ME AND MY MONSTERS

A multispecies study on schistosomiasis in Sub-Saharan Africa

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Abstract

For such microscopic creatures, schistosomes have become monstrous in scale and impact across the world's tropics, and particularly in Sub-Saharan Africa. Schistosomes are parasitic blood-fluke worms and their disease, schistosomiasis, is an ancient disease that has evolved with humans for centuries and it is through its connections to humans that it has thrived. This dissertation outlines the actor-network surrounding schistosomiasis through a multispecies lens. Tsing et al.'s (2017) 'monsters' is utilised to argue that schistosomiasis is a monstrous disease and our influence over nature only exacerbates the situation. Secondly, the purpose of this dissertation is to bring illness narratives to expand our understanding of what it is like to live with these parasites. Lastly, it analyses the social, economic and political structures that made and sustains schistosomiasis as the second most important neglected tropical disease in the world (Adekiya et al., 2020). This is a deadly, slow killing disease that affects millions of people around the world, yet it and the people most at risk of contracting it are severely neglected. It is only through an understanding of the interconnectedness of the actors in this network and acknowledging the social, economic and political processes that hinder, or even aggravate, the control of schistosomiasis that a holistic, successful intervention can be designed.

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Introduction

My story of living with schistosomiasis or bilharzia (as it is more commonly known, and the only name used by any of the people I knew living with the tropical disease) begins in Malawi. Throughout my childhood, my family moved around Sub-Saharan Africa, specifically, Eswatini, South Africa, Malawi and Zambia. All four of these countries have a high prevalence of bilharzia, however, the first time I remember hearing about it was in Malawi and even then, it was years before I understood the scale of the disease. My family and I moved to Malawi when I was eight years old and my brother was eleven. The first place we went to in Malawi was Lake Malawi (mostly just referred to as The Lake), where an expatriate family from South Africa, also working for the same company as my father, took us to enjoy what Malawi has to offer. You cannot go to Malawi and not go to The Lake. It is like going to the Western Cape and never seeing Table Mountain. I can vividly remember when I first realised that the water could be contaminated: when we returned in doors after having played all day outside in the sun with our host's children (most likely after having already swam in The Lake). I walked into the house and straight to the bathroom sink, opened the faucet and cupped my hands, only to have one of the girls stop me. I remember feeling chastised and embarrassed, when she told me I cannot drink directly from the tap. Stating very matter-of-factly that the water is not clean. Growing up in a wealthy neighbourhood in South Africa, I did not understand that the tap water could not be safe to drink; the same water used to bathe in, cook and clean with and the source was the lake we had been playing in and wallowing in like warthogs (an African wild pig that loves a mud bath on a hot summer in the savanna).

What is bilharzia?

Schistosomiasis is a disease that is caused by a type of microscopic blood fluke worm that lives in untreated freshwater sources in the tropics (Gryseels, et al., 2006:1106). The blood fluke worms are called "Schistosomatidae" or "schistosomes" and as mentioned above, they are transmitted in unsanitized freshwater, however, they cannot survive in the water on their own. Therefore, they need two hosts in their lifetime. They "have aquatic life cycles whereby the infective larvae (cercariae) develop in snails" (Appletona & Miranda, 2015:97) and another in which they infect a predominantly human or livestock host, depending on the species of worm. Schistosomatidae's life cycles "include a definitive (final) host, man, in

which the adult flukes live; and a single intermediate host, a snail, in which the flukes' larval stages develop" (Appletona & Miranda, 2015:97). The eggs will hatch upon entering the water. At this stage they need to find and infect a species of snail that is compatible with the species of schistosome. Once the larvae have matured, the snail "sheds" the larvae which swim to the nearest definitive host, human or animal, and penetrate the skin entering the peripheral blood capillaries, which carry them to the liver (Appletona & Miranda, 2015:98). The adult worms (schistosomulum, as they are now called), pair up in males and females, and migrate to their target organs; *S. haematobium* to the veins draining the bladder and female genital tract, and *S. mansoni* to the veins draining the lower intestine and rectum. They will then lay eggs which pass through and hook into the lining of either the bladder or intestines. When they mature, they "pass out of the human body, either in urine (*S. haematobium*) or faeces (*S. masoni*)" (Appletona & Miranda, 2015:98), and thus the cycle begins again.

Schistosomiasis is classified as the second most important "neglected tropical disease" by the World Health Organisation (WHO) and the "second most widespread" neglected tropical disease in Sub-Saharan Africa (Adekiya et al., 2020:181). Schistosomiasis affects 240 million people globally, of which 90% of infections and majority of morbidity occur in Sub-Saharan Africa. (World Health Organization, 2021). According to Nelwan (2019), the disease causes 280,000 deaths annually and 799 million people are at risk of being infected with schistosomiasis globally. Similarly, Berge et al. estimate that "annual global mortality could be as high as 300,000 cases, half of which are caused by urogenital schistosomiasis" (schistosomiasis that manifests in the urinary and reproductive tracts) (2011:22). In 2020, South Africa is estimated to have just over 59 million people (Worldometers.info, 2020) of which it is estimated 25.7 million people are at risk of contracting schistosomiasis and an estimated 4.5 million people who are infected (Berge et al., 2011). According to Bright (n.d.) this number has risen to 5.1 million in the last 11 years. Whilst schistosomiasis is considered the second biggest parasitic disease, after malaria, in terms of public health impact, it is a severely neglected tropical disease (Berge et al., 2011).

Vale et al. identify three main species of schistosomes, "*Schistosoma haematobium* in Africa and the Middle East, *S. mansoni* in Africa and South America, and *S. japonicum* in China and the Philippines," and two less common species, "*S. intercalatum* in Africa and *S. mekongi* in Southeast Asia" (2017:1). Schistosomiasis in humans in Sub-Saharan Africa is most commonly caused by the blood fluke worms, *S. haematobium* and *S. mansoni*. These two species are endemic in five of the nine provinces in South Africa and throughout Malawi, and

the two species my participants and I came into contact with. Therefore, they are the two species I will be focussing on. *S. mansoni* is less common in Sub-Saharan Africa and primarily affects the intestines. Thus, the symptoms are diarrhoea, blood in the stool, swelling of the liver and spleen (hepatosplenomegaly), vomiting blood (haematemesis) and a build-up of fluid in the abdomen (ascites) (Vale et al., 2017). On the other hand, *S. haematobium* is typically localised in the bladder, but has more frequently manifested in the reproductive organs as well. This has been termed urogenital schistosomiasis (Vale et al., 2017). The immediate and most common symptom among people I have spoken to, of *S. haematobium* infections, is the presence of blood in the urine. Other symptoms include difficulty or pain when urinating, the calcification of the bladder wall and the swelling of a kidney caused by a block in the renal duct by the schistosome eggs (Vale et al., 2017).

The eggs also cause scarring when they hook on the bladder or intestinal lining. This build up of scar tissue over time if the bilharzia is untreated or if the person is reinfected can lead to other complications like, urinary tract infections and lymphomas (Vale et al., 2017). Urogenital schistosomiasis's long-term effects are infertility and an increased risk of contracting HIV-1 (Vale et al., 2017).

What I know now, after years of just not knowing, because I was too young, and a few more years, where I was wilfully ignorant, is how seriously we should be taking this disease. This dissertation is an attempt to outline and understand how interconnected we are with the disease and how it connects us to other non-humans, other-than-humans, environments and materials. It questions how our 'mastering' of nature, lack of care and policies have only exacerbated and fed a monster within us monsters. Bilharzia has followed us and evolved with us over centuries as humans moved, conquered, stole and built. It has flourished in a world with overfishing, infrastructure development and neglect.

Researchers have tackled the disease from various perspectives and interventions with minimal long-term success. Bilharzia is too easy to contract, too widespread (specifically in rural and hard to reach areas), and too expensive to eradicate. The populations that are at the highest risk of contracting bilharzia are poor, rural communities that do not have access to sanitised water… a neglected community. I started my research wanting to work with a group that does research and in conjunction provides health care to people living with bilharzia in a heavily at risk area in South Africa. I wanted to interview young women who had (or still lived with) urogenital schistosomiasis, to understand their experiences and how it differed

from mine. However, due to multiple roadblocks, I changed my research to an autoethnography and family ethnography, which focussed on how my family struggled to rid ourselves of bilharzia and found other people we knew, in a similar demographic, who are from Malawi or here in South Africa who also had bilharzia. What I found was a story of exceptions. People who contracted the disease while on holiday at a water source they used recreationally, who knew of the disease and were treated directly afterwards. Some of us were 'cured' and some of us took a long time for the treatment to work. None of us struggled to access information or medication. As I was writing this dissertation I kept wondering towards the untold hidden story, the silence around those that do not know of bilharzia, do not know they are the highest risk, or know but do not have access to a solution. This is a study of ecologies of care or the lack thereof that created the monster of schistosomiasis and prevents vulnerable communities from accessing basic rights.

Theories and lenses

The lens one uses to view the world can alter one's understanding of it. The spread of schistosomiasis in Sub-Saharan Africa is not only a map of people who have tested positive for the parasite; or a report of the effectiveness of the medication; or a study on the stigmatisation of people with schistosomiasis. What one chooses to focus on in an encounter or assemblage of encounters between humans, non-humans, other-than-humans, materials, infrastructure and policies, will determine what is important or worth looking at in relation to the disease, or the people and communities at risk. This is what I struggled with the most in my research process. My supervisor told me one day that I was trying to do two masters dissertations in one; I think it was closer to three.

Schistosomiasis is a neglected disease and the people who are most at risk are even more so. In my research I found the lack of recognition whenever I spoke about bilharzia surprising. I grew up as an expatriate in Malawi, where we were warned as we were entering the country and were dosed (without being tested) at least twice a year. Why do people living in 'hotspots' not know of it? This dissertation draws on Actor-Network Theory (ANT) and Multispecies Theory to map out the interconnectedness of humans and schistosome worms and how we have come to make the monsters within us. Tsing et al.'s concept of 'monsters' (2017:M1) is used in the overarching argument that schistosomiasis has become a larger, deadlier and uncontrollable disease as a result of human intervention and serves as a warning

for future interventions. I also look at the concepts of 'care' to help me examine the disparities in access to care, knowledge and medicine. It also illuminates the power of attention and silence. 240 million infected people worldwide is not a small number.

I chose to utilize Multispecies theory and ANT as tools for understanding the complex relationships between schistosomiasis, its hosts (snail and mammalian), its environment (naturally occurring and human-made), political and medical actions, and other influences (materially or socially constructed). Multispecies theory is pivotal to understanding 'non-human' or 'other-than-human' actors as thinking, feeling, social beings that have a life of their own, as well as an influence on humans. Hall (2011) describes the multispecies method as recognizing non-humans as 'embodied individuals' and plants as 'intelligent beings' and Houston et al. describe them as "entangled with human and other nonhuman species and environments" (2018:198). Furthermore, Tsing et al. details 'entanglements' as the "complex relations of dependency and interdependence" between species and that "attention to this diversity can be the beginning of an appreciation of interspecies species being" (2012:144).

ANT was posed in the 1980s by sociologists that attempted to break away from the fixed categorizations and dichotomies of social theory and focus on a larger picture of multiple humans, non-humans, materials and concepts that all connect to one another. Law states that ANT "describes the enactment of materially and discursively heterogeneous relations that produce and reshuffle all kinds of actors including objects, subjects, human beings, machines, animals, "nature," ideas, organizations, inequalities, scale and sizes, and geographical arrangements" (2009:141). Thus, it is a tool that allows researchers to broaden their focus beyond the human to the larger 'network.'

Latour (1996:6) summarizes the concept of a network as:

> "Instead of having to choose between the local and the global view, the notion of network allows us to think of a global entity -a highly connected one- which remains nevertheless continuously local... Instead of opposing the individual level to the mass, or the agency to the structure, we simply follow how a given element becomes strategic through the number of connections it commands and how does it lose its importance when losing its connections."

Schistosomiasis is an ancient parasite, with two hosts, thus the 'number of connections' is large. What ANT can contribute to schistosomiasis research is a holistic and broader

understanding of the network and connections. Prevention programmes have often focussed on eliminating one connection in the network, however this often is not sustainable.

One of the largest contributing factors to bilharzia in South Africa is the increasing divide between those who have access to medicine and those who do not, which Petryna et al. referred to as the "values gap" (2006:6). This access, or lack thereof, reinforces the disparities between those that can afford private health care and live in areas with access to clean water supplies and those who live in remote areas where water supplies are not treated or tested regularly to ensure its safety. The values gap is "intensified by the choices made by industry: afflictions whose treatments are relatively easily produced and have ready markets that are deemed more worthy of research and development" (Petryna et al., 2006:6). The values gap between South Africans not only allows attention to be drawn away from the lack of access to medicine, but also the lack of access to clean, potable water sources and dissemination of information to the people at risk of infection and those in the public health sector. Silence and precarity go hand-in-hand.

