COMMUNITY KNOWLEDGE, ATTITUDES, PERCEPTIONS AND PRACTICES REGARDING SCHISTOSOMIASIS IN HA-NESENGANI, LIMPOPO PROVINCE

by

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DISSERTATION

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DEDICATION

To my mother and my father in heaven.

DECLARATION

I declare that the dissertation hereby submitted to the University of Limpopo for the degree of Master of Science in Geography and Environmental Sciences has not been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

Mothapo, NJ (Ms.) 09 November 2022

Surname, Initials (title) **Date**

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ABSTRACT

Schistosomiasis is a vector-borne disease expected to become more prevalent, as climate change improves environmental conditions for host snail maturation. Over 25.7 million South Africans are at risk, with approximately 4.5 million infected each year. Infection occurs through skin contact during freshwater-related activities in water bodies contaminated with snail vectors. The study's aim was to assess community's schistosomiasis knowledge, attitudes, perceptions and practices, as well as views about schistosomiasis-environment interactions, to enhance the development of infection-control programmes. An explanatory sequential mixed-method approach was employed using household questionnaires and in-depth interviews with 342 and 15 participants, respectively. Participants could identify the symptoms, however, knowledge of the cause and transmission was limited; eating too much salt was considered a transmission route, for example. Although the disease was considered serious, participants engaged in risky water practices. A good understanding of schistosomiasis-environmental interactions was revealed; high rainfall was considered to reduce disease infection.

KEYWORDS: Schistosomiasis; Bilharzia; Medical Geography; Knowledge; Attitudes and Perceptions; Practices.

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CHAPTER 1: INTRODUCTION & BACKGROUND

1.1 INTRODUCTION

This chapter provides an introduction and background on schistosomiasis knowledge, attitudes, perceptions and practices, as well as community perspectives on the relationship between environmental conditions and schistosomiasis occurrence. It begins by providing context for the study and study area, followed by the research problem, the rationale for conducting the study, and the study's aims and objectives. Finally, the study's ethical considerations and scientific contribution are presented.

1.2 BACKGROUND TO THE STUDY

Schistosomiasis, also known as bilharzia, infects over 240 million people across the world, with an additional 700 million at risk of contracting the disease (World Health Organisation, 2020). Despite having only 13% of the global population, sub-Saharan Africa is responsible for more than 90% of all reported schistosomiasis cases (Aula, *et al*., 2021:2). Even though it is not one of the top five countries in sub-Saharan Africa in terms of infection rate, schistosomiasis is endemic in South Africa and poses significant public health challenges, primarily in terms of adverse socioeconomic impacts and morbidity (Mbereko *et al.,* 2020:2). Each year, an estimated 4.5 million South Africans contract the disease, with another 25.7 million at risk of infection (Hambury, 2021:39). In 2004, according to a study conducted in the Vhembe district, schistosomiasis prevalence ranged from 78% to 86% (Samie *et al.,* 2010:7160).

Schistosomiasis is a significant public health threat. The disease is transmitted by freshwater snails that affects many people in over 78 resource-constrained countries (Karunamoorthi *et al.,* 2018:1) in Africa, Asia, the Middle East and Latin America (Odhiambo *et al.,* 2014:1; Sady *et al.,* 2015:2). It is regarded as the second most devastating parasitic disease in terms of socioeconomic impact, after malaria (Koffi *et al.,* 2018:2). It is also one of the Neglected Tropical Diseases (NTDs), a group of chronic communicable illnesses that have been ignored for decades and characteristically affect disadvantaged people living in areas with limited access to public health, modern water and sanitation facilities, and other resources (Adekiya *et al.,* 2020:1). This is typical of most water-related diseases, as described by medical geographers, in which the physical environment is primarily described as the primary

cause of illnesses, but the apparent influence of human circumstances in the role of disease cause is also mentioned (Burblow, 1982:869). In this regard, neglected tropical diseases, particularly water related diseases, have a negative impact on household and government economies in terms of health, socialisation, and financial resources (Adekiya *et al.,* 2020:1-2; Adenowo *et al.,* 2015:198).

The high prevalence seen in the majority of affected communities is exacerbated by a limited understanding of schistosomiasis transmission and treatment, which increases the possibility of infection (Mbereko *et al.,* 2020:2). As a result, community awareness of the disease and participation in disease control measures are regarded as the first steps in creating an enabling environment for schistosomiasis control and elimination (Sady *et al.,* 2015:2). Some affected countries have implemented educational health programmes and initiatives; however, these have been found to exclude caregivers and household heads and focus primarily on school-aged children, as they are more accessible (Sacolo *et al.,* 2018:2). While most children can serve as a source of information about schistosomiasis transmission and treatment, caregivers and/or household heads make the majority of decisions in many households. They may unintentionally expose children in their care and themselves to schistosomiasis infection by collecting water from a river or stream in an unsafe manner or allow children to swim in the river if they are unaware of the risks associated with contact with contaminated water (Macharia *et al.,* 2016:2; Sacolo *et al*., 2018:2).

South Africa signed the Resolution World Health Assembly (WHA) 54.19 (outlines activities to be undertaken to achieve a regular minimum target of chemotherapy administration) in 2001 but has yet to meet the minimum target of 75% treatment coverage for children with schistosomiasis, which was supposed to be met by 2010 (Magaisa *et al.,* 2015:4). Communication was identified as one of the challenges that limit the uptake and scale-up of schistosomiasis control initiatives in member countries in the World Health Organization (WHO) schistosomiasis progress report 2001-2011 and strategic plan 2012-2020. To address this issue, the following strategies were identified: increasing community awareness of the importance of schistosomiasis, raising awareness about disease control and elimination interventions, encouraging affected communities to take ownership of the programme, and overcoming the occasional negative reactions of targeted communities to control and elimination

initiatives. In light of this background, the study sought to assess schistosomiasis-related knowledge, attitudes, perceptions, and practices, as well as the community's views on the relationship between environmental conditions and the occurrence of schistosomiasis.

1.3 DESCRIPTION OF THE STUDY AREA

The study was undertaken in Ha-Nesengani, located 23° 5' 45.95" S and 30° 23' 43.69" E in Makhado Local Municipality in the Limpopo Province of South Africa. The area covers an extent of 11.02 km^2 with 3603 households and a population of 13 951 (Statistics South Africa, 2011). The area is predominantly rural and characterised by residents with access to essential amenities such as schools and primary health care services. However, due to the rural nature of the area, many still collect wood and water for domestic and other purposes from springs, wells and streams (Bornman *et al.,* 2012:4). Statistics South Africa (2011) further reported that only 19% of the community in Ha-Nesengani had access to piped water and 3.2% to toilet facilities connected to a sewage system. Formal employment opportunities in the area were also found to be few, resulting in many subsistence farmers (Bornman *et al.,* 2012:4).

The selection of the study area was encouraged by a reported high prevalence of schistosomiasis in the region (see Anyanwu *et al.*, 2020; Samie *et al.,* 2010). According to Samie *et al.* (2010:7161), *Schistosoma haematobium* infections are widespread in the region, with a high risk of infection, particularly among young adults, primary school children and females. Furthermore, water bodies in the area, particularly the Luvuvhu River, which flows through Ha-Nesengani, have been reported to be home to intermediate host snails that are schistosomiasis carriers (Dicken *et al*., 2020:62). This is represented in Figure 1.3.1 below, which indicates where intermediate host snails of the *Schistosoma* genus: *Bulinus globosus, Bulinus africunus* and *Biomphalaria pfeifferi* (in green, red, and yellow, respectively) were found in the water bodies of the Luvuvhu River.

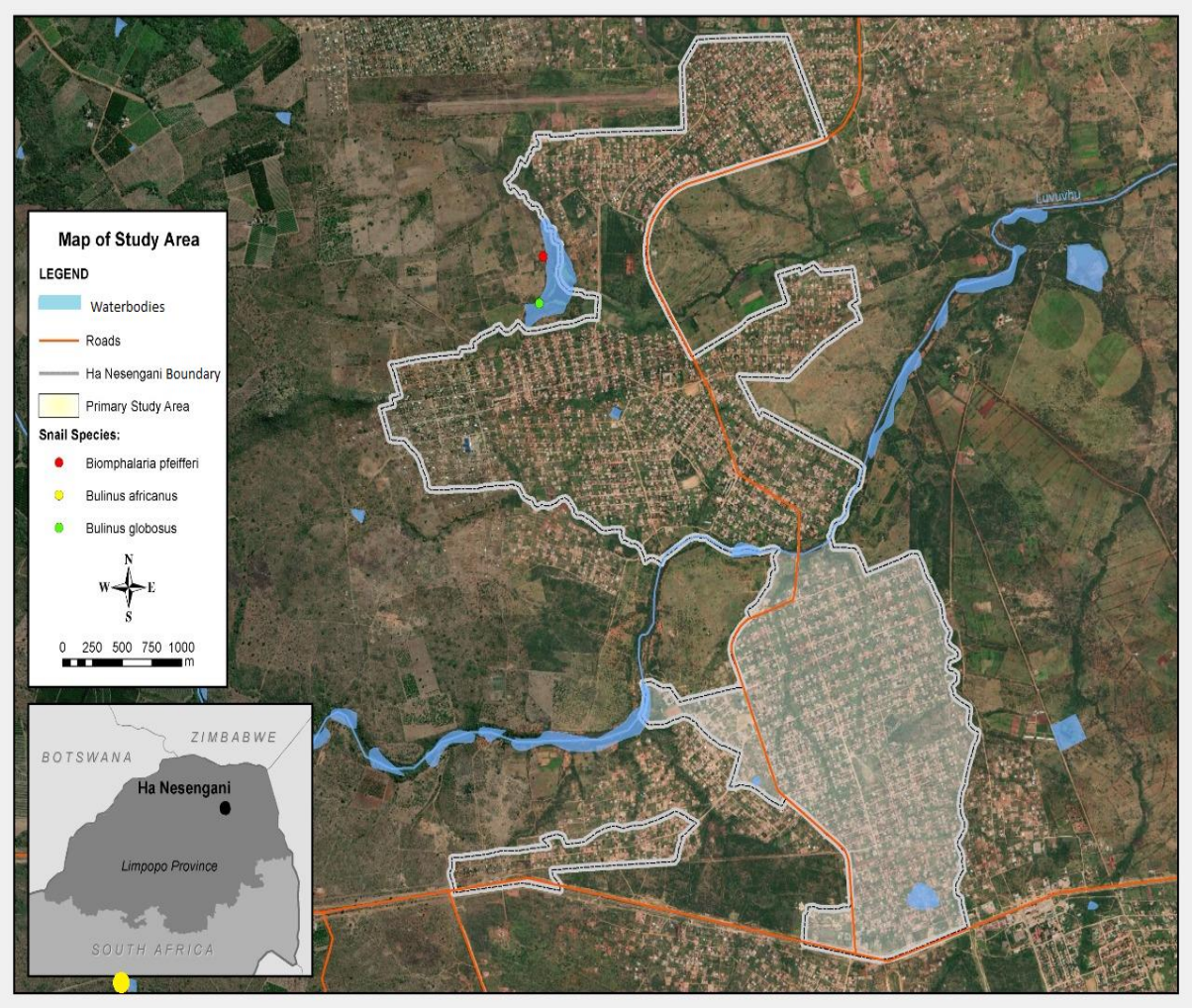

Figure 1.3:1 Map of Ha-Nesengani, with villages, physiographic setting and previously detected infectious snail species.

1.4 RESEARCH PROBLEM

The occurrence of schistosomiasis infection is projected to expand across the globe due to changes in climate conditions, especially in sub-Saharan Africa, where the highest proportion of impacted people reside (Adekiya *et al.,* 2017:1-5). Affected countries, together with organisations such as the World Health Organisation, have attempted to put in place various strategies, including increased access to safe drinking water, sanitation and hygiene, intervention subsidy, as well as institutional capacity and surveillance system reinforcement, to control and eliminate the risk of infection of the disease (Musuva *et al.,* 2014:646; Tchuenté *et al.,* 2017:3). Many of these programmes and initiatives, however, overlook the importance of monitoring and evaluation strategies such as assessing communities' schistosomiasis knowledge, attitudes, perceptions, and practices, even though these are critical factors in

developing compelling interventions for the ultimate schistosomiasis elimination (Musuva *et al.,* 2014:646). Data on community members' knowledge of the disease must be collected to aid in the development of educational health programmes and initiatives tailored to the needs of the affected communities to help control and eventually eradicate schistosomiasis in affected communities. Because this information is currently limited in the Vhembe district, the study hopes to generate a database of schistosomiasis knowledge, attitudes, perceptions, and practices in the Ha-Nesengani community to assist decision-makers in undertaking targeted knowledge dissemination processes.

1.5 RATIONALE

Medical geography, which is the discipline in which this study is conducted, studies both the geographic patterns of human health and disease, as well as the environmental and cultural factors that contribute to such conditions (Burblow, 1982: 869-874). The spread of schistosomiasis is linked to low socioeconomic status, a lack of safe drinking water, and poor environmental sanitation, all of which correlate significantly with schistosomiasis infection rates. This is also confirmed by the high prevalence of schistosomiasis in developing countries where people use freshwater sources like rivers, ponds, canals, or lakes to source water for their domestic needs or recreational activities (Hajissa *et al.,* 2018:1). The general lack of safe drinking water and sanitation provides an enabling environment for schistosomiasis infection, especially during times of drought due to climate change/variability, where people cannot harvest rainwater in their households and, as a result, rely solely on freshwater sources for water, which is often infested with infected snail vectors (De Leo *et al.,* 2020:3). All these factors are outside the control of the affected community members. However, when coupled with the lack of knowledge and inappropriate attitudes and practices regarding disease prevention, treatment, and control, infection rates in these communities can further increase. Although a study on schistosomiasis knowledge, attitudes, perceptions, and practices was conducted in the study area (see Anyanwu *et al.,* 2020), it did not focus on the knowledge, attitudes, perceptions, and practices of the overall affected communities, but rather on farm workers and school-aged children. The current study thus sought to assess the Ha-Nesengani community's knowledge, attitudes, perceptions, and practices (KAPP) regarding schistosomiasis to

determine whether there are any knowledge gaps, risky water practices, or other factors that may contribute to the community's risk of infection. With this data, a database on the community's KAPP will be available to aid in the development of community-centered interventions and, ultimately, the reduction of schistosomiasis in the study area.

1.5.1 Aim and objectives of the study

The aim of this study was to assess community knowledge, attitudes, perceptions, and practices regarding schistosomiasis in Ha-Nesengani, Limpopo Provinces, as well as to determine whether community members associated environmental conditions with the occurrence of schistosomiasis.

The specific objectives of the study are to:

i. assess the Ha-Nesengani community's level of knowledge on the transmission, cause and symptoms of schistosomiasis;
ii. determine the attitudes and perceptions of the Ha-Nesengani community members towards the treatment and prevention of schistosomiasis;
iii. identify the practices that expose the Ha-Nesengani community to schistosomiasis transmission; and
iv. determine the views of the Ha-Nesengani community members on the relationship between environmental conditions and the occurrence of schistosomiasis.

1.6 ETHICAL CONSIDERATIONS

All study procedures for the collection and analysis of the data followed the recommendations and guides from the Turfloop Research Ethics Committee (UL TREC) – Human Research Ethics, at the University of Limpopo and North-West University (NWU) Human Research Ethics Committee (NWU-HREC). Ethical clearance was granted by UL TREC (See Appendix A) and NWU-HREC (See Appendix B).

1.6.1 Informed consent

Prior to the start of the study, the research team obtained permission from the Nesengani Tribal Authority to conduct research in Ha-Nesengani village (see Appendix C). When interacting with respondents, all fieldworkers carried the letter of goodwill from the local tribal authority.

Following a description of the study's purpose, procedures, and objectives, as well as the respondents' role in the study from the fieldworkers, respondents were provided with the opportunity to sign an informed consent form (see Appendix D). The informed consent form also stated that their involvement in the study was voluntary and confidential and that they could leave the study at any time without consequence. The study only included respondents who signed an informed consent form and agreed to participate.

1.6.2 Confidentiality and anonymity

The respondents' anonymity and confidentiality were ensured by using unique participant numbers rather than names. All consent forms signed by the respondents were securely filed for record-keeping in accordance with the provision made by the North-West University Human Research Ethics Committee (NWU-HREC). After the study was completed, the hard copies were destroyed, and the scanned copies were filed on a secure university server, where they will be kept for five years. Other protocols and procedures were followed to ensure the privacy and confidentiality of respondents, as described in the guidelines from the Turfloop Research Ethics Committee (TREC) - Human Research Ethics at the University of Limpopo and the North-West University Human Research Ethics Committee (NWU-HREC).

1.6.3 Avoidance of harm

The risks of participating in the study were made clear to all respondents. These include the possibility of being emotionally triggered as a result of the unintentional sharing of personal or confidential information. The fieldworkers explained to the respondents, according to the consent form, that they could stop the questionnaire administration if they were uncomfortable, and they were not required to give a reason for doing so. As a result, respondents could leave the interview at any time and without penalty.

1.6.4 Respect

The respondents' dignity and autonomy were maintained through anonymity and confidentiality, by excluding their names from the questionnaire. Furthermore, the fieldworkers did not attempt to correct the beliefs and attitudes of the respondents during the research.

1.7 SCIENTIFIC CONTRIBUTION OF THE STUDY

Schistosomiasis public health intervention programmes are typically developed from the perspective of health policymakers, who are frequently unaware of the social context underlying disease transmission, infection, and control in communities, rather than from the experiences of the locals themselves. This approach is particularly true in most African countries, where the idea is that experts know best and need to tell uninformed locals how to protect themselves against prevalent diseases (Bruun & Aagaard-Hansen, 2008:VII). This study is a part of a larger interdisciplinary study funded by the Water Research Commission (WRC), in collaboration with the Unit for Environmental Sciences and Management at the North West University (NWU). The larger study's goal is to model the current and predicted future distribution of *Schistosoma* host snails in South Africa. In addition to snail sampling and the collection of schistosomiasis prevalence data from local clinics, the community's knowledge, attitudes, perceptions, and practices regarding schistosomiasis were assessed. The study's findings can thus be used as references for schistosomiasis prevention, treatment, and control/elimination in endemic areas across the country. Furthermore, as part of the study, YouTube videos in English and TshiVenda were created to address common misconceptions and beliefs about schistosomiasis infection, symptoms, and prevention. This will benefit many communities throughout the country and can be used to aid in the country's control efforts. Using the study's findings, South African institutions can design and implement policies, strategies, and programmes that are targeted and tailored to community needs and realities, as a result, the prevalence of schistosomiasis in communities such as the Ha-Nesengani community can be reduced.

Furthermore, as part of the larger study, the following research output has been achieved:

De Necker, L., Le Roux, H., Mothapo N, Lindeque, F., Smit, N.J. and Wepener, V. 2022. Schistosomiasis in South Africa: vector distribution and human perceptions and practices. *23rd WaterNEt/WARFSA/GWPSA Symposium*, 19-21 October 2022, North West university, Rustenburg, South Africa.

1.8 CONCLUSION

This chapter summarised the dissertation by providing context for the research. As a result, the chapter provided a summary of the study's purpose, as well as the nature and scope of the problem. The chapter also explained why the study was being conducted and it hoped to achieve. This chapter also discussed the study's ethical implications and scientific contribution. The second chapter will examine the literature on schistosomiasis knowledge, attitudes, perceptions, and practices, as well as community perspectives on the relationship between environmental conditions and schistosomiasis occurrence.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The literature on schistosomiasis and its relationship with sustainable development goals, as well as from the perspective of medical geography, is discussed in this chapter, with a focus on its cause, its impacts on affected communities and the factors that influence disease infection. This chapter also examines existing literature on community schistosomiasis knowledge, attitudes, perceptions and practices, as well as perspectives on the relationship between environmental conditions and schistosomiasis occurrence.

2.2 CONCEPTUAL FRAMEWORK

A conceptual framework explains the aspects to be studied and organises the key variables and their interdependence (McGregor, 2017:no pagination). One conceptual framework used for understanding, explaining, and predicting health behaviours is the health belief model. The health belief model seeks to understand the reason people fail to implement disease prevention strategies or screening tests, as well as people's reactions to symptoms and adherence to medical treatments. The model predicts the probability that a person will implement the recommended health behaviour or action based on their belief in their risk of disease and their belief in the effectiveness of the recommended health behaviour or action (Lothe *et al.,* 2019:2).

According to the health belief model, six constructs predict health behaviour: susceptibility to risk, risk severity, benefits to action, barriers to action, self-efficacy and cues to action. The health belief model's six constructs are designed to explain the beliefs and perceptions that interact within a person to determine an individual's willingness to act to prevent an adverse health condition (Glanz *et al.,* 2015:no pagination). These health behaviour constructs were found to be relevant to this study as they fit well with the purpose of this research, which is to investigate a community's knowledge, attitudes, perceptions and practices regarding schistosomiasis symptoms, transmission, treatment and prevention.

Another framework used to assess the vulnerability of people to waterborne diseases is the water-associated disease index (WADI). According to Dickin *et al.* (2013:2), "the WADI is constructed from composite indicators of exposure and susceptibility, where

susceptibility represents the existing social, economic or cultural conditions that render a population sensitive to a water-associated pathogen, and exposure represents conditions conducive to the presence and transmission of the pathogen within the environment." This study draws on concepts from both the health belief model and the water-associated disease index, as they both provide frameworks to better understand the complexities involved in public health issues like schistosomiasis, particularly from the viewpoint of medical geography. The constructs of the health belief model provide context for the knowledge, attitudes, perceptions and practices component of the study, whereas the WADI is aimed at establishing a link between environmental conditions and the occurrence of schistosomiasis.

