

Challenges: Stigma emerged both as a reaction by significant other participants upon symptom experience, but also as a pervasive challenge faced by participants with schistosomiasis-related symptoms. This was evident in the narratives where neighbours distanced themselves and families, including spouses and children, deserted the affected individuals. The stigma extended to such a point that individuals suffering from schistosomiasis were denied access to communal facilities like toilets, indicating a deep level of marginalization and discrimination. Stigma and discrimination related to health conditions can have severe consequences on individuals' psychological and social well-being (Parker & Aggleton, 2003).

As Goffman puts it, that stigma can lead to a 'spoiled identity', where individuals feel devalued, shamed, and excluded from normal social interaction (Goffman, 1963). Schistosomiasis can lead to social isolation, abandonment, and further psychological distress for the affected individuals. Such discriminatory behaviour towards diseased individuals has been documented in numerous health conditions, including leprosy, tuberculosis, and mental health disorders, leading to serious social and health repercussions (Dijkstra et al., 2017; Hotez & Kamath, 2009; Tsegay et al., 2018). This suggests a critical need for interventions including community awareness and education campaigns aimed at reducing stigma.

Another important finding from my current study was the narrative of self-pity expressed by participants. This underscores the profound psychological impact of schistosomiasis. Phrases of self-hatred and wishes for death allude to a severe mental health crisis among these individuals. The level of self-pity expressed by the participants suggests that schistosomiasis may have effects beyond physical harm. That is, it affects individuals' mental health and emotional well-being thereby disrupting their lives in profound ways.

These sentiments, coupled with stigma, isolation, and the myriad of other social and economic impacts of the disease, can intensify feelings of hopelessness, potentially leading to severe depression or even

suicidal thoughts. Other studies have also shown that the physical burden of disease can significantly lead to feelings of self-pity, depressive symptoms, and even suicidal ideation (Khazem et al., 2017). This aspect of the disease further underscores the need for psychological counselling and mental health support to be integrated into schistosomiasis management plans.

Related to self-pity were also the feelings of isolation and loneliness experienced by individuals affected by schistosomiasis revealing a stark social consequence of the disease. The narrations of schistosomiasis illness experience reported by some participants in this study reveal a disturbing trend of being shunned by their families and community. This is distressing, given the fundamental role family plays in providing emotional, practical, and financial support in disease management. It's important to note that families are often the first point of contact for individuals suffering from illnesses, making their role crucial in early detection, seeking care, and ensuring treatment adherence.

The above finding is in agreement with other studies on stigmatized diseases such as HIV/AIDS, leprosy, and mental health conditions, where social isolation has been identified as a critical factor affecting the patient's health and well-being (Parker & Aggleton, 2003). Most often, however, MDA programs only focus on drug distribution without paying attention to illness conditions the communities are going through. Future interventions could consider integrating psycho-social support aspects in their programming.

Findings from the study also reveal a loss of potency by male participants. Participants' testimonies also illuminated an often-neglected aspect of schistosomiasis - its impact on sexual health. Reports of decreased libido and potency also raise concerns about the disease's implications on personal relationships and mental health. It is also possible that self-pity, isolation and loneliness could have contributed to the loss of potency thereby making some participants attribute it to schistosomiasis directly. This could also explain why some participants experienced gender-based violence. My finding

resonates with another study indicating that schistosomiasis, like other neglected tropical diseases, can have adverse effects on the sexual and reproductive health of the affected individuals, even though the study talks of women being the most affected (Hotez & Kamath, 2009).

As already noted above, the impact on sexual health may lead to strained marital relationships degenerating into violence, decreased self-esteem, and increased psychological stress, all of which can further deteriorate an individual's quality of life. It is clear from the findings that, interventions should address sexual health concerns in the management of schistosomiasis. This could include providing sexual health counselling, integrating sexual health education into disease awareness programs, and treating sexual health issues as part of comprehensive disease management.

The current study also reveals that schistosomiasis poses serious economic consequences in various forms such as loss of household labour and jobs. Participants reported an inability to work due to the disease's debilitating effects, leading to a significant decrease in income and labour for their households. From the findings, the economic burden of schistosomiasis extends beyond the individual, affecting entire households and sometimes the community at large. This is likely to be true because when the man as a breadwinner falls sick, he will not be able to provide for the family's basic needs. For example, the family may go hungry, and fail to pay for medication, fees, and other necessities. Likewise, the community may miss out on the social contribution of such an individual. Such diseases can also cripple productivity, pushing families deeper into poverty. This finding aligns with findings from a previous study that illustrated the severe socioeconomic impacts of neglected tropical diseases, including schistosomiasis on the affected communities (Onwujekwe et al., 2013).

The impact of schistosomiasis on productivity highlights the importance of integrating economic and social protection measures into intervention strategies. Such measures could include skills training in income-generating projects to help individuals transition into less physically demanding jobs. Addressing

the economic implications of schistosomiasis is vital for ensuring a holistic approach to disease management, enhancing affected individuals' quality of life and reducing the disease's overall societal cost.

Coping Mechanisms: Adopting preventive measures was reported in this study as a key coping strategy by individuals who suffer from schistosomiasis-related illnesses. This is possible because some individuals perceive such symptoms to be severe. Symptom severity usually attracts immediate actions. No wonder, the majority of participants reported that they took certain actions on such symptom experiences to restore their health to normalcy.

The adoption of preventive measures reflects an understanding among participants of the importance of proactive behaviour in managing and preventing schistosomiasis. This finding is in line with the Health Belief Model which posits that perceived susceptibility to and severity of disease are critical determinants of preventive health behaviours (Janz & Becker, 1984). Perceived symptom severity is influenced by community knowledge and awareness of the disease and its manifestations. This calls for continuous health education and sensitisation strategies that heighten awareness of the risks associated with schistosomiasis to incite preventive actions.

The last positive coping mechanism was watching TV by some of the individuals. Such participants mentioned ever resorting to watching television to relax their minds and manage stress, and isolation. The use of entertainment such as watching TV as a coping strategy indicates the potential role of positive distraction in managing stress and negative emotions associated with the disease. Positive distraction can be an effective coping strategy as it helps divert attention away from the stressor and provides a sense of relief (Lazarus & Folkman, 1984). Interventions could, therefore, consider setting up social and recreational activities as part of comprehensive care and social support not only for people living with

schistosomiasis but also as a way of distracting children away from playing in the contaminated water sources further minimising infection risks.

This study found drinking alcohol as one negative coping mechanism by some participants. Such participants reported using alcohol as a way of dealing with their stress, isolation, stigma and others. This kind of coping mechanism can be harmful to people who go through such illness conditions. Health education and sensitisation should encourage people to seek medication from biomedical sources if they suspect themselves to be suffering from schistosomiasis, rather than resorting to the use of alcohol as a solution.

The above finding reflects a wider trend in which substance use is often associated with attempts to self-medicate or escape from the psychological distress caused by illness (Davydow et al., 2015). Health education and sensitisation play a vital role in debunking such misconceptions about the use of alcohol as a self-medication strategy further broadening the scope of behaviour change interventions.

5. Post-experience perceptions.

This current study reports that participants who had a positive perception of their experience with schistosomiasis usually reported successful treatments or had implemented effective coping strategies. The effect is that they were likely to form psychological adaptations to their disease experience thereby deciding to adopt preventive practices. This could signify that the individuals had developed new understandings of themselves, others, and the world around them because of their struggle with their illness.

Furthermore, this may also indicate that these individuals have gained a better appreciation of life, showing resilience and the ability to utilize available resources to cope with their condition, on top of appreciating the fact that the disease is a dangerous one. This was also reported in another study which

stated that overcoming adversity, like serious illness, can often lead to positive psychological changes, a process referred to as posttraumatic growth (Tedeschi & Calhoun, 2004).

Recurrent infections and the associated physical and psychological burden can engender negative perceptions about the disease. Studies, including the one by (Naylor et al., 2015), have highlighted the cumulative impact of recurrent diseases on a patient's quality of life and mental health. Chronicity and recurrence of infections can cause a significant deterioration in physical health, reduce productivity, and impose mental stress due to the persistent fear of relapse. Hence, there's an urgent need for robust disease management and prevention strategies that address not just the immediate infection but also aim to prevent recurrent infections.

4.3.4 Conclusion

This section presented results and a discussion on the lived experience of schistosomiasis by individuals in western Uganda. From the data, findings show that schistosomiasis causes fear, sadness, denial and worry in individuals who have never suffered from or known it before. Also, social and emotional support is critical for those suffering from the disease. Finally, people who have suffered from schistosomiasis tend to have a positive attitude and actively engage in preventive practices compared to those who haven't. Considering the above, the disease not only impacts the physical well-being of those affected but also their emotional and mental health, their relationships, and their economic stability. The next section presents results and discussions on health-seeking behaviour by communities of Kagadi and Ntoroko districts regarding the disease.

4.4 Exploring health-seeking behaviour for treatment of schistosomiasis-related signs and symptoms by communities of western Uganda.

4.4.1 Introduction

Not only is it enough to understand the everyday experiences of individuals when they are suffering from schistosomiasis, but it is also important to know what actions they take when they find themselves in such situations, where they go and what informs their decisions. And this is what David Mechanic refers to as illness (health-seeking) behaviour. David defines it as “ways in which given symptoms may be differentially perceived, evaluated, and acted (or not acted) upon by different kinds of persons (Mechanic, 1961). In this fourth section of the chapter, I present the findings of objective three which explored the health-seeking behaviour regarding schistosomiasis especially in the absence of MDA. Specifically, the study 1) explored the various health services for the treatment of schistosomiasis-related signs and symptoms accessed, and 2) assessed the determinants of their health-seeking.

4.4.2 Results

Findings from the data analysed are presented below.

1. Socio-demographics of participants

A total of 263 individuals out of the initially estimated 295, participated in the study. Among this, a total of 251 adult community members were engaged in 28 FGD sessions distributed evenly by gender that is, 14 for males and another 14 for females across the five sub-countries. A total of 29 adult community members out of the 280 initially invited did not participate, with some declining while others were not present during the sessions. In addition, 12 individuals, including three health workers, two VHT members, and seven local leaders participated in the in-depth interviews. Of the total sample, 134 participants (50.95%) were males, while 129 (49.05%) were in the age range between 18 and 67 years.

2. Sources of healthcare services accessed by participants in the absence of the MDA program.

Drawing upon Kroeger's model of health-seeking (discussed in chapter two on review of relevant literature), the qualitative data analysed reveals that participants seek treatment for schistosomiasis-related illnesses signs and symptoms of different types from different sources. These sources include modern health services, traditional treatment options, and self-medication.

The findings further indicate that village health teams and local leaders serving as community volunteers, were the most frequently mentioned sources of seeking healthcare. This was followed by private clinics and drug shops, together with witch doctors and herbalists, government hospitals and health facilities, self-medication, healer shopping and prayers, with others not taking any action. The subsequent sections provide detailed explanations of these findings.

Community Volunteers (VHTs and Local Leaders): The VHTs and local leaders emerged as the primary source for PZQ treatment according to participants. Individuals said they usually seek treatment from VHTs and local leaders whenever they experience symptoms such as swollen bellies, blood in stool, vomiting, diarrhoea and fever. The participants expressed said they go to the VHTs because they believe the VHTs should be having the drug as they are responsible for distribution.

Moreover, participants said the VHTs have good knowledge about the disease, which enables them to effectively assess the community members seeking treatment. It is important to note that VHTs have access to the PZQ solely during the MDA program. Occasionally, surplus drug stocks remain after the MDA program, which the VHTs distribute to those in need. Furthermore, VHTs refer those who present with such related signs and symptoms to health facilities for better management. According to R 11,

“They first come to me because they know I always have tablets; after that, I examine the person to see if it's bilharzia, and if it's beyond me, I refer them to the health centre” (Male IDI 11, Kanara Town Council).

Private Healthcare Sources: Utilisation of private for-profit compared to not-for-profit healthcare facilities was identified by both male and female study participants as equally important. Financial resource availability was cited by such participants to be a major reason for their choice of for-profit private healthcare facilities. That is, such participants, argued that whenever they felt schistosomiasis-related signs and symptoms and had the money, then they would rather go to private for-profit healthcare facilities. Also, the participants reasoned that private for-profit healthcare facilities, usually have the drugs and are easily accessible to communities. Distance to existing government facilities forces them to seek treatment from private healthcare sources. The findings signify the importance of private for-profit facilities as a healthcare option for the communities in the treatment of schistosomiasis-related illnesses. This view was mainly held by participants along the lakeshores.

R10: Yes, I went to a clinic in the village here. The doctor first tested me, and later he told me I had bilharzia and gave me medicine. I don't know the name of the medicine. That's the doctor's job to know the medicine I need, and he gives me the medicine I need to heal. I spent close to 45,000 UGX (approx. 11.00 Euros then) on tests and medicine" (Female FGD 17, Nyamasoga, Ndaiga sub-county).

Traditional healthcare sources: Findings from the data analysed also reveal that traditional healthcare sources such as witch doctors and herbalists were relied upon by some of the community members. This was particularly so, for those community members that are found near the lake shores. Witch doctors are people who use spiritual powers by invoking the power of the spirits to explain illness. In the study, participants cited previous experiences with similar signs and symptoms, such as swollen belly and blood in stool as reasons for choosing these traditional sources of treatment. Next, perceived severity, ease of accessibility of witch doctors, and prevailing misconceptions regarding disease aetiology were the other

reasons provided. Such belief in traditional sources and their influence on decision-making regarding health-seeking for schistosomiasis treatment is something that should be taken seriously.

“R8: The first thing I think of is getting treatment, in my case, since I have an experience from the previous time when I fell sick or got any other signs I go for, Munganga (witch doctor), because I know it’s a dangerous disease and you can easily die of the disease like the bilharzia. R5: Some people may end up visiting witch doctors because of ignorance about the disease. However, some people think perhaps such a disease is a result of eating poison” (Male FGD-2, Ndaiga sub-county)

On the other hand, herbalists are those who employ different types of herbs derived from tree leaves, shrubs, roots and other botanical or animal components to prescribe medication. This was also mentioned by some participants living along the lakeshores. Herbs were reported to be used more for children than for adults with emergencies. The reasons provided for this choice were the limited availability of health facilities and the inability to identify the disease. Participants mentioned skin rashes, body itching, fever and headache as the common signs and symptoms of illnesses for which the herbs are used.

R3: You see, we go to the hospital when we are worse off. We treat the early signs with herbal medicine when they don’t work; that’s when we go to the hospital. We go for herbal medicine because we don’t have an option and we are poor. R4: But what happens here with children is, when they get sick, they give them herbs, and sometimes these herbs work. But if they don’t work, you now go to the hospital” (Female FGD 11, Bwikara sub-county).

Although generally, a significant proportion of participants acknowledged the importance of traditional sources of healthcare sources, some of the participants had distrust in these sources. Such participants contended that schistosomiasis cannot be treated by witch doctors or herbal remedies alone. Such sentiments were further compounded by the worry and concern about the negative effects of the traditional sources of healthcare treatments, which further highlights the gravity and severity attached to

the disease by some members of the community. The participants likened being infected with schistosomiasis to receiving a death sentence with no cure.

“R7: Suffering from bilharzia, and then you go to the witch doctor? You can’t go to the witch doctor when you have bilharzia. The witch doctors can’t treat it; they will ask you for money and not treat you . . . yes, for other diseases and things, but not bilharzia” (Female FGD 5, Ndaiga sub-county)

Government Hospitals and Health Facilities: Government hospitals and health facilities were primarily sought by a greater majority of participants but only when they started experiencing severe and acute signs and symptoms like swollen bellies and vomiting blood. On the other hand, participants mentioned that they visit health centres II, III, or IV for other signs and symptoms such as stomach pain and headaches because such conditions are perceived to be less severe compared to swollen bellies and vomiting blood. For instance, a female FGD participant shared her experience of the disease wherein, she had a swollen belly and had to go to the hospital and was given the drug after diagnosis:

“R10: Yes, I had it before, and even now I have it, as you can see my swollen belly. I had it in 2012, and I got treatment from the hospital. The drug—I don’t know its name—but it looks white” (Female FGD 18, Kanara Town Council).

Relatedly, a male participant said he sought medical attention at a health center III, after starting to feel unwell and stomach pain. He also expressed disappointment with the facility because he did not receive the medication as the facility did not have the drugs. In his own words, the participant said:

“R4: Two years ago, at the Health Centre III, they didn’t get the disease and therefore didn’t give me any drugs. I went because I was feeling unwell; I had stomach pain and thought I had it. So, I said I should first go and check” (Male IDI, Kanara Town Council, Ntoroko)

Self-Medication: Self-medication was another of the actions taken by a few participants. Such participants argued when faced with financial constraints, they opt to simply buy drugs and self-administer them temporarily as they plan the next step. Additionally, when experiencing mild signs and symptoms, or when the illness strikes during late hours when healthcare facilities may not be readily accessible, the participants indicated they just buy drugs from the drug shops or get herbals from nearby available sources. According to one of the participants, she said:

“If someone falls sick in the night, you just buy Panadol for pain relief and wait until morning. The next morning, if you still feel sick, you can go to the health centre to get tested” **(Female FGD 17, Ndaiga sub-county, Kagadi District).**

Healer shopping/pluralistic health-seeking and prayers: A significant proportion of participants said they adopt multiple sources of healthcare sources of treatment simultaneously. For instance, they can buy drugs from drug shops, go to clinics, and engage in prayers at the same time. Ease of accessibility to the sources and the distance to hospitals were reasons cited by the participants for such actions. In the case of prayer, participants described engaging in personal prayer or seeking assistance from pastors depending on the specific circumstances. Also, some people start by praying for their conditions and only turn to other sources if prayers do not bring the intended results. Contrary to the above, other participants said they start by seeking treatment from other sources and only resort to prayers after these sources fail or as a supplementary alternative. This view was supported by quotes from one of the female FGD participants (R10) from the uphill side.

“Yes, there are some sicknesses which do not require going to the health centre. Sometimes I go to the hospital; they take my sample and test and don’t find any disease, yet I am not feeling fine, so I go to the pastor, and they pray for me” **(Female FGD 21, Kyaterekera sub-county).**

Not taking any action at all: Not taking any action in the face of schistosomiasis-related signs and symptoms was also reported by some participants in this study. Such participants gave reasons for their decisions such as the perception that the symptoms were mild and therefore not warranting any action. Some of the signs and symptoms mentioned by the participants include head and stomach aches. Other reasons provided were frustration of not getting drugs in the hospitals and health facilities whenever they go for treatment, as well as the failure to conduct diagnostic tests whenever patients visit the facilities. This lack of action due to a perceived lack of severity is an indication that some community members do not seek any form of medication, highlighting possible adverse effects on the prevention and control of the disease. According to R7,

“The majority suffer in silence, especially if it’s mild—let’s say a simple headache or stomach-ache—it’s the minority that seeks medical care” (Male IDI, Ndaiga sub-county).

3. Determinants of health-seeking regarding schistosomiasis signs and symptoms

Participants provided reasons that influenced their health-seeking choices from the various sources mentioned above. In line with Kroeger’s model, the factors were categorised into different dimensions comprising predisposing or individual factors, disease or perceived disorder-related factors, health system factors, and community-related factors. These dimensions of determinants are presented in the following sections.

Predisposing or individual factors: According to Kroeger certain personal characteristics and beliefs influence people to seek treatment from different healthcare sources. Such characteristics include age, gender, education level, cultural beliefs, social networks, socio-economic status, and experiences with the

illness. In this study, key themes identified from the data included gender, geographical differences, socioeconomic status, and social networks.

Gender and health-seeking decision regarding schistosomiasis: From the data analysed, participants reported how the males' decision-making role as the head of the household is recognised. Such participants noted that regardless of the kind of illness, husbands have ultimate authority and power to determine when and where a woman and her children should seek treatment. Furthermore, culturally, men are expected to perform the role of taking care of the family, they head the family, and they are breadwinners, income earners and final decision-makers. For instance, whenever a woman starts experiencing any signs and symptoms related to schistosomiasis such as diarrhoea, abdominal pain, or vomiting, she is obliged to inform her husband about such a condition. Subsequently, the man is the one to decide the next course of action, that is, whether she should go to the hospital, buy drugs or visit a herbalist. Also, the man is the one to provide the money for expenses like transport and any other treatment-related costs. These views are supported by the observations in the quotes below:

R7: It is my husband who decides. R2: It is my husband, just him alone, who decides. R4: I report to my husband and then he is the one to decide. And if he says I go to the government hospital, I will go, and if they prescribe medications, I still ask for money from him. It is he who provides me with the money”
(Female FGD 15, Kisenyi B, Kanara Town Council).

Marital status, geographical differences and health-seeking regarding schistosomiasis: Participants' views of seeking decision-decisions varied across the different geographical areas and according to marital status. For instance, participants from the lakeshores said that health-seeking choices vary from couple to couple. Other participants said the wives make their decisions independently. From the data analysed,

this view was commonly held by divorced women or those whose spouses were irresponsible. This category of participants said they would simply make their own decisions whenever they begin experiencing any schistosomiasis-related signs and symptoms, regardless of whether they have money or not. Reliance on friends and other well-wishers was, however, reported to be another financial shock absorber for divorced or women with irresponsible spouses.

R6: Our husbands are different, and we are all treated differently; like me, my husband was a drunkard. He didn't care if I was sick or not. So, I had to take myself. R8: You see, most of us here don't have money. Even if my husband is around, we pass a book around for people to contribute for us—at least 1,000 UGX—so that I can go to the hospital” (Female FGD 17, Nyamasoga, Ndaiga sub-county).

Social Networks: Social networks were also said to be relied upon by some participants, for advice and guidance before deciding on where and when to seek treatment. Some of the networks include family members, relatives, and friends. Of these groups of people, the women were said to make decisions of either going to the hospital or seeing an herbalist after being advised by their fellow women, upon experiencing any signs and symptoms associated with schistosomiasis. This reliance on social connections for advice and guidance signifies a notable role of social networks in decision-making regarding health-seeking and other complex social phenomena in society.