Anthropologists have been paying close attention to silence since Keith Basso analysed the cultural and social significance of how Western Apaches "refrained from speaking" in 1970. Dragojlovic and Samuels discuss a shift in focus of the anthropology of silence towards "the social, political and interpersonal dynamics that silences generate" (2021:420). Similarly, Wildman and Davis define silence as "the lack of sound and voice" and they continue by saying "silence may also arise from oppression or fear. Whatever the reason for silence, its presence means the absence of verbal criticism" (1994:885). This shift draws attention to less obvious silences, where the absence of certain populations' voices, means the absence of attention, which leads to inaction and further oppression. In my research I encountered multiple instances where schistosomiasis and the people most at risk of contracting it are ignored.

In conjunction with silence, 'care' or specifically the lack of care, can be a useful tool through which to analyse how the 'values gap' and inequalities are sustained in the context of schistosomiasis in Sub-Saharan Africa. Care is "a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web" (Fisher & Tronto, 1990:40). However, the world is not so simple, and neither is care. In a world with limited resources care is not

given freely or equally. As Tronto elaborates, “care is fraught with conflict. Indeed, conflict seems inherent in care. There are more needs for care than can ever be met. Determining which needs are important inevitably involves slighting other needs” (1998:17). Thus, someone will always be lacking, and in the case of schistosomiasis it is impoverished and vulnerable communities. In continuation, Tronto states “care involves power relations" where “the caregiver has some kind of ability, knowledge, or resource that the care receiver does not have” (Tronto, 1998:17). Using Fisher and Tronto’s definition of care as ‘world’ repairing, maintaining and continuing acts, this dissertation will argue that infrastructure, policies and interventions are included as acts of ‘care’ and therefore, a lack of access to clean water or medication, and a lack of information on the risk to a population’s health fall under a lack of care towards vulnerable communities. This is where ‘structural violence’ comes into play. Farmer et al. describe ‘structural violence’ as, “social arrangements” fixed in the “political and economic organisation of our social world” that place “individuals and populations in harm’s way” (2006:1683). This structural violence not only applies to the vulnerable communities that are at risk of contracting schistosomiasis but also the environment that is continually adversely affected by the spread and influence of humans and their little monsters.

In Dulcos and Criado’s (2020) reassessment of ecologies of care, they suggest that care should be considered in a broader evolving ecology. They critique the use of the concept of care in research for becoming a “placeholder for a shared desire for comfort and protection” (Dulcos & Criado, 2020:1), in which one is more concerned with “a politics of comfort and minimal existence that are problematic” (Dulcos & Criado, 2020:2) than the possibility of having a wide range of beings (human and non-human) flourish. Care cannot be given equally or applied the same across environments. The world is full of diverse cultures with many different practices and values that sometimes clash with the typical ‘Western’ idea and policies for health, care and medicine. The people living with schistosomiasis are treated as ‘patients’ in need of care or education without supporting infrastructure to sustain their health; without the empowerment to keep themselves, their families and communities safe. Instead of ‘ecologies of care,’ Dulcos and Criado pose the concept of ‘ecologies of support,’ placing a new focus on how “different kinds of bodies are differentially supported, cared for, and capable of influencing their own conditions of support” (2020:3).

Methodology

Nikiwe Solomon was inspired in her PhD thesis about the Kuilsrivier, by Michel de Certeau's "Walking the City" (1984), to use "walking as a methodological approach" (2022, 51). This concept draws on 'queering' and drawing attention to an environment we might take for granted and analysing it through a different lens. I might not have been able to physically walk through the 'field,' of my memories or the experiences of others, but I was inspired to think about talking as a methodological approach. Now this is not a new concept or methodological approach. Anthropologists and other social scientists have utilized many approaches that involve just talking, such as oral history, unstructured or semi-structured interviewing, and narratives to name a few, but it brings attention to and (maybe problematizes) how I found my 'sample group.' I was in an area with a high prevalence of schistosomiasis in South Africa trying to enter the 'field' when I found roadblocks that initially delayed my research and then ultimately changed it completely. During this time, I was staying with my parents and socialised with their friends, who are mostly ex-expatriates from Malawi, Tanzania, Zambia and Eswatini. Inevitably we would discuss my research and they all had a story to tell about their own experiences or experiences of someone they know with bilharzia, and even offered to be interviewed. Technically this is considered "snowball sampling" (Bernard, 2005:193), by which the researcher finds one or two participants and asks them to list other members of the population and recommend others to interview. In this case, my role was embarrassingly passive. I had my participants before I even knew my research had to change. Here the matters of attention, silence and privilege play a role. Whose voices are heard? Who gets a chance to talk and even a platform and whose voices are once again left in silence? In this case, those who I was given access to are: privileged, white voices, who had no shame or stigma associated with their disease. They are people who knew of the risk before entering the water and chose to do it anyway and for recreational use, not because of a need. They are people who had access to treatment and could easily afford it. Lastly, they are people who actively put themselves at risk again. They were not part of the majority of cases. They were not the vulnerable population that is at risk of reinfection everytime they need to use water (so everyday) and who cannot access medication easily, if at all. Certeau's (1984) queering of 'walking' made me scrutinise how 'talking' can be taken for granted, and what a large role it has played in my research process. Most evidently, in how little schistosomiasis is spoken of especially in South Africa, and especially among the most affected communities. I was barred from entering a highly at risk community because I posed

a risk of informing the community that they may have a deadly disease and the surrounding clinics were not equipped for their treatment.

I interviewed six people who were diagnosed and treated for bilharzia, at least once but most of them had multiple reinfections. Three of them are my family members, both my parents and my brother. I will only refer to them throughout this dissertation by their familial tie to me and the other participants have pseudonyms. We were all infected and reinfected at Lake Malawi, and while my parents were treated and 'cured,' my brother and I struggled to get rid of our worms. I also interviewed a good friend of ours, Coen, who lived in Lilongwe but often stayed in the cottage next to ours (owned by the company my dad worked for). He was born and raised in Malawi to Dutch parents, and knew the country and environment very well. He was the first person my father told me to speak to when I told him my research had changed and it is because my father said he always knew exactly what was happening at The Lake and often spoke to my parents about bilharzia. Another participant, Brent, is a colleague of my father who contracted bilharzia while he was studying, when he went windsurfing on Dudley Pringle Dam in Tongaat, KwaZulu-Natal (KZN). Lastly, I spoke to Dom from a town near Pietermaritzburg, KZN who contacted me after a mutual friend, who is also connected to my father's company, discussed my research with him. All of my participants are white and from a high economic bracket. Other than my brother and I, they are all above 55 years old and Dom is above 70. All of us were aware of bilharzia before we were infected and everyone except Dom, knew where we got it and were treated soon after. I also spoke to a doctor from KZN, briefly about bilharzia in Pietermaritzburg and informally with my own doctors and pharmacists in KZN and the Western Province.

Thus, my research 'field' is broad (geographically) and mostly virtual. Covid 19 prevented me from meeting people in person. I conducted semi-structured interviews (Bernard, 2005:211), in which I had a list of questions to guide our conversations around bilharzia. Questions can help shorten the length of the interviews but also allow for "reliable, comparable qualitative data" (Bernard, 2005:212). Thus, I could compare the experiences my participants had with each other, me and literature on schistosomiasis.

I encountered multiple ethical considerations throughout my research process. Firstly, my original research had to change because of a clash of ethics. I received ethical clearance to enter the 'field' in a high risk area in South Africa. I would have met my participants through a programme that spearheaded schistosomiasis research in the area, however my timing was

off by a few months because they had ‘paused’ community outreaches and treatment in order to ‘compile’ their findings and publish. I was asked to complete Good Clinic Research Ethics courses before they would ‘allow’ me to enter the field and they required that I hire one of their research assistants and a nurse before I could speak to anyone in the community. I was told that my presence in the community could put the community members at risk of discovering they may have schistosomiasis and that would make me ‘liable’ to provide medical support, because the clinics are not equipped to treat them. They said they wanted to prevent ‘mass panic.’ Although I did not need their permission to enter the high risk community, I realised that the politics in the area was more complicated than I expected. Consequently, this exchange alerted me to several issues. Firstly, this organisation had stopped providing any medical support for the community and clinics, while they were writing their research papers. Secondly, they were not encouraging any dissemination of information about schistosomiasis in the community, thus there were (at the time) no educational programmes active in the community and people were more than likely unaware that they have the disease. Lastly, the clinics are not able to provide enough people treatment for schistosomiasis.

In Wildman and Davis’s article, *Language and Silence: Making Systems of Privilege Visible* (1994) on privilege and silence and the role of a white researcher writing about people of colour, Wildman describes a dream her friend had of her and a white man talking over him and on his behalf. This scenario alerted her to the privilege she held as a white person to speak and view issues of race in a particular way that also allowed them to exclude those of which this discussion affects the most. A large part of this dissertation is formed around the privilege of access and attention, and the silence of precarity.

Anonymity is another concern I had throughout my research. The snowball sampling method relies on members of the same population knowing and referring to each other. In my case, my father is at the centre of this network. It was through his colleagues and friends that I found my participants. As a result, they may be able to identify one another even though I used pseudonyms and kept some information vague. I also made sure not to tell my participants who I had spoken to. However, it is a different case for my family. I chose to do an autoethnography because I wanted to understand how my experience with schistosomiasis fitted in with other people’s experiences. I wanted to understand why I struggled to be diagnosed in South Africa, if it is prolific in this country and why no one talks about it. Part of the comparison is about contextualising my experience, as a white woman from a high

income bracket who was ‘exposed’ to a parasite as an expatriate. Autoethnography “uses, and even foregrounds, a researcher’s subjectivity, reflexivity, and personal experience (auto-) in an attempt to represent (-graphy) cultural experiences (ethno-)” (Adams & Manning, 2015:351). Thus, it “can provide first-person details of culture—details that help us understand and critique the social structures and processes constituting that culture” (Allen & Piercy, 2005:162). Understanding my experience in context reveals what might not be visible or heard, which is the context in which one is not privileged with information and access.

Something I needed to keep in mind when interviewing my family was anticipating or coaxing a specific answer out of them. This was both an advantage and a disadvantage of using family ethnography. I knew exactly what my brother went through and the research my mother had done, thus I could ask the right questions to get specific responses. The advantage of this is an enriched narrative, where our collective memories tell a deeper story. However, this could easily create a biased narrative with a specific agenda. Biased narratives are inevitable in social research but being aware of how you, as a researcher, influence them is vital. Thus, I was conscious of asking my family the same questions as my other participants and to let them lead the discussions that followed each question.

How do you write about your own experiences of being an expat in Malawi without drawing your family and their personal experiences into your writing? What if you want to interview your family members on their experiences too? Can they effectively remain anonymous? No. How do you navigate this without negatively impacting their agency? What about the company my father works for and the insight I have on their methods of dealing with bilharzia cases among their employees? What about Michael? How do you talk about the dead? Can you ethically ask a widow whether she will consent to using her husband’s last months of life as another case in this study? What value does this case really add to the research that might not be seen by anyone other than supervisors and moderators? Is it then worth including it in this dissertation if it does not make any meaningful change? Is it ethical to use the knowledge I have of his experience without asking permission from his widow? No, I do not believe it is, even if it brings valuable academic insight to how bilharzia survives in the human body.

Chapter outline

This dissertation is divided into three chapters. The overarching argument throughout the three chapters employ Tsing's et. al's (2017) concept of 'monsters.' Humans' attempt at 'mastering' nature has made them monstrous beings that corrupt entanglements with other beings and pervert the balance, resulting in something more sinister and out of control. Humans have spread schistosomiasis across the world and cultivated the perfect environments for it to burgeon into an unstoppable monster.

The first chapter is Creating Monsters within Monsters, which takes a deep dive into the effect schistosomiasis and its treatment have on the human body. It draws not only from scientific research but also the illness narratives of people who have lived with schistosomiasis, which includes my family and my own subjective experiences of living in a high risk area, living with the disease and the road to diagnosis and treatment.

The second chapter: A Monstrous Lover's Embrace, attempts to map out the different relationships between humans, non-humans, policies, infrastructure and environments that all contribute to the spread of the disease. It delves into the history of humans and the parasite and demonstrates how entangled each actor in this network is with each other. ANT and Multispecies Theory are used in conjunction to trace the assemblages, with the parasite and the human as the focal point.

The last chapter is Monstres Sacrés. This chapter focuses on the human actions, such as a lack of attention, silence and lack of resources, that continue to perpetuate the spread of the disease and the disparities in the 'care' given to certain populations. Here the discussion looks at why schistosomiasis is still on the leaderboard for the most deadly tropical diseases if it is considered an 'ancient' disease and is treatable.