Figure 2.2.1 below illustrates how these frameworks based on the constructs of the health belief model and the water-associated disease index (WADI) are relevant to this study.

2.3 THE ASSOCIATION BETWEEN SUSTAINABLE DEVELOPMENT GOALS AND NEGLECTED TROPICAL DISEASES (SCHISTOSOMIASIS)

The goal of sustainable development is to achieve human development goals by allowing natural systems to provide essential natural resources and ecosystem services to humans. The desired outcome of this principle is a society in which living conditions and resources meet human needs without jeopardising the integrity and stability of the natural system. Simply put, sustainable development is development that meets the needs of the current generation without jeopardising the ability of future generations to meet their own (Mensah, 2019:5-6). The 2030 Agenda for Sustainable Development, which was adopted by all United Nations Member Countries in 2015, incorporates all three dimensions of sustainable development: economic, social and environmental, centred on the themes of people, planet, prosperity, peace and partnership. The impetus for the Sustainable Development Goals (SDGs) is the realisation that eradicating poverty and inequality, fostering inclusive economic growth, and protecting the environment are closely linked, not only to each other, but also in relation to public health (Bangert *et al.,* 2017:1-2). The following sections detail some of the Sustainable Development Goals that are relevant to the study.

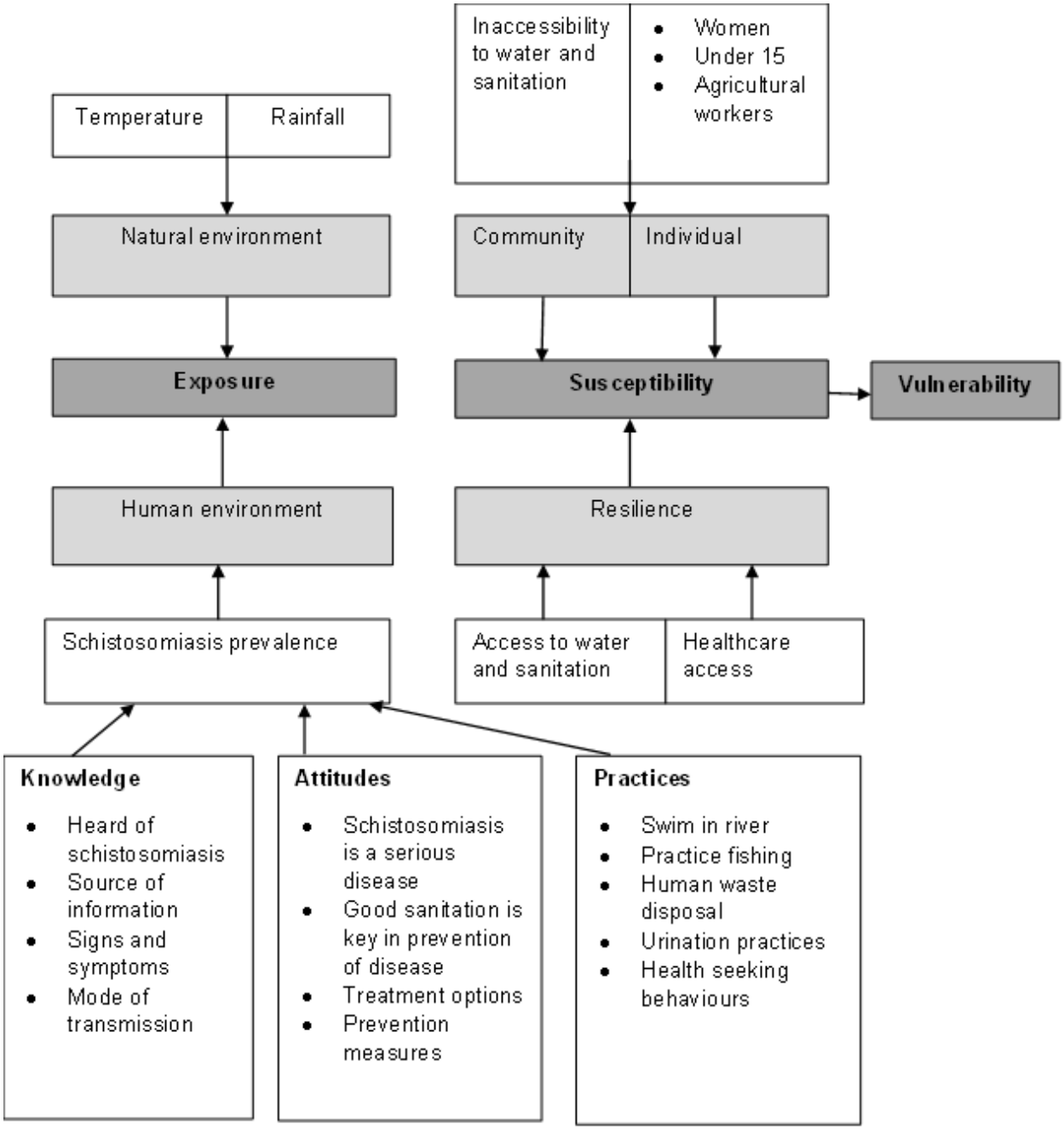

Figure 2.3:1: Conceptual framework developed for the study based on the constructs of the health belief mode and the water-associated disease index.

2.3.1 Sustainable Development Goal 3: Ensure healthy lives and promote well-being for all.

Sustainable Development Goal 3, also known as the health goal, is most relevant to Neglected Tropical Diseases (NTDs) and emphasises equity by ensuring that interventions reach people in need of health services, regardless of where they live or their circumstances. Target 3.8, Universal Health Coverage, is fundamentally aligned with the goal and cuts across all health-related targets and addresses linkages with

health-related targets from other goals. It ensures that critical services reach all those in need, and it is a key component of the World Health Organization's "roadmap for implementation" of the 2012 Neglected Tropical Disease Strategy, which identified preventative chemotherapy as a key strategy for combating neglected tropical diseases (Tchuenté *et al.,* 2017:3). In the same year, member countries endorsed World Assembly Resolution WHA65.21, which focused on schistosomiasis elimination and urged all endemic countries to intensify control interventions and strengthen surveillance. One strategy for achieving this goal was to treat at least 75% of children with praziquantel on a regular basis by 2020 (Bergquist *et al.,* 2017:2). This strategy was implemented in Sierra Leone, where mass drug administration began in 2009, resulting in treatment coverage that exceeded the World Health Organization's recommended 75% of the target population. In 2012 until 2016, infection assessments revealed a significant decrease in the study area (Bah *et al.,* 2019:2).

Target 3.3, "ensure healthy lives and promote wellbeing for all," on the other hand serves as a foundation for "ending the epidemic of Neglected Tropical Diseases by 2030." As a proxy indicator of disease prevalence, the requirements for mass and individual Neglected Tropical Diseases treatment provide important insights into how the burden is distributed. The intensity of schistosomiasis infection, as measured by the number of eggs detected in stool or urine using Kato Katz or urine filtration, respectively, is an important parasitological marker for estimating the disease burden associated with the infection. Currently, schistosomiasis is reported to cause over 1.8 million Disability-Adjusted Life Years (DALYs) globally, ranking it third among neglected tropical diseases after soil-transmitted helminth and dengue fever (Bartlett *et al.,* 2022:2).

Morbidity from schistosomes is commonly associated with moderate-to-heavy egg infection intensities and is progressive. When it comes to disease development, school-aged children are the most vulnerable age group because they harbour the most adult worms, with a large number of tissue-entrapped eggs causing systemic and organ-specific inflammation (Bartlett *et al.,* 2022:2). This is unfortunate because the infection causes the most physiological and developmental harm during this stage of development (Tchuenté *et al.,* 2017:2). According to research, children can contract schistosome infections in their first few months of life, causing early life organ damage and altered development, which manifests overtly in adolescence and early adulthood

and is facilitated by fibrotic lesions around tissue-trapped eggs (Danso-Appiah *et al.,* 2004:784). Praziquantel treatment may reduce worm burden and intensity of infection, as well as reverse schistosomiasis-associated morbidity in treated individuals. However, while praziquantel is effective in treating adult schistosome worms, it is not completely effective because it does not prevent re-infection, and it is also ineffective in treating the parasite's juvenile stages (Obonyo *et al.,* 2019:3). It is thus recommended that, in addition to the necessary treatment, water, sanitation and hygiene be provided to aid in the control and eventual elimination of schistosomiasis (Bergquist *et al.,* 2017:1).

2.3.2 Sustainable Development Goal 6: Ensure access to water and sanitation for all

Global access to safe drinking water, adequate sanitation, and hygiene (collectively known as WASH) is critical for preventing and treating most Neglected Tropical Diseases, as well as contributing to the achievement of SDG 3 to "Ensure healthy lives and promote well-being for all" (Bergquist *et al.,* 2017:6). Many of the pathogens that cause neglected tropical diseases thrive in areas with insufficient water and sanitation. Water contaminated with faeces and urine, for example, can contain worm eggs that contaminate surface water and lead to schistosomiasis transmission, especially where there are snail hosts. In this regard, any interventions on water supply improvements work to prevent the consumption of contaminated water where there is a concern for water-excreta related diseases. However, because schistosomes infect people via skin contact, the success of water and sanitation supply improvements in preventing schistosome infection is dependent on water contact and the prevention of excreta contamination of freshwater, rather than consumption. Similarly, because the parasite stage of excreta cannot directly infect people, hand washing after defecation or urination has no effect on schistosome transmission (Grimes *et al.,* 2015:1-2).

Neglected Tropical Diseases are diseases of poverty, not poor countries, and their impact is felt most strongly by poor communities in both poor and wealthy countries (Bangert *et al.,* 2017:2). People who have access to safe water and adequate sanitation have a significantly lower risk of contracting schistosomiasis than those who do not. This was confirmed in a study conducted in Ethiopia, where households without access to improved drinking water sources were more likely to have individual infections to schistosomiasis compared to those with access to water sources (Phillips

et al., 2022:8). People with lower socioeconomic status also have less access to water, inadequate sanitation, and hygiene, and are thus more vulnerable to infection due to a lack of health-related knowledge, poor healthcare services, and occupational exposure to infested water (Oskam *et al.,* 20214). In this regard, the impact of water access, adequate sanitation, and hygiene on schistosomiasis is highly context-specific, and depends largely on environmental factors such as the location of freshwater bodies and the presence of intermediate host snails, as well as social and cultural factors that govern people's water contact and contamination behaviour. For these reasons, multisectoral and integrated approaches to the control of schistosomiasis and other neglected tropical diseases are required (Grimes *et al.,* 2015:2).

2.3.3 Sustainable Development Goal 13: Take urgent action to combat climate change and its impacts

Climate change has a significant impact on vector-borne disease transmission, increasing the geographical distribution and burden of such infections (Bangert *et al.,* 2017:11). The simplest connections, temperature and rainfall, have all been reported to have an impact on schistosomiasis transmission, though it is unclear how these changes will vary by location (MCreesh & Booth, 2013:553). Temperature influences egg production, hatching, and death rates, so it is important in determining the limits of snail distribution and population size. Temperature also influences the rate of cercarial maturation within infected snails, which increases as temperature rises and slows and stops at low temperatures (MCreesh & Booth, 2013:549). In comparison, mean water temperatures in southern Europe are expected to rise, increasing snails' ability to hibernate which can lead to more schistosomiasis occurrences as experienced in France (Bangert *et al.,* 2017:11). Heavy rainfall has the potential to significantly reduce the number of snails found at a transmission site; however, snails may end up in favourable habitats and potentially establish new colonies as a result. This could reintroduce snails and schistosomes to previously eliminated areas, as well as facilitate the spread of snails, especially infected snails, to areas where snail populations and/or schistosomes are now viable (Adekiya *et al.,* 2020:7-8; McCreesh & Booth, 2013:551-552; Xue *et al.,* 2011:1105).

Monitoring human cases of schistosomiasis, the pathogen and species involved, the distribution and behaviour of the vector, and the climatic and environmental factors

that allow disease transmission can all aid in combating the disease's effects (Pley *et al.,* 2021:741). At-risk populations can be identified and included in future public health interventions by better understanding how climate change affects Neglected Tropical Diseases. Furthermore, by understanding the changing dynamics of disease-causing agents and their hosts, as well as their interactions with the environmental dynamics caused by climate change, future responses to schistosomiasis can be made more effective (Bangert *et al.,* 2017:11). All of this can be accomplished through modelling and surveillance, as these processes allow for the detection of human and vector behaviour, which aids in a better understanding of the conditions that enable transmission, such as community behaviours and environmental and climatic factors, which can significantly aid in mitigating potential consequences (Pley *et al.,* 2021:741).

To help combat the effects of climate change, target three of the goal focuses on awareness and education, where neglected tropical disease programmes are used to raise awareness and increase knowledge among people, public health practitioners as well as policymakers about vector-transmitted infections and their relationship to disease, which serves as the foundation for prevention strategies such as personal protection infection, improved hygiene and reduced exposure (Bangert *et al.,* 2017:1). As discussed in Olamiju *et al.* (2014:3 public awareness and perceptions are also critical factors in shaping the necessary policies for the control and eventual elimination of neglected tropical diseases and should thus be prioritised by affected countries.

2.4 WATER RESOURCES AND SCHISTOSOMIASIS: A MEDICAL GEOGRAPHY PERSPECTIVE

The study of the spatial distribution of disease occurrence, as well as the identification of potential "causes of disease" such as environmental exposure or socio-demographic factors, is central to medical geography. Using geography concepts, this field of study investigates the relationship between human health and the environment (Goovaerts, 2014:605). Water resources, as part of the natural environment, are important in medical geography studies because they are not only necessary for life but also provide recreational opportunities for communities. This frequently creates a difficult predicament in terms of health, as water is associated with more than 80% of all diseases in the developing world, including well-known waterborne diseases such

as cholera and typhoid fever, as well as parasitic worm infections such as schistosomiasis. When combined with climate change/variability, public health becomes even more vulnerable as it affects both natural and social environments (Ahmed *et al.,* 2020:4).

In most cases, the effects of natural hazards, primarily those caused by climate change, are described in terms of social determinants such as exposure and vulnerability, whereas the risk of infectious diseases is frequently described in terms of environmental determinants such as temperature and rainfall, without fully accounting for the socio-ecological processes that expose people to disease-causing agents. The risk of infection with infectious diseases are driven by three interrelated components: exposure, hazard and vulnerability. For schistosomiasis, exposure occurs through contact with water, which is often tied to daily activities. Water contact, however, does not imply risk unless the environmental hazard of snails and parasites is also present in the water (Lund *et al.,* 2021:1-4). Vulnerability to infection is also closely related to literacy rates, which are commonly low in most developing countries, particularly in rural areas, which are home to the most vulnerable communities. This has a direct impact on people's relationships with infectious diseases, as people end up using the same water for domestic, recreational, and agricultural purposes without realising the risks (Ahmed *et al.,* 2020:6).

2.5 KNOWLEDGE REGARDING SCHISTOSOMIASIS

Six known Schistosoma species infect humans; however, two major *Schistosoma* species, *Schistosoma mansoni* and *Schistosoma haematobium*, affect communities in sub-Saharan Africa, causing diseases known as intestinal schistosomiasis and urogenital schistosomiasis, respectively (Tchuenté *et al*., 2017:1). Infection with schistosomiasis occurs when people get exposed to water contaminated with *Schistosoma* eggs released through stool in the case of *Schistosoma mansoni* (intestinal schistosomiasis), or urine in the case of *Schistosoma haematobium* (urogenital schistosomiasis) during contact with infested freshwater sources (Colley *et al.,* 2014:2; Sanya *et al.,* 2017:2). Of the six *Schistosoma* species that cause human infection, *Schistosoma haematobium* is the only species that is accountable for urogenital schistosomiasis and has substantial connections with Human

Immunodeficiency Virus (HIV) and Human papillomavirus (HPV) (Tchuenté *et al*., 2017:1).

The disease primarily affects women, children and people working in water-related occupations (Banhela *et al.,* 2017:1). This is in alignment with a study conducted by Samie *et al*. (2010:7160-7161) in the Vhembe District where females, including primary school children, were found to be more prone to infection with schistosomiasis. Schistosomiasis is associated with school/working performance problems, tiredness and anaemia (Banhela *et al.,* 2017:1). Recurrence of infection may also result in bladder cancer, liver and spleen enlargement, bladder ulceration, and urinary tract blockage, all of which can lead to other complications (Karunamoorthi *et al*., 2017:2; Sacolo *et al.,* 2018:2)

2.5.1 Knowledge of the cause and transmission of schistosomiasis

Schistosomiasis is an infection caused by flatworm parasites of the *Schistosoma* genus mainly transmitted by snails that survive in freshwater sources; therefore, all *Schistosoma* infections occur because of direct skin contact with contaminated water in ponds, lakes, rivers and reservoirs (Hambury, 2021:51). *Schistosoma* species use an intermediate host snail to transmit the disease; however, this is often not comprehended by affected communities. In a study conducted in Yemen, knowledge of snails as a mode of schistosomiasis transmission was very low where study participants regarded snails as harmless creatures and stated that children in the community collected and played with them (Sady *et al.,* 2015:11). Similarly, in a Tanzanian study including children and their parents, only 40% of the children and 31% of the parents were aware that the disease is transmitted by snails (Angelo *et al.,* 2019:5). Due to a lack of understanding about the cause of schistosomiasis, the majority of affected communities may have a high prevalence (Mbereko *et al.,* 2020:2).

Participants in some studies were aware that the disease is transmitted when they come into contact with water, but there are numerous misconceptions about the disease's cause and transmission. According to participants in a Tanzanian study, the disease is hereditary, can be transmitted sexually, and is caused by consuming an excessive amount of tamarind fruit, excessive amounts of table salt, and drinking contaminated water (Angelo *et al.,* 2019:8). Similarly, participants in a study conducted

in Western Kenya associated schistosomiasis transmission with promiscuity, dirty drinking water, eating uncooked and contaminated food, and washing clothes in dirty water (Musuva *et al.,* 2014:650). In addition to the previously mentioned studies, research in South Africa revealed the misconception that schistosomiasis is transmitted sexually was prevalent among participants (Lothe *et al.,* 2019:5-9). This could be because some of the most common urogenital schistosomiasis symptoms manifest through reproductive organs (Rassi *et al.,* 2019:12).

Misconceptions and myths in affected communities are frequently social and culturally motivated, and they can reduce the effectiveness of schistosomiasis control efforts because people are less likely to stop doing something they don't believe puts them at risk of infection (Maseko *et al.,* 2018:108). This is seen in a study conducted in the Philippines where the participants due to the existence of control strategies implemented as part of the Research Institute for Tropical Medicine (RITM), were aware of the transmission mode of schistosomiasis and were also aware that snails are the cause of the disease (90.0%) (Francisco *et al.,* 2019:6-9). However, the interventions' effectiveness was reported to be limited by a lack of behavioural and sociocultural research, with participants' refusal to change risky practices that lead to infection being a concern (Francisco *et al.,* 2019:2-3).

2.5.2 Knowledge of the symptoms of schistosomiasis

The symptoms of schistosomiasis are manifest due to the body's reaction to the resulting eggs, rather than through the larvae released by the host snails. Adult worm eggs that are not excreted from the body can become stuck in the intestine or bladder, resulting in swelling, irritation or scarring (Bakare & Nwozo, 2016:2). The symptoms of intestinal schistosomiasis include blood in the stool or diarrhoea, as well as abdominal pain (Sady *et al.,* 2015:2). As the infection progresses, inflammatory reactions in the liver can occur which can also lead to enlargement of liver and spleen with ascites and high blood pressure (Sady *et al.,* 2015:2). On the other hand, urinary schistosomiasis primarily presents itself with blood in the urine (hematuria) and painful urination (dysuria) (Frigerio *et al.,* 2016:841). As the disease progresses, bladder wall calcification, bladder stones, cancer that forms in epithelial tissue of the bladder, and swelling of a kidney due to a build-up of urine might result in kidney failure (Danso-Appiah *et al.,* 2004:784).

There is a noticeable tendency in affected communities to use local names to refer to schistosomiasis, with these names typically used to describe what the community perceives to be schistosomiasis symptoms. In a study conducted with communities in northern Côte d'Ivoire and southern Mauritania, different names were reported in both areas, with the former using local names relating to the urogenital system and gastrointestinal tract and the latter diarrhoea with blood and mucus in the stool. *Firmaning,* which translates to "root of urine" in northern Côte d'Ivoire, was discovered to be related to genital tract disease and any sex-related disease, especially gonorrhea. Similarly, in southern Mauritania, community members mistook the symptoms of dysentery and schistosomiasis because they are similar (Koffi *et al.,* 2018:4). The same trend was discovered in a study conducted in South Africa and Zimbabwe, where people in Zimbabwe refer to schistosomiasis as *Inkabalo* or *Nxama-gazi* and people in South Africa refer to it as *isichenene* or *umkhazi*, both areas' local terms express the aspect of urine with blood (Mbereko *et al.,* 2020:5-6).

The knowledge that schistosomiasis primarily presents itself as urine with blood is not common among all endemic communities. In a study conducted in Yemen, knowledge regarding schistosomiasis among the respondents was found to be relatively low, with only 17.7% of the respondents indicating blood in the urine as a symptom of the disease (Sady *et al.,* 2015:11). While this is true, it should be noted that, unlike urogenital schistosomiasis, intestinal schistosomiasis does not manifest with blood in the urine. The lack of knowledge regarding urogenital schistosomiasis could imply that intestinal schistosomiasis is more prevalent in the area and vice vis. Even in areas where the two exist, it should be noted that, unlike urinary schistosomiasis, intestinal schistosomiasis has medical symptoms that are not readily apparent as infection with schistosomiasis to infected people, such as diarrhoea and blood in the stool (Mbereko *et al.,* 2020:7).