Socioeconomic status: The health-seeking decision for treatment of schistosomiasis-related signs and symptoms was also said to be determined by participants' socioeconomic status, especially those residing on the uphill sides. Such participants highlighted that low income influences their health-seeking decisions and actions. That is, some of the participants seek treatment from traditional sources simply because they

do not have the money to go to private facilities where they expect to get the drugs and to be provided better healthcare services. In this case, herbal remedies are the ones commonly sought by such participants as an alternative accessible source. This view is supported by a quote from one of the participants who said:

“Here, because we are poor and there’s usually no money, you give the child herbal medicine first, and you only go to the hospital if the symptoms persist” (Female FGD 11, Nyamarengo, Bwika sub-county).

Disorders and related perception factors: Disorders and their perceptions were also highlighted by this study based on Kroeger’s model of health-seeking. Disorders refer to the specific manifestations of illness signs and symptoms, while perceptions consist of the diverse views and opinions held by individuals regarding the signs and symptoms. Both aspects are crucial in determining whether a person should seek treatment, and when and where. Based on the data analysed, subthemes generated included acute or chronic, and severe or trivial signs and symptoms. Other subthemes were the aetiology and type of disorder, the level of satisfaction with past treatment experiences the anticipated benefits of seeking treatment, any dissatisfaction with the services received, and the prevailing medication conditions, all of which are presented in detail below:

Acute or chronic and severe or trivial diseases: Participants said generally, they visit the hospital for signs and symptoms (e.g., vomiting blood) that they perceive to be acute. The decision to go to the hospital is further backed by other factors such as distance from the facility, cost of medication, and fear of drug reactions. For other symptoms (e.g., swollen bellies, blood in stool, rashes that are perceived to be chronic), people often normalize them. For some participants, the decision to seek treatment for

schistosomiasis-related signs and symptoms largely depends on whether such signs and symptoms are severe.

The participants particularly those from the lakeshores argued that where they felt certain illness conditions were trivial, there would be no need to seek medication. Moreover, the participants said they would not bother seeking medication if they did not have any problems with such conditions. Meanwhile, other participants went ahead to say that drugs are only taken when someone feels sick. In this case, therefore, such participants had negative opinions about treatment based on such thoughts as presented in a quote by one of the participants below:

“R1: I wasn’t feeling any pain or sickness, so I didn’t swallow them. My wife is the one who swallowed them; she’s the one who was complaining of stomach pain before. R5: I don’t have the disease” (Male FGD 1, Bwikara sub-county).

Another participant added that;

“R1. I have stayed here twenty-nine years now, but I have never got the drug. I even drink lake water without boiling and I have not had any problem” (Male FGD 19 Kanara Town Council).

Aetiology and Type of Disease: Perceived aetiology and type of disease as a determinant of health-seeking regarding schistosomiasis-related signs and symptoms, was another set of sub-themes identified in the study. Some participants preferred to seek medication from witch doctors as traditional sources. The participants said they make such decisions, especially in situations where they are unsure of the case and nature of the illness, that is whether was associated with schistosomiasis or not. Such participants added that in instances where they can identify the illness conditions as schistosomiasis-related, then they would visit either government hospitals or private healthcare facilities, depending on how severe the condition is. It should be noted that decision factors included level of knowledge of the signs and

symptoms, previous experience with the disease, alongside the severity as demonstrated in the quotes below:

“If I don’t know that it’s bilharzia, I would take them to the traditional healers. If it persists, I take them to the hospital” (Male IDI 7, Ndaiga sub-county).

Dissatisfaction with PZQ: Dissatisfaction with PZQ treatment was echoed by some of the participants, particularly, those residing along the lake shores. Such participants asserted that the drugs were not effective since they always fell sick again even after taking the drugs. Consideration should, however, be made to the fact that the PZQ drug is administered to all eligible individuals in endemic areas without doing any specific diagnosis. Instead, only the heights and ages of the eligible people are used to give the drugs. This is based on the fact that those who live in endemic settings, are assumed to be having the disease and therefore, should take the drug so that it can kill the germs. This way, it will be easy to combat the disease. However, treatment alone is not absolute control if individuals continue engaging in risky behaviours such as contact with contaminated water and open defecation. This belief that PZQ treatment is not effective was shared by participants mostly from along the lake shores as one of them was heard saying;

“The problem is that even the medicine that they give us doesn’t work and people still fall sick” (Female FGD 28, Ndaiga sub-county).

Dissatisfaction with healthcare workers: Connected to the community’s dissatisfaction with PZQ treatment was also discontent with healthcare workers, and the services provided at the facilities. As will be observed, some participants particularly those residing along the lakeshores reported poor service

delivery, extended waiting time, denial of services, and unwanted and unexplained referrals, more so, to distant healthcare facilities.

As voiced by the participants, the limited accessibility and availability of healthcare professionals at the health facilities was a big concern to the participants. They noted that whenever they go to the facilities, either they do not find the staff, or they are overwhelmed. This challenge is compounded by the fact that PZQ drug is still not captured under the healthcare system, a fact that is attributed to its lack of consideration by the government. This also explains why the drug is not provided for in the healthcare facilities apart from district, regional and national referral hospitals as supported in the following quotes from participants.

“R10: The nearest health facility is Health Centre II, but if you go there, the health assistants are never there. R: We don’t have doctors who can check for bilharzia in this village. They will refer you to Health Centre III or the referral hospital. But that’s a waste of time because the line is always long and there are no doctors to help” (Female FGD 28, Ndaiga sub-county)

Medical Conditions: The decision of whether to seek treatment for schistosomiasis-related signs and symptoms was also determined by the existence of certain medical conditions. This view is supported by quotes from one of the participants who said that;

“But they don’t give them to pregnant women. Last year I had taken them, and I was pregnant, but the chairman of this village followed me and took them back from me” (Female FGD 25, Mpeefu sub-county).

Health service–related factors: In line with Kroeger’s model, health service enabling factors play an important role in individuals’ health-seeking behaviours. However, in this study, I consider health service

factors and community factors and I present them separately. In this section, I present findings regarding health service-related factors. Sub-themes under this section comprise shortage of the drug, and of health workers, negative attitudes toward health workers, inadequate equipment, high medication costs, and prolonged waiting times attributed to the work overload.

Drug shortage/inadequate drugs: Participants from both the lakeshores, and uphill regions expressed concern over the issue of drug shortage and availability. A significant proportion of participants expressed dissatisfaction with government facilities, for their failure to provide drugs for schistosomiasis treatment. Participants attributed their decisions to seek treatment from private clinics and drug shops to the lack of PZQ drugs from the facilities. Meanwhile, other participants with financial challenges said they either visited traditional healthcare practitioners or refrained from taking any action at all.

“R8: But the hospital doesn’t have drugs; they give only one type of drug and send you to another hospital. The problem with government hospitals is that we don’t get drugs when we go to the hospital. But we would love to have the drugs brought here” (Female FGD 18, Kanara Town Council)

Shortage of healthcare workers: Another concern raised by participants was about the scarcity of healthcare workers particularly at the government hospitals and healthcare facilities of different levels. The participants cited experiences where they would go to health facilities but would encounter limited staff. Such experiences, participants narrated would force them to seek treatment from sources other than the government facilities. The absence of sufficient staff undermines the effectiveness and efficiency of healthcare service delivery, leading to further dissatisfaction by communities. Some of the participants had this to say;

“R1: We never find the doctors who test for bilharzia. Unlike HIV, where you can even be tested in a clinic, you can’t find doctors to test you for bilharzia. On top of that, we have few doctors, yet there are many patients. That means sitting the whole day to see a doctor. All the nearby clinics will refer you to the health centre III. R4: You see, even if you go all the way to Bwikara Health Centre, there’s no doctor to test for bilharzia” (Male FGD 1, Bwikara sub-county).

Negative attitudes of healthcare workers: Linked to the problem of shortage of healthcare workers were also their negative attitudes displayed towards clients/patients. This though was more pronounced in the government healthcare facilities and experienced more by the female members. Such participants cited scenarios where they felt mistreated or poorly attended to by the health workers. In some cases, staff ignore the patients or do not communicate with them during their encounters. According to the participants, such experiences further exacerbated the already alarming challenges faced by communities in seeking treatment for schistosomiasis-related signs and symptoms and other health-related issues from government facilities. The participants complained that whenever they visit the facilities, health workers do not properly attend to them as supported by the below quotes.

“R2: Even if you go to the health centre, they just look at you. I was once sick, but when I went there, they just looked at me. I was suffering from a headache. Then I went to the clinic and bought medicine” (Female FGD 21, Kyaterekera sub-county).

Waiting time: Not only did participants raise the concern of shortage of staff plus their negative attitude, but some of the participants also reported their dissatisfaction with services at the government facilities because of long waiting times. Such participants shared their experiences of enduring long prolonged waiting periods before being attended to by healthcare workers. Worse still, when the healthcare workers

come, they simply refer the patients to other higher-level facilities without giving any explanations for their decisions. Such encounters are what the participants mentioned would force them to seek treatment from sources other than the government. As intimated by one of the participants,

“On top of that, we have few doctors, yet there are many patients. That means sitting the whole day to see a doctor. All the nearby clinics will refer you to a health centre III” (Male FGD 1, Bwikara sub-county).

Views and concerns raised by FGD participants regarding the availability and adequacy of PZQ were confirmed and re-echoed by VHTs and local leaders as well. They corroborated the community’s perspective, emphasising that, the supply of PZQ drugs is often delayed, insufficient, and is primarily targeted towards school-going children, leaving out the adult community members and those children who are not in school. Such findings highlight the limitations and challenges associated with the distribution and accessibility of PZQ drugs, suggesting the need for a community-involved and community-led approach to MDA.

“R11: But right now, I don’t think there is bilharzia medicine because I got a case that I referred to the health in-charge, and he said there was no medicine he had to first call the district to get the medicine here” (Male IDI, Kanara Town Council).

High cost of medication: Connected to the above factor was also the prohibitive cost of treatment especially at the private for-profit facilities such as clinics and drug shops that discourage them from seeking treatment from such sources. Despite this challenge, some of the participants still go to such facilities since they believe they can get drugs and receive better service, though one needs to prepare with a good amount of money.

*“R9: We have clinics, but if you don’t have the money, you can’t go there. The clinics are for people with money. For testing, it’s usually 20,000 UGX (Approx 5.00 Euros then), and then for pregnant people, going to the scan is 10,000 UGX (Approx 2.00 Euros then). Then medicine can cost you roughly 20,000 UGX (Approximately 5 Euros then) depending on what you are suffering from. But if you are going to a clinic, you can prepare in total 50,000 UGX (Approx 12.50 Euros then)”***(Female FGD 28, Ndaiga sub-county).**

Lack of equipment for testing schistosomiasis: Lack of necessary equipment was also observed by participants to be a barrier to health-seeking from modern healthcare sources. Participants noted that the limited availability of diagnostic testing equipment within the health facilities hinders the ability of such facilities to do a diagnosis of schistosomiasis. This discourages some people from going to the facilities thinking they will not be diagnosed. This was supported by quotes from one of the participants,

“There is no machine to do that. Even if you go to the main hospital, you can’t find it” **(Male FGD 24, Mpeefu sub-county).**

Community-related factors: Community-related factors play a crucial role in influencing individuals’ health-seeking decisions which can either enable or hinder their access to modern healthcare sources. Although Kroeger had grouped this with health-service enabling factors, in this study, I acknowledge such factors and barriers generally. From the data analysed, sub-themes that emerged consist of the long distance between communities and health facilities, high transport costs, and poor and inaccessible roads. Also, long stay in the water and migration from one landing site to another. All these factors make it difficult for community members to access treatment from modern sources of healthcare. As a result, they resort to either private or traditional sources as alternatives. These factors shed light on the

complexities that individuals go through in trying to access treatment not only for schistosomiasis-related signs and symptoms but for other illnesses as well.

Long distance from facilities: One of the significant factors that hinder people from seeking treatment from modern sources mentioned by the participants was the long distance from home to health facilities. This factor was predominantly voiced by participants living along the lakeshores who lamented how they have to walk a long distance to the nearest facilities. They highlighted the tiring journey, that requires them to walk some hours to the facilities as expressed by one of the participants in the below quote:

“It’s a 7-hour walk from here to Ndaiga Health Centre, and if you start walking at 6 a.m., you can reach it by midday” (Female FGD 28, Ndaiga sub-county).

Poor and Inaccessible Roads: The poor and inaccessible road conditions were also cited by some participants to be another factor influencing health-seeking decisions by community members. Such participants noted that most roads in their communities were substandard and in most cases difficult to use. This becomes worse during rainy seasons because heavy rain causes additional damage to the roads. As such, it poses a risk to access to healthcare facilities for those who must seek treatment. One of the local leaders supported the community participants’ concerns noting that these challenges hinder communities’ ability to promptly access necessary treatment regarding schistosomiasis-related signs and symptoms.

“R6: I would ask the government to bring the services closer to us because we have some maternity women who cannot even move; for example, yesterday when I was going to the hospital, I found pregnant women climbing the hill. The health centre and main government hospital are far from this village” (Male IDI, Ndaiga sub-county).

High transport cost: A significant proportion of participants especially from along the lakeshores also cited the high transport costs charged by motorcycle owners to take them to the facilities. Participants acknowledged this was mainly attributed to the poor road conditions which not only consume a lot of time to reach the facilities but also mean that they are charged highly unnecessarily. Even for the water transport which would be a potential alternative for the lakeside communities, they are still charged highly making it equally difficult to seek treatment from the modern healthcare facilities.

“R4: Like, for my case, I go to the hospital because they have the machine for testing it, and it is just nearby. We use water transport (canoe), and it is near enough to our place for us to go to Ntoroko. We pay 10,000 shillings to and from” (Male FGD 4, Ndaiga sub-county)

Long stay in the lake: A few other participants particularly those residing near the lakeshores, also attributed their health-seeking choices to the nature of the fishing activities they carry out. They observed that some of them often move deep inside the lake waters to engage in fishing for a long period which sometimes extends up to a month. This prolonged stay in the lake hampers their ability to be physically present during the PZQ schedule and they end up missing the drugs. Yet according to the guidelines, these drugs are supposed to be given to eligible individuals when they are physically present so that their heights are measured for appropriate dosage administration. One of the participants highlighted this challenge in his own words;

“Yes, indeed, some people don’t get it because they are always in the water and doing some fishing activities; also, some are working and do miss the time of taking their drugs” (Male IDI, Ndiaga sub-county).

Migration from one landing site to another: Linked to a long stay in the lake waters, was also the challenge faced by individuals who move from landing site to landing site in search of optimal fishing grounds. This, participants reasoned poses a challenge to PZQ distribution especially where people come after the registers of eligible individuals have been compiled. Also, some people move away from their areas of registration to another area, where their names were not registered. As a result, the individuals end up missing the drugs despite their being at high risk of infections.

4.4.3 Discussion

Health-seeking behaviour regarding schistosomiasis treatment using PZQ MDA has been widely researched across the globe (Lothe et al., 2018; Reis et al., 2010). However, with social mobilisation, the likelihood of demand for PZQ increases. It is important to properly understand where people seek treatment and the factors that influence their health-seeking regarding the disease. Therefore, guided by Kroeger's model of health-seeking behaviour, I conducted a community-based qualitative study to explore the health-seeking behaviour of the endemic communities of Kagadi and Ntoroko Districts in Western Uganda, at a time when the routine MDA program had been skipped. This section presents a discussion of the study findings.

1. Sources of health-seeking by participants

This study found that individuals seek treatment for schistosomiasis-related signs and symptoms from various sources with the VHTs, ranking high, followed by government hospitals in emergent situations and private and traditional sources in other situations.

The VHTs were mentioned as the main source people seek treatment for schistosomiasis-related signs and symptoms. This is possible because VHTs are known by the communities for distributing PZQ during MDA and so, they are thought to always have the drug (Ssali et al., 2021). Sometimes, some stock remains

with the VHTs after the exercise and so they give it to those who ask for it. Most times, however, the drugs get finished during the MDA program. VHTs are also the first point of contact for those with signs and symptoms of the disease. Strengthening the community-based volunteer approach to drug distribution could go a long way in ensuring services are easily accessible, owned and managed by the communities for sustainability purposes. This could be achieved by increasing the number of VHTs, adequately facilitating them and giving them more powers to manage the MDA,

Results from the study further revealed that the absence of PZQ from the VHTs and government facilities forces communities to seek treatment from private facilities, while others go to traditional sources for mild conditions or other unexplainable ones. Seeking treatment from sources other than modern is likely to compromise the efforts to increase PZQ uptake.

Findings from the current study resonate well with a study in Eastern Uganda that also showed people seek health services from various sources for different reasons, with some of them going to traditional sources. Even though this was reported to be mainly due to a lack of knowledge of the disease and long distances from health facilities, but not drug absence (Adriko, Faust, et al., 2018; Muhumuza, Olsen, et al., 2013; Tuhebwe et al., 2015; Van et al., 2020).

2. Determinants of health-seeking by endemic communities along Lake Albert

Various factors influence the decisions that individuals make when they experience the disease's signs and symptoms. Based on Kroeger, such factors can be categorised into individual or predisposing, disorder and their perceptions, and health service enabling factors. However, in this study, I found that there was nothing such as health-service enabling. Instead, Kroger refers to health services either health service hindering factors or community-related factors.

Regarding individual factors, this part of the study found that gender and geographical differences among others determine the community's health-seeking behaviour regarding schistosomiasis signs and symptoms, especially in the absence of the MDA program. Results show that female community members often ask their spouses whether and where they should seek treatment for schistosomiasis-related signs and symptoms.

The above could be true because of the cultural beliefs that attribute decision-making to men in these communities. Understanding gender factors is crucial for planning, designing, and implementing treatment and awareness campaign programs because it facilitates the inclusion of both men and women. A similar study also revealed that gender norms contribute to women and children missing medication while fetching water, washing clothes and utensils and men fishing, even though the study focused on the MDA program only but not in its absence (Dalisay et al., 2022).

Furthermore, studies on other diseases instead linked women's lack of decision-making to the stigma associated with some of the diseases, shame, and discomfort, among others (Wharton-Smith et al., 2019). This could be possible because of the different perceptions and interpretations of various diseases. Those from along the shores tend to take swift action to go to the drug shops or visit witch doctors and consult herbalists more often than those from the uphill. This is possibly due to the lack of health facilities nearby and the fact that witch doctors and herbalists live within the communities.

Concerning disorder- and perception-related factors, this study found that for acute and severe signs and symptoms of schistosomiasis, people go to government hospitals. While those signs and symptoms perceived to be chronic and less severe are not acted upon. Meanwhile, lower health facilities, herbs, or witch doctors are turned to for conditions for which the cause and type of illness are not known. This is most likely due to the absence of drugs and poor health services, leaving the communities with no choice

but to try those alternative sources mentioned. But this could also be attributed to myths and misconceptions held by the communities regarding the disease.

Myths and misconceptions were reported by another study to be affecting MDA uptake (Sacolo et al., 2018). Other studies have also indicated that health-seeking from either modern or traditional sources is influenced by the perceived severity of signs and symptoms (Awino, 2016; Lothe et al., 2018; Van et al., 2020). This study also found that some participants like children below five years of age, pregnant women, and those breastfeeding were not accessing the MDA on medical grounds. For instance, women who are in their first trimesters of pregnancy or are breastfeeding, are often refrained from taking PZQ drugs for the safety of the unborn child or nursing infant. This confirms the WHO's guidelines which among others, discourage pregnant and breastfeeding women, children below 5 years of age, and individuals with certain underlying medical conditions, from taking PZQ.

Regarding health service factors, long waiting times, health workers' negative attitudes, drug shortage, lack of equipment, and high cost of medication were found by this study, to hinder health-seeking from modern sources. This could explain the community's choice of health-seeking from alternative sources such as clinics, drug shops, witch doctors, and herbalists. Addressing some of these challenges could probably motivate communities to seek treatment from modern sources, thereby increasing trust in the PZQ and its uptake. Findings from this study are supported by findings from a study in Eastern Uganda that revealed institutional factors like inadequate preparation of children and teachers and facilitation of teachers as barriers to seeking treatment for schistosomiasis-related illnesses from modern sources (Muhumuza et al., 2015a).

Community-related factors, such as long distances, poor and inaccessible roads, and high cost of transport, were most pronounced among all other factors influencing participants' health-seeking

behaviour that this study found. This can discourage communities from going to health centres and hospitals, which could explain why people resort to nearby sources.

The study finding is inconsistent with a study in Ghana that found the perceived severity of disease, rather than long distance, was the main driver of health-seeking from modern sources (Anthony Danso-Appiah et al., 2010). Possible reasons for variations could be due to the difference in geographical settings whereby my study setting had some communities that are geographically hard to reach, while the setting in Ghana could be different.

4.4.4 Conclusion

In conclusion, this section was about the results of the health-seeking behaviours of individuals in Kagadi and Ntoroko districts regarding the disease. I utilised Kroeger's model of health-seeking to demonstrate how it supports my understanding and explanation of health-seeking regarding diseases. The findings demonstrate that the PZQ MDA program in Uganda still faces a serious challenge. Inadequate, delayed, and irregular drug supply, lack of community involvement and participation, as well as health systems and community factors, hinder the successful implementation of the MDA program. The next chapter presents findings and discussion on the co-design and implementation of behaviour change intervention regarding the disease.

CHAPTER FIVE: RESULTS AND DISCUSSION ON Co-DESIGN AND IMPLEMENTATION OF COMMUNICATION INTERVENTIONS REGARDING SCHISTOSOMIASIS BY COMMUNITIES OF WESTERN UGANDA

5.1 Introduction

This study aimed to investigate the involvement and contribution of citizen scientists in the collaborative design and implementation of behaviour change intervention regarding schistosomiasis. Before this, the research assessed the knowledge, attitudes and practices of the communities regarding schistosomiasis, along with their lived experiences and health-seeking behaviour. Furthermore, the study explored the preferred sources of schistosomiasis information among the communities. This chapter presents the findings regarding the communities' preferred sources of information, as well as their participation in the co-design and implementation of the intervention.

5.2 Results

1. Preferred sources of schistosomiasis information

The data analysed identified community radios (and megaphones), community volunteers known as village health teams (VHTs), local leaders, local FM radios, and health workers as channels for receiving schistosomiasis information. The study observed that some of the channels were actively being utilised for the dissemination of information regarding other health issues in the community, while others were either not in use, or less frequently employed.