Creating Monsters within Monsters

I could not stop the tears of horror and the feeling of unfairness that welled up in me when I first researched what bilharzia did (or currently was doing) in my body. I confess that I only started researching what exactly bilharzia did when I had to write an illness narrative for one of my honours' courses. I had a general idea of the hooked eggs and oddly shaped worms and their lifecycle, but no one could have prepared me for the images of the scar tissue. I later had my own photo of my own bladder to cry over. It was only then that I think I truly understood that this was happening to me, inside me and my whole body, and not to a detached organ that can just be fixed with a few ghastly pills.

In stark contrast, I remember the awe on my urologist's face when he came back with a photo of the scarring and his smile when he told me he could see them swimming in my bladder. I also remember the rage I felt because we had to insist he perform the uroscopy with retrograde when I received what he believed was a 'false positive.' The urologist's expression of excitement and insistence that a colleague in Pretoria, who specializes in parasites, would love to see these results made me feel like an experiment. I was a broken game of Operation (a popular board game that tests hand-eye coordination) and everyone wanted to see if they could win the game (or cure my disease). This reaction was not isolated to the medical field, I had an anthropology lecturer express the same excitement and suggestion of talking to his friend who specializes in schistosomiasis when I told him. I remember joking with my mom by saying my lecturer, his friend, my urologist and his colleague, the parasite specialist, should all form a study group, and then my brother and I can be their test subjects. It was a joke, but I felt like my experience, my suffering, was demeaned and reduced to a host of a monster that induced awe. I was not a person who had 21 years of experiences, interests, skills, memories, a family and friends, who also happens to be living with parasites. I was just a 'patient.'

This chapter details the devastation schistosomiasis causes within the body. It includes accounts from my participants' experiences and my own experience with the disease and the treatment for it. The purpose of this chapter is not only to inform the reader of the effect of the disease on a scientific level, but to invoke the same horror I felt when I first read about the disease while I still had my little monsters wreaking havoc within me; to invoke the paranoia and fear of these unseen parasites. There are no monsters without horror. My

intention is to reveal the monstrous qualities of the parasite in order to provoke fear in the reader. Just as humans have created this monster, humans need to stop it.

This chapter draws on Tsing et al. (2017) and their concept of 'monsters'. They use the example of jellyfish that have become monsters as they take over seas that have become warm enough for them to inhabit, they sink ships that accidently catch them in their fishing nets, they eat over ten times their weight in fish and have even become a bigger threat than sharks in some areas of Australia (Tsing et al., 2017:M1). The Merriam-Webster dictionary defines the noun 'monster' as: "1a: an animal of strange or terrifying shape, b: one unusually large for its kind, 2a: an animal or plant of abnormal form or structure, b: one who deviates from normal or acceptable behavior or character, c: a threatening force, d: something monstrous, d: one that is highly successful" (Merriam-Webster, 2022). Furthermore, it defines the adjective 'monster' as: "enormous or impressive especially in size, extent, or numbers" (Merriam-Webster, 2022). Schistosomes may not seem monstrous as individuals but once they become a collective and are paired with humans I argue that they fit the criteria above. Although schistosomes are microscopic worms, in terms of impact they are "unusually large of its kind," they are definitely "a threatening force" and "enormous or impressive in size, extent and numbers."

What the parasites do to the body

Although my story started in Malawi, I did not know that in my second year of university I would struggle to have my bilharzia diagnosed and then treated, and I did not know it was a story worth telling until I was in my honours year, taking a course in chronic illness narratives. Blood in one's urine is usually a sure sign that something is wrong with you. For people suffering from schistosomiasis, blood is one of the first, and clearest, indicators that you have *S haematobium* in your urinary tract. It is universally referred to as "red urine disease" in the field of medicine (Chitsulo et al., 2000:48). However, unfortunately for me, any blood I had in my urine was so microscopic, it was not clear in any of my urinary tract infection tests. This was the only symptom I had, in fact I thought it was the only isolated medical condition I had… and so did my doctors. The scarring in the bladder that is caused by the hooks on the eggs can, in turn, cause bacterial superinfections. In my case, I had four urinary tract infections in a period of six months, and in a year, I had six altogether. This is very unusual, yet the general medical practitioners that I consulted all told me not to worry, it

was only caused by stress. One in particular attributed it to both stress and being sexually active, sending me home with a prescription for antibiotics and instructions to shower and urinate after sex. At the time, the total embarrassment of being told my sexual hygiene was the cause left me too flustered to question him or to talk about it for years to come. My mother called immediately afterwards, knowing I was off to the doctor with another bladder infection and asked what he said. I told her, he said it was just stress, which she never accepted as the culprit and couldn't believe I did not ask for more details. I also never mentioned it in my illness narratives out of shame. I knew he was wrong, because I still got bladder infections and it was later determined to be bilharzia. On the other hand, I was and still am not one to question doctors. I would rather go to a different doctor than confront the one I have. As a white person, born in privilege, my shame silenced me, even though I had nothing to be ashamed of. If this was my experience, what are less privileged people experiencing? What about young women with urogenital schistosomiasis? Are they also shamed into silence with misdiagnoses and misinformation?

The average lifespan of a mature adult schistosome is three to five years but can be as long as 30 years (Gryseels et al., 2006:1106). My adult schistosomes were more than six years old when I was diagnosed. In the blood vessels of their host, the worm couples have been described as "permanently embraced" (Gryseels et al., 2006:1106), like long lost lovers. They can produce between hundreds and thousands of eggs per day, which then migrate to the opening of the bladder or intestines (Gryseels et al., 2006:1106). This description of the lovers and the number of eggs they produce, stuck with me in the years since I started doing research, and evidently it stuck with my mother as well. In our informal interview I asked her to tell me as much as she could about the parasite, in order to see how much people who have been diagnosed with the disease actually knew about it. Here is her summary of the life cycle of the schistosome:

> "So basically, it's a male and female that live connected to each other as a couple. So the egg begins in a host and then the worm must then go into the water before the cycle can be completed. So the eggs hatch in the body…" She then switched into English after I asked if it would be easier for her to explain it. "So the egg hatches inside the human host, or the animal host, and then leaves the human host through the urine into water and then develops inside a snail shell. It can only live in water where that specific snail is. And as soon as someone who has bilharzia enters water, they have a higher urge to actually urinate. So in that way the worm makes sure that it gets

> to leave the host and then it goes through a cycle in the snail before it's mature… in the snail's shell or the specific shell before it's mature and then it enters a host again but it can enter through the skin. It doesn't need to enter through a wound, it can enter into any part of the host, without leaving any sign or mark. Sometimes it's a bit itchy where it entered but usually— well, quite often you don't even know that the worms have entered your body. And then, one bilharzia couple can live in the human body for up to 30 years or more and it lays at least 400 eggs a day. Certain worms have a preference for certain parts of the body, the type that is in Malawi likes using the bladder as the host or an incubation for the eggs. And the eggs have hooks on them so that they can hook onto the lining of the bladder, which causes scar tissue and that lining can harden, because of the scar tissue and in the future, it can cause cancer. Because of the continuous scarring and it's the scarring in the bladder is what causes blood in the urine. And also the body's reaction to the actual infestation of the worms and the eggs— the immune system's reaction causes exhaustion."

After a pause she comically asked, "What more do you want to know?" Throughout her description of the parasite I could not help noticing how many times she stated facts practically verbatim to how I described bilharzia to friends and family members who made the mistake of politely asking what my thesis was about at social gatherings, for which my mother was often present and enjoyed relaying some gory facts, I tried to tactfully exclude. The only part of her narration that is not supported by medical fact is her suggestion that the schistosomes can make the host want to urinate when they are in water. This we heard on a news documentary years ago, which I could not find again.

After reading in detail about the parasite, you might understand why I remained wilfully ignorant about what might be going on in my body, and it was only years after having left Malawi that we found out I still had bilharzia. When I spoke to my father, I asked him if he remembers people talking about bilharzia in Malawi, he said:

> "Ja, there were many conversations about bilharzia. I also think we didn't really— well it was grown-up discussions and you were well… young. And also I don't think we wanted— maybe we didn't discuss it openly at home, because if you start going through the details it sounds horrifying. And it is horrifying if you think that worms go into you, or that larva thing goes into you, and then it grows in you and all that kind of things. I don't know how you— if you tell that to kids, what are they going to

> say? So I don't know. I don't think we purposefully didn't talk about it in front of you. I just think whenever we spoke about it, it was at a dinner party and you kids were elsewhere."

To fully understand what impact the bilharzia parasites have on the human host, you have to understand how the parasite lives, where it lives and what it does. Schistosomiasis has many different symptoms, which are also common symptoms for other diseases and people living with schistosomiasis might present different symptoms. Thus, it is important to understand how the disease might have manifested differently. This is a neglected disease that few people know about or really understand what it can do. Secondly, and because of this, people struggle to understand what it means when people who have lived with bilharzia struggle to have it diagnosed or treated. I want people to understand how the parasites live with their host, so that they can understand how I lived with them. Thirdly, to understand the life cycle of the parasite and its natural habitat allows for a more holistic approach to preventing the spread of the disease.

There are different types of schistosomiasis and different immunopathological reactions to the different schistosome eggs, which hook into the body tissue. However, I will only be focusing on *S. haematobium*, which is found in the urinary system and causes inflammation, obstructive diseases, and superinfections such as reoccurring urinary tract infections. Chronic schistosomiasis refers to longstanding infections, or re-infections, which is more prominent among permanent residents in infected areas (Gryseels et al., 2006:1106). Whereas, most people travelling through infected areas will only contract acute schistosomiasis, which is a feverish syndrome that often is diagnosed and treated quickly with a once off dosage of praziquantel. I have been diagnosed and treated for this species of schistosomiasis for the better part of seventeen years. The most common symptoms for *S. haematobium* are rashes, a fever, fatigue, muscle pain, blood in urine and an increase in white blood cells (Gryseels et al., 2006:1107). These symptoms are what medical practitioners are trained to decipher. However, as many of my interviews demonstrate, there are many more manifestations of bilharzia with a lot less, or very different symptoms. In chronic schistosomiasis, most of the scarring is not caused by the adult worms, but from the eggs that result in "granulomatous inflammation, ulceration, and pseudopolyposis [clusters of scar tissue] of the vesical and ureteral walls" (Gryseels et al., 2006:1108). I do not remember ever having any of the symptoms mentioned above, other than the fatigue (which could be a symptom of many different ailments, including stress), therefore, I was only diagnosed more

than six years after we had left Malawi. My symptoms were caused by the hundreds of eggs that were produced daily by an unknown number of schistosome couples hooking to the inside lining of my bladder. They had caused so much scarring that I contracted reoccurring urinary tract infections.

A long-term effect of this could be severe kidney damage and organ failure. Additionally, infection with *S. haematobium* is "classified as a group I biological carcinogen by the International Agency for Research in Cancer of the World Health Organization (WHO)" (Vale et al., 2017:1), meaning it can cause cancer. Furthermore, in women, urogenital schistosomiasis can result in genital discharge and reduced fertility. It can also cause lesions in the lining of the vagina, which lead to bleeding during examination or sexual intercourse. This can increase the risk of women contracting HIV/AIDS. In children, chronic schistosomiasis can result in the person becoming physically and cognitively compromised, stunted growth, anaemia, attention deficit disorder, learning disabilities, school absenteeism and an increase in high school dropout rates (Berge et al., 2011:22).

My brother even acknowledged the fact that it's the long-term effects of the bilharzia that is so dangerous. He said, "ja, it's an underlying worry because of its long term effects." Coen similarly dwelled on the long term effects of living with bilharzia by recounting his brother-in-law's experience with bilharzia

> Coen: "When my sister came here with her young family, back from [Europe], enjoying The Lake like we used to, and enjoy it, and just lying in the water and swim, they didn't realise that they were all getting infected by bilharzia, and went home to [Europe]. Literally, a few years later, her husband started getting paralysis of his legs. And it turned out, after a lot of checking, and cross checking, and test after test… It turned out the bilharzia had gone to his spine."
>
> Me: "and do you think it was the same species?"
>
> Coen: "yeah, it's the same species. It just finds its way into different parts of the body. They eventually got rid of it, but after that it had done a lot of damage to his nervous system and to this day he still has some issues with his calves- a lack of feeling in one of his calves and so on. So it's not a good disease to have in your body for a long time. So whenever we have visitors here, we give them- actually physically give them- the treatment, because it's easy to get here. And we advise them, 'in six to eight weeks they must take the full course.'"