2.6 ATTITUDES AND PERCEPTIONS REGARDING SCHISTOSOMIASIS

To be effective, schistosomiasis control efforts must be accepted by the communities in which they are implemented. Acceptance of schistosomiasis control efforts are frequently based on the communities' attitudes toward infection and perceptions of treatment (Musuva *et al.,* 2014:646). Furthermore, attitudes toward schistosomiasis are influenced by the disease's level of knowledge; a lack of knowledge or the

presence of misconceptions can further influence actions, determining whether control efforts will be effective (Humbury, 2021:32). Conversely, adequate schistosomiasis knowledge does not always give rise to positive behavioural changes that promote disease prevention and control; in many cases, social constructs are the primary drivers of these initiatives (Mbereko *et al.,* 2020:2).

According to a study conducted in the Philippines, while the majority of respondents (67.1%) regarded schistosomiasis as a very serious disease, 40.2% did not believe that the disease could be prevented; however, the majority of respondents (86.2%) were willing to participate in mass treatment, indicating future mass treatment programme compliance. When compared to younger respondents in the same study, older respondents were more hesitant to participate in mass treatments due to concerns about side effects (Francisco *et al.,* 2019:9). In a similar study conducted in Cameroon, the majority of respondents (80.0%) thought schistosomiasis was a serious disease because blood came out when they urinated. The study also found that, despite being aware of the risk of contracting an infection from contaminated water sources, respondents continued to visit the river because it was their only source of water. The study concluded that behavioural changes should be supplemented by the supply of clean water to reduce risky water practices (Folefac *et al.,* 2018:4).

The attitudes of community members can also have an impact on the effectiveness of control initiatives. According to a study conducted in Kenya, infected members of the community are frequently perceived as promiscuous because the symptoms can mimic those of sexually transmitted diseases such as syphilis (Musuva *et al.,* 2014:646). Urogenital schistosomiasis is a urinary tract infection that can manifest as genital wounds and sandy patches (areas that bleed easily) in the female reproductive organs. Due to these symptoms, the disease is often associated with sexually transmitted diseases (Lothe *et al.,* 2018:7). This type of attitude toward the disease can also influence affected individuals' treatment behaviours. In a South African study, respondents stated that because most people in the community regarded schistosomiasis as a sexually transmitted disease when someone became infected, they were afraid of sharing for fear of being judged. To that end, respondents revealed that while the drug is administered free in schools, they are frequently teased by other students and healthcare workers about receiving treatment (Lothe *et al.,* 2018:3-4).

Among the key approaches to the control of schistosomiasis in endemic areas, the mass treatment of people infected with schistosomiasis using praziquantel is reported as the pillar of all programmes (Secor, 2014:6). This is because praziquantel can be used for the treatment of all major *Schistosoma* species infections, and it can be administered to adults and children over the age of one (Magaisa *et al.,* 2015:4). While praziquantel is the most commonly used treatment, its availability varies, with some areas receiving it for free and others paying a fee for drug administration (Sanya *et al.,* 2017:11). According to a study in Kenya, respondents reported that they avoided going to hospitals to receive treatment for schistosomiasis as they regarded the process to be expensive as patients are required to pay the full amount before treatment can be provided (Musuva *et al.,* 2014:647-649). This is consistent with the findings of Magaisa *et al.* (2015:4) in South Africa, who report that mass treatment programmes are unaffordable and nearly impossible to implement in the country, and that praziquantel is not available in many local clinics due to its high cost.

Aside from the financial implications of praziquantel administration, it has been reported that some people do not seek medical attention because they believe the symptoms are not urgent and wait until they are severe (Musuva *et al.,* 2014:650). Furthermore, some participants refuse to take praziquantel because they are afraid of the potential side effects, which include dizziness, vomiting, loss of appetite, and fatigue (Sanya *et al.,* 2017:8). In a study conducted in northern Côte d'Ivoire and southern Maurutania, participants' health-seeking behaviours were entirely based on their perception of the type of schistosomiasis, which was thought to be natural or mystic. To treat the natural form of schistosomiasis, which is thought to be transmitted through contact with water, walking on goat or dog urine, the participants reported relying first on self-medication, local customs, and medicine sourced from the black market, with going to the hospital being a last resort practice. The mystic form, which is thought to be contracted through witchcraft, can only be treated by traditional healers, who use prayers and medicinal plants (Koffi *et al.,* 2018:8-9). This is similar to a study conducted in South Africa by Lothe *et al.* (2018:8), in which illnesses are classified based on beliefs about the cause of illness, with the two major categories "*ukufa kwabantu*" indicating diseases that only affect African people and "*umkhuhlane*" indicating diseases that affect all members of society. While schistosomiasis is classified as a disease that can infect anyone, it was also thought to be treatable with

either modern or traditional medicine. Many parts of Africa have seen the use of a combination of modern and traditional treatment, indicating that any meaningful treatment campaign must consider the treatment seeking behaviours of affected communities (Mwanga *et al.,* 2004:77).

2.7 PRACTICES RELATED TO SCHISTOSOMIASIS

Schistosomiasis is endemic in areas with poor living conditions and poverty, as are many other neglected tropical diseases (Mutsaka-Makuvaza *et al.,* 2019:2). People in these communities are typically low-income, with limited access to safe water and inadequate sanitation. As a result, they use water from rivers, lakes, streams, or ponds for industrial, agricultural, domestic, and recreational purposes daily. This is unfortunate because schistosomiasis infection occurs when the skin encounters water infested with cercariae released by intermediate host snails (Hambury, 2021:25).

Individuals most at risk of infection are women performing domestic tasks, children and preschool children who assist with domestic activities, those who swim or bathe in freshwater sources, and those who pass freshwater on their way to school (Karunamoorthi *et al.,* 2018:2). Adults from specific groups, such as fishermen and agriculturalists who come into contact with infected water, as well as entire communities living in schistosomiasis endemic areas, are included (Karunamoorthi *et al.,* 2018:4; Munisi *et al.,* 2017:4).

School-aged children and preschool children are reported as the most vulnerable to schistosomiasis infection (Tchuenté *et al.*, 2017:2). This is because children of this age are more likely to participate in water-related activities such as playing, swimming, and bathing (Joof *et al.,* 2021:3); furthermore, children under the age of five are at risk of infection when accompanying their caregiver to infested areas to perform household tasks (Mushi *et al.,* 2022:2). Among this age group, gender was discovered to be a predictor of schistosomiasis infection. In a study conducted in Gambia boys were regarded to be at higher risk than girls (Joof *et al*., 2021:3). According to Maseko *et al*.'s (2018:108) study conducted in Swaziland, girls are more likely to be exposed to schistosomiasis infection due to cultural roles such as fetching water for domestic purposes and doing laundry at the river, whereas boys are exposed through recreational activities such as swimming.

It is widely accepted that schistosomiasis infection occurs through contact with infested water, however, participants in other similar studies did not associate swimming in freshwater as a risky behaviour for schistosomiasis infection. To that end, 53.5% of participants in a Zimbabwe study indicated that they swam in the river, with 82.6% indicating that they swam at least once a week (Midzi *et al.,* 2011:7). Furthermore, in a study conducted in Cameroon by Folefac *et al.* (2018:3), participants did not actively avoid contact with water, with only 9.1% wearing water-resistant clothing when in contact with freshwater sources. While participants in these studies are sometimes reported to be aware of preventative measures that they can take, they may face challenges in implementing the measures because they are not practical. In a study conducted in Cameroon, for example, participants stated that wearing heavy boots while working in a rice field for long periods of time is not practical (Francisco *et al.,* 2019:11). In contrast, wearing shoes was associated with lower schistosomiasis infection in a similar study conducted in Northern Senegal (Frigerio *et al.,* 2016:846).

One of the risky practices that perpetuate the risk of schistosomiasis in endemic communities is urinating or defecating in open spaces and water sources during water-based activities. This was confirmed in a Cameroonian study, in which respondents admitted to public defecation and/or urination in water and fields while engaging in recreational and domestic activities (Folefac *et al.,* 2018:4). Similarly, a study conducted in Nigeria reported that the respondents also urinated and excreted in open areas although they had toilet facilities at their households (Dawaki *et al*., 2015:11). In terms of treatment-seeking behaviour, the studies examined revealed good practices. According to a Yemeni study, the majority of respondents (81.1%) go to the nearest clinic/hospital for treatment if they have gastrointestinal symptoms or haematuria, while the minority (4.5%) do not (Sady *et al.,* 2015:6).

2.8 COMMUNITY VIEWS REGARDING ENVIRONMENTAL CHANGE AND THE OCCURRENCE OF SCHISTOSOMIASIS

Climate change, including variations in temperature, rainfall, flooding, and drought, has been connected to the progression or growth of many neglected tropical illnesses (Adekiya *et al.,* 2020:2-3). The relationship between schistosomes and their intermediate hosts, snails, is influenced by temperature. In Uganda, schistosomiasis is spreading in regions that were previously thought to be too cold for the survival of

both the schistosome parasite and its host snails. This is evidence of the consequences of the rise in temperature (McCreesh *et al.,* 2015:1). Furthermore, rainfall creates conditions that enable enough water to build up in ponds and rivers, leading to an abundance of snail breeding habitats (Xue *et al.,* 2011:1109). On the other hand, flooding may cause snails to choose favourable environments and maybe start new colonies. This encourages the spread of snails, especially infected snails, to areas that are now suited for snails as a result of climate changes and reintroduce snails and schistosomes to previously eliminated locations (McCreesh & Bootha, 2013:553).

Schistosomiasis host snails are aquatic, meaning that they only reproduce in water. While this may be the case, practically all *Schistosoma* species have the ability to aestivate, which enables them to survive in water sources that are temporarily dried up. Host snails can only aestivate for a short time, therefore if a drought persists for an extended period and the soil moisture and certain other environmental factors become dry, host snails may disappear from the area (McCreesh & Booth, 2013:553). Uninfected host snails, particularly those that carry Schistosoma haematobium, can endure longer droughts than infected snails during aestivation (Adekiya *et al.,* 2020:8).

Temperature and rainfall are also reported to have an impact on schistosomiasis transmission by influencing human behaviour, with hotter seasons prompting an increase in recreational use of infected water sources and drier seasons prompting communities to collect and perform chores from contaminated water sources (Osakunor *et al.*, 2018:2). Codjoe and Larbi (2015) conducted a study in Ghana to determine respondents' perspectives on the links between climate change and schistosomiasis; the study's findings revealed that community members could only recognise climate change by discussing its effects. Despite the lack of a local title for the phenomena, the community was able to explain how it occurred and what the underlying changes in the environment were. For instance, the respondents claimed that rainfall no longer happens during a time when it used to. Additionally, the respondents linked extremely warm temperatures with a desire to go river swimming and engage in other activities like bathing and washing. The respondents also believed that dumping feces into the water was one of the practices that ultimately helped the disease spread, provided that the materials got into the water due to runoff (Codjoe & Larbi, 2015:7-9).

2.9 CONCLUSION

This chapter discussed a review of the literature on knowledge, attitudes, perceptions, and practices, as well as community perceptions of the relationship between environmental change and the occurrence of schistosomiasis. The following chapter discusses the research methodology and analytical procedures used in the study.

CHAPTER 3: METHODOLOGY AND ANALYTICAL PROCEDURES

3.1 INTRODUCTION

This chapter describes the methods and materials used to assess schistosomiasis knowledge, attitudes, perceptions and practices as well as the community's views on the relationship between environmental conditions and the occurrence of schistosomiasis. It provides an outline of the research design, target population, sampling techniques, data collection and data analysis procedures, as well as the validity of the data collection instruments, and the methods in which these requirements were met in the study.

3.2 RESEARCH DESIGN

The study adopted an explanatory sequential mixed-method approach as it provided an opportunity to delve deeper into beliefs regarding the cause and transmission of schistosomiasis (identified during the administration of the household questionnaires) through follow-up in-depth interviews. According to Creswell (2006:72), an explanatory sequential approach is a research method used when a researcher wants to supplement quantitative findings with qualitative data. In this regard, quantitative data collected through household questionnaires on knowledge, attitudes, and practices, as well as the community's link between environmental conditions and the occurrence of schistosomiasis, were clarified by qualitative data collected through in-depth interviews (Guetterman *et al.,* 2015:2). This provided for a more combined utilisation of data and more breadth and depth of understanding of the community's knowledge, attitudes and practices regarding schistosomiasis while offsetting the weaknesses inherent to using separate quantitative or qualitative data (Guetterman *et al.,* 2015:2).

3.3 POPULATION OF THE STUDY

According to the report on the census 2011, the Ha-Nesengani village had a total population of 13 951, with approximately 3 603 households (Statistics South Africa, 2011). The number of households in the community represented the sampling frame of the study. Correspondingly, the administration of the household questionnaires provided the basis for the population of the in-depth interviews. People who met the inclusion criteria for the study and were interested in future participation were asked

to provide their contact details. Overall, 24 people indicated an interest in future participation. Due to cost and time implications, not every household was included in the study, and not everyone whose contact was collected was available for interviews, thus sampling was undertaken (Garg, 2016:33).

3.4 SAMPLING PROCEDURES

3.4.1 Inclusion and exclusion criteria

The inclusion criteria describe the qualities that the sample is required to possess, whilst the exclusion criteria are the qualities that make a potential participant ineligible for the study (Garg, 2016:34). These factors are based on the aim and objectives of the study, which was to assess community knowledge, attitudes, perceptions and practices regarding schistosomiasis as well as views on the relationship between environmental conditions and the occurrence of schistosomiasis. The inclusion and exclusion criteria for the household questionnaires and the in-depth interviews are described in Table 3.4.1 and Table 3.4.2, respectively.

Table 3.4:1 Inclusion and exclusion criteria for the household questionnaires

No.	Criteria	Inclusion	Excluded	Justification
1	Age	All factually and legally competent adults (over the age of 18)	People under the age of 18	The National Health Act, No. 61 of 2003 in South Africa requires that consent be sought from a parent or legal caretaker for all research conducted with research participants under the age of 18 years (Zuch *et al.,* 2012:1). As the aim of the study was to assess community knowledge, attitudes, and practices regarding schistosomiasis, by including individuals that were factually and legally competent, a wider representation of participants was achieved.
2	Residence	Permanent residents of Ha-Nesengani.	People who work and live in other towns/provinces and only return to their residence in Ha-Nesengani sporadically (circular migrants)	As per the aim of the study, it was important to include participants who were residing in the area full-time, as they were more likely to be aware of the issues and needs of their community. Furthermore, allowing any adult household member that is a permanent household member to participate, provided a more representative dataset.

The criteria for the household questionnaire included age and residence; individuals over the age of 18 who were residing in Ha-Nesengani permanently at the time of the study were considered for sampling. Conversely, people in the risk groups, health care providers, and people who had been residing permanently in Ha-Nesengani for more than 15 years were included in the in-depth interviews. High-risk groups included people involved in agricultural activities and primary caregivers of children under 15 years of age. Healthcare workers and traditional healers that work within the community, regardless of the number of years they have lived and worked in the area, were also included in the in-depth interviews.

Table 3.4:2: Inclusion and exclusion criteria for the in-depth interviews

No.	Criteria	Inclusion	Exclusion	Justification
1	Age	All factually and legally competent adults (over the age of 18).	People under the age of 18.	The study only included factually and legally competent adults, thus participants under the age of 18 were excluded.
2	Healthcare providers	Healthcare workers and traditional healers working within the community	Healthcare workers and traditional healers that work outside the community.	Healthcare providers provided valuable insights into current incidence as well as positive and negative community practices.
3	Risk groups	Participants must be in a high-risk group: • Involved in agricultural work. • Primary caregiver (parent or guardian) of a child/children under the age of 15.	People who did not have contact with contaminated water bodies during their daily activities. • People who worked in an office or any environment that did not include contact with contaminated water.	People that work in an office environment or have access to piped water are at very low risk of schistosomiasis infection. As a result, they might not have the knowledge and/or preventative practices that they follow or have experienced to lower the risk of infection and were thus excluded from the in-depth interviews. Furthermore, primary caregivers of children under the age of 15 were included, as the study did not include participants in this age category; however, these are the most at-risk individuals due to their high contact with contaminated water (Kabuyaya *et al.,* 2018:104).
4	Residence	Participants had been residing in the area for at least 15 years.	Participants who had been residents of the area for less than 15 years.	This inclusion criterion was especially important for achieving objective 4 of the study. People who had recently moved to the area would not have been able to provide the necessary information on the environmental changes that had occurred over time, so those who had lived there for less than 15 years were excluded.

3.4.2 Sampling Method

The participants for the administration of the household questionnaires were chosen using a simple random sampling procedure. This method was used because it ensured that every member of the population had an equal and independent chance of being chosen. In this regard, the choice of one participant had no bearing on the choice of the other (Jakubiak *et al.,* 1990:8). Purposive sampling was used to select participants for in-depth interviews based on the study's inclusion and exclusion criteria. This sampling method was chosen because it involves selecting a subset based on the characteristics that they possess (Tashakkori *et al.,* 2020:no pagination). Participants were sought both during the administration of the household questionnaire and on the ground, as not all of those who expressed an interest in participating in the in-depth interviews were available.

3.4.3 Sampling size

(i) Household questionnaires

To ensure a representative sample, the sample size was determined using the 1977 Cochran formula, indicated as equation 1 below:

Equation 1: $$n_0 = \frac{z^2 pq}{e^2}$$

Where n = sample to be calculated, z = 1.645 (a confidence level of 90%), p = 0.5 and a confidence interval of +/-5%.

Calculation: $\frac{(1.645)^2(0.5)(0.5)}{(0.05)^2} = 271$

However, because the calculated sample size exceeded 5% of the population

(3603*.05= 180), the final sample size was calculated using equation 2 below which represented Cochran's (1977) correction formula:

Equation 2: $n_1 = \frac{n_0}{1+\left(\frac{n_0}{N}\right)} = \frac{271}{1+\left(\frac{271}{3603}\right)} = 252$

Where N= the population size of 3603, n_0 = the required sample size according to Cochran's formula (271), and n_1 = the required sample size because sample size > 5% of the population (Kotrlik & Higgins, 2001:46-49).

The total number of households required for the study was determined to be 252. An additional 90 household questionnaires were able to be administered as a result of adequate resources. For the study, 342 household questionnaires were distributed.

(ii) In-depth interviews

This study included a total of 15 interviews in order to gain a deeper understanding of schistosomiasis knowledge, attitudes, perceptions and practices as well as the community's views on the relationship between environmental changes and the occurrence of schistosomiasis in the Ha-Nesengani community. The sample size for the in-depth interviews was determined using the informational redundancy criterion proposed by Lincoln and Guba (1985) and cited in Vasileiou *et al.* (2018:2), which states that sampling is terminated when no new information is retrieved by sampling more units. According to Vasileiou *et al.* (2018:7), qualitative data collection techniques require a minimum sample of 12 to reach data saturation code saturation, at which point no new themes can be identified. In the current study, no new information was generated by the 15th interview, so sampling was stopped.

3.5 INSTRUMENTS FOR DATA COLLECTION

The study relied solely on the use of primary data, which was collected through household questionnaires and in-depth interviews. Secondary information, particularly literature was used to develop the household questionnaire, which was used to collect data for the study. Literature on similar studies was also examined to identify the misconceptions and myths that exist within at-risk communities that put them at risk of infection, thus perpetuating the disease. These findings were included in the household questionnaires to check whether the same applied to Ha-Nesengani participants. During the administration of the household questionnaires, misconceptions such as "eating too much salt" being the cause of schistosomiasis infection were uncovered. This sort of discovery formed the basis for the in-depth interviews, which were used to delve deeper into the root causes of such beliefs and misconceptions in the community.

(i) Household questionnaire

A structured questionnaire with closed-ended questions was used to elicit information on schistosomiasis knowledge, attitudes and practices as well as the relationship between environmental conditions and schistosomiasis (see Appendix E). It comprised (i) multiple-choice questions, (ii) the Likert rating scale, and (iii) dichotomous questions.

Multiple-choice questions required only one response, and the option was used for socio-demographic questions. It was made certain that the options did not overlap, and the "other" option was included where necessary. The Likert scale (five-point scale) question type was used to assess participants' schistosomiasis attitudes and practices, as well as their perspectives on the relationship between environmental change and the occurrence of schistosomiasis. This is because, unlike multiple-choice questions, they have an inherent quantitative value that allows responses to be meaningfully ordered from low to high. Dichotomous questions were the simplest form of closed-end questions as respondents were provided with two options to select from, i.e., yes or no. These were used for questions pertaining to knowledge of the cause, transmission and symptoms of schistosomiasis (Stead, 2001:94-95).

An introductory section was included at the beginning of the household questionnaire, which explained the motivation for conducting the research and emphasised that the participant’s responses were anonymous and confidential. Likewise, the last section of the questionnaire had a note of gratitude for the respondents for participating in the research. The questionnaire was divided into six sections: A, B, C, D, E, F and G:

- Section “A” included the inclusion/exclusion criteria to determine whether the respondents were suitable for participation in the study. If they did not meet the inclusion criteria, they were not allowed to complete the questionnaire.
- Section “B” comprised the socio-demographic information, which sought to obtain respondents’ details such as gender, level of education, occupation and access to water and sanitation.
- Section “C” sought to determine the level of knowledge the respondents had regarding the cause, transmission and symptoms of schistosomiasis.
- Section “D” sought to elicit the attitudes of the participants regarding the prevention and treatment of the disease.

- Section “E” was aimed at determining the practices that the participants engaged in that put them at risk of getting infected with schistosomiasis.
- Section “F”, this section was for caregivers of children under the age of 15 years and sought to find out the activities that their children engaged in that could lead them to exposure to schistosomiasis.
- Section “G”, this section was for participants who had been residing at Ha-Nesengani for a period of over 15 years at the time of the study and sought to determine their views on the relationship between environmental change and the occurrence of schistosomiasis.