Community radio and mobile radio/megaphones: Findings from the data analysed reveal that participants had a stronger preference for receiving schistosomiasis information through community radio, locally referred to as mobile radio, megaphone or mukalakasa in the local language. Community

radios are highly regarded for their effectiveness in disseminating disease-related information to a large number of individuals within the same geographic area. Community radios are often mounted on tall poles located in trading centres primarily for mobilisation purposes. Meanwhile, mobile radios also called megaphones or microphones, are small portable and hand-held and are typically utilised for door-to-door outreach, enabling information to be conveyed directly to individual household members.

“R1; the microphone because it is fast and quick. R4; The microphone because you can easily hear the person speaking even if you’re in a distance far away. R9; the best way to spread information about bilharzia is our local radio yes, megaphone” (Female FGD-5: Songarao village-Ndaiga Sub-county).

Community radios have emerged as the primary preference for conveying schistosomiasis information, particularly among participants residing along the lake shores, ranking second only to the VHTs and local leaders. The reasons cited for this preference included ease of use, wider coverage in densely populated villages, the ability to reach a large audience, and the efficiency in transmitting information promptly. This preference was also corroborated by the VHTs and local leaders themselves.

“R3; the chairman walks around with the microphone informing people. R5; a person with a microphone walks around and reaches all the villages informing us about the new disease outbreak” (Female FGD-5 Songarao village-Ndaiga sub-county)

VHTs and local leaders: VHTs and local leaders were also widely mentioned by participants across all five sub-counties, especially those residing along the lake shores. VHTs are community members selected by local leaders to volunteer and provide basic health services at the village level, serving as the initial point of contact in the healthcare system. Their roles include community mobilisation, sensitisation and active participation in community health outreaches. They also administer essential healthcare services such as

malaria testing and treatments, and distribution of family planning contraceptives. Notably, some VHTs utilise community radios or microphones for disseminating health information to the community. In support of their preference for the channel, participants highlighted convenience and reliability. At the shores, VHTs are recognised for their exceptional contributions to community mobilisation, sensitisation and drug distribution. VHTs are also preferred for their experience in effectively passing information on various health-related conditions beyond schistosomiasis.

“R1; now us here the VHTs have done a good job. For example, if a person has cholera they take him/her to the hospital and if it's true they come back and inform us” (Male FGD-22, Ntoroko East B Village-Kanara TC)

Notwithstanding, a few participants, suggested that the VHTs should first undergo some training on schistosomiasis and training on how to communicate the information to the community to improve their effectiveness. *“It requires the use of VHTs to be trained to come and sensitize us” (Male FGD-19, Kisenyi A Village-Kanara Town Council).*

Local leaders: A significant proportion of both male and female FGD participants, especially those residing along the lake shores, emphasised the potential resourcefulness of local council chairpersons in disseminating schistosomiasis information. The participants acknowledged the collaborative efforts between local leaders and VHTs in community mobilising and information dissemination. Local leaders were reported to be involved in community sensitisation through various approaches, including door-to-door visits and communication using community radio.

“The chairman usually calls for a meeting then he informs us. We don't have radios here. It's either the chairman of the “mukalakasa “(mobile radio) from Kitebere (neighbouring village).” (Female FGD-17, Nyamasoga village-Ndaiga sub-county)

The local leaders play a complementary role alongside VHTs in disseminating schistosomiasis-related information. Notably, certain community members expressed a preference for receiving information from the local leaders over VHTs. This preference stems from the respect and trust the communities hold for their leaders. The availability and easy accessibility of local leaders also contribute to their perceived credibility and influence in disseminating health information. Furthermore, local leaders possess in-depth knowledge of community problems and challenges, enabling them to provide context-specific schistosomiasis-related information. Such participants perceive local leaders as being responsive and supportive, always available to address any concerns or problems that may arise. Consequently, community members view local leaders as reliable sources of information and prioritise their messages regarding schistosomiasis.

“Through the chairman, because he lives in this village and they always call him and he reaches our households very fast” (Female FGD-27, Kayera village-Mpeefu sub-county).

In contrast, some male FGD participants expressed dissatisfaction with the performance of certain local leaders. According to these participants, some local leaders do not effectively fulfil their responsibilities. Consequently, such participants, rely more on VHTs and health workers as alternative sources of health information, and also advice from their neighbours and friends.

“At times the VHT do give us tablets but preferably to the women and the children only in this area of ours. Chairman does nothing and cannot even give us a piece of advice in the area” (Male FGD-4, Nyamasoga village-Ndaiga sub-county)

Healthcare workers: A few of the FGD participants expressed a preference for health workers as a source of schistosomiasis-related information, citing the health workers’ expertise and knowledge of the disease. The participants commended healthcare workers for their efforts in sensitising communities on water,

sanitation and hygiene (WASH) aspects, recognising their role in promoting preventive measures. However, the participants also recommended that healthcare workers should be the ones involved in the delivery of PZQ drugs since they possess the necessary capabilities to administer the treatment. It should be observed that it is VHTs who distribute and administer the drugs in the communities.

“R11: Through the health workers and bring us medicine, some for putting in water (Female FGD-15, Kisenyi East B village-Kanara Town council)

Local frequency modulation (FM) radios: Participants from uphill areas such as Mpeefu, Kyaterekera and Bwikara identified local frequency modulation (FM) radios as an important source of health-related information. The FM radio stations are predominantly owned by private individuals and are established to broadcast information within specific geographical catchments for commercial purposes. Others, however, are owned by faith-based organisations. The FM radios are spread throughout the entire country. Some of the radio stations have weaker signals making it difficult for communities in low-lying areas such as the Lakesides to receive.

“We always listen to news and programs on the radio” (Female FGD-11, Nyamarembo village, Bwikara sub-county)

Likewise, a few participants expressed a preference for receiving schistosomiasis information through FM radio stations and television. However, this preference was mentioned less frequently compared to community radios and village health teams. The main reason for this preference was the larger listenership and viewership associated with FM radio stations and television platforms.

“Radio is good because it can be listened to by very many and those who have not listened to will be informed by those who have” (KII-5, Kisuura-Bwikara Sub-county).

Contextualised information communication: Some KII participants however argued that the choice of which channel to use for information largely depends on information type, urgency, audience and time are some of the factors considered in choosing a channel to use as mentioned by one of the key informants.

“It depends on the information we are giving out if it's urgent and everyone should be aware of it like Ebola we use the mobile microphone because with that one people everywhere can hear the information. If the ministry of health with a sensitization meeting we mobilize people by word of mouth from house to house and tell them the venue and place where” (KII-3, Kanara Town Council)

Based on the above findings, it is evident that the local channels predominantly being used for disseminating health-related information at the community level were not being employed for relaying schistosomiasis. Instead, alternative channels such as television (TV), Information Education Communication (IEC) materials, and, to a lesser extent, local FM radios were being used for this purpose. However, it is notable that these channels were not preferred by the communities for receiving schistosomiasis information. The reasons provided by participants for lack of preference for the channels include lack of affordability of TVs and radios, poor or non-existent signal reception for some TVs and radios, and language barriers associated with the use of IEC materials.

2. Citizen science and dissemination of baseline findings

Data from the dissemination workshops reveal that citizen scientists and community groups collaborated effectively to and successfully identified the social and cultural risk factors that contributed to schistosomiasis infection and prevention. Among the key pressing problems identified were lack of access to clean and safe water sources, inadequate availability of healthcare services, an irregular and insufficient supply of praziquantel drugs within the facilities, widespread open defecation practices, poor health-

seeking behaviour, insufficient knowledge regarding schistosomiasis, absence of disease testing kits and pervasive poverty levels.

Furthermore, from the identified problems mentioned above, participants emphasised limited access to clean and safe water sources and common open defecation practices as the most serious problems. The problems were said to be prevalent in the lakeshores compared to the uphill sides, further confirming findings from the researcher. Additionally, myths misconceptions and stigma surrounding the disease such as attributing swollen bellies to poison were frequently mentioned by the participants, particularly those residing along the lakeshores. Connected to the above was also, the irregular, delayed and sometimes, unavailability of PZQ drug supply as well as limited access to healthcare services pointed out by participants as another major barrier.

The dissemination also revealed that for some citizen scientists and community members. It was their first time hearing about schistosomiasis signs and symptoms such as blood in the stool for the first time. Some of them were also surprised that they had schistosomiasis in their communities. Such participants said they never knew that the disease existed in the communities. Rather they used to associate the disease with those who live along the lakeshores. Furthermore, some of the local leaders like the witch doctors confessed their ignorance of the disease adding that they often received community members with such signs and symptoms but never knew it was associated with schistosomiasis.

Other witch doctors who participated in the dissemination workshop, however, acknowledged that they had unknowingly treated individuals with the identified signs and symptoms. Added to this point was the fact that other participants recognised the important role played by witch doctors in treating some of the identified signs and symptoms during the dissemination sessions.

3. Citizen science and the co-design of communication strategy

Findings from the workshop reveal that citizen scientists alongside community groups were able to identify key priorities for intervention. In particular, the participants came up with the behaviour change communication goal, the objectives, messages, channels and strategies including actors and audiences. Regarding goals, participants cited the main aim of improving community health by reducing the prevalence of schistosomiasis. To achieve this the following key objectives were identified: 1) the need for sustained knowledge, and a positive attitude to increase awareness to change the behaviour of the community; 2) improving access to and utilisation of clean and safe water and latrines; 3) debunking myths and misconceptions were prioritised; 4) increasing the drug supply and making it accessible to the community.

Concerning messages, participants emphasised the use of clean and safe water, avoiding contact with contaminated water, and emphasising the importance of constructing and utilising latrines. Other messages considered by participants were about dispelling myths and misconceptions such as the belief that defecating in the lake improves fish catch. Furthermore, participants suggested that people should be encouraged to seek treatment for schistosomiasis-related illnesses from hospitals and facilities. Lastly, communities should be about the signs and symptoms associated with schistosomiasis infection, the main transmission modes and how to prevent infection so that they take appropriate preventive measures.

On the channels and strategies to use for disseminating the messages, participants proposed utilising various approaches. These included door-to-door visits, community radios and community meetings, drama performances, songs, informal gatherings (such as churches, funerals, and wedding parties), posters and radio talk shows.

On the question of which actors should pass the messages, the participants prioritised the citizen scientists and VHTs as community volunteers and the local leaders such as village chairpersons, religious

and cultural leaders, as well as health workers. Observably, the community members had also highlighted the same channels as appropriate in receiving schistosomiasis-related information as indicated in my section on preferred sources of schistosomiasis information above. No wonder, the citizen scientists together with the community groups were in tandem with that of the community members.

Subsequently, findings revealed that the objectives, messages, and channels proposed by both the participants and communities, were later used to design a contextualised communication strategy. Regarding channels in particular, door-to-door, community meetings and community radios were considered for use more by individuals residing along the lakeshores. Conversely, drama, dance songs and community radio were suggested most by citizen scientists and community groups from uphill areas.

4. Citizen science and implementation of behaviour change intervention

This was the last phase in the intervention whereby the citizen scientists together with selected local leaders and community groups carried out the awareness campaigns using the key channels proposed above.

Direct interactions: Door-to-door visits conducted by citizen scientists enabled direct interactions with community members in their households. The visits also acted as personalised platforms for knowledge sharing, allowing community members to ask questions and receive immediate feedback. The collaborative approach ensured that accurate and comprehensive information was disseminated during the door-to-door visits, enhancing the effectiveness of the communication efforts.

Open discussions: The use of community dialogue meetings organised around landing sites, trading centres, markets, and health facilities, facilitated open discussions about schistosomiasis, addressing certain concerns that the communities had about the disease. The sessions were used as a platform for community members together with citizen scientists to engage in dialogue conversations. This way,

various aspects related to schistosomiasis were discussed and addressed. This helped to reinforce key messages in an interactive format.

Capturing community attention and engagement: The use of dramas and songs played a vital role in ensuring that communities responded to the mobilisation efforts. Also, the performances enabled the conveyance of schistosomiasis-related messages entertainingly and memorably. The choice of central venues identified by the citizen scientists in consultation with VHTs and village chairpersons also enhanced maximum community turn-up and attendance.

Leveraging popularity: Additionally, football tournaments were useful in leveraging the popularity of the sport to raise awareness among community members, particularly the youth. Football tournaments, therefore, acted more as a mobilisation drive rather than the actual passing of schistosomiasis messages. Using the tournament, citizen scientists were able to reach out to a vast majority of the spectators. This way, even those who had no intention of attending to the key messages were able to be reached. The use of radio talk shows was also an effective medium for mass communication, allowing for the dissemination of schistosomiasis information to a broader audience.

Visual reminders: The use of signposts strategically planted in hotspots for open defecation and risky water practices that carried messages in local languages also acted as visual reminders to community members. Over 80 signposts were strategically placed in specific hotspots for open defecation and risky water practices in Ndaiga and Kanara sub-counties, places with very high schistosomiasis prevalence. The signposts that contained key messages in local languages, served as visual reminders to communities to promote proper sanitation practices, including the use of latrines and the avoidance of open defecation. Additionally, the messages emphasised the importance of utilising clean and safe water sources while discouraging the use of contaminated water sources. With the messages visibly written in such hotspots, community members could read and easily follow the instructions.

Fostering local action: To incite local action, stakeholder dialogues were conducted whereby stakeholders such as sub-county chairpersons, health workers and sub-county and district level including district political and technical leaderships together with representatives from the ministries of health and water and environment and NGOs attended. The citizen scientists captioned the community perspectives of the key issues identified from the study findings to the relevant stakeholders. The forum provided a platform for voicing community concerns and possible local action.

These communication strategies helped to reinforce behaviour change and fostered a community-wide understanding of preventive measures against schistosomiasis. Using the channels, citizen scientists were able to effectively disseminate schistosomiasis messages around knowledge of schistosomiasis signs and symptoms, transmission modes, diagnosis, treatment and preventive ways. Using the communication skills acquired during training, the citizen scientists were also able to emphasise to the communities to always practice preventive measures such as constructing and using latrines, avoiding contact with contaminated water sources or acquiring and using protective gear for those that cannot avoid it.

Furthermore, citizen scientists were able to clarify certain beliefs and misunderstandings surrounding the disease spread and prevention using illustrative channels like drama and songs. This way, community members could easily understand some of the ideologies they had about the disease that were not true. Finally, to enhance drug uptake, the CSs used these fora, to encourage the communities to always seek medication from hospitals and facilities instead of using traditional sources. They further tipped the communities to always respond to mass drug administration programs positively. As a result, 18 villages, 10 parishes and 5 sub-counties with over 1000 households and about 9000 individuals were directly reached during the one-week awareness intervention.

5.3 Discussion

1. Preferred channels of health/ schistosomiasis information

Regarding this point, the study found that endemic communities prefer to receive schistosomiasis information using local channels such as community radios, and door-to-door visits by volunteers and local leaders. This was due to their simplicity ease of use, and effectiveness in delivering information to remote rural communities such as those along the lake shores. In addition, the channels were preferred because of were interactive, thereby allowing questions and answers for quick feedback. On the contrary, channels like television (TV), FM radio and magazines were not preferred by the majority of participants even though some of them acknowledged that such channels were being used for passing information on other diseases. This difference in preference is probably because the conventional channels use languages that make it difficult for the rural communities to understand, and they do not reach the rural settings as reported by some studies (Muhumuza, 2017; Natifu, 2006). The findings from my current study are important in guiding the design of contextualised communication strategies instead of the one-size-fits-all conventional approaches.

The current study also found that some community members prefer health workers, for passing schistosomiasis-related information, even though they are said to face challenges financial and logistical constraints. This could explain why the majority of community members do not think the health workers are appropriate in passing out schistosomiasis-related information. Other studies have also reported challenges faced by health workers in delivering outreach services to the communities such as limited facilitation, bigger areas to cover, transport problems and lack of motivation, among others (Kabatereine et al., 2014; Tuhebwe et al., 2015). Supporting the health workers to train and equip local VHTs with the necessary skills, knowledge and materials for creating awareness regarding health problems in the community could help to meet some of these challenges.

Finally, my current study revealed some notable findings contextualising schistosomiasis communication channels depending on different geographical, social and cultural factors. For instance, recommending the use of local FM stations instead of community radios and megaphones for areas that have good coverage and useability to complement the community volunteers and local leaders. This is crucial since it helps to address limitations of reach, coverage, accessibility, acceptability and affordability.

This idea of contextualising behaviour change strategy is an added value to how interventions have previously been done. It is a necessary basis for the co-design of a bottom-up behaviour change strategy that could accordingly be adopted or adapted for other future interventions. Previous studies have also highlighted the importance of taking into account social and cultural sensitivity in the selection of channels to use, for improved understanding, acceptability and uptake of the messages (Person et al, 2016).

2. Citizen science and the dissemination of study findings

This study reveals the engaging nature of citizen social science in the data party participatory approach that enables the interpretation of study findings. Using the seven guiding questions of the data party technique (Appendix 1), participants successfully interpreted findings from the baseline studies of KAPS, lived experience and health-seeking behaviour regarding schistosomiasis infection in their communities, identified social and cultural risk factors associated with the disease and prioritised and ranked the most pressing problems.

Furthermore, the CS together with the community groups were able to identify other myths and misconceptions that had not been highlighted in the KAPs baseline study. This participatory process allowed participants to appreciate the problem of schistosomiasis in their understanding. This is something that would not have been achieved if the findings had been “imposed” on them. The findings from this current study resonate with findings from other studies that also reported that citizen science

fosters a better understanding of human behaviour, enhances lay persons' knowledge, and facilitates community empowerment through the involvement of lay persons in the research process (Albert, 2018; Bisung et al., 2015; Ciasullo et al., 2021).

It should however be noted that such studies mainly looked at the involvement of citizens as lay persons in data collection only. My current study, therefore, provides interesting insights into how expert researchers can collaborate with local communities in other important phases of the research process (Senabre et al., 2018). Future research could adopt this strategy to build trust, honesty, transparency and accountability in study findings.

3. Citizen science and the co-design of communication strategies

Results from the current study further show that integrating citizen science within the participatory world café technique enabled the CSs to collect qualitative data to generate key messages and identify appropriate audiences, actors, and channels for use during implementation. Furthermore, the study revealed that participants were able to easily dialogue together, in a meaningful engagement that generated consensus around the topics, which also fostered mutual learning. This way, the CSs and community representatives were able to generate ideas and suggestions about the communication tools to be used during the intervention in a more democratic and knowledge-sharing manner.

Whereas the World café allowed contextualising the messages, citizen science allowed the participants to own the processes and outcomes. Research ownership is an important element since it empowers communities to have a voice in coming up with solutions to problems that affect them. Findings from this study are supported by another study which also revealed that World café as a participatory technique, facilitates dialogue and mutual learning, thus motivating their participation and responses (Löhr et al., 2020).

The world café as a PAR technique, is also a powerful tool that facilitates smooth knowledge generation by local communities (Broom et al., 2013). Also, a study in Zanzibar demonstrated that the co-design of schistosomiasis interventions together with communities enables them to contribute to the development of contextualised education campaigns (Person et al, 2016). Therefore, future interventions could consider employing local citizens as co-researchers in any of the research processes for easy acceptability by the community.

4. Citizen science and implementation of contextualised information regarding schistosomiasis

This last part of the study found that citizen scientists successfully carried out awareness interventions interactively and democratically. Using door-to-door visits, community meetings, drama, dance and songs, and organising tournaments, the CSs effectively delivered schistosomiasis messages to the communities.

Also, as many as over 1000 households were reached within a short time. This most likely wouldn't have been possible by the use of conventional approaches of TVs, radios and print media in such marginalised and endemic communities (Muhumuza et al., 2015b). Also, the public participation of citizens in research allows for the democratisation of knowledge acquisition (Strasser et al., 2019). Therefore, active involvement of communities in the design of behaviour change interventions to facilitate transparency, trust, ownership and inclusivity is highly recommended.

Furthermore, the current study reveals that the citizen scientists effectively mobilised and organised the communities to participate in the awareness intervention. This is critical as the first step in the successful implementation of any community-based behaviour intervention requires effective community mobilisation and organisation. Other studies have also underscored the importance of community mobilisation and organisation towards concrete action (Albert, Balint, et al., 2021), fostering a supportive

environment (Torres-Vitolas et al., 2023), adding voices to community members and awareness raising for informed action (MercyCorps, 2020). In another study in Mozambique, it was found that inadequate community mobilisation contributed to the knowledge gap regarding schistosomiasis with a recommendation to broaden the scope of community mobilisation by involving the locals themselves (Rassi et al., 2016).

Other critical success factors reported in this phase of the study were the participatory approach to CSs' selection and training, social media platforms for communication and feedback, regular encounters with the researcher and community engagement among others. Also, the CSs' acquisition of knowledge and skills on schistosomiasis, snail sampling and communication provided during refresher training and workshops are said to have contributed to the success of the implementation of the intervention.

Also, the financial compensation provided to the CSs both for their monthly operations and during the awareness period, plus other aspects could have played a significant role in the successful implementation of the behaviour change intervention by the CSs. The findings from this study are supported by other studies that also revealed that proper training enables citizens to collect quality data, provides opportunities to learn new ideas, and increases volunteers' perception of their capacity to overcome challenges and achieve desired objectives (Gommerman & Monroe, 2012; Kitamura et al., 2020; Torres-Vitolas et al., 2023).

5.4 Conclusion

In conclusion, bottom-up community-led approaches to behaviour change interventions have not been adequately researched. A few studies have documented participatory approaches generally, but not so much on citizen science, let alone combining them with other participatory approaches. As part of this study, this chapter was dedicated to presenting my findings and a discussion on bottom-up community-

led approaches using citizen science and other PAR techniques in various stages of research such as dissemination of baseline study findings, co-design and also, and implementation of the interventions. Of significance was also, the findings from the communities' views on the preferred channels for passing schistosomiasis-related information. As the next phase of my study concerned itself with the participatory evaluation of the application of citizen science and PAR in behaviour change intervention, I devoted it to the next chapter.

CHAPTER SIX: RESULTS AND DISCUSSIONS ON PARTICIPATORY EVALUATION OF THE CITIZEN SCIENCE APPROACH TO COMMUNICATION INTERVENTION REGARDING SCHISTOSOMIASIS

6.1 Introduction

This study evaluated the citizen scientists' involvement and participation in behaviour change interventions regarding schistosomiasis among endemic communities along Lake Albert, western Uganda. The CSs were selected using participatory approaches involving community engagement meetings. More details of the CSs' profiles and their selection criteria are provided in the study in a paper by Brees et al., (2021). This chapter presents the key findings from the data analysed and consists of four different sections. These are a) the most significant changes that have taken place to the CSs as a result of their involvement and participation in the intervention, b) community experiences and perceptions of the CSs approach, 3) challenges faced by the CSs during their involvement and participant in the intervention, and finally, 4) recommendations provided by both the CSs and community for improving implementation of similar interventions.