One of the knock-on effects of the high schistosomiasis infections, specifically chronic and reoccurrences of the disease, is the impact it has on the public health and economy of the country. According to Berge et al., "the effects on child development may result in a generation of adults disadvantaged by the irreversible repercussions of this infection, with significant deleterious consequences for public health and the economy" (2011:22). Similarly, King stresses the urgency behind treating parasitic infections to avoid the long-term effects such as, "under-recognized, 'subtle' morbidities such as caloric malnutrition, growth stunting, anaemia, and poor school performance" (2010:2). King continues by stating: "it is an inescapable fact that small deficits in performance status have a strong, asymmetric leverage on household productivity in the face of severe poverty" (2010:6). Thus, referring to the 'poverty trap,' in which physical labour is the main source of someone's income (just to break even or survive), one cannot afford to be drowsy, in pain or to lose concentration without losing income (King, 2010:6). Even the 'acute' symptoms of schistosomiasis are enough to keep someone in a poverty trap.

If the physical impact that schistosomiasis has on the body is not horrific enough, there is the paranoia that I have lived with for the last 6 years. I fear every pain in my urinary tract is another bladder infection and what does that mean for my bilharzia? Every medical issue is researched with its possible connections to bilharzia, just in case. I went to a doctor recently to check my immune system after two years of being sick with either Covid or the flu. We found that my vitamin B12 was extremely low and the first thing my mother and I did (without discussing it beforehand and on opposite sides of the country), was Google: "what causes a vitamin B12 deficiency?" In my research I noted some results, like a lactose free diet, which I used to lose my lockdown fat and it worked but I did feel weak afterwards. Another option was irritable bowel syndrome, which I have a mild case of. However, the option that stood out to both of us, which I rationalised cannot be an option but what my mother hyper-focussed on, was "parasites." Not again. Schistosomiasis can cause enough damage in one's intestines to prevent the absorption of some vitamins and minerals. Schistosomiasis can also cause iron deficiency anaemia from blood loss, all of which can cause a vitamin B12 deficiency. It has been 5 years since my first confirmed negative test and 3 since the last time I tested and it was negative again. Yet, the paranoia that any ailment or affliction I experience could be caused by the parasites has not lessened. Richards (2008) dwells on a similar experience after suffering from kidney failure and undergoing a transplant. She reflects, "I would not, 30 years later, still be haunted by my own vulnerability

so that every fever or unexplained symptom takes on a dreadful significance of impending doom. Even now I do not know what being well is" (Richards, 2008:1721). This last statement of hers is haunting. I am supposed to be 'cured.'

Praziquantel and the body

> "Biltricide only kills 90% of the worms. So if you have 20 worms inside you, then you can end up with still two worms left inside you. And those two worms can still lay 800 eggs. So what is the use if you can't kill all the worms?" My mother asked.
>
> "At least there are only two couples reproducing, instead of the hundreds," I replied.
>
> "If you live for 30 years with those two couples still living in your body, how much damage are they getting up to? And then you drink Biltricide again and it doesn't kill both couples. So at which point will you be bilharzia free?"

We do not know and as my mother pointed out "neither do the doctors."

This pill is commonly known as Biltricide among my family, friends and participants in my fieldwork. It is the only name for it that I heard growing up. However, Biltricide is the trademarked name by Bayer Pharmaceuticals for praziquantel. Praziquantel is considered a chemotherapy that targets the cells of adult parasitic worms in the body. It has a broad antiparasitic effect. Thus, it started out as a veterinary taeniacide (a substance that kills tapeworms) but was found to also work in humans with few side effects (McMahon & Kolstrup, 1979: 1396). It is currently the only recommended treatment for Schistosomiasis by WHO(WHO, 2022).

In order to understand the power of transformation of praziquantel, we need to understand what it is made of and how it affects the body. The praziquantel tablet is 2.5 cm long. The dosage is dependent on the weight of the 'patient,' therefore, the heavier the person is, the more tablets they need to swallow. It can be halved or quartered but not crushed. Although chopping it into smaller pieces might make the pill easier to swallow, it doubles or even quadruples the number of bitter pills you have to consume. Vale et al. briefly describes the praziquantel tablet as:

> "PZQ1 [Praziquantel] is a class II drug that displays a high ability to permeate tissues and low solubility (0.4 mg/ml) and proceeds through extensive metabolism […] via

> hydroxylation of the absorbed drug to inactive metabolites, such that only minimal concentrations contact the parasites within the blood system. Currently, PZQ1 is distributed as a racemate that includes equivalent proportions of the biologically active R-PZQ (PZQ2) and inactive S-PZQ (PZQ3) enantiomers, the consequence of which is that half the PZQ1 dose is pharmacologically inactive (2017: 4)."

This description reveals multiple interesting aspects of the medication. Firstly, the part that stood out the most (mostly because I did not need to google it to understand), was that half of the bullet-sized tablet does not affect the parasites. The 'class II' classification reveals that this is a highly controlled substance for which a prescription is needed from a doctor in order to purchase the medication from a pharmacy. It also explains why the exact amount necessary for treatment is given. The above quote essentially states that praziquantel is a highly controlled substance that easily passes into the bloodstream but does not dissolve easily. Before passing into the blood, the pill is broken down by the metabolism into PZQ2 (active) and PZQ3 (inactive) molecules. Thus, only half of the initial dose fights against the adult worms and the other half "unnecessarily doubles the size of the tablets (factors that render treatment less acceptable, especially to small children)" (Olliaro et al., 2014:863). This explains why the dosage of 40 mg/kg is so high. Vale et al. (2017) continue by stating that the inactive molecule, PZQ3 could contribute to the bitterness of the pill.

Reich et al. state there are only three drugs used to treat schistosomiasis "praziquantel, metrifonate, and oxamniquine" (1998:19). As they argued in 1998 and still relevant today, "praziquantel remains the drug of choice for all forms of schistosomiasis occurring in [humans], because of its high efficacy, its low toxicity, and its ease of single, oral administration" (1998:20).

In support of this, Berge et al. wrote thirteen years later, "praziquantel is highly effective in killing adult worms and cure rates are 75-85% for *S. haematobium* and 63-85% for *S. mansoni*. Given as mass treatment in the low transmission season, efficacy is even higher" (2011:23). In South Africa, winter is the low transmission season, when the worms have matured, making the praziquantel more effective. However, as mentioned above and by my mother before, praziquantel cannot kill all the parasites in the body or any juvenile worms or the eggs and on top of that, only half of the huge tablet is effective. This contributes to her own experience of the medication, where she considers whether it is worth the trouble of the

embarrassment of being weighed in order to determine her dosage, swallowing multiple oversized pills and then not having a guarantee that you are 'cured.'

As van der Geest et al. argue "the cultural efficacy of pharmaceuticals lies primarily in their capacity to carry meanings" (1996:169). They suggest that pharmaceuticals contribute to their cultural construction by being a tool through which people identify and interpret their disease or illness. Thus, "the character and gravity of sickness are often expressed in terms of kind and quantity of medicines" (van der Geest et al., 1996:169). Relating to this is how my brother talked about the meaning he placed, not on praziquantel, but his chronic medication. He said:

> "Getting older makes you think about… I mean I have to take cholesterol pills, because of genetics, and then chronic heartburn pills and… basically, I have a list of chronic pills that I am taking and I'm thinking, 'gees, okay, I'm aging!' I'm becoming unfit and senile, now that I've got my daily pill count."

Here, my brother demonstrates how his conception of the need to take chronic medicine as a sign of aging, has him reflecting on his own age, which is under 30. Keeping in mind that I am on the same chronic medicine that he is on and I'm only two years younger than him, this reveals how the same medicine can carry different meanings for different individuals and can affect the way one perceives oneself.

When I asked my mother about her experiences with the medication she immediately and comically detailed the embarrassment attached to it.

> My Mother: "So the first embarrassing thing about the pills is that you have to give your weight to find out how many pills you have to drink."
>
> Me: "[laughing] Have you ever lied, Mom?"
>
> My Mother: "No, because that doesn't help! Because then you get too few pills and then you'll only kill 60% of the worms! So, now you have to tell the doctor, 'listen here, I need like 9 pills' and then he gives you a [sideways] glance and says, 'uh, ummm… maybe… umm you should get on the scale.' And then you don't know if he's thinking you're exaggerating or he's thinking you're underestimating your weight."

> "So, ja, that's the first embarrassing thing, having to admit how many pills you need to drink. And then you get that whole handful of pills and you need to drink them all in one go. You are not allowed to… you can half them, but you are not allowed to crunch them. So at the most you can half them. So say you have 9 pills, or 8 pills or something, then you're sitting with 16 halves to swallow. So it's almost easier to swallow the 8 whole ones. But they are very big pills and then you're swallowing them with the idea that they might not even work. So it's a very bitter pill to swallow. Literally and figuratively."

I then told her that a lecturer of mine had warned me that I was lucky to only have the pills to swallow because when she was young and living in Zimbabwe, her treatment was the pills and an 'injection in the bum', to which my mother replied sarcastically, "Maybe they should bring the injection back again. Maybe that's why they can't get rid of bilharzia."

I found two bottles of Biltricide in my mother's first aid kit that we were given in 2015 with the half and quarter already divided in order to administer the exact amount according to our weight. The Biltricide information leaflet (Bayer (Pty) Ltd, 2021) for the 600 mg praziquantel tablet states the dosage at 40 mg/kg body mass once off. Therefore, if you were 60kg, the dosage would be four whole tablets. In my father's case however, he would have to swallow 7 and a quarter tablets because he weighed just over 108kg in 2015. This was clearly marked in a red marker on the side of the box by the company doctor who prescribed them, along with mine, my mother's and brother's dosages and the instructions: "Take as a single dose after an evening meal." Curiously, two things stand out about the medication; 1) the two bottles are half full, indicating that we did not all take our medication and 2) someone wrote in a black pen the numbers 9 and 7.2 next to my brother's and my names respectively, which seems to be an amendment to the dosage, upping it to one pill for every 10 kg. This could have been added by one of my parents and it could have happened a few years later when my brother and I were older and heavier.

However, I did note in my interviews with my parents and brother that they estimated that the dosage was closer to 1 pill for every 10 kg, which is a significantly larger dosage if you consider each tablet is 600mg. That said, my mother also complained that our doctors already worked out what each of our dosages were and did not even give us a quarter of a pill more than we needed.

I remember the snot and tears running down my face as I gagged and spat out the quartered pill again. “Fok Charne!” my mom exclaimed. I was probably around twelve and we had done this drill many times already and it seemed to be getting worse. Through my sobbing I could see my mom fish out what was left of the pill, rinse it quickly and stuff it in a chopped up Vienna sausage- an old trick we had used on the dogs- ready to be readministered. My Maltese poodle had the same reaction when the time came for her deworming pills. The more we did this charade, the less we had left to salvage of the pill, of which we were only given enough for each of us, no spares.

“Come on, we can’t do this all night. There are only eight more to go.” Eight more quarters. Two whole pills left. The next time we attempted this, my mother especially bought a jar of Nutella, which was expensive and hard to come by in Malawi. Similarly, I can also remember practicing how to swallow pills with a box of Smarties. What a waste. This is what I remember the most clearly of my childhood experience with Biltricide. I have always, and still have an aversion to swallowing pills, which I never understood. Even today, after years of swallowing the tiny contraceptive pill and a cholesterol pill every night, the thought of the pill getting stuck in my throat has me dreading the ordeal. According to my parents, we treated our bilharzia roughly every six months for the eight years we lived in Malawi.

In the case of praziquantel, the Biltricide information leaflet (Bayers (Pty) Ltd, 2021) specifies that the side effects vary, not only on the species of parasite but also the intensity of the infection (how many worms are in the body). The very rare side effects are listed as: allergic reaction, polyserositis (inflammation), eosinophilia (higher than normal count of white blood cells), seizures, unspecific arrhythmias (abnormal heart rate), and pruritus (itchiness). The common symptoms are: vertigo, somnolence (including drowsiness), anorexia, diarrhoea (very rarely bloody diarrhoea), myalgia (muscle ache), asthenia (weakness or lack of energy), and feeling unwell. Lastly, the very common symptoms are: headache, dizziness, gastrointestinal and abdominal pains, nausea, vomiting and urticaria (hives). Somnolence refers not only to sleepiness or drowsiness but also to sleeping for long durations and is the side effect of Biltricide that my family experiences the most and very intensely.

My father and brother went into detail about their experiences and the procedure for preparing for swallowing the tablets in our semi-formal interviews. As mentioned above, the treatment of the Parrott family was a whole occasion, as my father explains:

> "We went to the doctor to get tested and then they'd get back to us and say, 'Yes, it's positive' and then [the company doctor] organised Biltricide for us and then we'd choose a weekend and the Friday you drank your Biltricide, Saturday you were man-down, and you feel really bad, and- what the people would say, the worse you feel after the Biltricide, the more bilharzia you had. That shows that the Biltricide is working and that's why you feel so tired on the first day. We always designated Friday nights, we would drink the Biltricide, knowing that tomorrow we would have a slow day and then by Sunday you're fine again."