(ii) In-depth interview guide

The in-depth interview guide was developed following the administration of the household questionnaire and subsequent analysis of the data. The questions in the interview guide followed up on the questions from the household questionnaire and sought to explain concepts and information that were gathered during the administration of the household questionnaire. The in-depth interview guide was semi-structured and was developed to allow flexibility in the manner and order in which questions were asked to provide the opportunity for dialogue during the interviews (Bartlett & Vavrus, 2016:no pagination). This was achieved by using words such as why, what, who, where, when, or how were used to formulate the questions to help retrieve descriptive answers that would allow new concepts to emerge. During the period of the development of the interview guide, it was ensured that the questions were clearly worded, not leading, and were not multi-faceted (Ritchie *et al.,* 2013:no pagination).

The interviews consisted of two main sections: A and B (see Appendix F).

- Section “A” comprised the socio-demographic information, which sought to obtain respondents’ details such as gender, level of education, occupation and access to water and sanitation.
- Section “B” included interview questions in two levels: main questions and probes.

All the participants were asked the first three main questions, in varying orders, depending on the respondents' answers. Following this, the questions that were asked depended upon the criteria that were used to select them for participation. For example, following the three main questions and their probes, healthcare providers were asked questions that pertained to the examination of patients, treatment options available and groups that are most likely to visit the healthcare centre with schistosomiasis-related issues. This structure was followed for caregivers of children under 15 years, agricultural workers and participants who had been residing permanently at Ha-Nesengani for more than 15 years at the time of the study.

3.6 LIMITATIONS OF THE STUDY

Notwithstanding the valuable findings from the study, some limitations were experienced during the implementation of the study. The most recent population statistics for the Ha-Nesengani community were not available at the time of the study. As a result, the sample for the study was calculated using data from the 2011 Census, which may not have been the true number of households because communities grow over time. The nature of the research problem heavily influences the sample size of a study; if the sample size is too small, statistical tests may fail to detect significant relationships within the data set (Faber & Fonseca, 2014:27). However, a larger sample size is likely to produce more accurate results. The calculated sample size for this study was 252 households; however, 342 household questionnaires were distributed to the Ha-Nesengani community, to circumvent the challenge of under-sampling.

3.7 VALIDITY OF THE DATA COLLECTION INSTRUMENT

The validity of the household questionnaire was determined by face validity. This was addressed by formulating questions based on the conceptual framework of the study, which assisted in developing questions applicable to achieving the objectives. During this process, literature based on similar studies was rigorously consulted. Furthermore, as part of the application process for the North-West University Human Research Ethics Committee (NWU-HREC), a statistician was required to evaluate and review the data collection instrument. This process enhanced the face validity of the household questionnaire as the statistician evaluated the presentation, ease of

completion, and relevancy of the questions, which ensured that the data collected through the questionnaire could be analysed to the maximum effect.

3.8 METHODS OF DATA COLLECTION

The household questionnaires and in-depth interviews were administered and undertaken directly with the selected sample for the study. Overall, household questionnaires were administered to 345 participants, of which 342 were used for data analysis. The other 3 participants withdrew their consent; thus, their responses could not be used further. Conversely, 15 in-depth interviews were conducted. Figure 3.8.1 below indicates the process that was followed to retrieve the data used in the study.

Figure 3.8:1: Data collection process

3.9 METHODS OF DATA ANALYSIS

Data collected for the household questionnaires were captured and cleaned using Google forms and further imported into Excel Workbook format (.xlsx) for data pre-processing and analysis. Data cleaning included rectifying non-response errors. For, instance, some of the response options included dichotomous and Likert scales, and as shown in Table 3.9.1 below, each item was assigned a point based on the option that the participant selected. In this regard, if a participant had selected the correct option, their responses were allocated in chronological order. However, if they had

selected an option that was incorrect based on the question, then reverse coding was performed.

Table 3.9:1: Weighting of the household questionnaire instrument

	Points for correct options	**Points for incorrect options**
Yes	1	2
No	2	1
Strongly Agree	1	5
Agree	2	4
Neutral	3	3
Disagree	4	2
Strongly Disagree	5	1

Using Microsoft Excel 365, the sum of all items for each variable was calculated, and an average score was subsequently retrieved. The average scores were calculated to indicate whether the participants were knowledgeable about the disease, whether they had positive or negative attitudes and practices regarding schistosomiasis, and whether they associated environmental changes with the occurrence of schistosomiasis. This step in Excel was used to extract the numbers, and the actual determinations were performed in the Statistical Package for the Social Sciences (SPSS) version 26 software.

The calculated average served as the benchmark for determining the overall knowledge and attitudes about schistosomiasis. In this regard, for the knowledge variable, if the participant received a score below the average (27), they were considered knowledgeable, and above this, they were not knowledgeable. The conclusion of whether the participants had positive or negative attitudes regarding schistosomiasis are indicated in Table 3.9.2 below.

Table 3.9:2: Response options, items, average and formula used in Microsoft Excel

Variables	**Response options**	**Items**	**Average**	**Formula**
Knowledge	Dichotomous	21	27	=IF(Z2<28;2;IF(Z2>27;1)) 1= knowledgeable 2= Not knowledgeable

Attitudes	Likert scale	10	21	=IF(O2<21;1;IF(O2=21;2;IF(O2>21;3))) 1= Positive 2= Neutral 3= Negative

In SPSS version 26 software, analysis of the data was performed using descriptive statistics such as central tendency (mean) and presented in the form of tables and graphs. Initially, the socio-economic characteristics of the respondents, knowledge and attitudes were summarised using frequency and percentages. Furthermore, Pearson's Chi-Square Test of Independence was performed between the participants' age, gender, and level of education and their level of knowledge regarding whether they had positive or negative attitudes regarding and had positive or negative practices regarding schistosomiasis. The results are described based on the chosen significance level ($\alpha = 0.05$). Where the calculated p-value was greater than the significance level, it was concluded that there was no association (statistical significance) between the variables and vice versa.

Data from in-depth interviews were transcribed verbatim into Microsoft Word 365, then checked and verified for consistency against the audio files to ensure the transcribed files' accuracy. The checked transcriptions were read several times to ensure familiarity with the data, which served as the foundation for data analysis. The transcripts for each of the respondents were further examined manually to identify relevant text that would aid in explaining the results from the household questionnaires for the in-depth interviews. Emerging quotes that directly represented the concept were also sourced during this exercise. These were discussed in the results section.

3.10 CONCLUSION

The sequential explanatory research approach was adopted to assess schistosomiasis knowledge, attitudes, perceptions and practices as well as the community's views on the relationship between environmental changes and the occurrence of schistosomiasis. Initially, quantitative data were collected using a structured closed-ended household questionnaire, following the analyses of the quantitative data, an in-depth interview questionnaire was developed to explain the results obtained from the household questionnaires. Structured closed-ended

questionnaires were analysed using descriptive and non-parametric inferential statistics whilst in-depth interviews were analysed manually.

CHAPTER 4: PRESENTATION AND DISCUSSION OF RESULTS

4.1 INTRODUCTION

The purpose of this study was to investigate schistosomiasis knowledge, attitudes, perceptions, practices, and views about the relationship between environmental conditions and the occurrence of schistosomiasis in the Ha-Nesengani community. This chapter presents and discusses the obtained results. Following the presentation of the socio-demographic results, the results of the research objectives are presented and discussed in relation to findings from similar studies.

4.2 RESEARCH RESULTS AND DISCUSSION

4.2.1 Socio-demographic characteristics of study respondents

A total of 342 community members comprising 60% females, 39% males and 1% who did not want to disclose their gender were administered the household questionnaire. Most were between 35 and 64 years of age (45%). Fifty-nine percent (59%) had a secondary school education, whereas 4% did not have any form of schooling. Respondents were primarily unemployed (49%), with many of those who were employed working in the agricultural sector (27%) and performing activities such as farming or herding livestock for household or commercial purposes (Table 4.2.1). The majority of respondents (73%), in the in-depth interviews, were between the ages of 35 and 64, female (67%), and had secondary or tertiary education (40%, respectively). The respondents were also found to be in farming (33%), followed by health care (registered nurse, community health worker, and traditional healer, 13%, respectively).

Table 4.2:1: Demographic characteristics of respondents administered the questionnaire (n=342)

Variable	Category	Number of respondents (n)	Percentage (%)
Age	18 - 34 years	138	40
	35 - 64 years	153	45
	65 years or more	51	15
Gender	Female	205	60
	Male	134	39
	Prefer not to say	3	1
Level of education	Primary school	35	10

Variable	Category	Number of respondents (n)	Percentage (%)
	Secondary school	201	59
	Tertiary qualification	83	24
	Postgraduate qualification	10	3
	None	13	4
Employment status	Working full-time (over 30 hours per week)	39	11
	Working part-time (8 to 29 hours per week)	42	12
	Contract worker	24	7
	Unemployed	166	49
	Student	47	14
	Retired	24	7
Occupation description	Agricultural sector	92	27
	Office and administrative support	36	11
	Student	29	8
	Social grant	16	5
	Self employed	4	1
	Construction building and maintenance	36	11
	Retail and hospitality	19	6
	Unemployed	98	29
	Domestic worker	6	2
	Health care provider	6	2

4.2.2 Access to water sources and sanitation for the participants

Poor sanitation and a lack of access to a clean water source are two risk factors for contracting schistosomiasis (Kabuyaya *et al.,* 2017:37). According to the findings of the study, most respondents sourced their drinking water from piped water systems, which included communal taps (40%), pipes in the yard (21%), borehole water sources (15%), and a piped water system inside their home (11%). The same pattern was observed for water access for household needs, with respondents reporting that they used piped water from a communal tap (38%), piped water in the yard (21%), and borehole water (18%). Similarly, piped water from the communal tap (37%), a piped

water supply in their yard (20%), and water from a borehole (18%) were used to water gardens and crops. Only a small percentage of respondents said they used harvested rainwater (2%) or greywater (0.3%) to water gardens and crops (Figure 4.2.1).

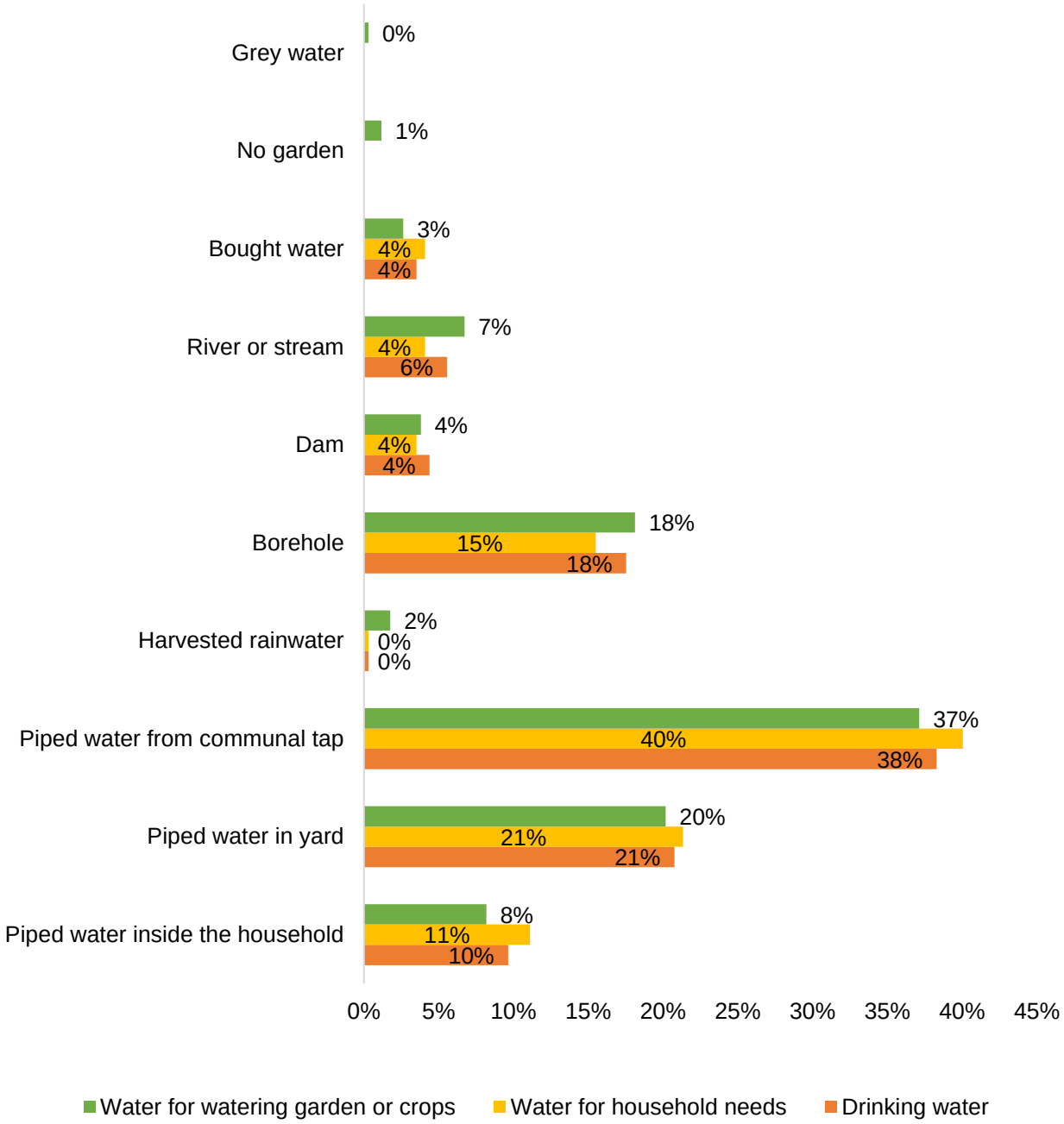

Figure 4.2:1: Main sources of water for watering gardens, drinking and other household needs (laundry, washing dishes and cleaning) (n=342)

While findings from the household questionnaires indicated that the respondents mostly used piped water (from communal taps, taps inside their yards, or boreholes) for drinking, domestic, and crop watering, the results from the in-depth interviews

revealed that most individuals in the community still went to the river to bathe or do laundry because communal pipes are not functional.

In-depth interviewees stated that those who have boreholes in their yards were fortunate, as there is a crocodile in the river that poses a risk to the users. According to a male resident, "*last year it swallowed a woman who was doing laundry, and while the community was out there in a search party for her, it swallowed another man."* The lack of water is a concern even in the surrounding areas, where people have been reported to be swallowed by crocodiles near the Nandoni Dam on the Luvuvhu River when they go to collect water, bathe, or do laundry (Sadike, 2022).

In terms of community sanitation, Figure 4.2.2 shows that the majority of respondents (87%) used pit latrine toilet facilities, while some (11%) used flush toilets and 1% did not have a toilet. Exum *et al.* (2019:14) argued that improved water and sanitation infrastructure does not ensure its use by the communities or lower infection rates. This was justified through in-depth interviews that revealed that, despite having access to toilet facilities at home, most people urinate or defecate in the river when doing laundry because if they got out of the river to urinate, the clothes would be washed away. They further added that even if toilets were installed near the river, most people would still urinate in the river, unaware that this would be the source of someone's infection further downstream. This is consistent with a study conducted in Nigeria in which participants stated that they urinated and excreted in open areas despite having toilet facilities in their homes (Dawaki *et al.,* 2015:11).

4.2.3 Schistosomiasis awareness among participants

The disease's local name, mutambotambo, was known to 93% of the 342 participants. The respondents were also familiar with the common name, bilharzia (70%), but not with the scientific name, schistosomiasis (29%) (see Figure 4.2.3). Respondents who were aware of mutambotambo stated that schools were their primary source of information (41%). These findings are consistent with those of Sady *et al.* (2015:10). They reported that only four participants named schools as a source of schistosomiasis information, and they concluded that schools can play a significant role in disease information dissemination. This was found to be the case in Ha-Nesengani. According to in-depth interviewees, while most adults in the community were aware of mutambotambo, many of the children were not. They agreed that the

school was the best place for children to learn about the disease because, at home, children undermined their parents and did not listen to their instructions, so the information could only be grasped in a school setting.

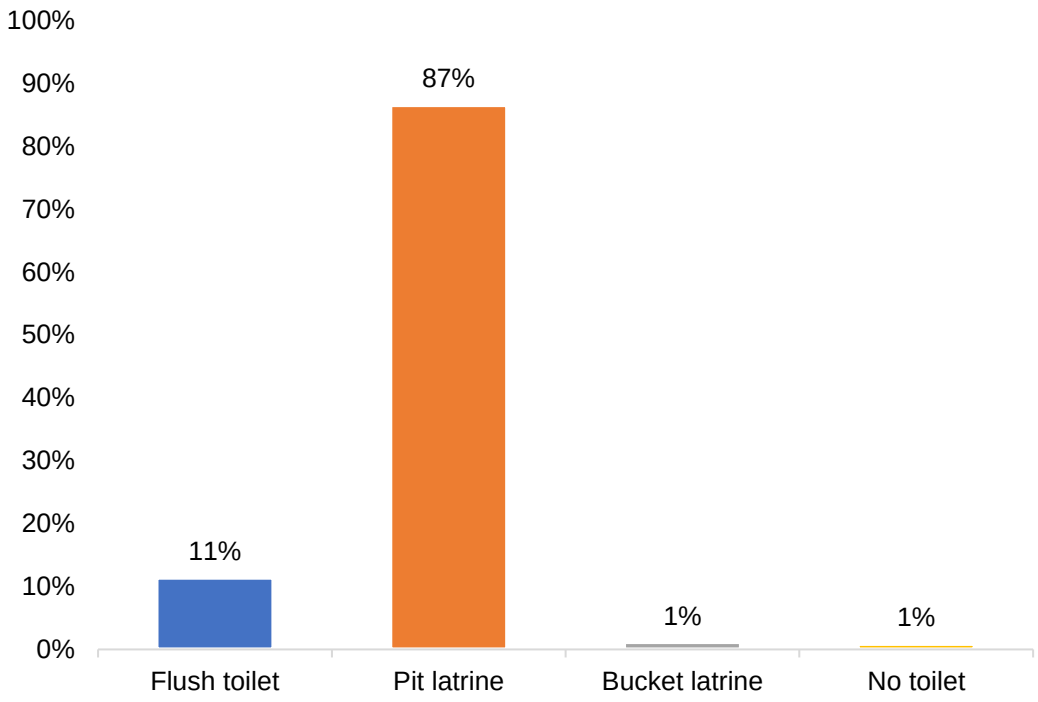

Figure 4.2:2: Type of toilet facility used in households (n=342)

Health promotion programmes are generally recommended as the preferred method because they teach learners how to protect themselves from infections and then further disseminate that information to the surrounding communities (Sady *et al.,* 2015:10). The nurses at the local clinic in Ha-Nesengani stated that in order to keep school-aged children safe and prevent them from swimming in the river out of boredom, the clinic used to host the children on weekends where they would participate in a variety of activities. Due to a lack of funds, the children were required to bring their own lunch, but this was not sustainable for the families, and the initiative was halted. Furthermore, the nurses interviewed for the study stated that they were unable to conduct school-awareness campaigns due to staff shortages at the local clinic. All of these factors have increased the risk of schistosomiasis infection in the community's school-aged children, who are the most vulnerable group.

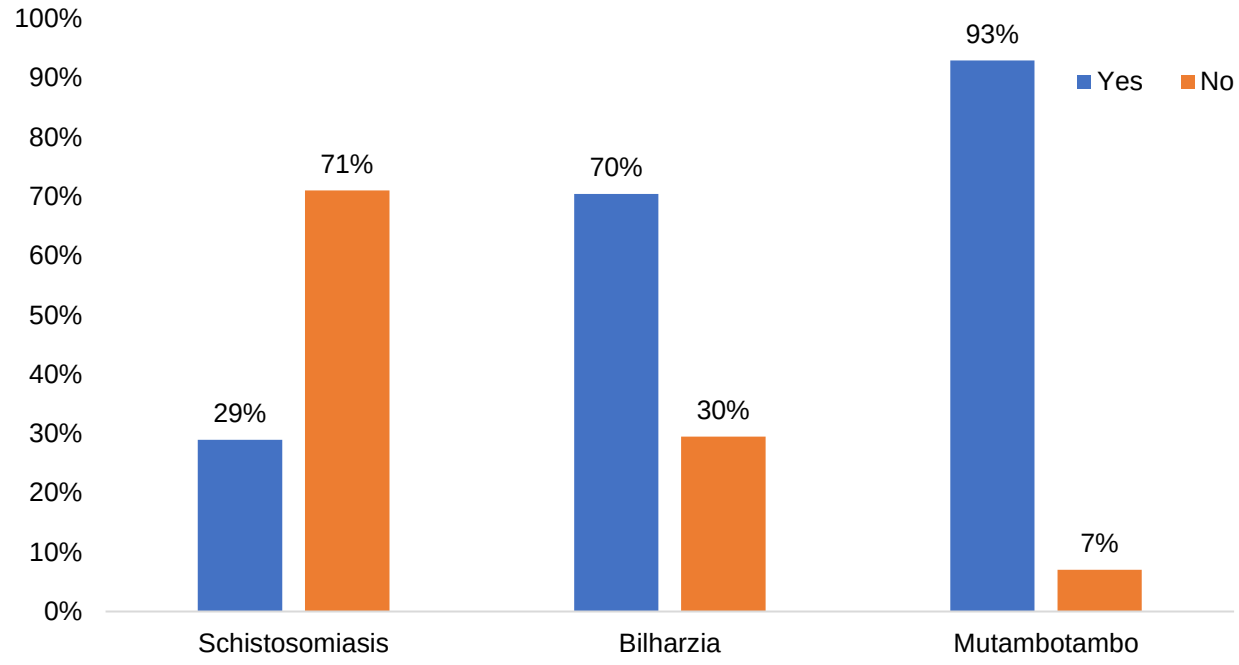

Figure 4.2:3: Respondents' awareness of the different terms of the disease (n=342)

4.2.4 Respondent's knowledge of the cause, transmission and symptoms of schistosomiasis

Through a multiple-choice questionnaire where respondents could select whether they agreed with the provided options, more than half (73%) of participants who said they were aware of mutambotambo knew it was caused by infected snails in freshwater sources. However, 84% of them incorrectly identified the disease as being caused by a virus in the water and 83% as being caused by bacteria in the water (see Figure 4.2.4). The respondents in this study also indicated that mosquitoes (81%) were not the cause of the disease. This is similar to a study conducted in north-western Tanzania, where only 3.32% of the respondents who had heard about the disease indicated that mosquitoes were the cause of the disease (Munisi *et al.,* 2017:4).