6.2 Results

1. Most Significant Changes by Citizen Scientists

From the stories narrated by the CSs, seven domains of change were identified include as a result of their involvement participation in the behaviour change intervention: 1) the ability to sample and report on snails; 2) the ability to effectively communicate with the community; 3) the ability to engage with stakeholders; 4) increased trust, respect, and social network; 5) change in social status (becoming

doctors); 6) increased knowledge and change in attitude, and lastly; 7) improved use of clean water, good hygiene practice.

Ability to sample and report on snails: One of the most significant changes that stood out most to the citizen scientists was their ability to sample and identify snails and report on them. They narrated that before their involvement, they never knew anything about snails and their association with schistosomiasis. However, after receiving the training they became proficient in identifying and sampling snails from various water sources. The citizen scientists expressed how this newfound skill positively impacted their lives and relationships within the community. These observations are substantiated by excerpts from stories by citizen scientist No.5:

“The most significant change that has happened to my life is that I can sample snails. Also, the change that has happened for me is being able to identify the different types of snails that spread bilharzia. Personally, because of sampling, people stop and ask me what I am doing and I feel good about it” (Citizen Scientist-5, Bwikara Sub-county).

Ability to effectively communicate to the community: Effective communication with audiences of diverse backgrounds was another significant change that emerged from the stories. The citizen scientists in their stories, shared that through the training, they acquired knowledge and skills in various aspects of communication, including types of communication, effective communication techniques, and identifying barriers and facilitators to effective communication. This change was mentioned by the majority of the citizen scientists as captured in the story of citizen scientist No. 5 who shared personal experiences of how her communication skills greatly changed after gaining confidence, and ease of public speaking.

“I acquired communication skills and this is a change because before I was shy to talk to people but from the ATRAP training about communication, I am confident and no longer shy to talk to people now. I easily talk to my community about bilharzia (Citizen Scientist-5, Bwikara Sub-county).

Community and stakeholders’ engagement: Linked to the Citizen scientists’ ability to effectively communicate was also their improved ability to engage with the community and stakeholders. The CSs recognised the significance of involving and engaging with various community leaders, including religious, cultural, and traditional healthcare practitioners in addressing schistosomiasis challenges. In their stories, the CSs mentioned that before their intervention, they did not perceive the importance of such engagement. CS-2 shared a story illustrating the value of engaging different stakeholders emphasising that it contributes to behaviour change by the community.

“Also, being involved with different stakeholders and even having traditional healers was a big change. I learned that different people like religious leaders or traditional leaders are important in the community. Also, during the communication campaign and going from house to house talking about bilharzia, people started to respect me more. They even call me the “water doctor”, most of the people in my community know me because of the communication campaign” (Citizen Scientist-2, Ndaiga Sub-county).

Increased Trust, Respect, Discipline, and Social Network: Results from the stories narrated by the citizen scientists also reveal a significant change in the perception and treatment of the community towards them. They reported experiencing increased levels of trust, respect, and discipline, improved family relationships and expanded social networks. The CSs attributed these changes to their active involvement in snail sampling and regular engagement with the community. Additionally, the CSs acknowledged the positive impact of their involvement in building trust and respect within their families. Also, their ability

to meet basic needs including food, clothing, and school fees, played a crucial role in fostering familial trust and respect. This change was best captured in a story by CS-5 as below.

“The changes that have happened to me respect me is that my family respects me and the community also respects me. The changes that have happened because of the awareness week is now people respect me and trust me as a good person in the community” (Citizen Scientist-5, Bwikara Sub-county).

The story recounted by CS-7 further reinforced the profound change in the lives of the CSs, particularly as a result of their participation in snail sampling and community engagement in their social standing within the community. According to the CS, they not only underwent a personal transformation but also their networks and friendships with fellow CSs and the community broadened. Ultimately, this altered the way they are perceived by the community, fostering a sense of belonging.

“Because of being a citizen scientist, I have become popular in my village, people know me because they see me scooping and they usually stand and watch me as I scoop or ask me questions related to bilharzia. I have also got friends from being a citizen scientist. My fellow citizen scientists are my friends and the ATRAP project team. So I can say I have gained friends” (Citizen Scientist-7, Mpeefu Sub-county).

Change in social status: The significant change in social status experienced by the citizen scientists was another notable outcome of their involvement in the intervention. According to the CSs, the community bestowed various titles and descriptions upon them such as “doctor”, “doctor of water”, “water doctor”, “snail doctors”, “doctor of bilharzia”, “researchers”, and “owner of snails” and “snail collectors”. These labels were associated with the CSs’ dual roles: researching snails and participating in social activities. On

scientific research, the CSs mentioned that their involvement in collecting data on snails and water parameters earned them such titles. Evidently, CS-1 narrated that;

“I also couldn’t have been part of ATRAP if I wasn’t trusted in the community but when I joined and started doing ATRAP work and people noticed it, the respect increased. This is evident in the way they treat or even call me certain names like the doctor” (Citizen Scientist-1, Kanara Town Council).

Meanwhile, their involvement in social activities like community mobilisation, sensitisation and awareness as well as community engagement also made the community attach such labels to them. This was due to their role as information providers, educators, and community leaders. Most especially, their participation in community awareness and engagement activities positioned them as valuable resources within the community thereby earning them such prestigious titles. Whether seen as water doctors advocating for the avoidance of contaminated water or in other similar descriptions, the CSs were recognised as individuals with high importance by the community. This sentiment was echoed by both the community leaders and members, as illustrated in the following excerpts. The account provided by CS-2 specifically highlights the community’s perception of the CSs as water doctors, emphasising the importance of raising awareness about the need to avoid contact with contaminated water.

“During the communication campaign and after going from house to house talking about bilharzia and telling them to avoid contact with contaminated water, people started to respect me more. They even call me the “water doctor”, most of the people in my community know me because of the communication campaign” (Citizen Scientist-2, Ndaiga Sub-county).

Increased knowledge and a change in attitude regarding schistosomiasis: Another significant change reported by the CSs was a notable increase in knowledge and a shift in attitudes towards schistosomiasis.

The CSs observed that initially, they had a limited understanding of the disease and did not perceive it as a serious health threat, leading to a lack of preventive measures. However, during the training and their engagement in sampling activities and active participation in awareness-raising campaigns, their knowledge and understanding of the disease significantly improved. The CSs said they now recognise the dangers of schistosomiasis and the importance of taking preventive measures. These changes were not only observed among the CSs themselves but also, within the wider community. The selected stories shared by CS-2 capture the changes as below.

“The change that has happened to me is that I never knew that the water we are using is harmful to our health. I learned that bilharzia is a serious disease that if not treated can result in death. I also learned more about the signs and symptoms of bilharzia. I learned to always wear my gumboots to prevent the parasites from entering the body. I used to think water from the stream is clean and safe compared to lake water. But when I started sampling, I realized there are dangerous snails that cause bilharzia in the stream too. I used to think that the bilharzia enters through the mouth but I learned that they enter through the skin” (Citizen Scientist-2, Ndaiga Sub-county).

Improved water sanitation and hygiene (WASH) practices: In their stories, the CSs also highlighted significant changes in their preventive practices regarding schistosomiasis such as the use of clean and safe water sources and defecating in latrines. They observed that previously, they used to engage in risky behaviours such as bathing, swimming, and using water from contaminated sources. However, after receiving training, engaging in snail sampling, and participating in awareness campaigns, they adopted preventive measures. For instance, they stopped using contaminated water sources and began boiling

water for household use. Other CSs also constructed latrines which they started using and ensured their maintenance. The story by CS-2 exemplifies the significant changes below.

“From the dissemination of KAPs results, I started boiling my drinking water. Before that, I always went to the lake to fish and drank the unboiled water. But after the dissemination, I always carry my boiled water from home when I am going to fish” (Citizen Scientist-2, Ndaiga Sub- County).

Likewise, the CS-5 added a narrative of how they began to use protective gear as a way of protecting themselves from getting infected by the disease.

“These days I wear my gumboots when I am going to dig or even fetch water. Before I used to dodge bilharzia tablets. But from the knowledge I have acquired, I ensure that I swallow the right dosage and encourage my community members to swallow the medicine. Before I was involved in this program I never used to boil water for drinking or even bathing but nowadays I boil my drinking and bathing water” (Citizen Scientist-5, Bwikara Sub-county).

Unexpected changes: The citizen scientists narrated in their stories, some of the things they never really expected would have happened to them. These changes were categorised into two: those related to snail sampling and the others related to community awareness.

Unexpected support related to snail sampling: facilitation in the form of financial compensation, access to equipment such as gumboots, smartphones, scoop nets and thermometers and the opportunity to own and use smartphones themselves stood out most.

Financial Facilitation: The CSs explained that the financial compensation provided to them was never expected, since in their previous volunteering with other organisations they had not been offered such

support. At the start of the project implementation, the CSs were briefed about their roles and responsibilities during their participation. They were also briefed about the project supporting them in terms of equipment and financial compensation which would be paid to them monthly. Each CS was to receive Uganda shillings 10,000/= for airtime and internet bundle, another 10,000/= for transport refund and 55,000/= as time compensation, altogether totalling Ug shillings 75,000/=. These amounts together with other important clauses were stipulated in a memorandum of understanding (MOU) that was signed between them and the project. The CSs therefore, gave testimonies of how the facilitations helped them meet their basic needs and alleviate some financial burdens. For instance, they were able to use the money to support their cultivation, buy food and clothes, as well as pay school fees.

Access to equipment: The equipment given to the CSs such as gumboots, smartphones scoop nets and thermometers to enable them to effectively deliver were other unexpected experiences. According to the CSs, access to equipment was unexpected but proved to be highly beneficial for their work. The gumboots, for instance, offered protection during fieldwork, scoop nets facilitated snail sampling, and thermometers aided in monitoring water temperature.

Ability to use smartphones: From the stories, it was also revealed that the majority of the CSs had never owned or used smartphones before. To such CSs, their involvement in the intervention gave them the unexpected experience of owning and using such phones. Although some of them faced challenges using the phones at the beginning due to their unfamiliarity with technology, they quickly learned how to operate it through training and constant support from the researcher. This improved their effectiveness and efficiency in carrying out their assigned tasks. CS-2's story provided a comprehensive account of these unexpected changes.

“The unexpected change I have experienced is being given facilitation. I thought I was only going to be a volunteer but later, the ATRAP (project) started giving me facilitation. Also, what I didn’t expect was having a smartphone to help me do my work. I also didn’t expect the refresher training. Other organizations or projects train you once and go but with ATRAP we get refresher training every beginning of the year” (Citizen Scientist-2, Ndaiga Sub-County).

Unexpected support related to community awareness: The ability to effectively communicate bilharzia information and to influence community behaviour change regarding the disease was something not expected by the majority of the CSs. The CSs expressed their surprise at their capacity to effectively convey information and positively impact the community’s response to the awareness campaigns. This unexpected outcome was attributed to the training in communication they acquired during the intervention. The knowledge obtained enhanced their communication skills, confidence, and interpersonal relations. Furthermore, the CSs noted that the perceived severity of the disease also played a role in facilitating the community’s acceptance of change. The story shared by CS-8 captures the CSs' satisfactory experiences in impacting the community’s knowledge and behaviour regarding schistosomiasis.

“I never expected to educate the community and I never expected that they would accept change. But I am happy that these things are happening. I think it is because they have been severely suffering from the disease” (Citizen Scientist-8, Ndaiga Sub-County).

Community expectations that were not met

Findings from the stories provided by the CSs also reveal that their community expected the project to provide clean and safe water infrastructure or at least, purifiers, particularly in communities experiencing

extreme water hardship. However, this did not happen. The story shared by CS-3 sheds light on these unmet expectations.

“I expected that the project would give the community safe water or water tanks but we haven’t gotten them from this project” (Citizen Scientist-3, Kyaterekera Sub-county).

2. Community’s perceptions of the citizen science approach

Findings from the data analysed reveal that the communities’ overall experience and perception of the citizen science approach to behaviour change was positive. Participants expressed appreciation for the CS selection and training process, snail sampling activities, and awareness campaigns. They described the CS approach as participatory, transparent, inclusive, practical, empowering, and effective.

Citizen scientists’ selection and training: A positive experience and perception were shared by participants in the key informant interviews who highly appreciated the project’s approach to selecting and training citizen scientists. They commended the process for being participatory, consultative, transparent, fair, impartial and promoting community engagement. The involvement of the community in determining selection criteria was particularly praised as a departure from previous practices by other non-governmental organisations, which were seen as politically and ethnically biased. This inclusive approach helped to foster trust in the volunteers as shared in the quotes below.

“R. You know when dealing with communities, we use the element of social inclusion and active participation. That is the community must be involved in every step of the project. I can say the exercise was good because the community was actively involved. It was also transparent and fair enough” (KII-5, CDO Ndaiga Sub-County).

Another participant appreciated the process of being neutral.

“R. Personally, I think this was a good method because the opinion leaders were used to giving names of people they know are hardworking and committed to the community” (KII-8, LCIII Chairperson Kyaterekera Sub-County).

Furthermore, participants emphasised that the selection criteria and process employed successfully identified individuals with strong public reputations. This sentiment was echoed by sub-county and local leaders comprising both male and female participants from various geographical regions within the study area. They attested that the selected citizen scientists possessed commendable track records, demonstrated diligence, maintained impartiality, enjoyed the trust of the community, exhibited competence, and possessed relevant experience.

“R. These people recruited are our own children from the community here who are trustworthy, competent and with no bad record” (KII-1, LCIII-Kanara Town Council).

Additionally, participants expressed their appreciation for the decision to conduct interviews as part of the selection process. They believed that this approach eliminated bias and ensured the recruitment of suitable and qualified volunteers.

“R. For me, it’s only right that you called us to help you identify the people who are hardworking and can volunteer because we know our people more than you. Also, your interviews helped you choose people who fit your criteria” (KII-9, LCI Chairperson Nyakatoj Village, Mpeefu Sub-County).

Furthermore, the focus group discussion (FGD) participants echoed the sentiments of the community leaders, expressing their appreciation for the approach used in selecting the citizen scientists. They highlighted that the selected individuals were well-known within the community, and recognised for their experience, trustworthiness, respectability, and sociability in their work. This further reinforced the positive perception of the citizen scientists and their suitability for the role.

“R8. The sub-county CDO came to this village, I knew about it and following the procedures he was successful. Because you cannot recruit someone who is not appropriate. Even the chairperson LC I was aware of it, and they were taken for training. R4. From my experience of the interview, there was no form of partiality and I wish other recruitment processes would be like that” (Male FGD-9, Ndaiga Sub-County)

Practical skills and knowledge: Findings from both KII and FGD participants highlighted the practical skills and extensive knowledge possessed by citizen scientists regarding schistosomiasis. The participants emphasised that the CSs demonstrated a high level of awareness and understanding of various aspects related to schistosomiasis. Specifically, they were knowledgeable about the life cycle of the parasite, the identification and control of snails, the sources of contaminated water, and the symptoms, prevention, and treatment of the disease. This comprehensive knowledge exhibited by the CSs was widely recognised and appreciated by the community, underscoring their positive perception of the CS approach as an effective means of addressing schistosomiasis.

“R. The CSs have knowledge and skills on how to handle the community, and on bilharzia. I am happy that I see them sensitising, moving home to home telling people what causes bilharzia and how they can prevent it” (KII-5, CDO Ndaiga Sub-County).

The extensive knowledge and practical skills acquired by the CSs through their training and engagement in schistosomiasis-related activities empowered them to effectively communicate with the community, based on information. With their in-depth understanding of the disease, its transmission, and preventive measures, the CSs were able to engage in meaningful and informed discussions with the community members. This enabled them to address misconceptions, debunk myths, and provide accurate and reliable information regarding schistosomiasis. The CSs’ ability to speak from a position of expertise and share

evidence-based knowledge further strengthened their credibility and fostered trust among the community members, enhancing the effectiveness of their communication and behaviour change efforts.

“R. My experience is that I think the citizen scientists have done a good job in being involved, they have gained a lot of information about bilharzia and can easily talk about it in the community” (KII-

7, LCI Chairperson Kitebere Village, Ndaiga Sub-County)

On snail sampling and reporting activities, participants' feedback varied within the study. Some participants, particularly those from FGDs, expressed limited knowledge and understanding of the CSs' work. They acknowledged seeing the CSs carrying equipment and scooping snails at different water points but lacked detailed information about the purpose and process until they received sensitisation sessions. Conversely, a few participants mentioned having direct interactions with some CSs during their work and even being told about their activities. Notably, a leader highlighted how the CSs informed him about their activities.

“R. The CRs did research and told me about the water sources and their conditions. On scheduled days, they go to the field at water sites and collect snails, they then tell me about it. They said lake water is not good for consumption because it is contaminated but a spring well is preferred only that it should be filtered or purified before use” (KII-3, LCI Chairperson Nyamasoga Village, Ndaiga

Sub-County)

Reach and coverage of messages: Participants generally had a positive experience with the awareness campaigns, highlighting their extensive coverage within the community. Specifically, KII participants commended the CSs for their thorough engagement with the communities and households, noting that this level of outreach had not been previously witnessed by other organisations or government initiatives. The CSs were acknowledged for addressing various aspects of the disease, including preventive measures. Community leaders echoed these sentiments, as illustrated in the following excerpts.

“R. You have really gone deep into the communities, you walked from house to house talking about Bilharzia, and other NGOs we just hear about them and it stops there. Even using drama was good for those that don’t know how to read and write they went back with a message on bilharzia. So, I must say it was good; everyone in the village knows the Bilharzia program” (KII-10 LCI Chairperson Rugarama Village, Mpeefu Sub-County)

In support of the findings, participants from both lakeshores and uphill sides in both male and female FGDs, shared positive experiences regarding the awareness campaigns, confirming the effective reach of the messages within the community. They reported receiving crucial preventive messages through the various approaches employed by the CSs, including house-to-house visits, drama, and community meetings.

“R3. On that day we had a break and a certain CS came on the microphone and started teaching about the disease and its preventive measures such as wearing protective gear and avoiding contact with contaminated water he thanked us. R6. Through the home visit, I learnt that we should protect ourselves whenever we come into contact with such water sources. We also learnt about how to prevent other diseases such as cholera” (Male FGD-12, Kyaterekera Sub-County)

A similar observation was made by female FGD participants as well, further affirming the effective dissemination of messages by the citizen scientists:

“R5. They taught us that we should always use latrines for defecation and wash our hands afterwards, and latrines should be far from home. R10. They told us to avoid defecating in the bush. Some people still defecate in the bush even among us here some still go to the bush because the soil is bad for latrine construction” (Female FGD-11, Ndaiga Sub-County)

Mode of delivery of the messages: Participants in both the FGD and KII positively acknowledged the citizen scientists’ effective mode of message delivery. They commended the use of interactive, simple, and clear messages, accompanied by illustrations and demonstrations that were easily understood by the community.

“R3. You used the right approach because it was appropriate the use of the local language made it easy for people to understand. R4. The campaign was interesting because it attracted community support, and I encourage you to use the same next time. R8. The messages were ok and simple, and even children could understand. R6. It was interactive using questions and answers which facilitated better understanding and elaboration as well” (Male FGD-7, Mpeffu Sub-County)

Communication approaches employed: The utilisation of diverse communication approaches the citizen scientists in conducting awareness campaigns received widespread appreciation and endorsement. The inclusion of house-to-house visits, drama, songs, and football as mediums of communication was regarded as innovative and impactful by participants in the male FGDs. This suggests that these creative methods effectively engaged community members and facilitated their comprehension of the messages conveyed. Some of the participants expressed satisfaction with the use of music and drama, stating that;

“R4. People enjoyed the awareness program as they were learning from the music and drama. R8. As someone who participated in the awareness using drama, I understood the message and it made me happy” (Male FGD-7, Mpeefu Sub-county).

The affirmation from the KIIs further validated the effectiveness of these approaches. Local leaders acknowledged the inclusive nature of the citizen science approach, emphasizing its ability to reach all corners of the community. One local leader highlighted the importance of citizen scientists coming from different parts of the village, stating that;

“R. I find the citizen science a good approach because the citizen scientists come from different parts of the village, which means they reach all the parts of the community” (KII-10 LCI Chairperson Rugarama Village, Mpeefu Sub-County)

Additionally, the KIIs revealed a sense of novelty and enthusiasm surrounding the CS approach. The involvement of citizen scientists in conducting house-to-house visits and organizing a football match generated significant community participation. This demonstrates that the CS approach distinguished itself from previous campaigns and captured community attention through its interactive and engaging activities. One KII remarked that;

“R. With the awareness campaign organised by the ATRAP project, we moved from house to house with the citizen scientists and it was a very good experience. The football match that was organized gathered lots of people, and it was a good way of communicating about bilharzia. There’s no NGO that has done this before.” (KII-8 LCIII Chairperson, Kyaterekera Sub-County)

Citizen science as a valuable resource: A noteworthy aspect highlighted by a considerable proportion of participants was their appreciation of the citizen science approach. They attributed this to the comprehensive knowledge and practical skills demonstrated by citizen scientists. Both the local leaders and the community members supported the idea that volunteers should possess practical skills to effectively educate and engage the communities. The CSs’ ability to establish a direct connection between schistosomiasis and its underlying causes, namely snails, contaminated water, and open defecation, was particularly lauded. One of the KII participants expressed admiration for the CSs’ work and acknowledged the differences between the CSs and VHTs, noting that the former was more extensively trained on schistosomiasis matters than the latter.