My father describes a very organised and straight forward approach to our bi-annual deworming, which contrasts greatly to my own hysterical memories of puking up the quartered pills multiple times and my brother's own dread of the side effects of the treatment. In our interview my brother delves into more detail about what it feels like and why he has not taken another dose since we left Malawi:

> "So for my weight, I have to have eight pills, eight and a half pills or nine pills? And that, just from my memory from when I was young, taking those it's like… it hits you within half an hour and then you… it's the worst. It's not a high. I don't know what you call it. It's just drug! It's unpleasantly drugged, where you can't feel and everything becomes loopy and you just sleep and get a massive… ah, I don't know. It's just an unpleasant… unpleasantness beyond description. It's not sore, it's just… like a hangover without being drunk. And that usually lasts for about three days. And so during my PhD now, especially when like every day is a crunch deadline, being out of the loop for three days feels like a lifetime. Even on a weekend. So, ja, that's the reason I'm afraid of the pills."

When I asked Coen about his experience of the treatment he instantly replied with "It's pretty ghastly!" However, like my father, he focussed on his strategy for the treatment by providing quick and easy tips for Biltricide consumption. "The key is to have it on a full stomach just before you go to bed. That's number 1. Make sure you don't combine it with alcohol. And then you have a real foul taste in your mouth the next day. And you have, like a queasy feeling in your stomach." When I pressed to find out if drowsiness was a side effect he ever experienced he said, "No, mainly nausea."

These different approaches reflect how people can attribute different meanings and significance to the same object. Here we have my father and Coen with a systematic attitude

that allows them to schedule time to do something they deem important, making it easier and quicker to do and move on. In direct contrast, my brother demonstrates how, although he deems it important, he attributed fear and dread with the taking of pills, not because of the act like I do, but because of the after effects. Arguably, my brother does experience the side effects more severely than the rest of my family, including me, but this has led him to avoid the treatment to the point that he has not taken the medication in the nine years since we left Malawi. In addition, as it has been posed before, praziquantel usually "induces only mild and transient side effects, if any. The frequency and intensity of these effects are correlated with the intensity of infection" (Vale et al., 2017:3-4). All of this my brother is aware of, but it does not change the fact that he has still not taken his prescribed medication since it was dispensed years ago. He asked for a course of Biltricide after months of feeling drained and as a precaution in response to my own experience of living with Bilharzia with little to no symptoms.

Side effects and their severity have been linked to people's perceptions of the efficacy of the medication. As van der Geest et al attest, "the appearance of side effects is often regarded as a sign that the medicine is strong" (1996:168). This is reflected above by my father's statement that the more severe your symptoms from Biltricide, the more severe your infection was (the amount of worms in your body). Similarly, in my informal interview with my brother we were discussing the side effects and the dosage, in that discussion stated:

> "After moving to South Africa, the first time that I took Biltricide again, they gave me the regular Biltricide [600mg], […] but then, when it didn't work, after going to the urologist, they gave me a lower dosage, which we were convinced it wouldn't work. But, apparently the first test we did, directly after taking the pills and doing- I think three weeks of drinking pills- they said, which was a lower dosage. I felt a big difference in the effects of the pills, compared to what we usually do, it didn't feel like the pills were working because my definition of 'pills are working' means that I get knocked-out in an hour and I can't remember walking to bed, I can't remember anything. I wake up feeling so heavy everywhere. And when I took the lower dosage pills, I didn't actually feel like that so I was convinced they couldn't have worked."

What I found interesting in my interviews with my participants was how each of them approached my question, "What was your experience of the treatment?" differently. My mother's answer centred around the process of obtaining the medication and comparing the

treatment in Malawi and South Africa. My father spoke mostly about the admin around scheduling time off for the treatment. My brother on the other hand, focussed solely on how the medication made him feel, which makes sense as he was young. Thus, he was only involved in consuming the medication, but he also had the most severe reaction to the medicine than anyone I interviewed. Coen had a similar attitude towards the treatment as my father, which was to list what should be done in an authoritative tone. Brent said he had no notable experience about taking the medication and Dom mostly described his road to diagnosis and treatment.

For such a microscopic being, this parasite has catastrophic repercussions on the person sharing a body with it. This chapter detailed the monstrous qualities of the schistosomes and live experiences of people that have suffered from this disease. However, what it lacks is an understanding of how these tiny worms have become such an uncontrollable force that keeps large populations in a poverty trap and upholds the status quo. In parallel, the treatment for schistosomiasis may be effective (in a majority of cases) but still does not change the severity of the prevalence of the disease across the world. WHO estimated 250 million people in 2021 were in need of treatment for schistosomiasis worldwide, of which 220 million are in Africa alone (WHO, 2022). To address these issues, we first need to understand how interconnected humans are with the schistosome parasite. Thus, the next chapter explores the history of humans and schistosomiasis and maps out the network that not only keeps the lifecycle of the parasite going but also allows it to flourish in a world moulded for them. Furthermore, it brings into question, if schistosomes are the monsters, then what are we for creating and feeding them?

A Monstrous Lover's Embrace

Can you remember how often you got into contact with a body of freshwater? How often had you thought twice before entering? I can remember, dozing off in a small blown up raft with my father when I was two years old, as it floated down a stream next to sugar cane fields in Eswatini. Getting a brain-freeze from drinking straight out of a half frozen stream in the Drakensberg when I was four. I lost count how many times we spent weekends swimming in Lake Malawi between the ages of eight and sixteen. At University, one committee I was a part of had an informal team building session, which was a trip to Idasvallei Dam. At the time, I think we believed we were swimming there illegally, and my brother also said he had done it and thought it was illegal too. We both also remember taking a dip in Coetzenburg Dam after a long day of lectures. More recently, I swam in Zinkwazi lagoon in KZN last year, while I was doing research on the prevalence of schistosomiasis in South Africa. My mother would 'have a heart attack' if she knew. For many people, my mother's reaction would be deemed irrational, and to be honest, after some deliberation between my own irrational fear of stagnant bodies of water and "FOMO" (the fear of missing out with my friends), I decided to take the risk. Besides, swimming in Coetzenburg dam was on the bucket list in our diaries for Stellenbosch students to complete before graduating. All of these memories I mentioned are in countries that are classified as requiring schistosomiasis interventions and three of which are ranked within the top twenty of the worst affected countries with schistosomiasis in the world by WHO (WHO, 2022).

There is no doubt that schistosomiasis has become a ravenous monster that has sunk its hooked talons deep within us, reaping horrors within our bodies. Yet how has something so miniscule managed to become the second largest tropical killer in the world? To answer this, we can look at Tsing et al.'s example of jellyfish again. They state, "if jellyfish are monsters, it is because of their entanglements with us. Jellies become bullies through modern human shipping, overfishing, pollution and global warming. In all our heedless entanglements with more-than-human life, we humans too are monsters" (Tsing, et al., 2017:M1). We need to understand the broad picture of schistosomiasis's impact on the world; more specifically Sub-Saharan Africa, and the interconnectedness of the environments, the snails, the mammal hosts and human development across the ages. This chapter will map the relationships that perpetuate and even spread the occurrence of schistosomiasis. It argues that this is a manufactured disease and we, as humans, are the creators. Once again, we are Dr

Frankenstein and schistosomiasis is our monster and we have and continue to cultivate the perfect home for it.

There have been many papers written on the disease, mostly from a quantitative approach and focussing on a specific factor of schistosomiasis, usually in a specific region (Appleton & Miranda, 2015; Maphumulo et al., 2020; Sokolow et al., 2015). The research often takes a micro-perspective, focussing on one aspect of the disease, such as the prevalence of the disease (Chitsulo et al., 2000; di Bella et al., 2018), the effectiveness of the treatment (Berge et al., 2011; Grimes et al., 2014; Lothe et al., 2018) or the population control of the snails (Adekiya et al., 2020; de Kock & Wolmarans, 2005). ANT, on the other hand, allows the researcher to broaden their focus to the relationships that sustain the bigger event; all the actors (human, other-than-human, material, social, conceptual, etc) that work together to allow schistosomiasis to thrive in the tropics. As Elder-Vass states, ANT "insist[s] on seeing each event as the outcome of a convergence of multiple interacting influences including those of material objects, all to be taken equally seriously by the investigator" (2015:101). Thus, the snail is just as important as the treatment; the government's policies on the distribution of praziquantel is just as relevant as the history of colonialism in Southern Africa; the parasite is just as valid as the person who lives with it.

Thus, this perspective allows us to explore the bigger picture of the spread and impact of the disease, and alternatively, what impacts the spread and condition of the disease, which can be used to explore other initiatives. Brown and Kelly highlight this in the following paragraph:

> "For ecologists, the interpenetration of human and animal bodies is obvious. However, when the social dimensions of transmission become the focus of study, the nonhuman forms of agency involved in pathogen exchange disappear. Understanding animals as co-participants rather than as vessels of disease could go a long way toward re-perceiving the varied encounters that lead to transmission" (Brown & Kelly, 2014:7)."

What ANT provides is the "attack on dualistic understandings of the social versus the 'natural' world, its insistence that other-than-human actors make a contribution to outcomes that are traditionally treated as social, and its demand that we do invoke the 'social'" (Elder-Vass, 2015:102). This means 'social interactions' or 'relationships' between humans, non-humans and materials can, and should, be just as relevant in the discussion of schistosomiasis.

That being said, the critique of this perspective is of losing the voice of the individual that (in this case) suffered from living with this disease. The parasite, as a living entity, is what these relationships sustain and a desire to write from its perspective takes away from the suffering the parasite causes to the people who lived, still live, or died from it. Similarly, the multispecies perspective that gives voice to the parasite may negate the seriousness and devastating crisis of schistosomiasis in the world. The parasite has created a poverty trap that does not give people the energy to sustain or improve their socio-economic status; children cannot concentrate in school and experience stunted growth; people unknowingly live with this disease for most of their life and the government policies do not support them. Thus, my use of ANT is done only as an attempt to highlight all the relationships and interactions of the different actors that specifically lead to the perpetuation of the disease in Southern Africa.

Our history

Schistosomiasis has long been considered an 'ancient' or 'old' disease by scientists, historians and even people I have spoken to. Their interpretation of those terms may differ in length of time or perceived threat, but the consensus is, people have been talking about this disease for (literal) ages. di Bella et al., outline the history of humans and schistosomiasis in their paper, which identifies the oldest confirmed presence of schistosome eggs in a human body was "found in the area of Tell Zeidan, an early settlement of farmers in northern Syria (5800–4000 years before Christ [BC])" (2018:269). Nevertheless, the origin of schistosomiasis is still considered to be the Great Lakes of Africa, namely Lake Victoria, Lake Tanganyika, and Lake Malawi (di Bella et al., 2018:269). These three large lakes of the Great Lakes border ten countries: Burundi, Ethiopia, Kenya, the Democratic Republic of Congo, Rwanda, Uganda, Mozambique, Zambia, Tanzania, and Malawi, but they drain through four major rivers; the Nile, Congo River, Zambezi and Shire River. Historians do not attribute the rivers with the spread of the parasite to Egypt. Instead, it is generally believed that bilharzia was introduced to Egypt through slave trade and even through the trade of monkeys, estimated to have been in 2494-2345 BC (di Bella et al., 2018:269). Subsequently, there is a hypothesis that schistosomiasis then spread from Egypt to Mesopotamia, from the discovery of *Bulinus* snails in the mud bricks of palaces and walls, which led to the proposition that the Biblical 'curse' of Jericho was in fact a severe infection of schistosomiasis (di Bella et al., 2018:270). In later years, evidence of schistosomiasis was noted in French troops who were stationed in Egypt in 1798, and in 1902 an Englishman who

had lived in the Caribbean had schistosomiasis in his intestines, which indicated *S. mansoni* was in the Americas (di Bella et al., 2018:271). Like in Egypt, it is postulated that schistosomiasis was introduced to the Americas through slave trade (di Bella et al., 2018:271).