All of the in-depth interviewees stated that contact with river water results in mutambotambo infection. Respondents specifically believed that schistosomiasis forms as a result of discarded nappies and feminine products in the river, developing as a "dirt" that cannot be seen with the naked eye. Only one farmer correctly associated the existence of snails in the river with the disease. Participants in a similar study in Northern Senegal were more knowledgeable about the disease's cause than those in the current study, with 66.1% believing it was caused by worms and 40.5%

believing it was caused by snails (Frigerio *et al.,* 2016:843). In addition, during the household questionnaire administration, many of the participants indicated that eating too much salt, particularly coarse salt could cause mutambotambo. This was expanded upon by in-depth interviewees, who stated that eating too much salt causes the kidneys to inflate and squeeze during urination, resulting in the excretion of blood in the urine, displaying the same symptoms as an infection caused by contact with water. In contradiction, some of the in-depth interviewees also stated that when they were younger, they would eat salt with pap, African vegetables with salt and pap, or mangoes with salt, and the elders would warn them that if they ate too much salt, they would get bilharzia. However, a male traditional healer stated that he had never treated someone whose cause of infection was due to eating too much salt. The myth that eating too much salt causes bilharzia infection could simply be an old lady's tale in the community used to keep people from eating too much salt. The perception that consuming too much salt has also been linked to schistosomiasis in studies conducted in North Senegal and the Philippines (Frigerio *et al.,* 2016:842-844; Lorenzo *et al.,* 2019:6).

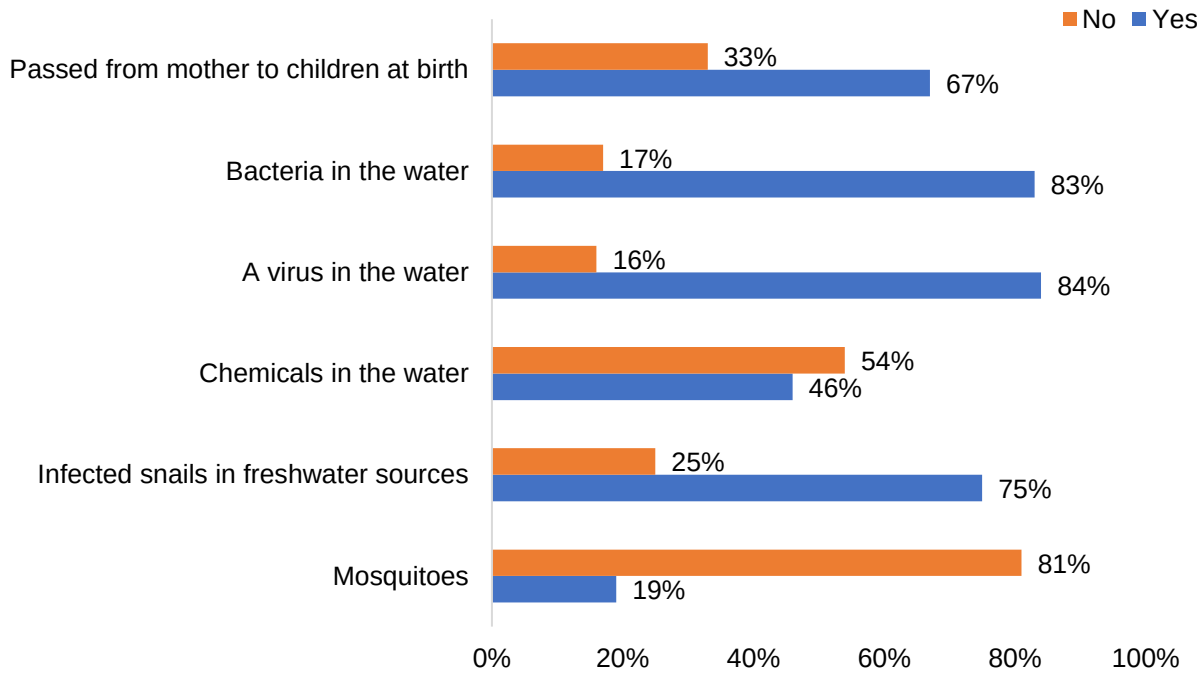

Figure 4.2:4: Knowledge of the cause of schistosomiasis (n=318)

In terms of disease transmission, adequate knowledge levels were observed among participants who were aware of mutambotambo. Contacting water where people urinate/defecate (89%), swimming or wading in water with snails (84%) and washing or bathing in river water (83%), were all mentioned as disease transmission routes (see Figure 4.2.5). However, because the participants were aware that schistosomiasis is a waterborne disease, many of them indicated that the mode of transmission was drinking unfiltered river water (86%) and drinking the same water as cattle (72%) (see Figure 4.2.5). Schistosomiasis differs from most waterborne diseases in that infection occurs when a person's skin comes into contact with a freshwater body containing the parasite, rather than through ingestion of contaminated water (Secor, 2014:1). In a similar study conducted in Tanzania, knowledge of disease transmission was high, with many respondents indicating that swimming in the lake (86.7%) and fishing (80.86%) cause infection, and fewer respondents indicating that drinking unboiled water (64.19%) and walking barefooted (56.27%) cause infection (Munisi *et al.,* 2017:4). Awareness about how infection occurs needs to be raised among the community of Ha-Nesengani.

While the study's in-depth interviewees were aware that infection occurs through skin contact with contaminated water, many of them also stated that transmission can occur when people gulp some water in pools where people urinate. This demonstrates an ignorance of the schistosomiasis life cycle, as the eggs require an intermediate host snail to develop into a parasite that can infect another person (Colley *et al.,* 2014:2). The household questionnaire respondents also indicated that having unprotected sex (76%) would not result in infection with mutambotambo; however, according to the in-depth interviewees, transmission can occur through the genital area when people are swimming, and thus symptoms manifest through the genitals. Participants in a similar study in Mozambique, however, believed sexual conduct was a route of transmission to schistosomiasis (Rassi *et al.,* 2019:4-12). Furthermore, Rassi *et al.* (2019:12) state that the misconception that schistosomiasis is a sexually transmitted disease is understandable, as the majority of urogenital schistosomiasis symptoms affect the reproductive organs.

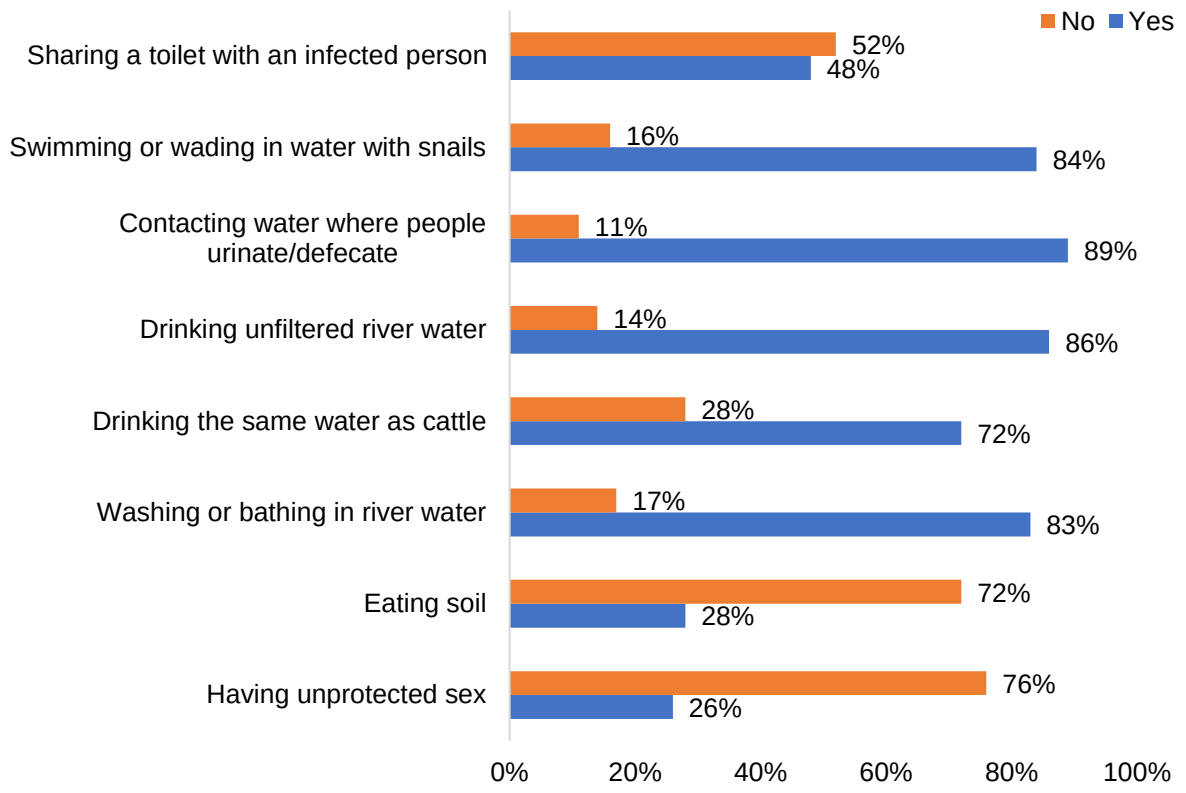

Figure 4.2:5: Knowledge of the transmission of schistosomiasis (n=318)

The study participants' knowledge of disease symptoms was found to be adequate. The disease's most common symptoms were blood in the urine (97%) and pain when urinating (85%) (see Figure 4.2.6). The findings agreed with those of a previous study conducted in South Africa (Ndumo) and Zimbabwe (Ntale), in which 82.5% and 77.0%, respectively, were aware of the symptoms of schistosomiasis, particularly blood in the urine (Mbereko *et al.,* 2020:4-5). Furthermore, abdominal pain and swelling (72%), blood in stool/feces (73%), and tiredness or body aches (67%) were identified as disease symptoms in the current study. The in-depth interviewees were also well-informed, indicating that symptoms of the disease include excreting blood during or after urinating, experiencing a burning sensation when urinating, passing small amounts of urine, experiencing headaches, pneumonia, and experiencing abdominal pain. The findings of this study contradicted those of a study conducted in Kenya, where participants did not know the correct sign and symptoms of the disease, with some stating that the symptom is when someone has cracks in their feet (Odhiambo *et al.,* 2014:4).

In addition to the common symptoms mentioned by the majority of respondents, healthcare providers (registered nurses and traditional healers) mentioned some additional disease symptoms. A nurse stated that the disease can present itself as painless hematuria while a traditional healer stated that mutambotambo is any type of abnormal blood, including nosebleeds in children and menstrual blood where a woman has her period three times a month (a total of 15 days is her usual cycle is 5 days). In a study where schistosomiasis is not endemic (United States of America), patients indicated that they had previously visited endemic areas and later presented with 1-6 months painless gross hematuria (Summer *et al.,* 2006:176-180). Due to the presence of schistosomiasis in the study area, it is possible that when patients at the clinic report painless hematuria, they were previously infected with the disease and were not reinfected.

Infection with *Schistosomiasis haematobium* causes *Female Genital Schistosomiasis* and as a result, women can develop uterine enlargement, menstrual disorders and infertility (Nour, 2010:31). In contradiction to the findings of the current study, according to a study conducted in Tanzania, healthcare providers had moderate knowledge levels regarding signs and symptoms with the only symptoms known were bloody stool (78.3%) and abdominal pain (82.6%) (Mazigo *et al.,* 2021:6).

4.2.5 Participants attitudes regarding the treatment and prevention of the disease.

Participants who were aware of mutambotambo were also assessed on their attitudes toward the disease. The respondents' attitudes toward the severity of the disease were positive; more than half strongly agreed that schistosomiasis is a serious disease (75%). The findings are in line with a similar study undertaken in Cameroon where 80.0% considered the disease to be serious (Folefac *et al.,* 2018:3). In some studies, the participants were found to underestimate the seriousness of the disease, as it was regarded as a disease that cannot cause death (Sacolo-Gwebu *et al.,* 2019:10) or because a mass treatment programme is in place in the area (Sanya *et al.,* 2017:11).

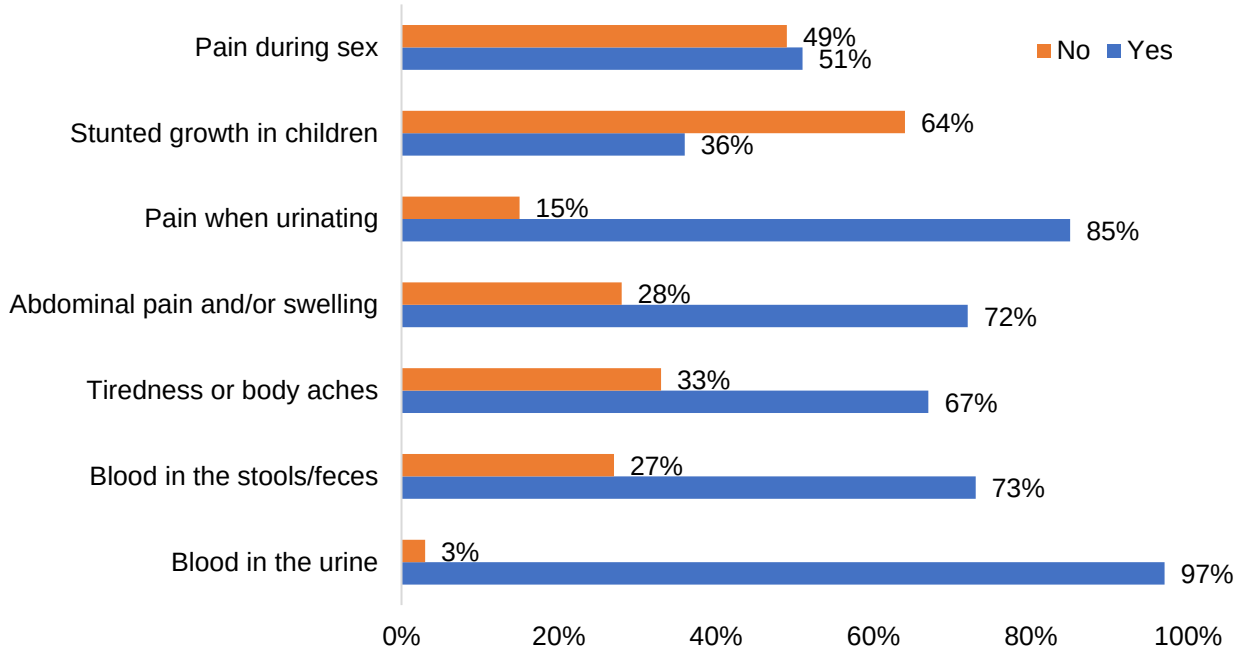

Figure 4.2:6: Knowledge of the symptoms of schistosomiasis (n=318)

The in-depth interviewees in this study were also of the opinion that mutambotambo is a serious disease and reasoned that a person could not live a long time while excreting blood every time they urinated, indicating the need for treatment. According to one female farmer, "*It is a serious disease that must be treated because one cannot live for very long if they are constantly urinating blood. You urinate blood the first time you go, the second time you go, and even when you wake up in the middle of the night to urinate. You will surely die*." The current study's findings are consistent with a study conducted in Cameroon, where respondents indicated that if a disease causes one to urinate blood, it is serious (Folefac *et al.,* 2018:4).

In terms of treatment, respondents strongly agreed that if someone passes bloody urine/stool, they should go to the hospital (76%) and that if infected, bilharzia medication should be taken as prescribed (79%). Many of the respondents (89%) also said doctors (72%) and nurses (56%) were the sole people who could treat the disease. A study conducted in Yemen was also in agreement with the findings and reported that 81.1 % of the respondents mentioned that they go to the nearest clinic/hospital for treatment, especially in case of haematuria (Sady *et al.,* 2015:6). In addition to believing that doctors and nurses could treat the disease, in-depth interviewees also indicated that traditional healers were also able to treat the disease.

A female farmer said, *"Even the traditional healers can treat it because they can give you medication that can stop the blood from coming out*. *They know how to treat mutambotambo because it is a disease that has existed for a long time; it was there even before modern medicine.*" Contrary to the current study, a previous study conducted in northern Côte d'Ivoire and southern Mauritania reported that affected people relied on self-medication, local customs and medication from the informal market; going to the hospital or clinic was the last resort option (Koffi *et al.,* 2018:9).

In terms of prevention, despite being aware that infection occurs through contact with fresh water sources, respondents demonstrated a lack of knowledge about the disease's proper prevention measures. Thirty percent (30%) of the respondents agreed that people could swim, fish, or collect water from the river without wearing any protective gear. The current study's in-depth interviewees agreed with this, stating that wearing protective gear when in contact with water was not functional. In a similar study conducted in the Philippines, participants were found to have a high awareness of prevention practices, however, only 58.5% said they actively avoided contact with water sources and only 67.1% they used protective gear such as boots in infected water (Francisco *et al.,* 2019:8).

During in-depth interviews, views on whether wearing protective gear when encountering "dirty" water could prevent infection depended on participant knowledge of the routes of infection and transmission. Those that indicated that infection is through the skin indicated that wearing protective gear could prevent infection. Those that indicated that infection is through the genitals indicated that if the protective gear covered the genitals, then protection would take effect. However, those that indicated that infection was through the mouth indicated that protective gear would not help and asked how people would be able to "swim with those things".

It was unclear whether respondents in the household questionnaires believed unprotected sex was a risk factor for schistosomiasis. This was also true among those who participated in in-depth interviews, who disagreed on whether schistosomiasis is a sexually transmitted disease. One community traditional healer believes the disease is not contagious and cannot be transmitted sexually, whereas another believes the disease, like herpes, is contagious and can be transmitted sexually. Others, however, claimed that because a person cannot excrete blood during sexual interaction, the

disease could not be transmitted sexually. Participants in a similar study conducted in South Africa believed that schistosomiasis could be transmitted sexually, with one participant indicating that "*I think that you can get schistosomiasis sexually because it is something inside you. It's the blood that is dirty inside you, right? So, when you have intercourse so definitely you will get it because the dirt will come inside you" (*Lothe *et al.,* 2018:3*)*. A study conducted in Mozambique also found widespread misconceptions about schistosomiasis being a sexually transmitted disease (Rassi *et al.,* 2019:12).

As shown in Table 4.2.2 below by percentages spread almost evenly across the Likert scale, there was no clear indication of whether household questionnaire respondents thought people could outgrow bilharzia or thought it was a disease that came with growing up. This contrasted with the perceptions of the in-depth interviewees, who stated that the disease primarily affected boys aged 5 to 17 years old, which happened to be the age range that frequently visited the clinic for schistosomiasis issues. According to a female caregiver of a child under the age of 15, *"...it infects children when they are still young before they know what sex is, an adult who is sexually active does not get infected with the disease."* Young boys were found to be more vulnerable to the disease than girls because they were more likely to swim in still waters along riverbanks. Furthermore, a female caregiver of a child under the age of 15 in the current study stated, *"I have never seen it with girls. We used to bathe in the river when I was younger, but we never heard of any girls contracting the disease. The disease would only infect the boys with whom we were playing."* These findings are consistent with a South African study that found that schistosomiasis is perceived as a disease that primarily affects boys because they were more likely to go swimming on warm sunny days (Lothe *et al.,* 2018:5-8). Although the majority of respondents in the current study were aware that adults could become infected if they swam in still contaminated water, they were not considered at risk of infection because they bathe and do laundry in flowing water rather than stagnant water. Avoiding contact with stagnant water as a form of a preventative measure has also been reported in a study conducted in Kenya (Odhiambo *et al.,* 2014:4).

The study's participants did not associate having unprotected sex with disease infection, with 28% indicating they were unsure. While this is true for household questionnaire respondents, in-depth interviewees had different opinions. "*When an adult comes in complaining about urinating blood, we suspect Sexually Transmitted*

Diseases..., furthermore if it's an adult lady, we suspect cancer," explained a nurse. This is consistent with a South African study in which a traditional healer indicated that the disease was dependent on age, wherein it was common to suspect sexual transmission if a patient is an adult (Lothe *et al.,* 2018:3). Furthermore, if an adult woman reported having schistosomiasis, people assumed she was hiding a sexually transmitted infection behind the disease (Lothe *et al.,* 2018:4).