“R. I appreciate the CSs’ work so much because here we are only two with my assistant. The CRs have been raising awareness about the disease and I think the community will positively respond. For us, we only train the VHTs for mass drug administration, and they don’t get a detailed package. Unlike the CSs, who have received training like communication skills, snail identification etc” (KII-6, DVCO, Kagadi district)

Community concerns regarding the CS approach: Whereas there was a dominant view that the CS was an effective approach, a few KII participants expressed concerns about certain aspects of the implementation. These concerns included a limited number of citizen scientists concerning the size of their operational areas, the distant location of some sampling sites, and the selection of a few individuals with questionable character. Participants noted that the presence and work of the CSs were not sufficiently felt in certain villages, thereby limiting their reach and impact. Additionally, the decision to assign a CS to work in a different parish could have deprived other community members of the opportunity to participate in the intervention. One of the KII participants highlighted that;

“R. I had no doubt in them and I am happy with the work they are doing, but they seem to be few for the whole sub-county” (KII-3, LCI-Nyamasoga Village, Ndaiga Sub-County).

Participants also explained that the CSs’ efforts in raising awareness about the signs and symptoms of schistosomiasis had led to increased demand for treatment. However, the drugs were not readily available, leaving community members frustrated as narrated by one of the KII participants below.

“These CSs really taught us a lot about the signs and symptoms like a swollen belly, brown hair, and a thin body some would go for traditional medication. Now people want drugs because they have understood the cause of their problem. But the drugs are not there, even the CSs don’t have them.” (KII-3 LCI Chairperson Nyamasoga Village, Ndaiga Sub-County)

3. Challenges of citizen science approach for implementing behaviour change

Findings from the data analysed, challenges encountered were categorised into three: 1) Challenges related to snails sampling and reporting; 2) Community awareness-related challenges; and 3) Natural challenges. The challenges were explained differently by the different participants mostly according to their personal experiences in the project.

Challenges related to sampling and reporting: The challenges related to sampling and reporting encompassed included an inadequate number of citizen scientists relative to the expansive geographical area, the significant distances between the CSs' residences and water contact points, limited and delayed availability of necessary equipment, insufficient and inconsistent facilitation, and challenges about the use of smartphones. Some of the citizen scientists and local community members, both residing along the lakeshores, and uphill sides, acknowledged that they were assigned water contact points that were far from their homes, leading to logistical difficulties.

“The challenge that I have faced is the fact that my water contact sights are far and sometimes the facilitation given doesn't cover the transport costs, especially with the increased fuel prices”

(Citizen Scientist-5, Bwikara Sub-county).

In addition to the above challenges, the issue of moving from one place to another posed further difficulty in ensuring comprehensive coverage of the sites. Due to limited transport challenges, the CSs reported facing obstacles in reaching certain locations, hence making it difficult to sample in some of the sites. This challenge was also acknowledged by a male participant from one of the FGDs in Ndaiga Sub-county who highlighted the substantial size of the village and unfavourable weather conditions, further hindering their work.

“R4. The major challenge is their walking from place to place while doing their work, especially on rainy days and sunny days as well yet this village is too big which makes it difficult for them to conduct the sensitization” (Male FGD-10, Ndaiga Sub-county).

Relatedly, the CSs faced difficulties in using smartphones for data entry and reporting, particularly since a good number of them were unfamiliar with owning and operating such devices. However, over time, citizen scientists were able to overcome these obstacles by learning and gaining proficiency in smartphone usage. The story by CS-3 captures this explanation below.

“At first, I had a problem with using the phones and internet data bundles for sending the data wouldn’t be enough.” (Citizen Scientist-3, Kyaterekera Sub-county).

Awareness-related challenges: These comprised the absence of umbrellas and transportation, inadequate prior engagement with the local community, high community expectations, low response to awareness messages, religious factors, disconnect between the CS and some community leaders, lack of reporting structures to local leaders and difference in priorities.

Absence of umbrella: On this challenge, participants from different categories highlighted the issue of the lack of umbrellas while walking long distances under the scorching sun during awareness campaigns. This was observed by both the CSs, local leaders and the community members. The CSs themselves explained that they expected the project to provide them with other important items such as umbrellas to help during rainy seasons, and bicycles or motorcycles to help with movements to facilitate sampling and community sensitisation.

“I expected to be provided with an umbrella to help when it’s raining and I have to go to my water contact points” (Citizen Scientist-5, Bwikara Sub-county).

In agreement with the CSs, the KIIs also reported ever seeing the CSs tracking long distances without anything to cover their heads.

“Walking on a hot sunny day without drinking water, umbrella, or bicycle, yet they are walking on their feet to different villages with no food to eat yet they have to carry out sensitisation the whole day”

(KII-3, Ndaiga Sub-county).

Furthermore, FGD participants identified a lack of identification during snail sampling and awareness activities as a challenge that hindered community members from easily recognising and knowing the citizen scientists. Participants expressed their concerns regarding the absence of distinctive attire or indicators that would allow the CSs to be easily identified within the community. Some participants also noted that the presence of CSs was not strongly felt in the community, speculating that various factors might have contributed to this observation.

“R1. No clothes for them to be identified. R2. Their presence in the community is still not felt much, I don’t know why. But could be due to many factors” (Male FGD-5, Kanara Town Council).

High expectations by the community: From the stories narrated by the CS as well as views shared by the local leaders in the KIIs, it came out clear that the community members displayed high expectations towards the citizen scientists' activities. Community members often anticipated financial incentives and facilitation, even for activities that were not included in the budget. This created challenges for the CSs, as they had to continuously clarify the objectives and benefits of the project to manage community expectations.

“The challenges I have faced are with the community members, some community members are biased and harsh especially when you try to tell them about bilharzia. The other challenge is when

I go to the community they ask me for money. They think I am making a lot of money so they ask me for money or sometimes soda” (Citizen Scientist-2, Ndaiga Sub-county).

Differences in priorities: Participants in the KIIs and FGDs highlighted a disconnect between the project’s priorities and the community's needs. Specifically, participants from the lakeshore areas emphasised the lack of access to clean water, inadequate health facilities, and limited availability of drugs as pressing issues in their communities. In contrast, the project primarily focused on awareness raising, leading to a misalignment of priorities between the project and the community.

“R7. I see they have a lot of challenges because the CSs have done adequate sensitization and we have got them but the biggest problem is the lack of access to clean and safe water. Because we cannot follow them if we don’t have water” (Female FGD-8, Ndaiga Sub-county).

The KII participants further expressed that the community had expectations for the citizen scientists to address various infrastructure and service-related needs. These included requests for healthcare facilities closer to their communities, access to clean water sources, and improved road infrastructure. However, the citizen scientists were unable to fulfil these requests as their scope of work was primarily focused on schistosomiasis awareness and prevention. This mismatch between the community expectations and the capabilities of the citizen scientists created a challenge in effectively meeting the community’s needs.

“R. The challenge the CSs faced was that the people in the community were asking them to bring the facilities nearer to them so that if they are infected with bilharzia they can go to that health centre. Also, they asked for good water, and the community also asked for roads which the CSs couldn’t provide these things” (KII-7, Ndaiga Sub-county)

Disconnect between the CS and community leaders: The CSs also encountered challenges with some local leaders reluctant to be involved or discuss bilharzia issues. This lack of cooperation can be attributed to the leaders' limited knowledge of the disease, which influences their attitude towards the project. According to a story by CS-2,

“Some local leaders are reluctant and don't want to be involved or even talk about bilharzia.....if only they can wake up and work with us in fighting against bilharzia, I believe this disease will be kicked out of our community” (Citizen Scientist-2, Ndaiga Sub-county).

Limited awareness about citizen scientists: Findings from the data reveal that initially, there was a lack of community awareness about the citizen scientists and their work and their benefits.

“R. On the CSs, most people still don't know what they are doing, they see the CSs always moving to water points to collect samples. Because when you go and ask the community about the CSs, but for us who are working with them we know when we are sensitizing. But the community doesn't know” (KII-2, VHT Coordinator Kanara Town Council).

Owing to the above, some CSs faced the challenge from community members who never wanted the CSs to carry out sampling on their land, allegedly attributing it to wrong schedules on a Saturday which is their prayer day. It meant that the CSs were not allowed access to the water contact point on such a day, so he had to change it to another day.

“The religious challenge I also faced was that one of my water contact points is in the land of the Seventh Day Adventists so the owner stopped me from going to that water contact point on Saturday so I had to change the day of sampling to another day” (Citizen Scientist-6, Bwikara Sub-county).

Slow and negative community response: Despite extensive community sensitisation efforts by the CSs, a portion of the community members exhibited resistance to behavioural change. This was often attributed to entrenched cultural beliefs and practices as captured in a story by CS-3 below.

“Some of the community members don’t want to change their habits, behaviours, and water practices. People still have their cultural beliefs about water practices. The human activities in places where I sample could hinder my sampling activity.” (Citizen Scientist-3, Kyaterekera Sub-county).

This sentiment was echoed by KII participants who highlighted instances of community members being resistant or dismissive when approached by the CSs, stating that;

“R. Some community members are adamant and didn't want to change when the citizen scientists talk to them about bilharzia prevention; when the CS go to their homes they are chased or even ignored” (KII-9, Mpeefu Sub-county)

Natural challenges: Rising water was a major problem for communities along the lake. As a result, over half of the landing sites and homesteads were displaced from their settlements. Meanwhile, heavy rains on the uphill side were observed by one of the local leaders. It should be noted that Lake Albert's water levels rose substantially higher than normal in the year 2020/2021. This study was conducted last year 2022 almost one year after the changes in water levels. These displacements caused by a rise in water levels and rain and sunshine also affected the implementation of the CSs’ work.

“R. During the start of the project, there was a flood at the sub-county that affected the CRs’ work. Also, the area is hard to reach, in fact, one of the landing sites has been left out due to the transport problem. (KII-5, Ndaiga Sub-county).

4. Recommendations for improving citizen science approach to behaviour change interventions.

The analysis of participants' data produced a range of recommendations proposed by the CSs, local leaders and the general community members in the MSC stories, KIs and FGDs. These encompassed various aspects such as managing community expectations, ensuring the provision of necessary equipment for the citizen scientists, and providing adequate facilitation. Further recommendations include addressing the community's real needs and strengthening community involvement among others.

Managing community expectations: Addressing the community's high expectations was a crucial recommendation for improving the CS approach to behaviour change intervention implementation. That is, the CSs emphasised the need to avoid creating dependency on financial facilitation during community meetings, highlighting that such practices are not sustainable in the long run. Instead, it was suggested that community benefits of the intervention should be communicated to them upfront, with explicit explanations of their roles and responsibilities. This was captured in the story by CS-2 as illustrated by the below quote.

“The community shouldn't be given any money, because when people get used to getting money, it becomes a habit. The community needs to learn that these projects come to help them so they shouldn't expect anything like money from the project” (Citizen Scientist-2, Ndaiga Sub-county).

In line with the above recommendations, participants suggested the need for prior information and awareness raising, particularly facilitated by local leaders. They emphasised the importance of informing the community that the citizen scientists are volunteers and do not receive any substantial monetary compensation. The CSs only received monthly financial compensation of Ug. Shillings 75,000/= (Seventy-five thousand only) equivalent to approximately 18.75 euros. It calls for transparent communication and

ensuring that the community has accurate information about the roles and motivations of the citizen scientists, hence facilitating shared understanding and expectations. This was captured in a story by CS-1.

“The community should be informed that we are only volunteering and not earning a lot of money. There’s a way it affects your mindset especially when you’re volunteering and people think you’re earning a lot of money” (Citizen Scientist-1, Kanara Town Council).

Strengthening community involvement and leadership: To address the problem of a lack of community response and disconnect with leaders, participants highlighted the need to strengthen the involvement of local leaders right from the beginning including decisions on the research topics. Participants recognised that the limited participation of some leaders initially could have contributed to the low community response. Participants stressed the need for collaboration and cooperation between citizen scientists and local leaders to effectively communicate about bilharzia. The story by CS-2 highlights some of these recommendations.

“The local leaders should be involved in sensitization and passing on bilharzia messages in the community. There should be a way in which the leaders should cooperate and work hand in hand with the citizen scientists to communicate about bilharzia in our community” (Citizen Scientist-2, Ndaiga Sub-county).

The importance of local leaders’ involvement in project interventions as a bridge between the project and the community was also captured in a story by CS-3

“We should continue involving local leaders in this program since they are closer to people and people can listen to them. The local leaders are key people in the community and we can’t do anything in the community successfully without their involvement” (Citizen Scientist-3, Kyaterekera Sub-county).

Addressing the real needs of the community: Some KII participants emphasised the importance of addressing the community's real needs in addition to awareness raising. They specifically highlighted the need for clean and safe water access as a critical issue that should be addressed alongside ongoing sensitisation programs. This was captured in a story shared by CS-3

“The project should provide clean and safe water to the communities and also continue with this sensitization program that has been started” (Citizen Scientist-3, Kyaterekera Sub-county).

Enhancing collaboration with local NGOs: Participants recommended strengthening collaboration with local NGOs as a crucial step towards ensuring the long-term sustainability of the approach. By partnering with other organisations, the project can foster continuity of ongoing programs and initiatives. Additionally, such collaborations would facilitate the engagement of a wider range of stakeholders in the implementation process.

“If there is a way, there could be advocates for NGOs and other organizations to help because the catchment area is too big. If possible other CRs could team up in one sub-county then others are recruited. I think looking for the sustainability of the project is also important like continuing with sensitization through saying football, forming SACCO, and integrating other projects into the ATRAP for it to continue” (KII-9, Mpeefu Sub-county).

6.3 Discussion

1. Significant changes that have taken place to citizen scientists

Ability to sample and report on snails: The current study reveals the ability to sample snails and report on them using smartphones as one of the most significant changes that had taken place the citizen scientists. The CSs narrated how the training provided to them by the ATRAP researchers equipped them with the knowledge and skills to collect data on snails. This change demonstrates the achievement of one

of the project's objectives of empowering local citizens to collect data on snails thereby putting science into practice. The findings from this study are comparable with a study in the United States of America (USA) in which the clinical scholars reported that the training provided by the program made them practical in the way they did their work (Henry et al., 2022).

Furthermore, the CSs stated from their stories that their relationships with the community and the way they do their tasks greatly improved as a result of snail sampling. The CS gave accounts of how they could explain their work to the community whenever they were asked. This finding is supported by another study in which one of the beneficiaries, a midwife narrated how the training provided to them had improved her management skills stating an improvement in the way she supervises subordinates and how she does her work generally (Limato et al., 2018). MSC, therefore, allows the capturing of beneficiaries' views and experiences with interventions in real-life situations.

Ability to effectively communicate about schistosomiasis: Another MSC reported by the CS was their ability to effectively communicate with the communities about schistosomiasis. The CSs explained that they got the ATRAP project trained them on verbal and non-verbal communication skills which they were able to apply easily to deliver messages to the community. This they said was not possible before. In their stories, the CSs narrated how they used to be shy to speak in public before they participated in the project. This is supported by previous studies that have also shown that effective communication skills were useful in building coalitions and advocating for better service delivery (Henry et al., 2022).

Interventions focusing on using a community citizen science approach for community-based behaviour change intervention could borrow a leaf from this current study by equipping communicators with knowledge and skills on how to communicate. However, a study that evaluated the caregiver-young

adolescent sexual and reproductive health communication revealed that caregivers were willing to communicate on comfortable topics while leaving out the sensitive ones (Akaturkwaswa et al., 2023).

Community and stakeholder engagement: Findings from this current study are also supported by another in the US which revealed that through the leadership training program, clinical scholars acquired skills on how to engage with local leaders to influence legislation outcomes, introduce new ideas, and advocate for behaviour change by the community (Henry et al., 2022). Community engagement is also reported by some other studies, to lead to improved uptake of praziquantel drug due to its potential to promote a deeper understanding of the problem (Spencer et al., 2022). Contrary to this study finding, another study in China that evaluated a school-based physical activity intervention, instead revealed that community engagement was limited to specific groups of people (Wang et al., 2022).

This difference could be because my current study did not focus on any specific group of people in the community. Rather it looked at all age groups, gender and other socio-demographic factors. This is also because my study was about schistosomiasis which affects people of all categories. Despite this variation, community and stakeholder engagement is considered an important component of behaviour change intervention for improving health outcomes (Martin et al., 2021).

Increased knowledge and a change in attitude regarding schistosomiasis: It should be observed that knowledge, attitude and practices are among the common measures used in evaluating intervention outcomes, whether at individual, institutional or community levels (Somerville & Wehn, 2022). No wonder, another change that received wide recognition from the citizen scientists in their stories as reported in this study, was the increased knowledge of and a big change in attitude towards the disease.

Findings from my previous study of KAPs regarding schistosomiasis reported adequate knowledge and a positive attitude toward the disease (Anyolitho et al., 2022). Interestingly, in this current study, the CSs reported aspects of the disease that they and the community, did not know about, including some of the signs and symptoms, and transmission mode. In addition, in this study, the CS said the communities never used to take schistosomiasis to be dangerous, which in a way, could have contributed to the communities' engagement in risky practices.

It is, therefore, likely that the intense campaigns could have unearthed knowledge gaps and enlightened the community accordingly. Findings from the current study are supported by other intervention evaluation studies that also reported an increase in knowledge and change in attitude regarding schistosomiasis by the communities (Akaturkwa et al., 2023; Dahmen-Adkins & Peterson, 2019; Gommerman & Monroe, 2012; Helinski et al., 2015). On the contrary, a study to evaluate the "obulamu" program in Uganda, reported that exposure to intervention did not lead to an increase in knowledge of delayed sexual activity, antiretroviral therapy, or breastfeeding infants by the participants (Burke et al., 2021).

Improved preventive practices regarding schistosomiasis: An improvement in preventive practices such as using boiled water at the domestic level and constructing and use of latrines for sanitation (WASH) was also reported by the CSs to be one of the most significant changes. These changes according to the CSs, occurred both at individual, family/household and community levels.

Findings from the current study are supported by other studies that also revealed significant changes in behavioural practices by communities such as improved facility visits by pregnant mothers (Limato et al., 2018), changes in parenting practices (Shah, 2014), improved behaviour of healthcare providers (Ho et al., 2015), active involvement in institutional/organisational activities (Dahmen-Adkins & Peterson, 2019),

adopting family planning methods (Aisiri et al., 2020), and improved sexual and reproductive health behaviour (Akaturkwaswa et al., 2023). These observed changes are a clear indication that if well planned and implemented, behaviour change intervention was effective and successful in causing significant change to the community.

Increased trust, respect and discipline: The CSs also reported in their stories that their involvement and participation in the behaviour change campaigns led to increased trust and respect by the community. The CSs noted that although the community used to trust them, the level was low. But after experiencing what the CSs were doing, and the evidence of their work in research, people in the community started giving them much respect and always listened to what the CSs told them. This is probably attributed to the improved communication skills acquired and the knowledge of the disease. Some studies have reported that community engagement fosters trust and confidence in volunteers since there is constant and open communication and dialogue (Shah, 2014).

Change in social status (Citizen scientists as doctors): This current study makes another interesting finding of the most significant change that happened to the CSs, that is, becoming experts on schistosomiasis issues. Findings demonstrate how the community refers to or views the CSs as snail doctors, water doctors, snail researchers, water doctors and community leaders (MP) among others. This is proof that the community recognises and values very much, the work of the CSs.

A similar finding from a participatory evaluation of a community-university collaboration program in Noto, Japan also reported that the awarding of formal certificates to participants created positive recognition and offered opportunities for mutual collaboration between the institution and the communities (Kitamura et al., 2020). Although in the case of ATRAP, no certificate of recognition was made, the

community still believed and recognised that the CSs did a great job and were equated to experts like doctors or professional researchers, hence earning such titles. Future interventions could look at formalising training and knowledge provided to community volunteers, not only for motivation purposes but also to incorporate such training into the education program. For instance, the government could come up with basic training certificate qualifications for community volunteers as this is found to improve their motivation.

2. Community's experience and perceptions regarding citizen science approach to behaviour change intervention

CS selection/recruitment and training: Recruitment has been defined as the “procedures used to approach and attract prospective program participants” (Cissell, 2004). In this study, I found that the community was very appreciative of the approach used by the project in recruiting CSs. The communities further noted that the process was transparent, participatory and engaging which allowed the selection of people who were trustworthy, hardworking, social, experienced, and competent.

The above could be true because the project engaged the community in the whole selection process, starting with the development of selection criteria, the communities recommending people through the local leaders and then local leaders participating in interviews as well as providing recommendations on who they thought was the most appropriate candidate. This in a way fostered trust, confidence and ownership of the selection outcomes.

A similar finding was also reported in a previous study which revealed that of the various recruitment methods used, non-formal face-to-face conversations with participants were the most effective because it was interactive, participatory and productive compared to other approaches like voluntold (asked to volunteer), monthly hazards inspection, newsletters and fliers (Van Eerd et al., 2018).

Contrary to findings from this current study, a study in Nampula province, Mozambique that evaluated the feasibility and acceptability of a community dialogue intervention in the prevention and control of schistosomiasis reported that the project could not realise their targeted number of community volunteers recruited (Martin et al., 2021). The study attributed this challenge to failure to reconcile the list provided by the health facility and that from the census, and also a difference in understanding of the term “communities”.

However, the variation could also have been because the project used a less engaging approach since the project relied on lists of community members provided by different sources instead of actively engaging with the local leaders to identify the volunteers. Furthermore, a process evaluation of the Communication for Healthy Communities adolescent health program in Uganda observed that though vital, the female sex educators “ssenga” who were recruited to provide sex education to the adolescents, had a disconnect with the adolescents as the educators could not use advanced communication technologies. This variation highlights the importance of participatory development of selection criteria to consider such contexts. The current approach of engaging with communities right from the development of selection criteria up to actual selection, therefore, provides a good foundation for the successful implementation of an intervention.

Practical skills and knowledge: My study findings also show that the communities appreciated the citizen scientists because they have practical knowledge and skills regarding schistosomiasis. The knowledge and skills acquired during training plus snail sampling and awareness raising increased community trust, confidence and respect in the CSs. No wonder, some of the CSs were able to impart their knowledge to their fellow volunteers who also successfully took up the tasks.

The findings of this study are supported by another study which also revealed that communication skills for example, enable actors (in this case, the CSs) to develop confidence and bring messages clearly to the general public (Asadullah & Muniz, 2015), effectively accomplish tasks assigned to them, take up responsibilities in the community as well as diffusing knowledge to their existing networks (Vohland et al., 2021).