Thus, schistosomiasis's history with the movement of water, and the people who inevitably follow it, is demonstrated in how the parasite moved across Africa. In consequence, the spread of schistosomiasis across the tropics was made inevitable with the conquering, colonizing and trade of humans across continents. All that was needed was the right snails (of which there are many species found in abundance in different water sources) and mammals that consistently revisit this water site. As di Bella et al. eloquently state, "water and life have always been interconnected, therefore, it does not sound strange that schistosomiasis have accompanied the history of ancient civilisations over the millennia" (di Bella, 2018:269). In conjuncture, Bonds et al. demonstrate the interconnectedness of humans, economy and schistosomiasis with the statement:

> "Large-scale economic processes are coupled to nonlinear, potentially erratic biological phenomena. Indeed, infectious diseases are not only the leading killers of the poor (World Health Organization, 2004), but have been argued to be the dominant predators of humans throughout history and thus have constituted an important selective force on human evolution (2010: 1185)."

Furthermore, Bonds et al. (2010) hypothesised that not only was there a causal relationship between health and poverty, the relationship also worked in reverse. This means, in the context of schistosomiasis, not only does the disease decrease how much work someone can do, thus decreasing their income, people living with a lower income, in rural areas where access to clean freshwater is scarce, increases the probability of contracting the disease. This is what Bonds et al (2010) describe as the 'poverty trap.' However, when considering that there is a second host for the parasite's life cycle, the "entanglement" between the environment, the snail, the mammal and the parasite becomes more complex.

Our interconnectedness

What conditions allow for the proliferation of schistosomiasis in Sub-Saharan Africa? As mentioned before, schistosomes are particularly interesting parasites because they need two

hosts in their lifecycle and they undergo two different forms of reproduction in each. So what does a schistosome need to survive? Firstly, they need water, specifically freshwater sources that also happen to be populated by a specific species of aquatic snails. However, each species of schistosome needs a particular species of snail. Adekiya et al. identify four genera of snails that "serve as intermediate hosts for the parasite which include *Bulinus*, *Biomphalaria*, *Tricula*, and *Oncomelania*," which have been subdivided into two according to their habitats (2019:4). *Bulinus* and *Biomphalaria* are mostly aquatic but have been known to survive for short periods of time outside of water and *Oncomelania* and *Tricula* snails can survive in and out of water . The *Bulinus* and *Biomphalaria* are the two genera of snails that transmit the two most common species of schistosomes in Sub-Saharan Africa. *S. haematobium* is one of the "nine species of Schistosoma transmitted by *Bulinus*, three that infect humans and six that infect Bovids or rodents" and Biomphalaria transmits *S. mansoni* (Adekiya et al., 2019:4).

In the schistosome's lifecycle, the eggs hatch when they make contact with freshwater and immediately search for a snail host, in which the worms will mature and asexually reproduce (Nelwan, 2021:6). At this point, the juvenile worms are called cercariae and once they reach sexual maturity they will leave the snail in search of their secondary host, the mammal. According to Nelwan, "snails can shed hundreds of cercariae daily: about 200 for *S. haematobium*, 15 to 160 for *S. japonicum*, and 250 to 600 for *S. mansoni*" (2021:6).

In the same way that the schistosomes need a particular species of snail, they also need a specific species of mammal to cross their path in order to survive. Schistosomiasis and humans have a long standing history of migration together. Not only do humans act as a vessel for the parasites, humans also move other animals, such as rodents, monkeys and bovines, who are also hosts to schistosomes. Initial research into schistosomiasis revealed that human schistosomes cannot be carried by other mammals, however, research into *S. japonicum* in China detected "that more than 40 mammal species can act as reservoir hosts" (Wu et al., 2007:80). This means that schistosomes can infect bovines (for example) and travel to other water sources, in which the eggs will be transferred through urine or faeces into the new water source, infect the snails there and after maturing, could infect a different species of mammal (such as humans). More recently, research in Malawi has uncovered mutations in *S. haematobium*, as Webster et al. explain, "our genetic analysis demonstrated the presence of *S. haematobium* group hybrids in Malawi as introgressed (a transfer of genetic material from one species into the gene pool of another) forms of *S.*

haematobium–mattheei and *S. haematobium–bovis*" (2019:1247). They continue by stating, the "detection of these 2 hybrid schistosomes strongly suggests interactions of *S. haematobium* with the ungulate schistosomes *S. mattheei* and *S. bovis*" (Webster et al., 2019: 1247). Alarmingly, *S. bovis* has not been detected in Malawi before this, which implies urogenital schistosomiasis is caused by multiple schistosomes and could also be transmitted through other mammals (such as livestock) (Webster et al., 2019).

In conjunction with the movement of people and animals, humans have attempted to master nature for years and their development of water irrigation, dams, and overfishing have all contributed to the prevalence and spread of this disease. In terms of physical environments, the distribution of the snails in freshwater and the presence of mammals around the freshwater site, determine where schistosomes will thrive. Furthermore, de Kock and Wolmarans' research indicate "that temperature and type of water-body seemed to be some of the major factors determining the distribution of this group in South Africa" (2005:117). Thus, the distribution of the snails could be used to determine in which regions there might be schistosomiasis infections among the populations. In their study, de Kock and Wolmarans investigated the distribution of *Bulinus africanus* and *Bulinus globosus* across South Africa and the optimal environmental factors for each. They sampled multiple different types of water bodies, including: channels, concrete dams, dams, ditches, irrigation furrows, pans, ponds, quarries, rivers, springs, streams, swamps, wetlands and pools (de Kock & Wolmarans, 2005:119).

Shockingly, they determined that the *Bulinus africanus* could potentially inhabit most freshwater bodies. Furthermore, in times of high rainfall, runoff water creates more spaces for breeding snail hosts and in turn, promotes contact between the snails and the parasites (Adekiya et al., 2019). However, Adekiya et al. (2019) do note that too much movement of water can disturb the habitats of the snails resulting in a decreased probability of schistosomes surviving. Similarly, they discovered that during flooding, "a huge number of people encounter contaminated water resulting in infection with the schistosome parasite" and "it was observed that the habitats of snails present during the years when flooding occurred were 2.6–2.7 times larger than in those years when water levels were normal." (Adekiya et al., 2019:7). In addition, in areas in which the snails or schistosomiasis were eradicated, snails and schistosomiasis reappeared due to floods (Adekiya et al., 2019). Lastly, in terms of the salinity of the water source, "a decline in cercariae production occurs as salinity concentration reduces. Moreover, the overall impact of high salinity has been

associated and is more favourable towards schistosome parasites rather than their intermediate snail hosts" (Adekiya et al., 2019:9).

However, what is also important to note about schistosomiasis is how it can spread through water-based development and migration (both of humans and animals) (Nelwan, 2019). This is corroborated by Reich et al., who state: "the spread of schistosomiasis is often associated with water resource development projects (dams and irrigation schemes) that create new habitats for the snail vectors through ecosystem changes and alter human behaviour and settlement patterns in ways that increase exposure to the parasite" (1998:13). What is not mentioned above is how the resource development projects and the spread of human industries, like fishing, in these areas have unwittingly affected other animal species that served as predators to the hosts of the parasites. A befitting example of this is both the Diama Dam and Lake Malawi. The Diama Dam in Senegal was built in 1986 and shortly afterwards "an unprecedented, massive, and persistent schistosomiasis epidemic swept through the villages along the river and its tributaries" (Solokow et al., 2015:9650). It was determined this was a result of the construction of the dam, which cut off the flow of saltwater, lowering the salinity of the freshwater, which made the dam more hospitable for the algae and vegetation and in consequence, more hospitable for the snails. More importantly, the dam impeded the migration of river prawn from the saltwater into the freshwater river to reproduce, and in doing so, eliminated the primary predator of the snail (Sokolow et al., 2017). It was later used as a case study to determine whether the reintroduction of the natural predator of the snail, would reduce the number of schistosomiasis infections in the surrounding area, and saw an 80% drop in schistosomiasis infections in the snails (Solokow et al., 2015).

In the case of Malawi, my participant Coen (who was born and raised in Malawi) detailed his understanding, experience and history of schistosomiasis at the Lake:

> "You know the occurrence of bilharzia is only something that started in the early 90s in Malawi or in Lake Malawi. So before that, when I was a child, we never had bilharzia and we always used to swim for hours and hours at The Lake. So, the reason why it occurred is because the natural predators of the co-host, which is a snail, was being fished out. So the snails began to flourish, and were prolific. And as a result, the bilharzia was finding its way into that part of the cycle and that's how The Lake became infested. If we could get the fish back- which we are trying in front of our

> cottages at The Lake, we're trying to not allow people in front of our cottage to fish, and we're seeing a reduction in the numbers. But, the biggest problem we have now is that you've got the pathogen, or the parasite, in the population; it's endemic in the population. So if you are to stop it, you will have to mass-treat and you'll have to mass-treat a number of times. So, everybody gets the treatment, and everyone is encouraged not to urinate and not to defecate in The Lake and then you do a treatment again, six weeks later. And then, six weeks after that. And by that time, you should have eradicated it out of that population. And if you do that together with trying to eradicate the co-host, then eventually you'll get rid of it."

Although, according to Stauffer et al. (2007), schistosomiasis was widespread in Malawi since the 1920s, it was only in the 80s that they discovered it to be in the open waters of The Lake. In my conversation with Coen, I followed this remark with a question about the success of a programme that we knew was being conducted at Lake Malawi to eradicate bilharzia, to which he responded:

> "So there was a programme at Cape Maclear, which was funded by the Danish government and they did a number of mass treatments. But then they didn't follow it through and there wasn't enough effort to break the rest of the cycle- so getting rid of the snail."

The programme was conducted by the Danish Bilharziasis Laboratory, which was later changed to DBL- Institute of Health and Development (Olsen et al., 2013), with the purpose of "advising and training local researchers and health workers" (Olsen et al., 2013:64). They also were instrumental in identifying the predator of the snail. As Olsen et al. state, "while several cichlid species living in this habitat are known to feed on snails (molluscivorous), the fish density has declined" (2013:64). However, Stauffer et al. alert us to the fact that Lake Malawi is still under researched. They state:

> "A comprehensive understanding of any ecosystem requires a basic knowledge of the species that occur within such a system. In Lake Malawi, more than two thirds of the cichlid species are undescribed, the taxonomy of the *Bulinus* snails is poorly known, and the strains of *S. haematobium* have not all been identified (Stauffer et al., 2007:1143)."

Furthermore, they pose, “if, in fact, the increased prevalence of schistosomiasis in Chembe Village [at Lake Malawi] is directly linked to overfishing, this is the first example of overharvesting leading directly to the spread of a human disease” (Stauffer et al., 2007:1143).

Another factor contributing to the situation in South Africa is the lack of control programmes to prevent the spread of the disease. In 2010, the WHO recommended the regular mass treatment of at least 75% school-aged children in schistosomiasis endemic areas (Maphumulo et al., 2020:2). At the moment, there are only two treatments for schistosomiasis (both *S. haematobium* and *S. mansoni*) available in South Africa, Biltricide from Bayers and Cysticide from Merck. This is due to a restriction of generic praziquantel by the South African government. WHO and other donors have a programme that provides countries with praziquantel at low cost or even for free, however in South Africa, it still costs over “50 times higher than the WHO standard treatment used in the rest of Africa” (Berge et al., 2011:23). Thus, it cannot be feasibly distributed to high-risk populations. In addition to the lack of medication, “mass treatment campaigns in South Africa have the disadvantage that tablets must be distributed by health professionals” (Randjelovic et al., 2015:60), unlike other countries that tap into the trust between students and schools, thus allowing teachers to distribute the tablets. There was a mass treatment programme run in schools in the Ugu District of KZN that only reached 44% of the learners, rather than the WHO target of 75% (Randjelovic et al., 2015). So why did they fail to reach a majority of learners? This could be attributed to the stigmas and misconceptions of the disease. Firstly, unsigned or unreturned consent forms posed the largest obstacle to the mass treatment programme, which could be attributed to distrust, stigma, lack of comprehension or illiteracy (Randjelovic et al., 2015). Similarly, a distrust of unfamiliar medical practitioners also caused absenteeism on days of mass treatment (Randjelovic et al., 2015). Some students also believed schistosomiasis to be a female specific disease or that it is self-healing (Randjelovic et al., 2015).

Other prevention programmes include snail control through pesticides and biological control. Bayluscide and other molluscicides developed to kill the snails were only successful in “geographically isolated areas like oases, that is, places where water was not flowing from a non-treated site to a treated site, and where the administration of the pesticide was in the hands of one local or national government” (Reich et al., 1998:16). Thus, it was determined to be less effective and less feasible than praziquantel, as Olsen et al. state, “with the appearance of praziquantel, emphasis was moved to treatment of infected people and snail control became almost neglected by many control programmes” (2013:64). Biological

control, on the other hand, has become more researched in recent years. It involves the use of predators of the snails, such as Trematocranusplacodon fishes (e.g., tilapia), Cairinamaschata (e.g., muscovy ducks) (Adekiya et al., 2019) and the river prawns (Solokow et al., 2015). Lastly, another form of snail control researched is the genetic control in which the genes of the snail is modified to become resistant to schistosome infections (Adekiya et al., 2019:13).