Table 4.2:2: Respondents' attitudes towards schistosomiasis (n=318)

Items	Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	
	n	%	n	%	n	%	n	%	n	%
Bilharzia is a serious disease	238	75	61	19	12	4	2	1	5	2
Bilharzia is part of growing up	60	19	54	17	75	24	71	22	58	18
One outgrows bilharzia	51	16	50	16	87	27	83	26	47	15
Having unprotected sex can lead to infection with bilharzia	68	21	53	17	89	28	58	18	50	16
Defecating in the toilet is very important	214	67	61	19	33	10	9	3	1	0
When someone passes bloody urine/stool they should go to the hospital	243	76	49	15	16	5	5	2	5	2
A person can be infected with bilharzia many times	163	51	70	22	46	15	19	6	20	6
People can swim, fish or collect water from the river without wearing protective gear	94	30	69	22	56	18	44	14	55	17
It's important to learn about bilharzia	232	73	68	21	12	4	3	1	3	1
If infected, it is important to take bilharzia medication as prescribed	251	79	48	15	15	5	0	0	4	1

4.2.6 Practices of respondents regarding schistosomiasis

The risk perception of study participants was assessed, as shown in Table 4.2.3 below. The majority (69%) agreed that staying indoors is the best way to avoid disease infection. The current study's findings contradicted those of a Swaziland study, in

which only 2.7% saw staying indoors as a preventative measure against schistosomiasis infection (Maseko *et al,* 2018:105). Avoiding contact with river water (46%) was not a viable preventative measure according to the current study's participants, which is likely because, as the in-depth interviewees indicated, communal taps are not functional, making going to the river a necessity rather than a choice. This is consistent with a study conducted in Egypt, in which participants stated that even if public water taps are available, they could not stop using canals because there is sometimes no water in the tap for days on end (Elmorshedy *et al.,* 2020:7).

Furthermore, 42% of respondents said that vigorously towel drying after an unintentional, brief exposure to water does not help protect people from disease infection. According to a study on the prevention and control of schistosomiasis, vigorous towel drying after a brief accidental contact with infected water can help prevent cercariae from penetrating the skin (Inobaya *et al.,* 2014:70).

Table 4.2:3: Participants' discernment of risk (n=342)

Items	**Strongly Agree**		**Agree**		**Unsure**		**Disagree**		**Strongly Disagree**	
	n	**%**	**n**	**%**	**n**	**%**	**N**	**%**	**n**	**%**
Staying indoors	235	69	68	20	15	4	8	2	16	5
Avoid contact with river water	25	7	15	4	47	14	97	28	158	46
Avoid direct contact with rainwater	38	11	31	9	56	16	90	26	127	37
Wear protective gear when in contact with river water	141	41	78	23	48	14	39	11	36	11
Vigorous towel drying after an accidental, very brief water exposure	31	9	27	8	66	19	74	22	144	42
Boiling or filtering collected water from the river before use in the household	47	14	21	6	26	8	23	7	225	66

The results relating to the water-related practices among the 342 study participants showed that 63% never urinate in water and 61% never pass stool in a bush or water (see Table 4.2.4). In a similar study undertaken in Tanzania, boys were reported to urinate everywhere, including the bushes, rivers and ponds (Person *et al.,* 2016:8). In

terms of treatment-seeking behaviour, 72% indicated that they go to a health facility when passing blood in the urine/stool. The in-depth interviewees indicated that it was important for people who are seeking treatment to take their medication as prescribed. Whilst the clinic in Ha-Nesengani does not provide medication or treatment for people who test positive for schistosomiasis, a female community health care worker indicated that "*if a person has tested positive and is given medication to drink, I can explain to them to drink medication as prescribed and after a meal... I will also warn them about going back to the river to swim as they will be infected*."

Sixty percent (60%) of respondents said they never fish or swim in a river, lake, or stream. However, during the in-depth interviews, a male resident stated that he enjoys fishing in the Luvuvhu River during the rainy season. The respondent did not consider this to be a dangerous water practice because the water is clean during the rainy season, as all the dirt that gathered during winter flows downstream, lowering the risk of contracting the disease. The respondents reported good hygiene, with the majority stating that they almost always wash their hands after using the restroom (78%) and that they wash fruits and vegetables before eating (78%). In contrast to the findings of this study, a similar study in the area found that hygiene habits were inadequate, with only 20% of participants indicating that they washed their hands every time they visited the restrooms (Samie *et al.,* 2010:7162).

Table 4.2:4: Risk perception and practices of the respondents towards schistosomiasis (n=342)

Item	**Almost always**		**Sometimes**		**Every once in a while**		**Rarely**		**Never**	
	n	**%**	**n**	%	**n**	%	**n**	%	**n**	%
Fish or swim in a river, lake or stream	49	14	47	14	12	4	29	9	205	60
Wash your hands after using the toilet	268	78	54	16	3	1	6	2	11	3
Wash fruits and vegetables before eating	266	78	50	15	10	3	10	3	6	2
Wear protective gear when in contact with water	99	29	50	15	27	8	61	18	105	31
Let livestock drink from the river	102	30	39	11	19	6	23	7	159	47

Item	Almost always		Sometimes		Every once in a while		Rarely		Never	
	n	%	n	%	n	%	n	%	n	%
Urinate in water	24	7	38	11	15	4	48	14	217	63
Have protected sex	136	40	105	31	30	9	22	6	49	14
Avoid using untreated water for other domestic uses	148	43	68	20	32	9	30	9	64	19
Pass stool in a bush or water	39	11	45	13	21	6	30	9	207	61
Take antibilharzia tablets	91	27	44	13	23	7	38	11	146	43
Go to a health facility when passing blood in urine/stool	245	72	37	11	6	2	6	2	48	14

Participants who were caregivers (parents and guardians) for children under the age of 15 were asked to answer a few questions in order to learn about the practices of children in the community who were deemed at risk but were excluded due to the study's inclusion criteria. Only 210 (66%) of the 342 people who filled out the questionnaires were caregivers for children under the age of 15. Figure 4.2.7 shows that children in the respondent's care never swim or play in river water (73%), collect river water for domestic purposes (72%), or cross the river to go to school or see others (75%). Caregivers of children under the age of 15 stated in semi-structured interviews that their children never swam or played in river water, collected river water for domestic purposes, or crossed the river to attend school or visit others. However, all respondents agreed that children in the community were the most vulnerable to the disease because they were the ones who went swimming in the river despite their parents' prohibitions. "*I don't have a child who goes through the river on their way to school, but there are some kids who go through the river on their way home from school,*" a female farmer added. Furthermore, according to a male farm manager, "*when women go to do laundry with their young children, they will not just stand there and watch their mother's washing clothes, they will get into the water to swim."*

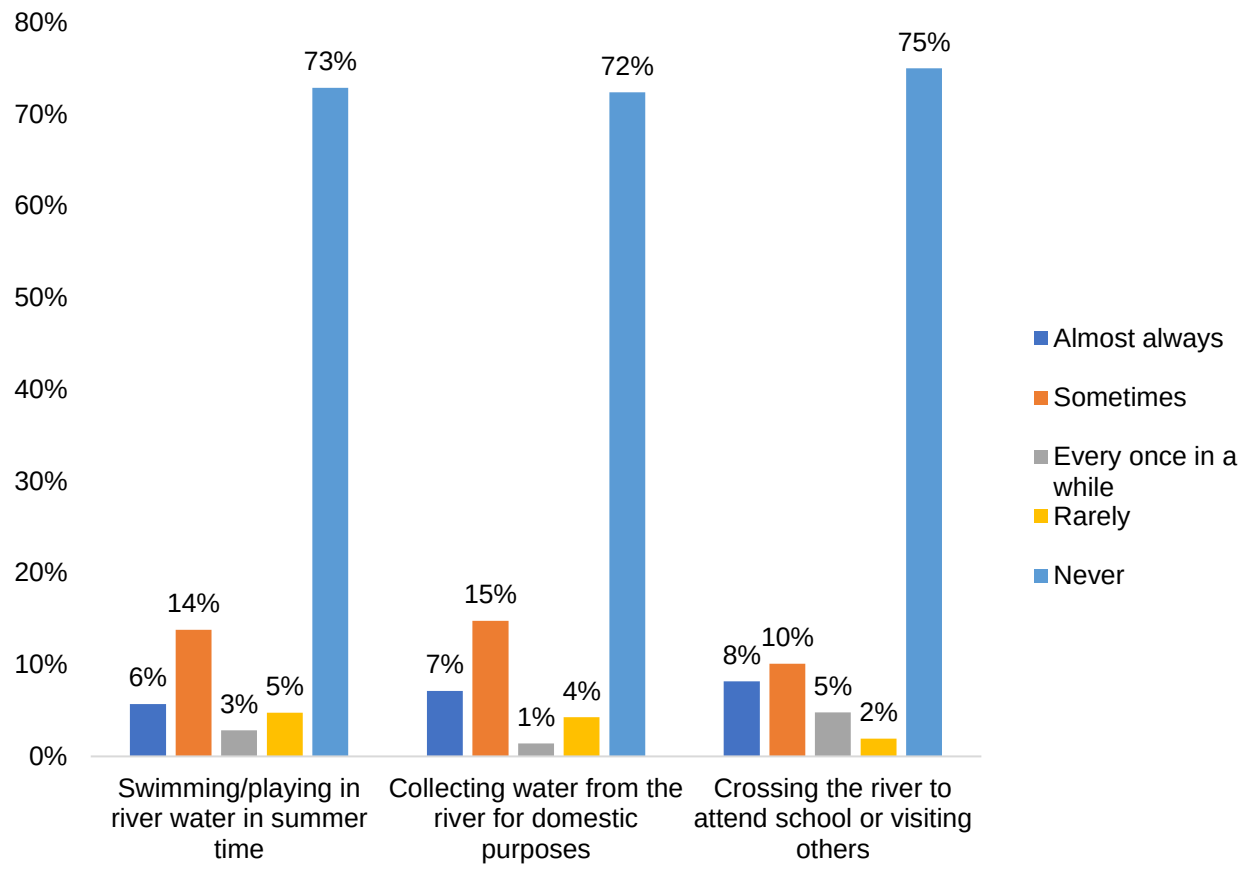

Figure 4.2:7: Practices of children under 15 years under the care of the respondents (n=210)

4.2.7 Participants' perceptions of environmental conditions and the occurrence of schistosomiasis

Out of the 342 respondents who were administered the questionnaire, 235 (69%) had been residing at Ha-Nesengani for over 15 years at the time of the study. Tshanduko ya mupo (the local term for climate change) was more familiar to respondents (79%) than climate change (64%) (See Figure 4.2.8). Those who said they were aware of tshanduko ya mupo correctly identified the effects: high rainfall (floods) (95%), very little rain (94%), hot weather (91%), and tropical storms (84%). Those who indicated knowledge of climate change performed worse in terms of determining the effect of the phenomenon. Sixty percent (60%) cited very little rain as an example of climate change, followed by heatwaves (57%), heavy rainfall (60%), and tropical storms (56%).

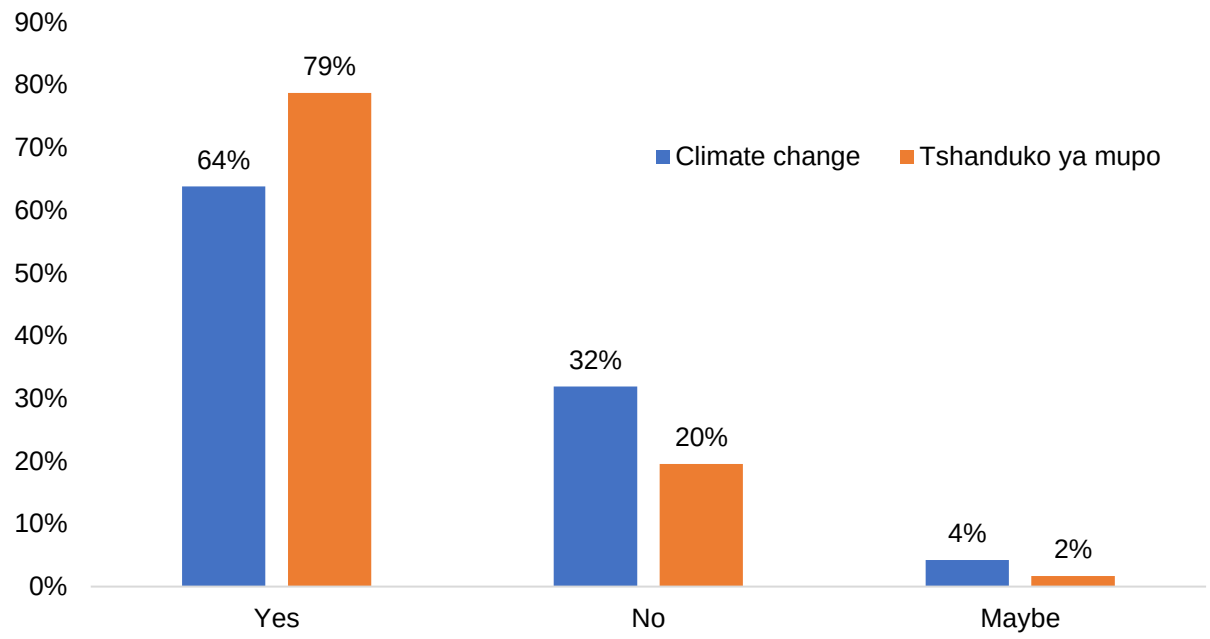

Figure 4.2:8: Respondents' awareness of the phenomena (n=235)

Tshanduko ya mupo was known to the in-depth interview respondents, but they thought it was synonymous with the weather. A male respondent stated that "*because it rained on the weekend but not during the week, that is indicative of tshanduko ya mupo, which means that climate changes time and again*." A female farmer also stated that "*today is sunny, yesterday there were clouds and the other day there was rain.*" Most of the participants were only able to recognise tshanduko ya mupo as climate change when asked about floods, increases in temperature and drought. A male respondent in the in-depth interviews also recalled a period of drought when he was young, which he said was in 1981 or 1982 when the only maize meal available was yellow due to a lack of rain and a low harvest. In all the shops, the only maize meal available was yellow. The findings are consistent with the findings of a study conducted in Ghana, in which participants provided examples and instances of the climate change phenomenon in order to demonstrate the phenomenon's occurrence in their community (Codjoe & Larbi, 2014:7).

Table 4.2.5 shows the responses of people who had been living permanently at Ha-Nesengani for more than 15 years at the time of the study. About one-third of the respondents (34%) strongly agreed that the rise in temperature increases the survival and number of infected snails, 37% were unsure of whether a temperature rise can

increase the intensity of bilharzia infection and 41% were unsure of whether the rise in temperatures could reduce snail survival and numbers.

When asked if temperature influences the occurrence of bilharzia, some in-depth interviewees indicated that there is a link because when it is sunny and hot, more people may go to the river to cool off. According to Osakunor *et al.* (2018:2), climatic changes have a significant impact on human exposure patterns, with exposure increasing during hotter seasons when more people are exposed to infected water sources during recreational activities. This is consistent with a study similar to the current study, which was conducted in Ghana, where respondents stated that they went to the river to cool off despite being aware of the dangers of doing so (Codjoe & Larbi, 2014:8). Nevertheless, a male respondent in the current study stated that the only factor influencing disease occurrence was pollution: *"...whether it is hot or cold, people can still get infected. Temperatures have fluctuated over time, but the disease has remained constant*." This indicates that the respondents did not associate environmental changes with the occurrence of schistosomiasis. In addition, another in-depth interviewee stated that higher temperatures did not affect the occurrence of schistosomiasis, saying, "*I don't think high temperatures can cause bilharzia because if temperature affected bilharzia, then everyone in Limpopo would have bilharzia."* Because Limpopo Province is considered a hot area, the respondent further stated that if the sun had an effect on the disease, everyone would be sick, from adults to children.

When asked whether intense rainfall (flooding) expands areas where snails are found, the same pattern was observed with questions about the impact of temperature increase, with 35% unsure whether intense rainfall (flooding) expands areas where snails are found. Similarly, 36% of respondents were unsure whether intense rainfall (flooding) destroys snails and their habitats due to fast-flowing water. High rainfall periods, according to in-depth interview respondents, are associated with a decrease in schistosomiasis infection because people can harvest rainwater in their homes and do not need to go to the river to swim because the weather is cooler during the period. Furthermore, respondents indicated that because mutambotambo is caused by "dirt in the water," when it rains, the river fills up and moves downstream, causing all of the dirt in the water to be moved.

In terms of the effect of droughts on the occurrence of schistosomiasis, 32% of respondents strongly agreed that during times of low rainfall and drought, more people rely on rivers for water, and 36% strongly agreed that the construction of a dam increases access to water, resulting in a decrease in bilharzia infection. However, 34% of respondents were unsure whether low rainfall reduces bilharzia infections. According to in-depth interviewees, there are more cases of the disease during a period of drought because people get hot and go to the river to cool off. This contradicts a similar study conducted in Ghana, where respondents stated that during low rainfall periods, the water turns green and cannot be used for bathing or swimming, as usual, thereby reducing schistosomiasis infection (Codjoe & Larbi, 2014:8).

Table 4.2:5: Respondents' association of environmental change with the occurrence of schistosomiasis (n=235)

Items	Strongly agree		Agree		Unsure		Disagree		Strongly disagree	
	n	%	n	%	n	%	n	%	n	%
Rise in temperature increase the survival and number of infected snails	80	34	62	26	72	31	13	6	8	3
A rise in temperatures reduces snail survival and numbers	38	16	45	19	96	41	26	11	30	13
A rise in temperature increase the intensity of bilharzia infection	78	33	57	24	87	37	6	3	7	3
Intensive rainfall (flooding) expands areas where snails are found	81	34	54	23	82	35	9	4	9	4
Intensive rainfall (flooding) destroys snails and their habitats due to fast-flowing water	57	24	47	20	85	36	22	9	24	10
During times of low rainfall and drought, more people rely on the rivers for water	76	32	58	25	72	31	9	4	20	9
Fewer people get infected with bilharzia during times of low rainfall	76	32	46	20	80	34	15	6	18	8
As a result of the construction of a dam, more people have access to water leading to a reduction in bilharzia infection	85	36	49	21	83	35	5	2	13	6

4.2.8 Overall knowledge, attitudes and practices of participants regarding schistosomiasis

The respondents' knowledge of the cause, transmission, and symptoms of schistosomiasis was assessed using 27 items. According to the findings, only 37% of respondents who knew the local name, mutambotambo, could correctly answer all of the questions about the disease's cause, transmission, and symptoms, while 64% could not (Figure 4.2.9). To account for this, while the majority of respondents (93%) knew the disease's local name, many were unaware of its cause, with a large proportion of them (84%) incorrectly identifying the disease as being caused by a virus in the water and 83% incorrectly identifying it as being caused by bacteria in the water. Knowledge of the mode of transmission was adequate, and knowledge of the symptoms was significant. In a similar study in Botswana, in addition to low levels of awareness regarding the disease, only 42% of respondents have heard of the disease and 52% knew its local name (Gabaake *et al.,* 2022:5). The results are similar to those of a study conducted by Odhiambo *et al.* (2014:6) in Western Kenya. Odhiambo *et al.* (2014:6) discovered that, despite being aware of the disease, people had a general lack of knowledge about schistosomiasis.

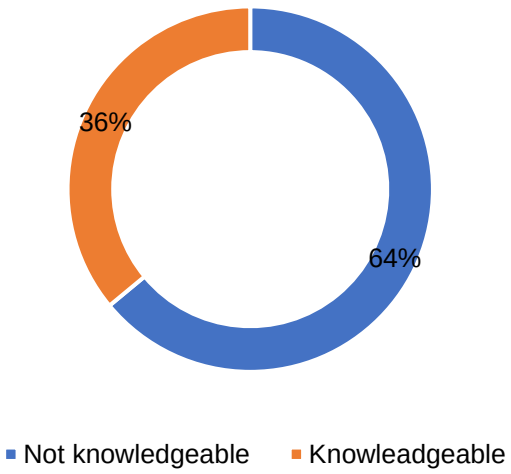

Figure 4.2:9: Household questionnaire respondents' overall knowledge of the cause, transmission and symptoms of schistosomiasis

There was no significant difference in attitudes between those who thought schistosomiasis was a serious disease that should be treated and prevented. Positive attitudes toward the disease were held by 48% of participants, compared to 46% who did not (see Figure 4.2.10).

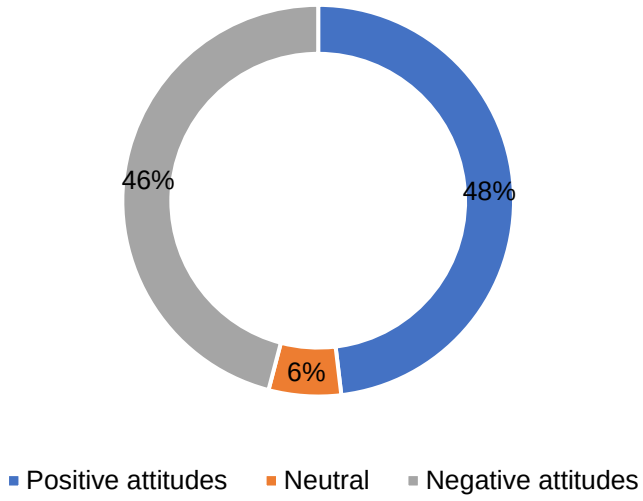

Figure 4.2:10 Household questionnaire respondents' overall attitudes towards schistosomiasis

4.2.9 Comparisons of respondents' levels of knowledge and attitudes with their age, gender, and level of education

Multivariate Statistics from the Statistical Package for the Social Sciences (SPSS) were used to demonstrate the relationship between household respondents' knowledge and attitudes and their age, gender, and level of education. Table 4.2.6 shows that the respondents aged 18 to 34 years (the youngest category) had the least knowledge of schistosomiasis in the current study (28%). This is consistent with findings from a Yemen study, in which respondents under the age of 40 were found to have greater knowledge of schistosomiasis symptoms than those over the age of 40 (Sady *et al.,* 2015:6). At a significance level of 0.05, the age and knowledge of the cause, transmission and symptom of the disease were found to be statistically significant (0.049).