Furthermore, this study found that the CSs demonstrated unique communication skills coupled with different modes, such as questions and answer sessions, illustrations and demonstrations. This could explain why the community appreciated the CSs because they were able to understand the messages clearly. This finding is supported by a study that evaluated the Obulamu program in Uganda that attributed the success of the intervention mainly to the communication skills of the caregiver adolescents and not necessarily the messages therein (Burke et al., 2021). Therefore, future interventions could emphasize the need to equip community volunteers with communication skills that could enable them to effectively deliver behaviour change communication intervention.

Approaches used: Related to the above, the current study found that the CSs used different but simple approaches to delivering messages to the communities. For example, the drama was highly appreciated by the majority of participants. The use of simple approaches also helps to ensure messages reach the intended audience. The door-to-door for example, is relevant to those who stay in their homes, while, the community meetings are appropriate for people in public places. Understanding these dynamics is important in designing contextualised communication strategies for good coverage and message reach. Moreover, the use of the CSs themselves as people who come from the same communities was another added advantage since they used local languages that everyone understood. The use of local channels to deliver messages by local communities themselves is also cost-effective, allows messages to reach the

intended audience, and is culturally appropriate as well. Moreover, this allowed other members of the community to get involved in channels such as drama, songs, and football tournaments, making it even more participatory and messages receptive. This finding is supported by a previous study in Uganda that evaluated the level of knowledge, attitude and practices (KAPs) regarding schistosomiasis. The study found that some communities had difficulties understanding the messages put across by the health workers. Besides, the IEC materials were inadequate and could not reach rural communities (Muhumuza, 2017). Behaviour interventions that aim at rural communities could borrow from this strategy to effectively cause a change in the communities.

Reach and coverage: This current study also found that the intervention had good reach and coverage. Reach in this context is used to refer to the extent of receipt of different messages passed to them. The fact that the CSs traversed different homes villages and different public places implies there was a good reach. Meanwhile, coverage is about the kind of information received by the audience. In this study, participants said they received messages about snails of different types, water sources of different types, signs and symptoms of the disease including transmission modes, diagnosis and preventive ways among others. They were also advised to always seek treatment from the health facility and not to rely on certain beliefs. All these could have mainly been due to the approach used, modes of delivery and the unique skills and knowledge of the CSs.

The decision to use volunteers from their community settings was another added advantage that future interventions could borrow from. The findings of this study are supported by other studies which also reported good interventions to reach and coverage indicated by improved health (Pramanik et al., 2012). An evaluation of the Obulamumu program in Uganda also reported limited reach and coverage of messages

which was attributed to the use of a one-size-fits-all approach and mode of delivery of the program such as reliance on commemorative days instead of going down to the communities (Burke et al., 2021). Similarly, an evaluation of the communication for healthy communities adolescent program in Uganda, revealed that the messages were limited in reach and coverage because the implementors only concentrated in urban areas while using conventional channels like print materials and TVs and radios as a top-down strategy (Nalukwago et al., 2020). A few studies have reported the benefits of top-down approaches to behaviour change interventions vis a viz the current bottom-up strategy employed in this study, future interventions could consider incorporating bottom-up approaches for effectiveness.

6.4 Conclusion

In this chapter, I presented findings and discussion on the participatory approach to the evaluation of citizen scientists' involvement in communicating schistosomiasis information to the community. From the chapter, community involvement is critical not only to data collection analysis, and implementation but also to the evaluation of the intervention. I demonstrate the significant changes that occurred to the CSs and the community's experiences and perceptions of the approach.

6.5 Theoretical and conceptual discussions

This study employed interpretivism as the dominant research paradigm supported by critical realism as the second research paradigm. From the results presented, the study has made significant theoretical contributions to the paradigms as illustrated in my sections below:

Contributions to the interpretivism: To begin with, the interpretive philosophical perspective says that the purpose of research should be to understand (verstehen) the meaning behind social reality as opposed to the positivist standpoint of explaining (Neuman, 2014) and that, reality is socially created in the process

of interaction, it is not an objective phenomenon as posited by the positivists. These assumptions resonate well with the objectives of my current study. For example, using the perspective I was able to understand and explore in-depth, the communities' views, perspectives and opinions regarding schistosomiasis, lived experiences, health-seeking decisions and reasons behind their actions, as well as their experiences and perceptions of the CS approach rather than simply explaining the phenomena.

Secondly, the use of qualitative data collection methods like in-depth and key informant interviews, and focus group discussions, enabled me to discover how schistosomiasis is socially and culturally created. As already pointed out in chapter four of the results above, using social constructionist thinking, I found out how the communities socially create meanings to schistosomiasis, its signs and symptoms, diagnosis, transmission as well as treatment and prevention. For example, the community shared their views on how they describe schistosomiasis signs and symptoms of swollen belly to a balloon, being pregnant or a rich person and thinning of the body as someone suffering from HIV/AIDs, etc. Also, the idea that human faeces are used as fish bait and that herbs can cure the disease were all socially and culturally created.

Another contribution of interpretivism is that it assumes that humans are interactive social beings who create reality and its meanings through interaction, they are not objects as the positivists had assumed. Also, there are multiple facets of reality not just one. These assumptions were proven to be true in my study because I found that the communities are indeed social beings who create their reality of the disease and the meanings attached to it. As already illustrated above, the communities have a way of interpreting signs and symptoms and taking action accordingly. They could also understand how difficult it is to take preventive measures.

Furthermore, the assumption that there are multiple realities was confirmed by this study. Again, as I illustrated above, different people have different understandings of what schistosomiasis is, its signs and symptoms, transmission modes, health-seeking actions and their reasons, as well as preventive practices.

From the study, I found that some people used to think that bilharzia is only transmitted through contact with lake water and no other sources of water like swamps, ponds, and rivers, while some people used to associate the signs and symptoms with poison or witchcraft.

The assumption of an inductive approach to reasoning can also be scientifically explained by this study. Inductive reasoning refers to understanding the meaning, processes, contexts and interpretations of the different aspects of reality (Yilmaz, 2013). Using different methods of qualitative data collection and analysis explained in Chapter Three above, I understood through my interaction with participants, the meanings the communities attach to schistosomiasis, the processes they go through in their experience of the illness and the different health-seeking and preventive actions they take. This idea of an inductive approach to reality is different from the positivist idea that reality can only be deductively studied.

The interpretive idea that reality is context-specific i.e., it varies from person to person, community to community and from setting to another also came to the fore (Creswell, 2014). For instance, I found out from my study of the KAP that communities uphill side had different knowledge dimensions of the disease compared to their counterparts at the lakeside. As already explained in chapter four of the results, those from the uphill side had some myths that eating cold food can make a person get bilharzia, and also that, taking certain herbs can help cure it. I also found that different people have different experiences with the disease, which influence them to take actions differently and for different reasons.

Similarly, there were different challenges with the signs and symptoms experienced and different reactions by the significant others. For some, the signs and symptoms were greeted with worries, sadness and denials, while others straight away related it to the disease, which in a way made it easy for them to navigate through. Also, for some people, they were stigmatised, isolated and discriminated against by people around them. Meanwhile, for others, they received emotional and social support as well as empathy from loved ones.

From the explanations above, interpretivism was instrumental in helping me understand the research topic. I believe that by connecting the theoretical analysis in chapter two with the results presented in chapter four above, readers should be able to appreciate the relevance. However, two critical areas remain unanswered by the paradigm, 1) an explanation of the extent of the phenomena and its associations, as well as 2) the transformative actions that can be taken by those affected by the problem. This is where critical realism finds relevance.

As mentioned earlier, critical realists agree with both positivist and interpretivist thinking. However, in critical realism, the fundamental nature of social reality is that it has multiple facets: the empirical, real and actual layers of reality (Neuman, 2014). In Neuman's explanation, critical realists posit that reality has the observable, unobservable that we can interpret and the causal mechanisms existing in the unobservable realm. Taking this line of thinking, researchers can therefore use both deductive and inductive approaches to reasoning also referred to as abductive or reproductive reasoning. Abductive/reproductive reasoning refers to the conduct of research in which investigators rely both on objective and subjective lenses in studying a given phenomenon (Bryman, 2012).

Abductive reasoning acknowledges that on the one hand, standing aloof (etic) is good for objectivity purposes because it allows the investigator to separate personal feelings and opinions from those being studied while observing the phenomena (deductive reasoning) (Neuman, 2014). Although the approach misses out on the underlying no observable aspects of the phenomena (the insider goings-on). On the other hand, immersing one's self in those being studied allows the researcher to understand the phenomena from the point of view of those being studied (emic), which is inductive reasoning (Creswell, 2014). Combining the two approaches leads us to use both objectivity and subjectivity to study given phenomena (Bryman, 2012). This line of thinking was relevant to my first study objective of the community's KAP regarding schistosomiasis. That is, deductive reasoning enabled me to determine the

level of KAPs and their association with various socio-demographic aspects. Meanwhile, inductive reasoning enabled me to unearth the communities' views, opinions and perspectives of the disease. This way, I was able to capture information on both the observable and non-observable aspects of the community's KAPs regarding schistosomiasis.

Critical realism also argues that the purpose of any investigator is not only to reveal what is hidden but also so that the revelations help to liberate those affected by the problem by getting empowered to take action towards addressing the problem (Creswell, 2014; Wagner et al., 2012). Additionally, people have the potential for change, only they are blindfolded by the positivist unfounded illusion of objectivity and the false consciousness of interpretivism (Neuman, 2014). This is also what Creswell refers to as the transformative worldview (Creswell, 2014). That is, research needs to be aligned with change agenda for the disadvantaged, oppressed, and disempowered of different categories and at different levels. This line of thinking tallies well with my participatory approach to the design and implementation of the behaviour change explained in chapter three of methodology and the results displayed in chapter four above. That is, the approach enabled me to disseminate baseline study findings which opened up the communities' minds about the problem of schistosomiasis and what they could do to address it. But also, using citizen science and PAR, I was able to engage the communities to take action in raising awareness for behaviour change regarding bilharzia. This way, it is hoped that people will adopt preventive practices. This is the transformative nature of research posited by Creswell (Creswell, 2014).

In the preceding sections, I explained the significance of interpretivism and critical realism to embody my understanding of theorising the problem of schistosomiasis and what community engagement can do to address it. In my explanation, I demonstrated how interpretivism as an overarching paradigm can be used to explain our understanding of social and cultural risk factors of schistosomiasis from different families of interpretivism such as symbolic analysis social construction of reality and phenomenology. These

theoretical lenses find merit in this study as one can easily connect theory with empiricism. Similarly, critical realism is instrumental in my study to explain my mixed methods approach to the KAPs study and, the participatory approach to design and implementation of the behaviour change intervention. Using critical realism, I find it interesting to situate people's critical analysis of phenomena such as schistosomiasis. But also, it augurs well with the transformative argument raised by the paradigm which fits the explanation of my objectives four and five above.

I note, however, that while both paradigms are well fitted to the explanation of my research project, left alone, none of them could ably ground the research project. Therefore, I find it naïve to rejoice in the use of either, rather than both. One question that arises from these arguments is: Can we find a parent paradigm that embraces all facets of this study? Can we do with one and leave the other? I have perused through the classical paradigms of positivism, interpretivism, post-positivism, critical realism and others, but I still have a hunger for a holistic paradigm.

Although this is often a daunting task for any other researcher, I have thought about marrying the different approaches and in my theoretical journey tried to come up with an approach that combines both the baseline critical realist and interpretive families of thoughts, together with those transformative thoughts such as citizen social science, that may or may not necessarily be hinged on critical realism. This quest for a central and holistic paradigm has only, so far led me to a unified theoretical model of citizen social science and PAR, based on analysis of social, political, cultural and historical contexts of a given phenomenon (explained in my conceptual framework 1.10.5 above). I hope that in the meantime, this will be able to give a comprehensive analysis of the problem of schistosomiasis and what actions people can take to address it. Future research needs to look at the complex social phenomena that are trans or multi-disciplinary, multi-faceted, multi-paradigmatic as well as multi-phased. The next chapter looks at conclusions and recommendations of the different findings.

CHAPTER SEVEN: CONCLUSIONS AND RECOMMENDATIONS

7.1 Introduction

This PhD project looked at the potential of community engagement approaches for behaviour change interventions related to schistosomiasis prevention and control. In particular, it employed citizen science and other participatory action research (PAR) techniques to engage with local communities in disseminating study findings, design and implementation of intervention as well as evaluation of the intervention. Five objectives guided the conduct of this study. These objectives included 1) determining KAPs of the community regarding schistosomiasis, 2) gaining insights into lived experiences of schistosomiasis, 3) Exploring health-seeking regarding schistosomiasis, 4) documenting the application of citizen science and other participatory approaches to the design and implementation of behaviour change interventions regarding schistosomiasis, and finally, 5) evaluating the application of the citizen science approach to behaviour change regarding schistosomiasis.

The studies were implemented in three phases: baseline (refer to the first three objectives), intervention (objective four above), and participatory evaluation (objective five above). Different methods were employed for sample size determination, participant selection, data collection and analysis as presented in Chapter Three above. Findings and discussions of results are presented in chapters four and five above. This chapter presents the conclusions, recommendations as well and implications of the study.

7.2 Conclusions

To understand social and cultural factors influencing schistosomiasis infection and reinfections among communities of western Uganda, and to inform the design and implementation of contextualised

interventions, I conducted three different baseline studies of KAP, lived experience and health-seeking behaviours.

On KAP specifically, previous literature indicated a significant relationship between knowledge, attitude risky practices and infection. Limited knowledge of schistosomiasis was reported to contribute to high infection among communities along Lake Victoria in Uganda. However, in this study, I found that the communities were knowledgeable of the disease and had a positive attitude towards preventive measures. On the contrary, I found common risky water practices due to lack of access to clean and safe water together with open defecation caused by low latrine coverage, especially by communities among the lakesides as the main problem.

Higher knowledge was reported about the signs and symptoms, transmission modes and preventive ways compared to the knowledge of the diagnosis. Furthermore, knowledge of the disease was higher for communities along the lake than those on the hillsides. Also, those with education, higher income levels and the elderly had higher knowledge than their counterparts. This was coupled with some persistent myths and misconceptions regarding the disease. These findings present new insights into the fight against the disease whereby instead of focusing on knowledge, and attitudes, interventions could focus on WASH infrastructures. Failure to address these challenges is likely to inhibit the elimination targets set both nationally and internationally.

Linked to knowledge, attitude and practice is a person's lived experience of a disease. In this study, I aimed to dig deeper into how the lived experience of individuals influences their perceptions, attitudes and therefore, preventive practices. Not much literature documented this problem, except the lived experiences of community health extension workers with MDA implementation. This study found that the disease not only impacts the physical well-being of those affected but also their emotional and mental

health, their relationships, and their economic stability. The findings highlight the multi-dimensional nature of schistosomiasis.

Linking it to knowledge, the study revealed that individuals with limited knowledge and experience of schistosomiasis tend to perceive it negatively compared to those who have some level of awareness of the disease. Meanwhile, those knowledgeable about schistosomiasis tend to have a positive perception of preventive measures. In some cases, however, knowledge and awareness alone are not sufficient to cause a behaviour change, as some members of the community never take preventive measures seriously. Furthermore, schistosomiasis illness experience causes a lot of fear, sadness, denial and worry especially if one has limited knowledge and awareness. In some cases, and due to strong cultural attachments, being knowledgeable alone is not adequate as some people still want to link the disease to conditions other than schistosomiasis itself, like malaria and HIV/AIDS. The sub-study also acknowledges the importance of social and emotional support mechanisms as the two strong coping strategies that individuals who suffer from schistosomiasis turn to. Other coping mechanisms include hanging with friends and watching movies are practised, even though some of the individuals end up indulging in negatively oriented solutions such as alcoholism and violence. Lastly, those who have suffered from schistosomiasis tend to have not only a positive perception of its prevention but also a favourable attitude towards taking preventive measures. They can, therefore, be very suitable people to act as change agents for implementing any behavioural change interventions regarding the disease. Therefore, interventions aimed at addressing schistosomiasis should look beyond the drug, WASH and knowledge and attitude, to include psychosocial and economic support to the communities.

As indicated above, understanding health-seeking behaviour regarding schistosomiasis by communities is critical to designing appropriate interventions. In this study, I explored the health-seeking behaviours of communities in western Uganda regarding schistosomiasis, especially in situations where there is no MDA

program or it has been delayed. From the findings above, I conclude that the current MDA implementation strategy falls short of expectations. Further, lack of community involvement and participation seems to compound the already challenging health systems and community barriers. Future interventions could consider a bottom-up approach with active community involvement in the whole process of MDA and social mobilisation.

The above conclusions also mean that effective co-design and implementation of bottom-up community-led behaviour change intervention regarding schistosomiasis is possible when the real problems as told by the sufferers are critical. As indicated in the conclusion of the baseline studies above, lack of access to clean and safe water, coupled with poor hygiene and myths and misconceptions, stigma hinder control and prevention of the disease. Based on these factors, there was a need to identify appropriate messages and channels through which messages would be delivered to the communities. As such, I found that communities that participated in this study prefer to receive schistosomiasis information using local approaches as opposed to conventional channels and using local language. No wonder, the citizen scientists together with community groups and local leaders were able to effectively co-design contextualised communication tools and to conduct the awareness using such channels as door-to-door approach, community dialogue meetings, drama, songs, dance and football infotainment. Interventions targeting endemic communities should therefore understand which channels are appropriate.

As already pointed out earlier, most interventions have been conventional in nature applying a top-down strategy. However, in this study, I employed a bottom-up community-led approach to the design and implementation of interventions. Using the above approach, the results indicated that the local communities included in this study can better understand and appreciate schistosomiasis problems when they are actively involved in interpreting the study findings. Furthermore, the communities can also voice their concerns and recommendations for appropriate actions based on their understanding of the

problems. Combining CS with other PAR methods is therefore one of the very suitable and promising approaches to engage communities in implementing behaviour change regarding schistosomiasis. The successful implementation of this study is a testament that it is possible to do so, moreover, with less effort and resources compared to the conventional ones. This study therefore concludes that integrating citizen science and PAR approaches has the potential to not only disseminate study findings but also to co-create and implement effective and inclusive schistosomiasis awareness campaigns in a contextualised manner. The collaboration between academic researchers and citizen scientists joined by other community leaders and groups to design and implement awareness-raising campaigns makes it even more insightful as different stakeholders are involved in the research process.

It is also important for communities to not only get involved in the design and implementation of interventions but also in the evaluation. Community involvement and participation in intervention evaluation reinforces outcome ownership and informs future design and implementation. However, previous studies from the literature reviewed indicated that most evaluations were done by experts to the exclusion of the beneficiaries and actors of the intervention. In this study, I employed participatory techniques to evaluate the citizen science approach to intervention regarding schistosomiasis.

From the findings, I conclude that a well-planned CS project together with the community right from the beginning, can facilitate community empowerment, transparency, accountability, inclusivity, trust, local leadership, participation and involvement and it allows smooth running implementation of the intervention. In the end, it ensures that the communities are in charge of their affairs, an important factor in the sustainability of health interventions. Secondly, the approach has the potential to achieve its intended goal of behaviour change regarding schistosomiasis. It is therefore proper to say that change, and tangible change, are possible when communities are involved in implementing interventions to

address problems that concern them. Lastly, the citizen science approach has the potential to influence policy and action at the local level.

If well planned and carefully implemented by involving the local communities right from the start of the research process like community engagement mobilisation and sensitisation about the project, identifying the research problem, agreeing on study sites, as well as selecting the citizen scientist, the citizen science approach can be a good engine for not only behaviour change, but also wider for overall socioeconomic development through influencing policy and action at different levels. From these findings, I can confidently conclude that the study provides significant insights into the application of the CS project for behaviour change regarding schistosomiasis as an NTD.

7.3 Policy recommendations from the study findings

This section presents policy recommendations for improving knowledge and attitude regarding schistosomiasis as well as addressing psychosocial challenges faced by people who suffer from the disease. The section also provides policy recommendations for the implementation of behaviour change interventions aimed at improving the uptake of preventive measures. Additionally, the section looks at policy recommendations for improving drug praziquantel uptake by adopting a bottom-up community-led approach to MDA as opposed to the current top-down. Finally, it presents information on recommendations for future research, study limitations and general conclusions about the PhD thesis.

1. Policy Recommendations for addressing Water, sanitation and hygiene (WASH)

From the baseline study of knowledge, attitude and practices regarding schistosomiasis, lack of access to clean and safe water was observed as a key barrier to prevention and control of the disease. Efforts should be made to provide WASH infrastructures where they are not available and improve them where the

availability is low. As far as this study area is concerned, the only available water source is the lake, plus other streams, ponds and rivers. Few taps and boreholes exist in the upstream. That is why communities especially those along the lake side cannot avoid contact with the lake source even if they are knowledgeable and would wish not to get into contact. Therefore, there is a dire need for the government to put in place deliberate policies to address this problem. The government needs to bring together the different ministries such as the Ministry of Health and the Ministry of Water and Environment to allocate budgets and ensure clean and safe water is provided to endemic communities. Furthermore, there is a need for the government to come up with policies for development partners to include the WASH component in all interventions that are implemented in endemic communities.

Linked to WASH was also the problem of local beliefs, myths and misconceptions, stigma, isolation and discrimination among others as barriers to the prevention of the disease. Furthermore, even though there was adequate knowledge and a positive attitude, some areas still did not have adequate awareness of the disease. This calls for constant and regular awareness to clarify information, demystify myths and reinforce existing knowledge base. Previous studies have also indicated that the existence of WASH infrastructure alone may not lead to behaviour change. Likewise, awareness and positive attitude alone may also not translate to behaviour change. This implies that on top of addressing the dire need for clean and safe water sources for all and ensuring proper sanitation and hygiene among the communities, the government has to come up with a specific communication strategy that targets awareness raising in these communities so that they can take appropriate preventive measures. Furthermore, to address the challenge of stigma, discrimination, isolation and economic factors, the government should ensure intervention policies are holistic in nature, not only focusing on drug administration and knowledge and awareness.

Finally, as already mentioned in the 2022 WHO's revised recommendation for 2030 goals, community engagement is key. This fact was confirmed by my current study which revealed that a lack of community involvement and participation in the MDA program hinders its successful implementation. Furthermore, my current study showed that active participation and involvement of communities in design and implementation have the potential to produce tangible outcomes. Therefore, the government needs to review its current intervention strategy and adopt a bottom-up community-led approach to not only the MDA but also social mobilisations, health education and sensitisation as well as any other prevention and control programs that it may deem necessary. Including the local communities in the intervention process right from the design to implementation and evaluation is critical for its tangible and sustainable outcomes.