All these programmes have seen various levels of success, however, as Adekiya et al. point out, they are all "time-consuming and require huge financial resources to be implemented" (2019:13). Moreover, "these control measures are unable to prevent total eradication and reinfection with the disease, hence the need for an alternative control strategy" (Adekiya et al., 2019:13). To fully understand the interconnectedness and complexity of the schistosome network, consider the scenario below:

Medical practitioners cannot keep treating bilharzia if the people will get reinfected; they cannot prevent people from becoming reinfected without providing knowledge of how reinfection occurs; they cannot provide knowledge if there is no alternative to their water source; they cannot provide new water sources without infrastructure; building dams cut off predators of the snails; more snails, more bilharzia.

This demonstrates only a fraction of the network in which bilharzia flourishes. Humans' influence over our environments has not only created the perfect home for our monsters but we only continue to do so with the spread of the tropics as climate change warms the waters and overfishing removes predators. This chapter demonstrates how complicated prevention programmes need to be to have a sustainable impact, thus we need to pay attention to the larger network of assemblages, encounters and ecologies of care (or lack-thereof) that cultivate this environment. We are not easily separated from our monstrous lovers.

Monstres Sacrés

> "My affinity to The Lake far outweighs my aversion to the disease. If you were hoping for a better, smarter, more informed decision or choice… no. I would go to The Lake in a heartbeat."

This quote from my brother demonstrates how privilege allows him to be blasé about this monstrous disease that kills thousands of people a year and negatively affects the livelihoods of millions. Why then can he afford to be so blasé even though he struggled first hand to get rid of his parasites? This chapter will scrutinize the social structures that allow for such a disparity in different people's experiences of a disease.

My participants and I come from vastly different backgrounds to those most at risk of contracting schistosomiasis. We had full access to information about the disease, easy access to technology that allowed for the diagnosis and treatment of it and the security of knowing we could choose whether to be infected again or not. Even if people living in high risk areas are aware of the presence of schistosomes in their water, they may not have the luxury of choosing whether or not to enter or use the infected water. It is often the only source of water for drinking, fishing, cooking, bathing or cleaning. Similarly, once infected, the nearest clinic could be too far away from rural communities and often are overburdened and lack the technology for testing. In addition, praziquantel is a heavily controlled drug and expensive, which means free health clinics might not have enough stock to treat a whole community. Lastly, if this community is treated for schistosomiasis, the moment they return to the infected water, they are at risk of contracting schistosomiasis all over again. This hypothetical, only covers a few of the social, political and environmental structures that preserve this cycle of violence.

This chapter will focus on the structural violence embedded in the human's construction of the world that has real effects, not only on the people living in high risk areas, but also on the environment and non-human actors in this network. The social structures that perpetuate the continual infection and spread of schistosomiasis are not only neglectful but violent. It is undeniably a death sentence for many. This not only applies to the people who live in areas with a high risk of schistosomiasis infection, but also to the decisions made to uphold the monster network. As Farmer divulges, "structural violence is violence exerted systematically—that is, indirectly—by everyone who belongs to a certain social order: hence the discomfort these ideas provoke in a moral economy still geared to pinning praise or blame

on individual actors" (2004:307). Schistosomiasis is not a problem for individuals, it is by its nature a collective. It needs other beings to survive (at least two different species of hosts), one in a mammal, it is 'permanently intertwined' with a mate and lays thousands of eggs. This is a monster that our lack of control over is draining communities and resources. Farmer expands on the concept of structural violence by declaring, "structural violence is intended to inform the study of the social machinery of oppression" (2004:307). The structures in place that continue this network are supporting a system of oppression.

All this leads to the schistosomes becoming 'monstres sacrés.' According to the Collins dictionary, the direct translation of this French term is "sacred monsters" or "holy monsters" (Collins, 2022). It was used in France in literature, plays and cinema to refer to "someone of great renown" (Landmann, 2013:134), however, adopted a negative connotation once it was assumed by the English language. Now, it refers to "a venerable or popular public figure who is considered above criticism or attack despite eccentricity, controversy, etc." (Collins, 2022). Here, it is used to illustrate how schistosomes (and their disease) has become a sacred monster that cannot be touched, and although we might criticise it and the handling of it, there are man-made structures in place that are protecting its hold on humanity.

Attention

An absence of attention can be another form of silence. It also highlights the lack of care given to these communities and the schistosomiasis network. This section looks at why attention is an essential part of healthcare interventions and the significance of a neglected or ignored disease. As Wildman and Davis assert, "What we do not talk about, maintains the status quo" (1994:885). People do not talk about schistosomiasis like they might HIV/Aids or Tuberculosis. In my experience, when people do recognise it, they call it an 'old' disease or 'poor' disease. It needs to be mentioned that most of these people do not live near high risk areas and like my participants, can afford to act like the treatment for life threatening disease is a chore to get over with every few months. However, what I question is how much do the people living in these high risk areas know about schistosomiasis and are their voices being heard?

As mentioned many times throughout this dissertation, in the context of healthcare impact, schistosomiasis is the second most important tropical disease, second only to malaria. Why is it then that schistosomiasis is not on every person living in the tropics' radar? According to

my mother, I was not the only one in the family who did not initially understand what bilharzia was or how serious it could be:

> "Most people don't know about bilharzia, and there are even people who were in areas with bilharzia that don't even know that there is such a thing. So I have spoken to some people about it and then afterwards they went for a bilharzia test and they find out that they actually do have bilharzia. So yes, it should definitely be more talked about, so that people are aware of it— because we went, for example, to Malawi without having known that there was such a thing as bilharzia. By the time we found out, we already had bilharzia."
>
> "So [the company] never told you about it?"
>
> "No, no, no. No. They didn't say, 'listen here, be careful you'll get bilharzia if you go to The Lake.'"
>
> "And malaria? You probably knew about malaria?"
>
> "Yes, we knew about malaria. Yes. Yes, yes, definitely. Everyone tells you about malaria and what the rules are for malaria. But… So what we must also remember is that The Lake is a luxury that [the company] doesn't have to offer us. So the fact that we could go to The Lake on weekends, doesn't mean that [the company] said, 'Listen, there is The Lake and you must use it and you don't have a choice.' It was a luxury that we were just lucky enough to have. So it's not really [the company's] fault that we got bilharzia. It's entirely our fault that we got it, because there isn't bilharzia in the areas where [the company is based]."

Although my father disputes our ignorance by stating, "no, from Day One people warned us and told us, 'listen here, be careful of bilharzia and you should just get pills, Biltricide.'" However, he also noticed that malaria seemed to have more radio time than bilharzia in Malawi, so much so he believed it was masking the actual prevalence of bilharzia in the country and, more specifically, among his colleagues and their families living near the company-sponsored clinics.

> "That clinic, there in Cape Maclear, put more effort into malaria and we [the company] also always supported them with malaria. You see… I think that is the big problem why bilharzia isn't diagnosed correctly. If people have any symptoms, in Malawi, it doesn't matter— it's like, the other day, [one of my father's colleagues in

> Malawi] says, ‘no, he doesn’t feel well today.’ Then he says, he thinks he has malaria. It’s the first thing they say. They are so aware of malaria and any symptom— they think it's malaria, then they’ll get treated for malaria and that’s how they get diagnosed. I know… there are many of them that misdiagnosed bilharzia. If someone comes in and they have bilharzia, and he doesn’t feel well and he’s tired, then they say, ‘No. Malaria. Here’s your malaria pills.’ I don’t know, maybe the malaria pills make you feel better when you have a headache or a fever. And I think because malaria is such a big problem in Malawi— I think it’s like our company, as well. It’s HIV/aids and malaria. Those two things are where we spend lots of money, put a lot of effort into and I think we have some of the best programmes in Africa to manage those two in all the countries in which we operate. But no one talks about bilharzia. There are no statistics… I remember we used to monitor how many hospital visits we have a month and then they show how many have HIV and how many are malaria and other cases, and so on. But bilharzia was never mentioned; never singled out as an issue.”

Death and suffering is uncomfortable to think about. Pair it with poverty and appalling access to clean resources and you have silence. Tronto (1998) delved into questions relating to care and vulnerability. She argues, “embracing care as a part of human life, recognizing its role in creating interconnections and relationships of receiving and giving over a lifetime, may provide us with a way to rethink some of the ways in which we now seem unable to cope with human vulnerability” (Tronto, 1998:19). This advocates for small, continuous and ‘caring’ steps towards change. Who needs to be making these steps? Maybe all of us. The Bright research group in KZN have run their health care interventions and research in high risk communities. They have worked with doctors, local clinics and the community. However, they cannot bring lasting support without less expensive medication or better water and sanitation infrastructure. Who is lobbying on their behalf? What about the rest of South Africa or Sub-Saharan Africa?

However, what is also crucial to note here is the role misinformation can play in healthcare and attention. Ciu et al. summarise the effects in their study on detecting healthcare misinformation by attesting, a “community’s trust and support for public health agencies is undermined” (2020:492), which could result in people not seeking help from doctors or distrusting medication. Secondly, “health rumors that circulate on social media could directly threaten public health” (Ciu et al., 2020:492). Information technology has a large role to play

in my family and my own experiences with schistosomiasis, however it can have the adverse effect of spreading misinformation.

Access to knowledge and infrastructure

The WHO has been running a multifaceted deworming programme across the globe to eradicate schistosomiasis as a health problem by 2030 (WHO, 2022). The programme uses mass drug treatment and education concurrently to help prevent reinfections (WHO, 2022). However, what needs to be considered when discussing access to knowledge is the complexities behind disseminating information and effecting behaviour change. Although they use educational programmes such as WASH, which is an acronym for safe-drinking water, sanitation and hygiene (WHO, 2022), this information needs to reach a large population, in rural areas, in a language they comprehend and the behaviour change needs to be sustained. In conjunction, as Manderson (1998) mentions, "the interventions require substantial financial investment for water and sanitation infrastructure, and major health education campaigns" (1998:1022). However, it is still more complex, in vulnerable communities, access to clean water and infrastructure is often questionable.

When discussing health in the context of Africa, a huge factor to consider is access to clean water. A well-researched aspect of schistosome literature focuses on water sanitation as a method of control to run alongside mass chemotherapy. In a study analysing the relationship between access to clean water, sanitation, good hygiene and schistosomiasis, Grimes et al. determined that safe water supplies resulted in significantly less infections with *S. haematobium*, *S. mansoni* and *S. japonicum* and sanitation reduced *S. haematobium* and *S. mansoni* (2014:8). Remember, WHO estimated the number of individuals in South Africa requiring preventive chemotherapy for schistosomiasis annually was 4,628,843, and in Malawi, it was 9,097,490 (WHO, 2022). In 2020, South Africa is estimated to have 59,308,690 people and Malawi is estimated to have 19,129,952 people (Worldometers.info, 2022). Thus, South Africa could have roughly 9% of its population infected with bilharzia and 48% of Malawi's population is estimated to be in need of praziquantel. Similarly, Lothe, et al., state, "in South Africa it has been estimated that 4.5 million people are infected with *S. haematobium* and there are some foci of *S. mansoni*, the majority of who live in KZN, Eastern Cape, Limpopo, Gauteng, and Mpumalanga Provinces" (2018:2).

Water scarcity, sanitation and inequality are major issues in Southern Africa. The majority of populations in Malawi and South Africa rely on untreated freshwater sources, like The Lake and rivers. Harshfield et al. (2009) reveal in their case study of water sanitation in Limpopo, South Africa, that the residents relied on piped water from the mountains, which when sampled tested positive for E. coli, salmonella, bilharzia and other water-borne diseases, even though the municipality provided taps. This is because the municipality only distributed water in these taps "infrequently, sometimes only once or twice a month, thus failing to provide an adequate supply of potable water" (Harshfield et al., 2009:2). Interestingly, Grimes et al. also discovered an absence of toilet facilities resulted in a lower chance of *S. mansoni* infections (2014:9). This may seem surprising at first but when considered in conjunction with sewage infrastructure the correlation becomes more clear. As Herbig highlights in his paper on waste mismanagement in South Africa, it was estimated in 2015 that 80% of South Africa's fresh water resources are polluted beyond purification for consumption (2019:1). Similarly, he reveals that only 60 of the 824 sewage treatment plants in South Africa, release clean water (Herbig, 2019:1).

South Africa's National Water Act 36 of 1998 stipulates its purpose is:

> "[T]o ensure that the nation's water resources are protected, used, developed, conserved, managed and controlled in ways which take into account amongst other factors - (a) meeting the basic human needs of present and future generations; (b) promoting equitable access to water; (c) redressing the results of past racial and gender discrimination; (d) promoting the efficient, sustainable and beneficial use of water in the public interest; (e) facilitating social and economic development; (f) providing for growing demand for water use; (g) protecting aquatic and associated ecosystems and their biological diversity; (h) reducing and preventing pollution and degradation of water resources; (i) meeting international obligations; (j) promoting dam safety; (k) managing floods and droughts (1998: chap 1)."