In the current study, females were found to be more knowledgeable about the disease (36%) than males (28%). In similar studies, the knowledge of males and females was found to be different. Females were found to be more knowledgeable about schistosomiasis than males in a study conducted in Zimbabwe (Mutsaka-Makuvaza *et*

al., 2019:12). However, according to a Nigerian study, males had higher levels of knowledge regarding schistosomiasis compared to females (Dawaki *et al.,* 2015:7). There was no statistical significance between gender and knowledge in the current study, with a p-value of 0.118. In another South African study, no significant relationships between knowledge of schistosomiasis and gender were found; however, females were more likely to be knowledgeable about schistosomiasis (*p = 0.031*) (Anyanwu *et al.,* 2020:3)

When compared to the other education categories, respondents with secondary education were found to be the least knowledgeable (35%) about schistosomiasis. Similar studies in Nigeria and Zimbabwe found that educated respondents were more likely to identify disease symptoms than uneducated respondents (Dawaki *et al.,* 2015:7-8; Mutsaka-Makuvaza *et al.*, 2019:12). A p-value of 0.004 indicated that there was a statistically significant difference between education level and disease knowledge.

Table 4.2:6: Relationship between the level of knowledge regarding schistosomiasis and age, gender and educational level (n=318)

Variable		**Knowledgeable**		**Not Knowledgeable**		**Total**	
		n	**%**	**N**	**%**	**n**	**%**
Age	18 – 34 years	38	12	88	28	126	40
	35 – 64 years	63	20	81	26	144	45
	65 years or older	15	5	33	10	48	15
Age/Knowledge Pearson Chi-Square		0.049					
Gender	Females	78	25	113	36	191	60
	Males	37	12	88	28	125	39
	Prefer not to say	1	0.3	1	0.3	2	1
Gender/knowledge Pearson Chi-Square		0.118					
Level of education	Primary school	13	4	19	6	32	10
	Secondary school	76	24	111	35	187	59
	Tertiary school	19	6	57	18	76	24

Variable		Knowledgeable		Not Knowledgeable		Total	
		n	%	N	%	n	%
	Postgraduate qualification	7	2	3	1	10	3
	None	1	0.3	12	4	13	4
Level of education/knowledge Pearson Chi-Square		0.004					

Respondents aged 35 to 64 had neither positive nor negative attitudes toward the disease (21% vs 21%), whereas respondents aged 18 to 34 tended to be more positive (20%) (see Table 4.2.7). There was no statistically significant relationship between respondents' ages and their attitudes ($p = 0.441$). Females (29%) were more positive about the disease than males (20%). The current study's findings are consistent with another study conducted in the South, in which male participants underestimated the severity of schistosomiasis and had poor health-seeking behaviours compared to females (Sacolo-Gwebu *et al.,* 2019:10). There was also no statistically significant relationship between respondents' gender and their attitudes ($p = 0.097$). Secondary school graduates were found to have neither positive nor negative attitudes (27% vs 28%), whereas tertiary graduates had positive attitudes (16%). The level of education of the respondents had statistical significance ($p = 0.007$).

Table 4.2.7: Attitudes on the treatment and prevention of the disease with age, gender and educational level.

Variable		Positive attitudes		Neutral		Negative attitudes		Total	
		n	%	n	%	N	%	n	%
Age	18 – 34 years	65	20	8	3	53	17	126	40
	35 – 64 years	68	21	10	3	66	21	144	45
	65 years or older	20	6	1	0	27	9	48	15
Age/Attitude Pearson Chi-Square		0.441							
Gender	Female	91	29	12	4	88	28	191	60
	Male	62	20	6	2	57	18	125	39
	Prefer not to say	0	0	1	0	1	0	2	1

Variable		Positive attitudes		Neutral		Negative attitudes		Total	
		n	%	n	%	N	%	n	%
Gender/Attitude Pearson Chi-Square		0.097							
Level of education	Primary school	9	3	2	1	21	7	32	10
	Secondary school	86	27	13	4	88	28	187	59
	Tertiary school	51	16	3	1	22	7	76	24
	Postgraduate qualification	3	1	0	0	7	2	10	3
	None	4	1	1	7	8	3	13	4
Level of education/Attitudes Pearson Chi-Square		0.007							

4.3 CONCLUSION

The findings on schistosomiasis knowledge, attitudes, perceptions, and practices, as well as the participants' perspectives on the relationship between environmental conditions and the occurrence of schistosomiasis in the Ha-Nesengani community, were presented in this chapter. The findings were then discussed and compared to those of similar studies. Chapter 5 summarizes the findings, draws conclusions, and makes recommendations for schistosomiasis control and elimination, as well as future research in the study area.

CHAPTER 5: SUMMARY, RECOMMENDATIONS AND CONCLUSION

5.1 INTRODUCTION

The study assessed schistosomiasis-related knowledge, attitudes, perceptions and practices as well as the community's views on the relationship between environmental conditions and the occurrence of schistosomiasis. This chapter summarizes the findings on (i) the community's level of knowledge on the cause, transmission and symptoms of schistosomiasis, (ii) the attitudes and perception of the community members towards the treatment and prevention of schistosomiasis, (iii) practices that expose the community to transmission with schistosomiasis, and (iv) the views of the community on the relationship between environmental conditions and the occurrence of schistosomiasis and further draws the conclusion and make recommendations made based on the results.

5.2 SUMMARY AND INTERPRETATION OF THE RESULTS

The aim of this study was to assess community knowledge, attitudes, perceptions, and practices regarding schistosomiasis, as well as to determine whether community members associated environmental conditions with the occurrence of schistosomiasis in Ha-Nesengani, Limpopo Province. According to the socioeconomic profile of the study area, the majority of the respondents for the household questionnaires were females. Most respondents had a secondary school education and were primarily unemployed, with those who were employed working in the agricultural sector and performing activities such as farming or herding livestock for household or commercial purposes. In the in-depth interviews, the majority of respondents were female, aged 35 to 64, and had a secondary or tertiary education.

In terms of water access, most respondents from the household questionnaires indicated that they mostly used piped water (from communal taps, taps inside their yards, or boreholes) for drinking, domestic, and crop watering; however, respondents from the in-depth interviews indicated that most people in the community still bathed or did laundry in the river because communal pipes were not functional. In terms of community sanitation, the vast majority of respondents used pit latrine toilets, while

some used flush toilets and 1% did not have a toilet. Participants in in-depth interviews stated that, despite having access to toilet facilities at home, most people defecate in the river when doing laundry because if they got out to urinate, the clothes would be washed away.

Community's level of knowledge on the cause, transmission and symptoms of schistosomiasis.

The findings on the **community's level of knowledge on the cause, transmission and symptoms of schistosomiasis** revealed that almost all respondents were familiar with the disease's local name, mutambotambo, and that school was their primary source of information. The common name, bilharzia, was also known to the respondents, but not the scientific name, schistosomiasis. In-depth interviewees stated that, in comparison to adults in the community, children in the community were unaware of the disease, and that they should be taught about the disease in school because they tend to disregard their caregivers' instructions at home.

Knowledge of the cause of schistosomiasis was found to be low with the majority indicating that it is caused by a virus or bacteria in the water. In-depth interviewees had little knowledge of snails as the cause of the disease. The respondents had the misconception that eating too much coarse salt can result in mutambotambo. Furthermore, the majority of respondents indicated that contacting water where people urinate/defecate, swimming or wading in water with snails, and washing or bathing in river water would result in disease infection; however, the participants also incorrectly indicated that drinking unfiltered river water and drinking the same water as cattle would result in disease transmission. Misconceptions about disease transmission were also noted among in-depth interviewees, who claimed that infection occurs in pools where people gulp some urine-contaminated water while swimming. The current study's respondents had a high level of knowledge about the disease's symptoms.

Further analysis of the data revealed that only 37% of those who knew the local name, mutambotambo, correctly selected all of the correct options regarding the disease's cause, transmission, and symptoms, while 64% did not. Respondents aged 18 to 34 years (the youngest category) had the least knowledge of schistosomiasis, and females were more knowledgeable about the disease than males. When compared to

the other education categories, respondents with secondary education were the least knowledgeable.

Attitudes and perceptions of the Ha-Nesengani community members towards the treatment and prevention of schistosomiasis

The results on **the attitudes and perceptions of the Ha-Nesengani community members towards the treatment and prevention of schistosomiasis** revealed that there was no significant difference between those who had positive attitudes and those who had negative attitudes. Forty-eight percent (48%) of participants had positive attitudes toward the disease, compared to 46% who did not. Notwithstanding this, most of the participants strongly agreed that schistosomiasis is a serious disease and reasoned that a person could not live a long time while excreting blood every time they urinated. The participants also indicated that the disease should be treated, especially by doctors. Traditional healers were also able to treat the disease, according to in-depth interviewees, because mutambotambo "*is a disease that has existed for a long time; it was there even before modern medicine*." Knowledge of preventative measures was found to be lacking among the participants with the vast majority indicating that people could swim, fish, or collect water from the river without wearing any protective gear; additionally, wearing protective gear when in contact with water was not functional, according to the in-depth interviewees.

Practices that expose the Ha-Nesengani community to schistosomiasis transmission

The findings on the **practices that expose the Ha-Nesengani community to schistosomiasis transmission** demonstrated that the majority of study participants never fish or swim in a river, lake, or stream, urinate in water, and never pass stool in a bush or water. Participants also demonstrated positive treatment-seeking behaviours and indicated that they visited a health facility when they are excreting blood. Respondents also reported good hygiene, with the majority indicating that they always wash their hands after using the restroom and wash fruits and vegetables before eating. Participants who were caregivers (parents and guardians) for children under the age of 15 indicated that children under their care never swim or play in river water, collect river water for domestic purposes, or cross the river to go to school or

visit their peers. However, all respondents in the in-depth interviews agreed that children in the community were the most vulnerable to the disease because they were the ones who went swimming in the river despite their parents' prohibitions.

The views of the Ha-Nesengani community members on the relationship between environmental conditions and the occurrence of schistosomiasis

The results on the **views of the Ha-Nesengani community members on the relationship between environmental conditions and the occurrence of schistosomiasis** revealed that many of the respondents were more familiar with the local term for climate change, tshanduko ya mupo, than the term climate change. Furthermore, those who were aware of tshanduko ya mupo were also able to correctly identify the effects: high rainfall (floods), very little rain, hot weather, and tropical storms compared to those who indicated awareness of climate change. The participants in the in-depth interviews, however, indicated some confusion between weather and climate change but were able to recognise tshanduko ya mupo as climate change when asked about floods, the increase in temperature and drought. When asked if temperature influences the occurrence of bilharzia, some in-depth interviewees indicated that there is a link because when it is sunny and hot, more people may go to the river to cool off. High rainfall periods, according to in-depth interview respondents, were associated with a decrease in schistosomiasis infection because people can rain harvest in their homes and do not need to go to the river to swim because the weather is cooler during the period. The participants also indicated that there were more cases of the disease during a period of drought because people get hot and go to the river to cool off.

5.3 CONCLUSION OF RESEARCH FINDINGS

Based on the analysis of quantitative and qualitative data collected through household questionnaires and in-depth interviews, it is possible to conclude that the community's lack of access to a safe and clean water supply is the primary contributing factor to risky water practices and the resultant perpetuation of infection in the community. The findings show that the majority of participants knew the disease's local term, mutambotambo, and could correctly cite the disease's signs and symptoms, as well as perceive the disease to be serious and require treatment; however, there was a general lack of knowledge regarding the disease's lifecycle, which, when combined

with a lack of access to clean water, can increase the risk of schistosomiasis infection in the community. This shows the importance of accessibility to clean water, especially in rural communities where the disease is endemic.

The study's findings also revealed that due to a clinic staff shortage, nurses no longer go to schools to conduct awareness campaigns. Furthermore, the findings indicate that due to financial constraints, the local clinic's infection prevention activities with children in the community are no longer taking place. This is very unfortunate as the study found that the youngest age group was the least knowledgeable about schistosomiasis, and children aged 5 to 17 years were the most vulnerable to infection with schistosomiasis. Furthermore, the respondents demonstrated deeply rooted misconceptions about disease transmission by indicating that eating too much salt causes disease infection and that transmission primarily occurs through ingestion of water while swimming or through the genitals, but the disease was not considered a sexually transmitted disease. Many respondents also did not consider wearing protective gear when in contact with water as it was not functional. According to the findings, community-wide awareness campaigns, particularly about the disease's life cycle, are needed. This will also ensure that the correct information is disseminated throughout the community and make away with the misconceptions or beliefs that may exist.

5.4 RECOMMENDATIONS

Because of the rural nature of the area, there is a lack of access to clean and safe water supply, which poses the greatest risk of infection in the community because many community members go to the river to collect water for domestic purposes, bathe, and do laundry. To help mitigate the disease's impact, consistent access to clean and safe water sources must be ensured in the community. Furthermore, there is a critical need for community-based awareness initiatives to help do away with the community's deeply ingrained misconceptions about the cause and transmission of the disease. This can be accomplished by implementing the following:

- Providing the opportunity for professional nurses working at the local clinic to attend workshops regarding schistosomiasis prevention and control.
- In-service training is to be conducted with community healthcare workers working at the clinic to explain the life cycle of schistosomiasis, its mode of

transmission, preventative measures and treatment. This will ensure that the right information regarding the disease is disseminated to the community.

- Information leaflets and posters need to be made available at the clinic and disseminated to schools to educate patients and school-going children about the disease.

In addition, further studies can be undertaken in the community in line with the following:

- A knowledge dissemination session based on the findings of this study will be held with community members; therefore, it is recommended that a study be conducted to determine whether there have been any improvements in community members' knowledge, attitudes, perceptions, and practices regarding schistosomiasis.
- Because the current study was limited to people over the age of 18 in the community and the participants indicated that the most vulnerable group to schistosomiasis infection is between the ages of 5 and 17 years old, it is recommended that a study of schistosomiasis knowledge, attitudes, perceptions, and practices among secondary primary and secondary school children be conducted within the study area.

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7. APPENDICES

APPENDIX A: TURFLOOP RESEARCH ETHICS COMMITTEE (TREC) – HUMAN RESEARCH ETHICS, AT THE UNIVERSITY OF LIMPOPO APPROVAL LETTER

University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 3935, Fax: (015) 268 2306, Email: anastasia.ngobe@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE

ETHICS CLEARANCE CERTIFICATE

MEETING: **08 December 2021**

PROJECT NUMBER: **TREC/337/2021: PG**

PROJECT:

Title:	Investigating Community Knowledge, Attitudes, Perceptions and Practices Regarding Schistosomiasis and Environmental Change in Ha-Nesengani, Vhembe District, Limpopo Province.
Researcher:	NJ Mothapo
Supervisor:	Ms F Lindeque
Co-Supervisor/s:	Prof T Maluleke Ms C Mothapo
School:	Agricultural and Environmental Sciences
Degree:	Masters of Science in Geography and Environmental Sciences

PROF P MASOKO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:

i) **This Ethics Clearance Certificate will be valid for one (1) year, as from the abovementioned date. Application for annual renewal (or annual review) need to be received by TREC one month before lapse of this period.**

ii) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee, together with the Application for Amendment form.**

iii) **PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.**

Finding solutions for Africa

APPENDIX B: NORTH-WEST UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NWU-HREC) APPROVAL LETTER

Private Bag X1290, Potchefstroom
South Africa 2520

Tel: 086 016 9698
Web: http://www.nwu.ac.za/

North-West University Health Research Ethics Committee (NWU-HREC)

Tel: 018 299-1206
Email: Ethics-HRECApply@nwu.ac.za (for human studies)

14 September 2021

ETHICS APPROVAL LETTER OF STUDY

Based on approval by the North-West University Health Research Ethics Committee (NWU-HREC) on
14/09/2021, the NWU-HREC hereby approves your study as indicated below. This implies that the NWU-HREC grants its permission that, provided the general conditions specified below are met and pending any other authorisation that may be necessary, the study may be initiated, using the ethics number below.

Study title: Current status and future predicted distribution patterns of bilharzia transmitting snails
under climate change and implications for vector-borne diseases
in South Africa Principal Investigator/Study
Supervisor/Researcher: Dr L de Necker Student: -

N	W	U	-	0	0	4	5	2	-	2	0	-	A	1

Ethics number:

Institution Study Number Year Status
Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

Minimal

Application Type: Larger study
Commencement date: 14/09/2021 **Risk:**
Expiry date: 30/09/2022

Approval of the study is provided for a year, after which continuation of the study is dependent on receipt and review of an annual monitoring report and the concomitant issuing of a letter of continuation. A monitoring report is due at the end of September annually until completion of the study.

General conditions:

While this ethics approval is subject to all declarations, undertakings and agreements incorporated and signed in the application form, the following general terms and conditions will apply:

- *The principal investigator/study supervisor/researcher must report in the prescribed format to the NWU-HREC:*
  - *Annually on the monitoring of the study, whereby a letter of continuation will be provided annually, and upon completion of the study; and*
  - *without any delay in case of any adverse event or incident (or any matter that interrupts sound ethical principles) during the course of the study.*
- *The approval applies strictly to the proposal as stipulated in the application form. Should any amendments to the proposal be deemed necessary during the course of the study, the principal investigator/study supervisor/researcher must apply for approval of these amendments at the NWUHREC, prior to implementation. Should there be any deviations from the study proposal without the necessary approval of such amendments, the ethics approval is immediately and automatically forfeited.*
- *Annually a number of studies may be randomly selected for active monitoring.*
- *The date of approval indicates the first date that the study may be started.*
- *In the interest of ethical responsibility, the NWU-HREC reserves the right to:*
  - *request access to any information or data at any time during the course or after completion of the study;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research or the informed consent process;*

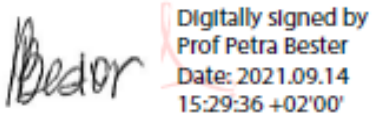
- *withdraw or postpone approval if:*
  - *any unethical principles or practices of the study are revealed or suspected;*
  - *it becomes apparent that any relevant information was withheld from the NWU-HREC or that information has been false or misrepresented;*
  - *submission of the annual monitoring report, the required amendments, or reporting of adverse events or incidents was not done in a timely manner and accurately; and/or*
  - *new institutional rules, national legislation or international conventions deem it necessary.*
- *NWU-HREC can be contacted for further information via Ethics-HRECApply@nwu.ac.za or 018 299 1206*

Special conditions of the research approval due to the COVID-19 pandemic:

Please note: Due to the nature of the study i.e. (collection of both quantitative and qualitative data from community members, health care workers and traditional healers in a community setting), this study will be able to proceed during the current alert level, following receipt of the approval letter. No additional COVID-19 restrictions have been placed on the study, other than that indicated under the COVID-19 risk mitigation strategy in the application. The researcher must, however, ensure that before proceeding with the study that all research team members have reviewed the North-West University COVID-19 Occupational Health and Safety Standard Operating Procedure.

The NWU-HREC would like to remain at your service and wishes you well with your study. Please do not hesitate to contact the NWU-HREC for any further enquiries or requests for assistance.

Yours sincerely,



_____

Chairperson NWU-HREC

Current details:(23239522) G:\My Drive\[1]. Research and Postgraduate Education\9.1.5.4 Templates\9.1.5.4.2_NWU-HREC_EAL.docm 20 August 2019
File Reference: 9.1.5.4.2

[1] .1.5.4.2 Ethics Approval Letter of Study 2

APPENDIX C: LETTER OF GOODWILL

MAKHADO LOCAL MUNICIPALITY WARD O4

P O Box 1676
Vuwani
0952

Enq: Cllr Balibali T
Contact: 076 990 7008

Email Address: balibalitshisa@gmail.com

To whom it may concern

CONFIRMATION LETTER

This serves as confirmation that after a meeting (dated 26 February 2021 at Royal palace) between Nesengani traditional leadership, Ward Councillor and the research team from The Department of Geography and Environmental studies at the University of Limpopo

Permission was granted to the research team from GAES to collect data regarding schistosomiasis and environmental change in Nesengani Area, Makhado local Municipality ward 04, Vhembe District Municipality, Limpopo Province

And we agree that after data collection a Research Team will share findings with the community

Hoping that you will take this matter into consideration

Warm regards

.....
MR T. BALIBALI
WARD COUNCILLOR

WARD COUNCILLOR STAMP
CELL NO 076 990 7008
WARD 4
HOUSE NO. 262
NESENGANI NDITWANI
VUWANI, 0952
AUGUST 2016 – AUGUST 2021
Signature: ..... Date: 30/06/2021

APPENDIX D: INFORMED CONSENT FORM

University of Limpopo

Faculty of Science and Agriculture

School of Agricultural and Environmental Sciences

Department of Geography and Environmental Studies

Private Bag X1106, Sovenga, 0727, South Africa

Tel: (015) 268 4825, E-mail address: farina.lindeque@ul.ac.za

Title of the research study: INVESTIGATING COMMUNITY KNOWLEDGE, ATTITUDES, PERCEPTIONS AND PRACTICES REGARDING SCHISTOSOMIASIS AND ENVIRONMENTAL CHANGE IN HA-NESENGANI, VHEMBE DISTRICT, LIMPOPO PROVINCE.

Ethics reference numbers:

Postgraduate student: Nape Josephine Mothapo

Supervisor: Ms Farina Lindeque

Contact number: 015 268 4825

You are being invited to take part in a **research study** that forms part of a Master's degree research project. Please take some time to read the information presented here, which will explain the details of this study. Please ask the researcher or person explaining the research to you, if you have any questions about any part of this study. It is very important that you are fully satisfied; that you clearly understand what this research is about and how you might be involved. Also, your participation is entirely **voluntary,** and you are free to say no to participation. If you say no, this will not affect

you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part now.