7.4 Recommendations for future research

To address the methodological limitations of the KAPs study, the future should look at the effects of social-cultural factors on the communities' level of knowledge regarding schistosomiasis. This can be done by employing multivariate techniques to identify the interrelationships between the socio-demographics and test for multicollinearity. This way, the findings can provide in-depth and explanatory insights and models on which factors specifically pose a challenge to the communities.

One of the significant findings of my KAPs baseline study was the community's continued risky WASH practices. This was further confirmed and emphasized by the community both during participatory dissemination results and the design of interventions. At the co-design stage, communities strongly emphasise the need to address the problem of lack of access to clean and safe water and the issue of latrines. Unfortunately, due to the project's limited resource envelope, it could only focus on awareness raising, something they were also only able to do collectively with the community. This study, therefore,

strongly recommends future research that looks at a community-led approach to integrating WASH in the prevention and control of the disease from the community's perspectives as this is a crucial factor not only in the prevention of schistosomiasis but also in other diseases. This could for example also be done in close collaboration with local NGOs such as Join for Water and Raising the Villages.

Furthermore, as the last objective of my PhD research only looked at the involvement and participation of CSs in the project, it is only noble that an evaluation of the impact of behaviour change intervention on the community's KAPs, and perspectives be conducted. This way, it will demonstrate the extent to which the intervention impacted the community level.

Lastly, most studies on schistosomiasis have been either quantitative or qualitative or both. Not much is documented in in-depth ethnographic studies to provide a deeper understanding of the origin and reasons behind the myths and misconceptions of the community regarding the disease. These insights are needed to further study and develop effective and culture-specific strategies to combat these myths and misconceptions. Future research could look at this gap.

Similarly, there is no documented evidence to support the often-stated categorisation of endemicity. It is therefore not clear whether the communities understand this kind of description and categorisation. Endemicity here is scientifically determined by the prevalence of schistosomiasis. Whereas, the community may have their parameters and characteristics that they use to understand the problem of schistosomiasis. Understanding a community's perspectives of what is endemic and not endemic is important in initiating community engagement activities for the prevention and control of the disease. Probably, an ethnographic study to characterise schistosomiasis endemicity from a community perspective could help complement, clarify or even dispel some of the so-called scientific categorisations. In this context, the question could be, how endemic is endemic from the community's lenses?

7.5 Study limitations

Despite the significant findings of the study, there were some limitations as well. For instance, while the mixed method of equal weight design enabled me to determine KAPs regarding schistosomiasis and to explore and understand the reasons behind the disease, I could not ascertain which socio-demographics are the strongest predictors of knowledge, attitudes, and practices. This however was still important in showing the relationships between such factors and KAPs.

Next, this study employed largely qualitative designs in the sample size determination, participants' selection, data collection and analysis respectively. Due to this approach, there could have been some limitations. Firstly, on the representativeness of sample size, as this study focused on individuals within the western Uganda communities, it may not be representative of the experiences of schistosomiasis sufferers in other geographical regions, or in urban or more diverse populations. Therefore, the results and recommendations may not be generalizable to other contexts without further research.

Furthermore, the potential for bias: Due to the qualitative nature of the research, there is potential for bias in the data collection and interpretation. Participants might have altered their responses due to the presence of the interviewer (response bias). Similarly, the researchers' preconceived notions or experiences could have influenced the interpretation of the data. While this is possible, it is difficult to ascertain the extent to which they could have affected the outcomes of the study. However, I employed some control measures to minimise cases or the potential of bias occurring. For instance, in some of the sub-studies, I involved the community leaders in selecting study participants. Also, for data collection, I made sure I obtained the services of professional translators to transcribe the recordings. On analysis, I ensured that another person reviewed the transcripts and gave feedback on their authenticity and credibility.

Regarding study objectives two and three specifically, the phenomenological approach that deals with participants' subjective accounts, emphasizes the subjective experiences of individuals. This can be rich and insightful but can also limit the ability to draw objective or general conclusions. That is, two people with the same condition can have vastly different experiences based on personal circumstances, and these individual narratives might not capture all possible experiences of the disease.

There are various categorisations of the citizen science approach with some approaches being informative, contributory, and participatory. In this study, the involvement and participation of citizen scientists as community volunteer researchers only began from the dissemination of study findings to the end. They were not specifically involved in identifying study sites, defining research questions and designing the methods as well as in data collection exercises, which are important steps in the conduct of research. It is my considered view that this lack of citizen scientists' participation at the early stage of research could have had a significant impact on their knowledge, views and opinions regarding the research problem. However, it could also have had a significant impact on this study and the overall ATRAP study itself, as involving the citizens right from the start might have advanced the study even more or helped to generate other insights.

Also, the study site had limited geographical coverage, with no set organisation structure and monitoring and evaluation (M&E) targets at the beginning, thereby limiting the extent of the impact. Content-wise, the intervention only looked at awareness raising and no other community-pressing needs such as WASH, which are urgent too (see recommendation *supra*).

Finally, in my last objective, I methodologically employed a qualitative approach to evaluate citizen scientists' involvement and participation in behaviour change intervention as individuals and the community's perception of the approach. These methods could not ascertain the impact of the

intervention on the community's level of KAPs regarding the disease as this was outside the scope of this study.

7.6 General conclusions

As a general conclusion, this study aimed to evaluate the application of bottom-up community-led approaches to the implementation of behaviour change regarding schistosomiasis. Adopting a citizen science and participatory action research approach, the study was conducted in three phases, consisting of baseline studies of KAPs, lived experiences and health-seeking behaviour regarding the disease. Findings from these studies provided evidence-based information for the design and implementation of a contextualised behaviour change intervention.

The baseline studies revealed a high level of knowledge about schistosomiasis with some variations in understanding among different demographics. Despite this, there were localised interpretations of symptoms, reflecting socio-cultural influences. Also, while positive attitudes towards prevention were prevalent, misconceptions and barriers, such as inadequate access to clean and safe water and sanitation facilities persist, posing challenges to prevention efforts.

Lived experiences were found to greatly influence perceptions of schistosomiasis, with limited knowledge of the disease leading to negative perceptions, while awareness tends to foster positive attitudes. The illness experience was found to generate fear, sadness, denial and worry, with cultural factors contributing to varying interpretations of the disease. Social and emotional support mechanisms play a crucial role in coping. Those who have suffered from schistosomiasis tend to have a positive perception of prevention and can serve as effective change agents for behaviour change interventions. Health-seeking behaviour is influenced by challenges in mass drug administration (MDA), including delayed and irregular drug supplies and concerns about side effects. Lack of community involvement exacerbates

these issues, leading community members to seek treatment from private facilities, herbalists, witch doctors, and religious leaders. Addressing these challenges is vital for effective schistosomiasis treatment and control.

There is a high preference for localised channels for passing schistosomiasis messages by the communities. Citizen science and participatory action research approaches proved effective in co-designing and implementing context-specific awareness campaigns. Engaging communities in interpreting study findings and allowing them to voice concerns and recommendations enhances the effectiveness of behaviour change interventions. Finally, a well-planned citizen science project involving communities from the outset empowers, builds trust, and ensures local leadership and sustainability. Therefore, the CS approach has the potential to achieve behaviour change regarding schistosomiasis by increasing community knowledge attitudes and practices. Furthermore, it can influence policy and action at local and national levels, making it a valuable tool for addressing public health issues.

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Appendix Two: Informed Consent Form for In-Depth Interviews (IDIs)

Appendix Two: Informed Consent Form for In-Depth Interviews (IDIs)

**NERABARA UNIVERSITY OF SCIENCE AND TECHNOLOGY
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INFORMED CONSENT FORM

This document outlines the research study and conditions for potential participants. It should be written in language which is clear and easy to read.

Introduction

- The wording of the question should be directed to the potential participant (not the researcher).
- If a technical term must be used, then define it in the language to be used and the researcher's explanation should be written on the form next to the term.
- All the sections of the document should be completed without any omission of information.
- Please read a copy of this form to each participant before the question of the form. Explain the form and discuss it with them.

Study title - This describes the study as an of other documents relating to the study.

Community Engagement and Institutional Review - A biological Institute of the United Nations World Health Organization (WHO) is conducting research on the prevalence of malaria in Harare.

Research investigator

Introduction

What you should know about this study:

- You are being asked to participate in a research study.
- The research form contains the research study and your part in the study.

Leave blank for signature **RESEARCHER USE ONLY**

APPROVED BY: _____
APPROVED DATE: _____
RESEARCHER NAME: _____
RESEARCHER ID: _____

- Please read it carefully and take as much time as you need.
- You are a volunteer. You can choose not to take part and if you do, you may quit at any time. There will be no penalty if you decide to quit the study.

Brief background to the study

Malaria is a leading cause of illness and death in many parts of the world. In Zimbabwe, malaria is a major cause of illness and death. The research project is part of a five-year project (2015 to 2020) funded by the National Research Council (NRC) and the National Science Foundation (NSF) with the main goal of this project is to aid in the prevention of malaria in Zimbabwe thereby lowering the burden of disease caused by this parasite. The project that is being implemented in the two districts of Harare and Masvingo in Western Zimbabwe, is a collaboration between Masvingo University of Science and Technology (MUST) and the National Science Foundation (NSF). The information for which you are being asked to participate in, is a study that focuses on the prevention of malaria in Zimbabwe. It is hoped that the outcome of the study will greatly help in the prevention of malaria in Zimbabwe by bringing positive change to behaviour of the community.

Purpose of the research project

Include a statement that the study involves research, estimated number of participants, an explanation of the benefits of the research project and the expected duration of the subject's participation.

The purpose of this study is to examine the effectiveness of various control methods to community engagement to the prevention of malaria in Zimbabwe among selected rural communities of Masvingo Zimbabwe. The study objectives are to determine community knowledge, attitudes and practices regarding malaria, their health seeking behaviour, practices and attitudes, local perceptions and acceptance regarding malaria, implementation of control methods. The study will be used to assess the impact of malaria control methods (MCM) for some selected communities of the community that shall be determined during the study term. The estimated duration for the research shall be about one hour.

Why you are being asked to participate?

Explain why you have selected the individual participants in the study.

You have been asked to participate in the study on the basis that you have read and understood the importance of participating in the study and that you will provide the necessary information required for the study.

Leave blank for signature **RESEARCHER USE ONLY**

APPROVED BY: _____
APPROVED DATE: _____
RESEARCHER NAME: _____
RESEARCHER ID: _____

Procedure

Provide a description of the procedures to be followed and identification of any procedures that are experimental or unusual. It may be useful to describe the procedures in detail, including a statement regarding the extent to which the procedures are usual for the research.

The data collection procedure shall involve your participation in an in-depth interview on knowledge, attitudes, and practices including health seeking behaviour, local perceptions and acceptance regarding malaria, their health seeking behaviour, practices and attitudes, local perceptions and acceptance regarding malaria, their health seeking behaviour, practices and attitudes, local perceptions and acceptance regarding malaria. For proper collection of data, all answers will be recorded both in a note book and in an audio recording device.

Risks or discomforts

Describe any risks or discomforts that are anticipated or that have occurred in other research of this nature. If the research is not likely to benefit personally then the experimental procedure may also be considered as a risk.

There are no any known or anticipated risks associated with your participation in the study. There are no risks or discomforts that will be incurred in the process of the study. They shall be kept to bare minimum possible.

Benefits

Describe any benefits to the subject or other individuals that may reasonably be expected from the research. If the research is not likely to benefit personally then the experimental procedure may also be considered as a risk.

There are no any specific benefits of this study but generally, findings of the study will help to increase community knowledge and attitudes towards malaria, to identify and address social and cultural factors that prevent malaria, to create awareness on malaria, and to build an community involvement in malaria prevention.

Incentives or rewards for participating

As a participant that there are no any incentives or rewards provided to research participants. Any payments to be made to the subject, or other incentives, other than the experimental procedure may also be considered as a risk.

There are no any incentives or rewards attached to this study. As part of expenses regarding the data collection, each participant will be given a high 5000, plus transport cost as per request for the group upon while participating in the study and transport refund where applicable of up to 5000. These financial findings only, shall also be provided.

Leave blank for signature **RESEARCHER USE ONLY**

APPROVED BY: _____
APPROVED DATE: _____
RESEARCHER NAME: _____
RESEARCHER ID: _____

Protecting data confidentiality

Provide a statement describing the extent to which confidentiality or privacy identifying the subject will be maintained. It may be useful to describe the procedures in detail, including a statement regarding the extent to which the procedures are usual for the research.

Any information shared with the research team will be treated as confidential. After processing and analyzing the information to generate all of data will be coded. This means that you can identify a participant as an anonymous "number" but cannot tell who that person was.

Protecting subject privacy during data collection

Describe how the privacy of the research will be maintained during the process of data collection.

All interviews shall be conducted in a private and quiet place chosen by the respondent/participant. No sensitive question that may require affect you shall not be asked.

Right to refuse or withdraw

Include a statement that participants in voluntary and the subject's participation will involve no penalty or loss of benefits to which the subject is otherwise entitled.

Your participation in this study is voluntary. You have the right not to participate in the study if you do not wish to do so at any time. There is no any penalty or loss of benefits to which you would be entitled if you decide not to participate.

What happens if you leave the study?

Describe the conditions and any other arrangements or any other conditions or loss of benefits to which the subject is otherwise entitled.

There is no penalty that shall be levied to you if you decide to leave the study at any moment of the study. You may withdraw from the study at any time. There is no any penalty to participate in the study.

Who do I contact if I have questions or a problem?

Include your name and telephone number for the study, you may contact the (Principal Investigator) Masvingo University of Science and Technology (MUST) Research and Ethics Committee (REC) on Harare telephone on Tel: +263-92-545-0793 or office on +263-92-545-0792. For any questions.

Leave blank for signature **RESEARCHER USE ONLY**

APPROVED BY: _____
APPROVED DATE: _____
RESEARCHER NAME: _____
RESEARCHER ID: _____

Signature of subject/participant _____

Signature of Researcher/Principal Investigator _____

Date _____

Signature of Researcher/Principal Investigator _____

Date _____

Signature of Researcher/Principal Investigator _____

Date _____

Leave blank for signature **RESEARCHER USE ONLY**

APPROVED BY: _____
APPROVED DATE: _____
RESEARCHER NAME: _____
RESEARCHER ID: _____

Signature of subject/participant _____

Signature of Researcher/Principal Investigator _____

Date _____

Signature of Researcher/Principal Investigator _____

Date _____

Signature of Researcher/Principal Investigator _____

Date _____

Leave blank for signature **RESEARCHER USE ONLY**

APPROVED BY: _____
APPROVED DATE: _____
RESEARCHER NAME: _____
RESEARCHER ID: _____

Appendix Three: Informed Consent Form for Focus Group Discussions (FGDs)

Appendix Three: Informed Consent Form for Focus Group Discussions (FGDs)

INDONESIA UNIVERSITY OF SCIENCE AND TECHNOLOGY
RESEARCH ETHICS COMMITTEE
 271 Ave 2025 Makassar, Tel: +622-401-001-2740, Fax: +622-401-001-2740
 E-mail: informed@ugm.ac.id, research@ugm.ac.id

INFORMED CONSENT FORM

This document outlines the purpose, goals, and procedures for the proposed research. It should be written in language that is understandable to the participants.

Introduction

- The purpose of this document is to provide information to the potential participants and to obtain their informed consent.
- All information provided in this document is true and accurate.
- The purpose of this document is to provide information to the potential participants and to obtain their informed consent.

Study Title: The study is titled "The Effect of ... on ..."

Researcher's Name and Affiliation: A Researcher of the ...
 ...
 ...

Researcher's Name: ...

Researcher's Address: ...

Researcher's Contact Information: ...

Researcher's Signature: ...

Researcher's Stamp: ...

Researcher's Title: ...

Researcher's Institution: ...

Researcher's Address: ...

Researcher's Contact Information: ...

Researcher's Signature: ...

Researcher's Stamp: ...

Researcher's Title: ...

Researcher's Institution: ...

What background to the study

The purpose of this study is to ...

Purpose of the research project

The purpose of this study is to ...

Why are you being asked to participate?

You are being asked to participate in this study because ...

What are the risks and benefits of participating?

The risks of participating in this study are ...

What are the benefits of participating?

The benefits of participating in this study are ...

Researcher's Name: ...

Researcher's Address: ...

Researcher's Contact Information: ...

Researcher's Signature: ...

Researcher's Stamp: ...

Researcher's Title: ...

Researcher's Institution: ...

How the data will be collected

The data will be collected through ...

How the data will be analyzed

The data will be analyzed using ...

How the data will be used

The data will be used for ...

How the data will be stored

The data will be stored in ...

How the data will be shared

The data will be shared with ...

Researcher's Name: ...

Researcher's Address: ...

Researcher's Contact Information: ...

Researcher's Signature: ...

Researcher's Stamp: ...

Researcher's Title: ...

Researcher's Institution: ...

Protecting data confidentiality

The data collected during this study will be treated as confidential. ...

Protecting data confidentiality

The data collected during this study will be treated as confidential. ...

Protecting data confidentiality

The data collected during this study will be treated as confidential. ...

Protecting data confidentiality

The data collected during this study will be treated as confidential. ...

Protecting data confidentiality

The data collected during this study will be treated as confidential. ...

Researcher's Name: ...

Researcher's Address: ...

Researcher's Contact Information: ...

Researcher's Signature: ...

Researcher's Stamp: ...

Researcher's Title: ...

Researcher's Institution: ...

What if you have any questions related to the study?

If you have any questions related to the study, you may contact the researcher of ...

What if you have any questions related to the study?

If you have any questions related to the study, you may contact the researcher of ...

What if you have any questions related to the study?

If you have any questions related to the study, you may contact the researcher of ...

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If you have any questions related to the study, you may contact the researcher of ...

What if you have any questions related to the study?

If you have any questions related to the study, you may contact the researcher of ...

Researcher's Name: ...

Researcher's Address: ...

Researcher's Contact Information: ...

Researcher's Signature: ...

Researcher's Stamp: ...

Researcher's Title: ...

Researcher's Institution: ...

What if you have any questions related to the study?

If you have any questions related to the study, you may contact the researcher of ...

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Researcher's Name: ...

Researcher's Address: ...

Researcher's Contact Information: ...

Researcher's Signature: ...

Researcher's Stamp: ...

Researcher's Title: ...

Researcher's Institution: ...

Appendix Four: Survey questionnaire to households for KAPs study

Community Engagement and Schistosomiasis Prevention: A Sociological Analysis of the Citizen Science Model among Selected Communities of Western Uganda

Respondent Code:

Name of village..... Parish..... Sub-county.....

INSTRUCTION: Please read the questions carefully and tick or circle the letter/s that correspond/s to the correct answer

A. SOCIO-DEMOGRAPHIC CHARACTERISTICS

1. What is your gender?

1. Male
2. Female

2. How old are you?..... (age in years only)

3. What is your marital status?

1. Single (not married)
2. Married (spouse has one partner)
3. Married (spouse has more than one partner)
4. Widowed
5. Divorced
6. Separated
7. Others specify.....

4. If you are married, what form of marriage?

1. Customary
2. Civil
3. Religious

5. What is your highest level of education?

1. No formal education
2. Primary level
3. Secondary level
4. Tertiary level
5. Post-graduate

6. Which of these is your ethnicity?

1. Mutoro/Mutuku
2. Mukiga
3. Munyoro
4. Mukonjo
5. Mufumbira/Munyarwanda
6. Alur
7. Mwamba

8. Other, specify.....
7. **What kind of affiliation is customary in your clan?**
1. Matrilineal (mother's side)
 2. Patrilineal (father's side)
 3. Bilineal
8. **What is your religious affiliation?**
1. Catholic
 2. Anglican
 3. Muslim
 4. Pentecostal/Born Again/Evangelical
 5. Seventh Day Adventist
 6. Traditionalist
 7. Faith of unity
 8. Orthodox
 9. Others specify.....
 10. Non-Religious
9. **What is your main source of income?**
1. Crop growing
 2. Fishing
 3. Fish farming
 4. Livestock rearing/animal husbandry
 5. Business
 6. Employment
 7. Others specify.....
10. **What is your average monthly income?**
1. Less than Ugx: 100,000/=
 2. Ugx: 100,000/= - Ugx: 199,999/=
 3. Ugx: 200,000/= - Ugx: 299,000/=
 4. Ugx: 300,000/= - Ugx: 399,000/=
 5. Ugx: 400,000/= - Ugx: 499,000/=
 6. Ugx: 500,000/= - Ugx: 599,000/=
 7. Ugx: 600,000/= and above
11. **How many members are in your household?.....**
12. **What is the estimated distance from the nearest health facility? (in kilometres)**
13. **How many water sources (domestic and others) are present in the village?.....**
14. **What is the estimated walking time to reach the nearest source of water for domestic use by your household? (estimate in minutes)**
- B. PRACTICES TOWARDS BILHARZIA**
15. **Which of these is the most commonly used source of water? (Tick all that apply)**
1. River
 2. Lake

3. Stream
4. Pond
5. A developed well
6. An undeveloped well
7. Borehole
8. Piped tape
9. Other.....

16. Which kind of activities are carried out at the respective water sources selected above? (Tick all that apply)

1. Drinking water
2. Washing clothes
3. Washing utensils and dishes
4. Washing vegetables
5. Fishing
6. Bathing
7. Taking animals for drinking
8. Swimming
9. Washing motorcycles
10. Defecation
11. Urination
12. Playing by children
13. Irrigation
14. Others specify.....

17. On average, how many times a day do you get into contact with the water?

1. Once a day
2. Twice a day
3. Thrice a day
4. Four times a day
5. Five times a day
6. Others specify.....
7. Do not get into contact with water
8. Not sure

18. Do you have a toilet facility? (If no, go to question #23)

0. No (Give reason(s).....)
1. Yes

19. When was the last time you defecated outside the toilet?

1. Less than a week ago
2. More than a week ago but within a month
3. More than a month ago but within the last three months
4. More than three months ago but within the last six months
5. More than six months ago but within this year
6. More than a year ago
7. I can't remember
8. I have never defecated outside the toilet

20. Where exactly did you defecate outside the toilet?

1. In an open space

2. In the bush
3. In the water
4. Near the water
5. I don't remember

21. How often do you defecate outside the toilet?

1. Quite often
2. Less often
3. Rarely
4. It was only once
5. As and when nature calls
6. Don't know
7. Other specify.....