This study has been approved by the Turfloop Research Ethics Committee (TREC) – Human research ethics, at the University of Limpopo (TREC/337/2021:PG) and the North-West University (NWU) Human Research Ethics Committee (NWU-HREC). In this regard, the study will be conducted according to the ethical guidelines and principles of Ethics in Health Research: Principles, Processes and Structures and other international ethical guidelines applicable to this study. It might be necessary for the research ethics committee members or other relevant people to inspect the research records.

What is this research study all about?

- *We plan to gather information on the knowledge, attitudes, perceptions and practices regarding bilharzia (also called schistosomiasis) in your community. We believe that you can help us by telling us what you know about:*

    - *What Bilharzia is, how it can be transmitted and how it is treated;*
    - *How you think Bilharzia is linked to changes in the environment;*
    - *How you think environmental changes has influenced the occurrence of Bilharzia in your area; and*
    - *How you believe Bilharzia can be controlled and prevented in your community.*

- *This study will be conducted by experienced researchers trained in the concepts of research and techniques related to data collection. Data collection will only occur during one season; your participation will be once off.*

Why have you been invited to participate?

- *You have been invited to be part of this research because you are above the age of 18, have been living in the area for more than 15 years, you can communicate in the local language, you are a healthcare provider in the*

community, you are a caregiver of a child between the ages of 5 and 15 years and/or you have contact with possibly contaminated water sources during your daily activities.

- *You will unfortunately not be able to take part in this research if you're under the age of 18 years; you do not come into contact with possibly contaminated water sources during your daily activities, participated in the pilot study, or have not signed this consent form.*

What will be expected of you?

- *You will be expected to participate in a semi-structured interview that will take 60-90 minutes or participate in a survey that will take 15-20 minutes to complete.*

For the in-depth interviews:

The interview will be conducted by a trained interviewer, who will ensure that you are comfortable. The interviewer will also answer any questions that you might have about the research. We will ask you questions about bilharzia and give you the opportunity to share your knowledge and experience with us. The questions will be about bilharzia in your community, how it is recognised, how people get exposed to it, what people do to stop it from spreading, who people go to for help and what happens when people become sick with it. If you do not wish to answer any of the questions during the interview, you may say so and the interviewer will move on to the next question. No one else but the interviewer and/ the translator will be present unless you would like someone else to be there. The entire interview will be tape-recorded, but you will not be identified by name on the tape. The recording will be stored electronically as an encrypted file to allow access only to the research team to ensure quality control. The information recorded is confidential, and no one else except for the researchers will have access to the recordings, which will eventually be deleted.

For the household questionnaires:

This will be administered by trained field workers using tablets and Google forms. We will not ask you to share personal beliefs, practices or stories and you do not have to

share any knowledge that you are not comfortable sharing. The survey will be used to determine whether you know what bilharzia is, where and how you can be infected as well as whether you know about treatments and precautionary measures. Your survey answers will be stored electronically as encrypted files to allow access only to the research team to ensure quality control. We will not store your personal information; therefore, your responses will be anonymous. The information recorded is confidential, and no one else except for the researchers will have access to the recordings, which will eventually be deleted.

Will you gain anything from taking part in this research?

- *There will be no direct gains for you in the study.*
- *The researchers hope to help inform the development of improved complimentary public health interventions such as educational campaigns. As such, being part of the study may help the community at large in the future.*

Are there risks involved in you taking part in this research and what will be done to prevent them?

- *The risks to you in this study are the questions, which may trigger some of your emotions. There is a risk that you may share some personal or confidential information by chance. The risk will be limited by ensuring that you do not answer any question or take part in the interview if you don't wish to do so. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview. You can stop the interview at any time, with no consequences.*

How will we protect your confidentiality and who will see your findings?

- *Anonymity of your findings will be protected by ensuring that your information is retained only by the researchers and is not shared with anyone outside the research team. Your privacy will be respected by replacing your name with a number. Only the researchers and research funders will be able to look at your findings. Findings will be kept safe by locking hard copies in locked cupboards in the researcher's office and for electronic data the files will be password protected. (As soon as data has been transcribed, it will be deleted from the recorders). Data will be stored for 5 years and then deleted. No research reports or publications will contain your name or personal details and findings will be shared with the community.*

- *The data might be inspected by the funder of this study or by a research ethics committee for quality control purposes.*

What will happen with the findings or samples?

- *The findings of this study will be used to complete a Master's degree dissertation and will also be part of a larger research report for the Water Research Commission. The findings will also be published in reputable scientific journals.*

How will you know about the results of this research?

- *A community workshop will be organised to share the findings of our study with your community. All published reports and journal articles will be sent to your community representative and will be available for you to access.*

Will you be paid to take part in this study and are there any costs for you?

- No you will not be paid to take part in the study because participation is voluntary and will not require a great time commitment from you.

Is there anything else that you should know or do?

- You can contact Farina Lindeque if you have any further questions or have any problems.
- You will receive a copy of this information and consent form for your own purposes.

Declaration by participant

By signing below, I ……..……. agree to take part in the research study titled: …….

I declare that:

- ≠ I have read this information/it was explained to me by a trusted person in a language with which I am fluent and comfortable.
- ≠ The research was clearly explained to me.
- ≠ I have had a chance to ask questions to both the person getting the consent from me, as well as the researcher and all my questions have been answered.
- ≠ I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- ≠ I may choose to leave the study at any time and will not be handled in a negative way if I do so.
- ≠ I may be asked to leave the study before it has finished, if the researcher feels it is in the best interest, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…….. on (*date*) ……...…….. 20....

Signature of participant **Signature of witness**

…… **…….**

Declaration by person obtaining consent

I *(name)* ……..…… declare that:

- ∉ I clearly and in detail explained the information in this document to

…….

- ∉ I did/did not use an interpreter.
- ∉ I encouraged him/her to ask questions and took adequate time to answer them.
- ∉ I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- ∉ I gave him/her time to discuss it with others if he/she wished to do so.

Signed at (*place*) .....…….. on (*date*) ……...…….. 20....

Signature of person obtaining consent

……

Declaration by researcher

I *(name)* ……..…… declare that:

- I explained the information in this document to …….. **or** I had it explained by …… who I trained for this purpose.
- I did/did not use an interpreter.
- I encouraged him/her to ask questions and took adequate time to answer them or I was available should he/she want to ask any further questions.
- The informed consent was obtained by an independent person.
- I am satisfied that he/she adequately understands all aspects of the research, as described above.
- I am satisfied that he/she had time to discuss it with others if he/she wished to do so.

Signed at (*place*) .....…..…….. on (*date*) ……...…….. 20....

Signature of researcher

……

APPENDIX E: HOUSEHOLD QUESTIONNAIRE

SURVEY: COMMUNITY SCHISTOSOMIASIS KNOWLEDGE QUESTIONNAIRE

Please ll out this Google Form

*Required

1. Please provide email address *

Participant details

(Questionnaire will auto submit if participant does not meet the criteria i.e. 1) has not signed the consent form; 2) be above 18 years of age; and 3) be a resident of the area for at least 15 years.

2. Was the informed process explained and followed and is the informed consent * form signed by all relevant participants?

Mark only one oval.

- Yes
- No

3. What is your age? *

Mark only one oval.

- [ ] Under 18 years
- [ ] 18 - 34 years
- [ ] 35 - 64 years
- [ ] 65 years or older

4. Are you a permanent resident of Ha-Nesengani? *

Mark only one oval.

- [ ] Yes
- [ ] No

5. If the answer was YES in the previous question, how long have you been a resident of Ha-Nesengani? *

Mark only one oval.

- [ ] Less than 5 years
- [ ] 5-10 years
- [ ] 11-14 years
- [ ] 15 years and above

6. Household code number (Quadrant & House Number) *

_____

7. Interview date *

_____

Example: 7 January 2019

8. Interview start time *

_____

Example: 8.30 a.m.

Demographic and Basic Household Information

9. What is your gender? *

Mark only one oval.

- ◯ Female
- ◯ Male
- ◯ Prefer not to say
- ◯ Other: _____

10. What is your highest level of education? *

Mark only one oval.

- ◯ Primary school
- ◯ Secondary school
- ◯ Tertiary qualification
- ◯ Postgraduate qualification
- ◯ None

11. Are you currently employed? *

Mark only one oval.

- ◯ Yes
- ◯ No

12. Are you involved in any agricultural activities? (Growing crops for your family, * herding livestock or working on a commercial farm).

Mark only one oval.

- Yes
- No

13. Are you a caregiver for any children under 15? *

Mark only one oval.

- Yes
- No

14. What is the main source of drinking water in the household? *

Mark only one oval.

- Piped water inside the household
- Piped water in yard
- Piped water from communal tap
- Borehole
- Dam
- River or stream
- Bought water
- Other:

15. What is the main source of water used for other household needs? (laundry, * washing, dishes, other cleaning) *Mark only one oval.*

- [ ] Piped water inside the household
- [ ] Piped water in the yard
- [ ] Piped water form communal tap
- [ ] Borehole
- [ ] Dam
- [ ] River or stream
- [ ] Bought water
- [ ] Other:

16. What is the main source of water for watering gardens and crops? *

Mark only one oval.

- [ ] Piped water inside the household
- [ ] Piped water in the yard
- [ ] Piped water form communal tap
- [ ] Borehole
- [ ] Dam
- [ ] River or stream
- [ ] Bought water
- [ ] Other:

17. What toilet facilities are available to your household? *

Mark only one oval.

- [ ] Flush toilet
- [ ] Pit latrine
- [ ] Bucket
- [ ] latrine

Other:

18. Do you regularly or your child spend time at the river? (Fishing, swimming, * harvesting grass or other river plants?) *Mark only one oval.*

- Yes
- No
- Maybe

Knowledge

19. Do you know what schistosomiasis is? * *Mark only one oval.*

- Yes
- No
- Maybe

20. Do you know what bilharzia is? * *Mark only one oval.*

- Yes
- No
- Maybe

21. Do you know what Muthambothambo is? * *Mark only one oval.*

- Yes
- No
- Maybe

22. How can you get infected with bilharzia? (choose all the answers you think are correct) *

Tick all that apply.

- [ ] Having unprotected sex
- [ ] Eating soil
- [ ] Drinking dirty water
- [ ] Eating contaminated food
- [ ] Being in places where people urinate in public
- [ ] Sharing a toilet with an infected person
- [ ] Urinating/defecating in rivers, streams and lakes
- [ ] Passed from pregnant mother to their children at birth
- [ ] It is an inherited disease
- [ ] I'm not sure
- [ ] Other:

_____

23. What are the main symptoms of bilharzia? (choose all the answers you think are correct) *

Tick all that apply.

- [ ] Blood in the urine
- [ ] Blood in the stools
- [ ] Abdominal pain and/or swelling
- [ ] Pain when urinating
- [ ] Pain during sex
- [ ] Stunted growth in children
- [ ] Tiredness
- [ ] Body aches
- [ ] I'm not sure
- [ ] Other:

_____

24. Can bilharzia infection be prevented? *

Mark only one oval.

- ◯ Yes
- ◯ No
- ◯ Unsure

25. Can Bilharzia be treated? *

Mark only one oval.

- ◯ Yes
- ◯ No
- ◯ Unsure

26. If answer is YES in previous question, Who, in your opinion, can treat bilharzia?

Mark only one oval.

- ◯ Doctor
- ◯ Nurse
- ◯ Traditional healer or herbalist
- ◯ Pastor
- ◯ Other: _____

Attitudes and perceptions

27. Is bilharzia a serious disease? *

Mark only one oval.

- ◯ Yes
- ◯ No
- ◯ Unsure

28. Should infected persons seek treatment for the disease? *

Mark only one oval.

- Yes
- No, it will go away
- No, it is part of becoming an adult
- Np, the treatment has too many side effects
- No, it is part of life
- Other: _____

29. Does the environment play a role in bilharzia infection? *

Mark only one oval.

- Yes
- No
- Maybe

30. In your opinion, what environmental factor plays the biggest part in bilharzia * occurrence in Ha-Nesengani?

Mark only one oval.

- Temperature
- Rainfall
- Drought
- Being close to the river
- Spending time in the river

31. Do you think climate change will impact the amount of bilharzia infections in * Ha-Nesengani?

Mark only one oval.

- Yes
- No
- Maybe

Practices

32. Do you (or children in your care) do any of the following on a regular basis? *

Mark only one oval per row.

	Yes	No
Fishing in a river, lake or stream		
Washing your hands after using the toilet		
Eating soil		
Wash fruits and vegetables before eating		
Wash laundry in or fetch water from a river stream or lake		
Use river water to irrigate crops		
Let livestock drink from the river		

33. Do you do anything to avoid being infected with bilharzia? *

Mark only one oval.

- Yes
- No

34. If you answered YES to the question above, what do you do to avoid infection?

Mark only one oval.

- Avoid drinking dirty water
- Have protected sex
- Wash hands after using the toilet
- Use of toilets/ avoid urinating and defecating in open areas
- Wash fruits and vegetables before eating
- Avoid using untreated water for other domestic uses
- Avoid swimming, playing or shing in rivers, streams, ponds or lakes
- Take medicine
- Use protective gear when in contact with open water sources Other:
- _____

End

35. Interview end time *

_____

Example: 8.30 a.m.

APPENDIX F: IN-DEPTH-INTERVIEW GUIDE

University of Limpopo

Faculty of Science and Agriculture

School of Agricultural and Environmental Sciences

Department of Geography and Environmental Studies

Private Bag X1106, Sovenga, 0727, South Africa

Tel: (015) 268 4825, E-mail address: farina.lindeque@ul.ac.za

Greetings,

My name is Nape Mothapo, I am a student at the University of Limpopo, studying towards a Master of Science in Geography and Environmental Science. In collaboration with the University of North West and the Water Research Commission, we are currently carrying out a study to explore the impact that climate change has on the occurrence of bilharzia in the Ha-Nesengani area. This specific study, however, focuses on your community's knowledge, attitudes, perceptions and practices with regard to bilharzia. We would also like to know how the disease has transformed over the years in terms of transmission and prevalence. You have been invited to partake in this interview because your community has been identified as an area that is common to bilharzia and we would like to hear your view of the disease.

With your permission, I would like to audio-record the interview and take notes. This will help me remember our conversation better and make for better analysis and reporting. Please note that the audio recording will not contain any personal identifying information such as your name and surname, anonymity will be ensured. The audio recording and transcript of the interview will be kept as a password protected electronic file on a secure University of Limpopo server. Only I and my supervisors will have access to the files. The recording will be kept on the server for 5 years after the conclusion of the study and publishing of results after which it will be deleted.

Remember that you do not have to take part in the discussion if you prefer not to. You do not have to answer any question you don't feel comfortable with and you can stop the interview at any time.

Can I ask you to read this consent form?

Do you have any questions about the information in this form? If you consent to participate in this discussion, can I please ask you to sign the form?

Thank you very much for agreeing to participate in the interview. I will now switch on the audio recorder.

IN-DEPTH INTERVIEW GUIDE FOR: Healthcare workers and traditional healers that work within the community, community members over 18 years in a high-risk group (e.g., involved in agricultural work, primary caregiver of a child under the age of 15) and residents living in Ha-Nesengani for at least 15 years.

Section A: Participants Demographic information

1. Participants code number and grouping: _____

2. Interview date: _____ Time: _____

Participants' demographic characteristics

What's your age?	
18 - 34 years	
35 - 64 years	
65 years or older	
What is your gender?	
Female	
Male	

Other	
What is the highest level of education that you have completed?	
Primary school	
Secondary school	
Tertiary qualification	
Postgraduate qualification	
None	
Please describe your employment status	
Are you a caregiver for any children under 15?	
Yes	
No	
Sometimes	
How long have you been a resident of Ha-Nesengani?	
Less than 5 years	

5-10 years	
11-14 years	
15 years or more	

SECTION B: INTERVIEW QUESTIONS

Knowledge

1. **Please tell me all that you know about bilharzia.**

Probes:

- What was your first source of bilharzia knowledge? Where did you learn this?
- How does one get infected with bilharzia?

(If they mention the river, ask the following)

- Ø You have told me that you get bilharzia from the river. How does one get bilharzia from the river? What is in the river that causes bilharzia?

Are there any other ways in which bilharzia can be contracted other than in the river? What are those ways?

- Can salt cause bilharzia? How?
- Can you please tell me some of the symptoms that are associated with bilharzia?
  - Ø Are there any other symptoms that you associate with bilharzia other than blood in the urine? What are those symptoms?

Attitudes and Perceptions

2. **What do you know about bilharzia treatment?**

Probes:

- Is bilharzia a serious disease? Why or why not?

- Do you think that bilharzia should be treated? How should it be treated?
- Should you realise that you are infected with the disease, where is the first place you would go to (or where do people with bilharzia infection go to) when you (or the other person) start feeling pain and/or urinating blood?
    - Please tell me the process of treatment from this particular place.

3. **What do you know about bilharzia prevention?**

- In your view, can bilharzia be prevented? How can it be prevented?
- What do you think could be done to prevent people from getting bilharzia?

Practices

4. **Please tell me about the behaviours or habits of people within the community that make them vulnerable to bilharzia.**

Probes:

- Do people regularly swim or bathe water in the river?
- Do people collect water from the river or ponds?
- Do people wade through water to get to the other side of the river?
- Are there alternative options that people can use other the river?
- Where do people urinate or go to the toilet when around the river?
- How can we change those behaviours of urinating in the river while playing and bathing in infected water?

Primary healthcare nurses only

5. **Can you please take me through a typical examination of a patient with bilharzia?**

Probes:

- What are the typical questions that you ask a patient before you determine whether they required a test for bilharzia?
- What are some of the common occupations that people who come to the clinic partake in? Do these people collect water in open water sources for their daily domestic activities?
- What do you use to test for bilharzia?
- How long does it take for results to come out? Do patients return to get their results?
- Based on the results from the tests, how do you determine whether the patient has bilharzia or not? What do you find in their results i.e., eggs, blood?
- What are some of the common symptoms that patients report?
- According to you, how do people get infected with bilharzia?

6. **When patients test positive for bilharzia, what medication are they prescribed?**

   Probes:

   - How are the patients supposed to take the medication? With meal? On an empty stomach?
   - Are adults and children given the same medication? What are the similarities or differences between the medication?
   - How long are patients required to take the medication?
   - Are patients required to come back for a follow-up? If yes, do they come back? Why or why not?

7. **In your experience, which groups (adults, children, the elderly) are most affected by bilharzia?**

   Probes:

   - Which groups of people are most likely to consult with problems regarding bilharzia?
   - Are any groups targeted in treatment campaigns (if available)? Why are they targeted?

8. **In your view, do you think enough attention is given to the control and treatment of bilharzia in the community? What initiatives do you think work or could work?**
9. **What advice do you have for people living with bilharzia?** (If not addressed: What does bilharzia mean to you)

Traditional healers

10. **Can you please take me through a typical consultation with a patient who has a problem with bilharzia?**

    Probes:

    - What are the typical questions that you ask a patient before you determine whether they required treatment for bilharzia?
    - Based on the patients' answers, how do you determine that a patient has bilharzia?
    - What questions do you ask to determine the sort of activities that the patient participates in that might've placed them at risk?
    - What are some of the common symptoms that patients report?
    - According to you, how do people get infected with bilharzia?

11. **When patients test positive for bilharzia, what medication are they prescribed?**

    Probes:

    - When is the best time for the patients to take the medication?
    - How long are patients required to take the medication?
    - Are patients required to come back for a follow-up? If yes, do they come back? Why or why not?

12. **In your experience, which groups (adults, children, the elderly) are most affected by bilharzia?**

    Probes:

- ∉ Which groups of people are most likely to consult with problems regarding bilharzia?
- ∉ Are any groups targeted in treatment campaigns (if available)? Why are they targeted?

13. **In your view, do you think enough attention is given to the control and treatment of bilharzia in the community? What initiatives do you think work or could work?**
14. **What advice do you have for people living with bilharzia?** (If not addressed: What does bilharzia mean to you)

Residents who have lived in Ha-Nesengani for more than 15 years

Environmental change as defined in this study refers to changes in rainfall patterns, delay in the onset of rainfall and increase in temperature.

15. **Can you please tell me about instances of environmental change that have occurred in Ha-Nesengani?**

Probes:

- Do you remember any period of drought or floods?
- How has the temperature changed over the years? Is it colder or hotter now than 15 years ago? How so? What are the telling factors?
- Has a dam or reservoir been built in or around the area? When was this? Where were people getting water prior to the establishment of the dam?

16. **How can you relate the changes in the environment and bilharzia occurrence?**

Probes:

- When there is a shortage of rainfall (water), where does the community collect water? Similarly, when there is an abundance of water through rainfall where do people get their water?
- How was the transmission of bilharzia during that period (drought or floods)? Do people get infected, or infection rates reduces?

17. **What do you think is the cause of bilharzia?**

Probes:

- Where do people get infected with bilharzia?

18. **Do you remember a time when there were no incidences of infection with bilharzia? If yes, what do you think brought about the cause of prevalence or transmission in Ha-Nesengani?**

Probes:

- In your view, how have the cases of bilharzia in the community changed? Are there more cases today or are they less than 15 years ago?
- Are more people infected with bilharzia to than 15 years ago?

For agricultural workers only

19. **Please tell me about the type of work that you do**

Probes:

- What type of agricultural activity do you work in?
- What kind of area is the work in? Are there paddies, ponds, or paddles?
- Do you wear any sort of protective gear at work? Why or why not?
- Do you think it is important to wear protective gear when in contact with water?

For caregivers of a child/children under 15 years only

Caregivers as defined in the study refers to parents and guardians among community members

20. **Could you please tell me about your child's association with river water?**

Probes:

- Does your child encounter water on their way to or from school?

- How are the behaviours of children in winter and summer? What do they do in winter that they don't do in summer? Are there any other places where they can do this?
- Do you encourage or forbid your child from playing in the river?
- Does your child participate in any mass drug administration campaign? Why or why not?