22. What would be the main reason for you to defecate outside the toilet?

1. I don't have a toilet
2. I don't like using the toilet
3. The toilet is very far
4. The toilet is spoilt
5. My culture doesn't allow the use of toilet
6. Because of the need to respond to nature's call
7. Other specify.....

23. When was the last time you urinated outside the toilet?

1. Less than a week ago
2. More than a week ago but within a month
3. More than a month ago but within the last three months
4. More than three months ago but within the last six months
5. More than six months ago but within this year
6. More than a year ago
7. I can't remember
8. I have never urinated outside the toilet

24. Where exactly did you urinate outside the toilet?

1. In an open space
2. In the water
3. In the bush
4. I don't remember

25. How often do you urinate outside the toilet?

1. Quite often
2. Less often
3. Rarely
4. It was only once
5. As and when nature calls
6. Other specify.....

26. What would be the main reason for you to urinate outside the toilet?

1. I don't have a toilet
2. I don't like using the toilet
3. The toilet is spoilt
4. My culture doesn't allow the use of toilet

5. Because I am pressed by nature's call
6. Other specify.....

C. KNOWLEDGE AND AWARENESS OF BILHARZIA

27. **Have you ever heard about bilharzia?** *(If no go to question 34)*

0. No
1. Yes

28. **If you have ever heard of bilharzia, where did you first hear about it** *(Tick only one option)*

1. Newspapers and magazines
2. Radio
3. TV
4. Billboards
5. Brochures, posters and other printed materials
6. Health workers
7. Family, friends, neighbours and colleagues
8. Religious leaders
9. Political leaders
10. Teachers
11. Other
12. Never heard of bilharzia

29. **If you have heard about bilharzia, which of the following is the correct meaning of bilharzia?** *(Tick only one response)*

1. It is a disease
2. It is a curse
3. It is a symptom
4. Others specify.....
5. None of the above
6. Don't know

30. **If you have heard about bilharzia, what are the signs and symptoms of bilharzia?** *(Please Tick all that apply)*

1. Abdominal pain
2. Diarrhoea
3. Blood present in stool
4. Belly enlargement
5. Severe Fever
6. Skin rash
7. Stunted growth
8. Reduced learning ability
9. Other specify.....
10. Do not know

31. **If you have heard about bilharzia, how can a person get bilharzia?** *(Please Tick all that apply)*

1. Handshakes
2. Contact with water
3. Witchcraft
4. Misfortune
5. Violating traditional taboos
6. Do not know

7. Other.....

32. How can a person know that they have bilharzia? (Tick all that apply)

1. Signs and symptoms
2. Urine test
3. Stool test
4. Ultrasound scan
5. Other specify.....
6. I don't know

33. How can a person prevent infections from bilharzia? (Please Tick all that apply)

1. Medication
2. Avoiding contact with water
3. Avoid open defecation
4. Avoid open urination
5. Avoid eating unwashed vegetables
6. Avoid uncooked meat
7. Snail control
8. Do not walk barefoot
9. Boiling water from a river or lake
10. Other specify.....

34. Have you or any of your family members had any of the following symptoms? (Read all responses)

1. Abdominal pain
2. Diarrhoea
3. Blood present in stool
4. Belly enlargement
5. Severe Fever
6. Skin rash
7. Stunted growth
8. Reduced learning ability
9. Other specify.....
10. Do not know

D. ATTITUDES TOWARDS SCHISTOSOMIASIS

Now I would like you to give your opinion on schistosomiasis by stating the extent to which you agree or disagree with each of the following statements. The options range from Strongly Agree (SA), Moderately Agree (MA), Agree (A), Not Sure (NS), Dis-Agree (DA), Moderately Disagree, Strongly Disagree (SD)

Q n	Statement	S A	M A	A	N S	D A	M D	S D
35.	Bilharzia is a very serious disease							
36.	It is necessary to prevent infection from bilharzia							
37.	It is my responsibility to prevent infection from bilharzia							
38.	It is important to know whether I have bilharzia or not							

39.	It is important to avoid contact with water							
40.	Defecating in the toilet is important for my health							
41.	Urinating in the toilet is important for my health							
42.	I sometimes eat uncooked meat							
43.	I eat unwashed vegetables quite often							
44.	I would take action if I found that I had bilharzia							
45.	Taking medication for bilharzia is important for my health							
46.	If I find that have bilharzia, I should go to the hospital							
47.	If I find that have bilharzia, I should see a traditional health practitioner							
48.	I need to be informed about bilharzia							
49.	I would like to get more information about Bilharzia							

E. SCHISTOSOMIASIS INFECTIONS, RE-INFECTIONS AND HEALTH-SEEKING BEHAVIOUR

50. In the past year, have you ever suffered from bilharzia? (If your response is no, skip to Q52)

- 0. No
- 1. Yes

51. How many times have you ever suffered from bilharzia?.....

52. If no, has any of your family members ever experienced any of the following symptoms?

- 1. Abdominal pain
- 2. Diarrhoea
- 3. Blood present in stool
- 4. Belly enlargement
- 5. Severe Fever
- 6. Skin rash
- 7. Stunted growth
- 8. Reduced learning ability
- 9. Other specify.....
- 10. Do not know

53. How many of the members have ever experienced the above symptoms?.....

54. In the past year, did you or any of the relatives seek help from anywhere about the symptoms?

- 0. No (If no, why?.....)

1. Yes

55. **If yes, where did you seek help from?** (*Tick all that apply*)

1. Health facility
2. Traditional health practitioner
3. Treated my self
4. Others specify.....

56. **If you sought help from the health facility, which facility was it?** (*Tick all that apply*)

1. Private for-profit clinic
2. Private not-for-profit health facility
3. Government health facility (like HCII, HCIII or HCIV)
4. Bought medicines from drug shop/pharmacy (mention drug.....)
5. Other specify.....

57. **If you sought help from a traditional health practitioner, which of the following did you seek help from?** (*Tick only one option*)

1. Witchdoctor
2. Traditional birth attendant
3. Took herbal medicine (specify.....)
4. Other specify.....

58. **If you treated yourself, what exactly did you do?**

1. I bought some drugs
2. I got some herbs
3. I prayed

F. SCHISTOSOMIASIS INFORMATION & COMMUNICATION

59. **Which of the following information about bilharzia would you wish to get most?** (Mention all)

1. Causes
2. Signs and symptoms
3. Prevention
4. Cure/Treatment
5. Care for the sick
6. Drug availability, accessibility & affordability
7. Side effects of drugs
8. Myths and misconceptions
9. Where to report cases/symptoms
10. Others
11. Don't know

60. **Which of the following sources of information on bilharzia do you think can most effectively reach you?** (*Please choose only the three most effective sources*)

1. Newspapers and magazines Ne
2. Radio stations
3. TV channels TV
4. Theatre plays

- 5. Mobile Phone messages
- 6. Billboards
- 7. Brochures, posters and other printed materials
- 8. Health workers
- 9. Family, friends, neighbours and colleagues
- 10. Religious leaders
- 11. Politicians
- 12. Famous actors or singers
- 13. Teachers
- 14. Other (specify).....

61. Do you have anything else to say?

- 0. No
- 1. Yes

If yes state here.....

Thank you very much for your participation in the study!!

Appendix Five: Interview Guide to community members for KAPs study



Topic: Community engagement and schistosomiasis prevention: A sociological analysis of the citizen science approach among selected rural communities of western Uganda

IN-DEPTH INTERVIEW GUIDE WITH SELECTED COMMUNITY MEMBERS & AND LEADERS

1. Introduction of interviewer/researcher and purpose of the interview
2. **Demographic Information:** Briefly introduce yourself in terms of your age, gender, level of education, working status, marital status and nearest health facility from your home (probe for any information not mentioned).
3. **Practices regarding schistosomiasis**
 - Explain to me the common sources of water in your area and their different uses. (Probe for each source of water mentioned)
 - What type of latrines do you have in your homestead? Explain their conditions, and how you use them (*probe for type, defecation and urination, use by age, gender, etc.*)
4. **Knowledge your understanding, what do you know about bilharzia?**
 - Briefly tell me what you know about bilharzia i.e. what it is, signs and symptoms, risk factors etc
 - What are some of the water-related activities that lead to infection from bilharzia and how?
 - How does defecating outside the toilet lead to infection from bilharzia?
 - How does urinating outside the toilet cause infection from bilharzia?

- What should a person infected with bilharzia do?
- What medications are given to people who are infected with bilharzia (probe for type, availability, affordability, accessibility)
- In your opinion how can a person prevent infection from bilharzia?
- In what ways can the community get involved in the prevention of infection from bilharzia?
- What information about bilharzia would you need to be given? And how would you need to receive information about bilharzia?

5. Attitudes

- In your opinion do you think bilharzia is a serious disease? If so, why? And if not, why?
- Personally, do you think it is necessary for you to be bothered about bilharzia? Why?
- Some people say that it is necessary to prevent bilharzia infection. What do you have to say about it?
- What would you do if you found that either you or your close relative had bilharzia?
- When was the last time you checked for bilharzia? If not, would you be willing to check for bilharzia?
- In your opinion how important is it to defecate or urinate in the toilet?
- What is your opinion about avoiding contact with water?

6. Health-seeking behaviour

- What actions do you take when you fall sick or feel unwell? (*probe for a place of medication, private clinic, pharmacies/drug shops, traditional medication, prayers, finance, distance, gender dynamics etc.*)?
- What actions did you or your close relative take when you or that person found that you or the person had bilharzia?
- Where do people in your community go when they find that they have bilharzia or its symptoms?
- What reasons do people give for taking medications for bilharzia from where they go

7. Awareness and behaviour change campaign strategy

- Where do you currently get health information from, which of the sources of health information do you trust most and why?
- If you have ever heard about bilharzia, where did you first hear from?
- If you have ever heard of bilharzia or not, we would like to make sure more people receive correct information about bilharzia, in your opinion in which way can we best spread information on bilharzia to reach as many people as possible?

8. Gender dynamics and complexities

- What are some of the household assets and who has ownership over them and why?
- Which activities are mostly done by women (and girls) and which ones are done by men (and boys)?
- Who decides what should be done in the household and why?
- Which water-related activities are specifically done by women and which ones are done by men? And who decides on the water-related activities done by each gender and why?
- Between women and men, who are more likely to get bilharzia and why?

- 9. Conclusion:** Thank you very much for taking the time to participate in this study; before we end the conversation, I would like to know whether you have any feedback on the conversation and whether you have anything else to say.

Thank you very much the conversation has ended.

Appendix Six: Focus Group Discussion guide to community members for KAPs study



Topic: Community engagement and schistosomiasis prevention: A sociological analysis of the citizen science approach among selected rural communities of western Uganda

FGD GUIDE WITH SELECTED COMMUNITY MEMBERS FOR KAPs STUDY

1. **Introduction:** The research team, purpose of the meeting including some brief background to the study
2. **Demographic information**
 - I would like to ask you to start by giving me your background in terms of age, gender, level of education, working status, marital status and nearest health facility to your home (probe for any information not mentioned).
3. **Practice**
 - Which sources of water do you have and what common activities are carried out at each of the different water sources? (probe for fishing, bathing, swimming, washing utensils, clothes etc.)
 - Do people in your community have latrines? Which type and how do you use them? What challenges do you face with them?
 - Are there some people in your community that defecate or urinate in the open? (probe for bush, water, road etc) If so, which age group and gender is the most common and why? Why would they defecate or urinate in the bush?

4. Knowledge of bilharzia

- In your understanding, tell me what you know about bilharzia (signs and symptoms)
- How do people get infected with bilharzia and which categories of people can get infected?
- Do you think that a person who has ever been infected earlier can get it again or not? If so, why and how?
- Explain ways in which bilharzia can be prevented
- What are the available treatments, where and the associated treatment costs?
- Describe some of the water-related health problems of this community (probe if bilharzia is not mentioned)
- How is defecating and or urinating in open/water related to bilharzia?

5. Community attitudes towards bilharzia

- Some people say bilharzia is a very serious disease, what do you have to say about it and why? How would you react to signs and symptoms of bilharzia and Why?
- In your capacity what would you do to prevent infection from bilharzia?
- What is your opinion on the idea of avoiding contact with water to prevent infection from bilharzia and Why? (probe for swimming, fetching water, washing clothes and utensils, etc.)
- Do you think defecating or urinating outside the toilet is bad? If so why? Why do some people still defecate and or urinate outside the toilet?
- What actions would you take if you or a close member of your household had bilharzia?
- In your opinion, would it be necessary to get any information about bilharzia? If so, why?
- When was the last time you checked for bilharzia? If not, would you be willing to check for bilharzia?

6. Health-seeking behaviour

- Symptoms experience-how does the community know when a person has bilharzia?

- What do you do when you discover you have bilharzia? Who decides on what to do?
- Health seeking on bilharzia –What medications do you take for bilharzia?
- Where do you go for medication for bilharzia?

7. **Gender and children**

- Risk of exposure- How do gender differences in water-related activities influence the risk of bilharzia infection?
- Gender dimensions of health decision-making making; Which medications do the different genders take and where do they go for medication?
- What support would the men give if their wives or children got infected with bilharzia? (probe for escorting women, taking children to hospital, financial support, social support, psychological support etc.)

8. **Information and communication**

- What are the most commonly used sources of health information by the community currently?
- Which sources of health information would you prefer and why?
- When was the first time you heard information about bilharzia? What is your view on current information about bilharzia in terms of ease of accessibility, affordability, availability etc.?
- In your opinion, what is the best way of spreading information on bilharzia in your community?

9. **Conclusion:** Thank you very much for taking the time to come and participate in this important discussion on how we can address the problem of bilharzia. Before we end, I would like to know if any of you have any further contributions to make.

Thank you very much the meeting has ended.

Appendix Seven: Interview Guide to Communities for Lived Experiences of

schistosomiasis

a. Introduction:

I am conducting a study about the lived experiences of communities regarding schistosomiasis infection and how this shapes their perceptions towards the disease. Findings from this study will provide baseline information for developing behaviour change interventions for the community in preventing schistosomiasis. I therefore request you to answer for me a few questions that I will be asking. It will be conversational and the whole session may take about one and a half hours at most.

b. Socio-demographic characteristics:

- To begin with, I would like to know you generally i.e. your age, marital status, education status, religion, working status and income including the number of children you have.

c. Pre-experience perceptions:

- How did you feel about schistosomiasis before your experience?

d. Symptom experience:

- Describe your experiences with the symptoms, manifestations, magnitude/gravity, emotions and feelings caused (state this for each of the signs and symptoms)
- What came to your mind when you had the symptoms experience?

e. Impact of the experience on significant others

- How did the experience impact your relationships with others? How did others around you view you? What did others say about your conditions, worries, annoying, support

f. Actions taken

- What actions did you take? (Prob for medication seeking decisions/actions and factors influencing decision, sources of medication, treatment experience and outcomes of treatment-satisfaction, side effects.)

g. Challenges faced

- Explain some of the challenges you faced during your experience with the disease. (food-related, medication, social relations, emotional etc.)

h. Coping mechanisms

- Other than seeking medication, what were some of the things you did to manage your situation? Probe-prayer, relaxation, games, work, talking about it, sharing with others

i. Perceptions about the disease

- How did the experience influence your perspectives on schistosomiasis? How has it impacted your view of water, and related practices and fishing, swimming, drinking, bathing, washing etc?

j. Advice to those who have not experienced or are suffering from the disease

- What advice would you give to a person who has not had such an experience? (Behaviour-related advice- water practices, hygiene and sanitation-open defecation and urination, eating half-cooked food etc.)

- k. Do you have anything else to say?

Thank you very much for your participation

Appendix Eight: Focus Group Discussion Guide to Communities for Lived Experiences of

Schistosomiasis

a. Introduction:

I am conducting a study about the lived experiences of communities regarding schistosomiasis infection and how this shapes their perceptions towards the disease. Findings from this study will provide baseline information for developing behaviour change interventions for the community in preventing schistosomiasis. I am therefore requesting you to participate in this study by way of question and answer sessions in a group. We shall have about one and a half hours of discussions around key topics. I emphasize that there is no right or wrong answer, so feel free to express your view.

b. Socio-demographic characteristics:

- To begin with, I am requesting each of you to tell me more about yourself, i.e. your age, marital status, education status, religion, working status and income including the number of children you have so that we somehow know who we are interacting with.

c. Pre-experience perceptions:

- How did you feel about schistosomiasis before your experience? How did you use to view the disease?

d. Symptom experience:

- What came to your mind when you started experiencing the symptoms? (Emotions and feelings)
- Describe your experiences with the symptoms they manifested, the types, and how they manifested- mild or grave (state for each of the signs and symptoms). How did you conclude that it was schistosomiasis?

e. Impact of the experience on significant others

- How did others around you view or react to you? What did they say or do about your conditions, worries, annoyance, and support?

f. Actions taken

- What actions did you take and why did you take such action/s? (probe for health seeking on medication, factors influencing decision, sources of medication, treatment experience and outcomes of treatment-satisfaction, side effects).

g. **Challenges faced:** Explain some of the challenges you faced during your experience with the disease (food-related, medication, social relations, emotional etc.)

h. **Copying mechanisms:** Other than seeking medication, what were some of the things you did to manage your situation? Probe-prayer, relaxation, games, work, talking about it, sharing with others

i. **Perceptions about the disease:** How did the experience influence your perspectives of schistosomiasis? How has it impacted your view of water, and related practices and fishing, swimming, drinking, bathing, washing etc..

j. Advice to those who have not experienced or are suffering from the disease

k. What advice would you give to a person who has not had such an experience? Behaviour water practices, hygiene and sanitation-open defecation and urination, eating half-cooked food etc. Do you have anything else to say?

Thank you very much for your participation

Appendix Nine: Ethical Approval by Research and Ethics Committee of Mbarara University of Science and Technology (MUST)



MBARARA UNIVERSITY OF SCIENCE AND TECHNOLOGY
 P. O. Box 1412, Mbarara Uganda. Tel: +256 40423700, Fax: +256 404 20702
RESEARCH ETHICS COMMITTEE
 E-mail: REC@must.ac.ug

Ref: MUREC/17

Date: December 16, 2020

Mr. Anyolithe Munson Kenneth
 Postgraduate student

Re: Submitted protocol on "Community Engagement and Schistosomiasis Prevention: A Sociological Analysis of the Citizen Science Model among Selected Communities of Western Uganda" 09/10-20

Type: Initial Application
 Protocol Amendment
 Letter of Amendment (LOA)
 Continuing Review
 Material Transfer Agreement
 Other, specify: _____



APPROVED
VALID UNTIL DATE SHOWN ABOVE

Reference is made to the above protocol which was resubmitted to the Research Ethics Committee for reconsideration and approval.

It is noted that you have addressed all the concerns earlier raised by the Committee.

I am pleased to inform you that your study has been approved for a period of one year from **December 16, 2020 up to December 15, 2021**.

As Principal Investigators of the research, you are responsible for fulfilling the following requirements of approval:

- All co-investigators must be kept informed of the status of the research.
- Changes, amendments, and additions to the protocol or the consent form must be submitted to the REC for review and approval prior to the activation of the changes. The REC application number assigned to the research should be cited in any correspondence.
- Reports of unanticipated problems involving risks to participants or other must be submitted to the REC. New information that becomes available which could change the risk: benefit ratio must be submitted promptly for REC review.
- Only approved consent forms are used in recruitment of participants. All consent forms signed by subjects and/or witness should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
- Regulations require review of an approved study not less than once per 12-month period. **Therefore, a continuing review application must be submitted to REC eight weeks prior to the above expiration date of December 15, 2021 in order to continue the study beyond the approval period.** Failure to submit a continuing review application in timely fashion may result in suspension or termination of the study, at which point new participants may not be enrolled and currently enrolled participants must be taken off the study.

4. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of documents approved in the application:

Document	Language	Version
Protocol	English	2
Data collection tool	English, Kinyarwanda, Rukomoti	December 2020
Consent form	English, Kinyarwanda, Rukomoti	December 2020

I wish you all the best.



Dr. Francis Bajajjira
CHAIR,
MUST RESEARCH ETHICS COMMITTEE



**Appendix Ten: Ethical Approval by Uganda National Council for Science and Technology
(UNCST)**



Uganda National Council for Science and Technology
(Established by Act of Parliament of the Republic of Uganda)

Our Ref: SS836ES

21 September 2021

Maxson Anyolitho

MBARARA UNIVERSITY OF SCIENCE AND
TECHNOLOGY

Mbarara

Re: Research Approval: Community Engagement and Schistosomiasis Prevention: A Sociological Analysis of the Citizen Science Model among Selected Communities of Western Uganda

I am pleased to inform you that on **21/09/2021**, the Uganda National Council for Science and Technology (UNCST) approved the above-referenced research project. The Approval of the research project is for the period of **21/09/2021** to **21/09/2024**.

Your research registration number with the UNCST is **SS836ES**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project. As the Principal Investigator of the research project, you are responsible for fulfilling the following requirements for approval:

1. Keeping all co-investigators informed of the status of the research. K
2. Submitting all changes, amendments, and addenda to the research protocol or the consent form (where applicable) to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days. Su
3. For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority and a notification to the UNCST. Fo
4. Unanticipated problems involving risks to research participants or others must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST notification after review by the REC. U
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records. O
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project. A

Please note that this approval includes all study related tools submitted as part of the application as shown below:

No.	Document Title	Language	Version Number	Version Date
1	Survey Questionnaire	English	FINAL	21 April 2021
2	Informed consent	English	FINAL	21 April 2021
3	In-depth interview guide and Focus Group Discussion Guide	English	FINAL	21 April 2021
4	Interview guide for Lived experience study	English	FINAL	21 April 2021

5	Focus Group Discussion Guide for Lived Experience	English	FINAL	21 April 2021
6	Project Proposal	English		
7	Approval Letter	English		
7	Letter of clearance-Kagadi district	English	One	25 January 2021
8	Ntoroko Research Clearance	English	One	28 January 2020
9	Covid Risk mitigation plan- REC Approved	English	One	22 January 2021
10	Informed Consent forms	English	Two	04 September 2021

Yours sincerely,

Hellen Opolot

For: Executive Secretary

UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

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