The reality is there is no governing body ensuring the compliance of municipalities with the Act. Herbig outlines this dilemma in the following quote:

> "The principles of cooperative government discourage litigation between and among government departments and spheres of government, with the repercussion that neither national nor provincial governments have the political will to take municipalities to task where they fail to deliver water services (2019:14)."

In fact, Herbig (2019) considers the government's mismanagement of water waste a "conservation crime," meaning "any intentional or negligent human activity or manipulation that impacts negatively on the earth's biotic and/or abiotic natural resources, resulting in immediately noticeable or indiscernible (only noticeable over time) natural resource trauma of any magnitude" (Herbig & Joubert, 2006:96). To state this simply, the neglect of water sanitation and resource management will affect the balance in the ecosystem, whether it is living organisms or non-living factors that affect living organisms (such as shade, sunlight, etc.) over time, creating larger and lasting damage. Thus, the neglect of high risk communities means schistosomiasis spreads with the movement of people, the reliance on neglected water sources allows for the continuation of the schistosome's life cycle and any destruction of the ecosystem (such as overfishing) will reduce the natural population control for the worms, allowing them to reproduce exponentially.

Access to technology

We could go into a debate on whether access to technology should be a human right or not but that would be another Master's dissertation on its own. Instead, this section will demonstrate how technology helped in the process of diagnosing me and my participants with schistosomiasis and argue the lack of access to technology is another example of structural violence. Cui et al. discovered in their research on healthcare misinformation, that "patients often browse the Internet looking for information about illnesses and symptoms. For example, nearly 65% of Internet users use the Internet to search for related topics in healthcare" (2020:492). This illustrates the role information technology plays in the lives of people living with illnesses. Here, knowledge and technology go hand-in-hand. Knowing the risk of contracting schistosomiasis in a particular area aids in the use of technology to access more information. Similarly, technology assists in the formal diagnosis done by medical professionals, through testing equipment and treatment.

From what I gathered in my interviews with my family and people who live in Malawi and had bilharzia, there is a consensus that we all contracted bilharzia from Lake Malawi. This is not to say that we could only have contracted it there, it is just what all my participants believe. When I asked my mother if she knew of bilharzia being anywhere else in Malawi she said, "I don't know. I don't know if it's in Dwangwa or Nchalo. Because there's no bilharzia in Blantyre." She seemed certain of that. Then continued, "but the people that I know, who

have had bilharzia, went to The Lake. And our big problem, why we struggled with bilharzia is because we kept going back. Re-infected."

My brother came to the same conclusion as my mother, also noting how his school friends in Malawi spoke about the disease. He told me,

> "If there was, then… it wasn't common knowledge. Ummm… and it's not the kind of thing high school kids talk about or know about. It's also not something that would have been communicated by the doctors. Whenever you went for bilharzia tests or you talked about having it, everyone's first assumption was, 'Oh, did you go to The Lake?' So, no. I don't think I got it from the city, but that's purely because I wouldn't know if there was a risk of contamination from the city."

Though my father came to the same conclusion, he used his own experiences. When I asked my father where in Malawi he thought he was first infected with bilharzia he simply and confidently stated "at The Lake." Straight to the point. I might as well have given him a survey. Luckily, when I prompted him to speculate whether the lake was the only source of bilharzia or if it could have been in our home town, Blantyre, he went into more detail:

> "Yes… yes I think so because I can always remember if we went into the water, when we came out, my ankle always itched. I never knew why. I only later realised it's where those little [worms] entered and that's why your ankles would itch. So, yes. I think it was only at The Lake… let me just think where else we were… I was at places like, Cahora Bassa Dam and I was— when we were in Zambia, at the Lower Zambezi. But I don't believe I got it from there. I think it is all from Lake Malawi."

Another participant, Coen, who has lived in Malawi his whole life, shed a bit more doubt by considering two locations in Malawi as possible sources of bilharzia. Specifically he states, "From The Lake. Lake Malawi and maybe from the canals in Nchalo on the estate." Nchalo is known to many Malawians for its sugar plantations and uses the Shire River, which is sourced from Lake Malawi, for irrigation and the locals use it for their main source of freshwater. When I asked Coen whether he believed that there was bilharzia in his hometown, Lilongwe, he confidently stated "No." Prompting me to quickly stumble on to the next question.

Another obstacle to treatment is misdiagnosing the disease, by professionals, the people living with the disease and other people in their social lives. According to one diagnostic tool,

the Standard Treatment Guidelines and Essential Medicines List for South Africa, produced by the Health Department, acute schistosomiasis syndrome "typically occurs in travellers to endemic areas with freshwater exposure," and people living with chronic schistosomiasis are asymptomatic (2019:2).

Acute schistosomiasis syndrome can be identified by the following symptoms: "fever, rigors/chills , urticaria (hives), angioedema (swelling underneath the skin), myalgias (muscle pain), arthralgias (stiffness), dry cough, diarrhoea, abdominal pain, and headache. Symptoms are usually relatively mild and resolve spontaneously over a period of a few days to a few weeks" (National Department of Health, 2020:10.15). These symptoms are very common and difficult to attribute to schistosomiasis specifically. A common misdiagnosis by health professionals and misconception of this disease is as a sexually transmitted infection (STI). Lothe et al., delved into these misconceptions in their study in the Ugu District in KZN, which revealed that children often hid their diagnosis, if they even went to get tested in the first place, because of their fear of the stigma placed on schistosomiasis (2018: 3). Similarly, an adult woman recounted her experience with a nurse who suggested her schistosomiasis was contracted sexually (Lothe et al., 2018:3). My own experience with a medical practitioner reflected this when my doctor misdiagnosed my urinary tract infections as an STI and explicitly stated that it was common in students and "I should be more careful in the future." These misconceptions are dangerous, because not only is the person living with schistosomiasis not receiving treatment for a deadly disease, but there is a level of shame that is associated with them that prevents them (and others who witness this) from seeking further help, and creates a distrust with medical practitioners.

During our interview, my mother reflected on how she perceives the relationship between people and their doctors. She has fibromyalgia, which took her years with a vast variety of different symptoms and many visits to many doctors and specialists to diagnose. Her observations were:

> "So I have also found that the older generations, and I think it's more widely spread than we might think, over more generations as well, that people see the doctors on a pedestal… and they think doctors are all-knowing and all-seeing. And then they don't want to tell the doctor something minor because it's—they're wasting the doctor's time. and if the doctor says, no, he doesn't think so, then that word is law. So it's almost as if the doctor is a god and they can't upset the god. Or they can't question the

> god. So they won't go to the doctors with minor problems that aren't clear, physical problems. So they won't tell the doctor, 'oh, I'm just permanently tired,' because many of them see tiredness as just… laziness. So they won't admit that they're lazy, according to them. Meanwhile, you're not lazy, you're physically tired, because your body is tired, because your body is busy fighting something. So they see tiredness and laziness as the same thing. So they won't admit it to themselves, then they won't admit it to the doctor. So if they don't actually physically have blood in their urine, they won't tell the doctor, 'listen, I have a problem.'"

When asked about her visits to the doctor and how much she divulges, my mother said that her doctor is "understanding" and she listens to everything my mom mentions when making a diagnosis. Then she continued:

> "But what people don't realise is that if you don't have a sympathetic doctor, then you can go look for a different doctor. You don't have to stay with the impatient doctor that doesn't listen to you. So if you come in repeatedly saying 'I'm tired and it's getting worse,' and the doctor ignores you… or 'I have a pain and the pain won't go away,' and he gives you pills and the pills don't work and you go back and say, 'the pills aren't working,' and he just gives you other pills, and he doesn't try to find the source of the pain, then you need a different doctor. If you repeatedly have bladder infections and the doctor doesn't try to find out what the cause is…other than the general causes then you need a different doctor. Ja. Basically, if you have a doctor that treats the symptoms instead of looking for causes, you need a new doctor. many people just go with the symptoms… they just name the symptoms… and the doctor won't even explain what could be the causes. And the people themselves don't even think of finding the causes, they think the symptoms are the only thing."

The counter argument made recently by a friend, who has a heat rash that keeps returning, and was diagnosed as a flare up of a fungus and treated two years ago, said he is worried about consulting another doctor because he, "spent too much time and too much money on this one already. And it's just a guessing game." So he was afraid the next doctor will have to start from scratch.

Who would have come to the conclusion that a student living in the Western Cape in South Africa would have parasites in her blood? My mother did. After the fourth or fifth urinary tract infection, she did what she does best; she googled "what causes bladder infections?" In

the long lists Google produced she found the word that resonated with us Parrotts, that we are too familiar with: bilharzia. If the medical practitioners had read further into my file they would have seen that I have lived in Malawi, which I know was written in there in my first year at university, and they probably would have made the same connection.

It was only during my holiday, when I returned to Durban, that my mother took me to her General Practitioner who was happy to test for bilharzia. No questions asked. As soon as I was tested and diagnosed with schistosomiasis I was given the correct dosage of praziquantel (the only treatment), which did not kill all the parasites because they only target adult worms. Urine sample tests are the preferred method for testing for schistosomiasis, because antibodies can be detected in the blood for at least two years after treatment (Gryseels et al., 2006:1111). However, the medical practitioners I worked with often tested both. When my blood and urine tests came back positive again I was passed on to the next specialist. By the time I came to a urologist, he refused to believe the tests and insisted on a cystoscopy with retrograde pyelogram. This meant sending a tiny camera up my ureter to record what was going on in my bladder. The photos he took clearly show the clusters of scar tissue and eggs clinging to the ureteral walls. He also excitedly recalled seeing the worms swimming in my bladder. I did not reciprocate his enthusiasm. The urologist was generous enough to give me the photos, which is the only time I regretted having photos to remember a moment.

I must give my mother credit for having known a lot about bilharzia before I started research on it. When I asked why she knows so much detail about the life cycle and effects of bilharzia she said, “mostly through research on the internet,” which she did when my brother initially struggled to get rid of his bilharzia. This demonstrates how access to technology, like the internet, and thus, access to knowledge, helped my family to understand what our symptoms could be an indication of, which in turn helped us inform the medical practitioners of a potential diagnosis they might not have ordinarily considered. Alternatively, people living in rural communities will not have easy access to these resources and if they are diagnosed, the next obstacle is their access to medicine.

Access to medicine

The complexity involved in reducing the infection and reinfection of bilharzia through the dissemination of knowledge and behavioural change emphasises why the diagnosis and treatment or mass treatment in preventative programmes are where researchers and medical

practitioners focus their attention. However, there are still factors preventing these programmes from being implemented or succeeding. This section answers the questions: why is there a lack of access to medicine, who is disproportionately affected and what impact does it have?

Whyte et al.'s (2002) *Social Lives of Medicine* is used as a lens through which praziquantel is explored. The significance and meaning that is placed on the tablet that influences how it is handled and how it moves, as well as the power that the tablet itself possesses through our interactions with it can give another understanding of how the medication contributes to the continued neglect of schistosomiasis. Medicine is a powerful tool and those who control it are even more powerful. This section approaches the crisis that is schistosomiasis in Sub-Saharan Africa through the movement (or in some cases, immobility) of praziquantel and how it reveals the structural violence that allows the parasites to thrive.

As an argument for why medication is a good lens with which to understand humans and human culture, Whyte et al. explain, "they embody anthropological ideas about the power things have over people, and about the power relations between people mediated through objects, about symbolization, about medicalization, and about the process of globalization" (2002:163). Thus, through this lens we can trace the actors and pathways that connect them as praziquantel travels across the world, between people, formally and informally, the power structures and imbalances as the medication is given or blocked and the significance people place on the medication. As Whyte et al. point out, objects do not have social lives in and of themselves, it is through their interaction with people and between people that give them social lives and "these lives are imbued with the practical artfulness and purpose that characterize technology. They are lived in relation to problems and contexts" (2002:14). However, it is also important to remember that medicine is not purely academic and the power medicine has to alleviate pain and suffering, to physically transform the body.

However, typically we attribute this transformation in a positive way; medicine is supposed to cure or prevent diseases. This, as Whyte et al. point out, isn't always the case: "the term for medicine in many African languages refers to harmful, as well as wholesome substances" (Whyte 1988:218) and, similarly, "the old Greek word pharmakon, from which 'pharmaceutical' derives, also meant poison" (Whyte et al., 2002:6). This demonstrates the ambivalence surrounding medicine and their roots and is still relevant today, where medicine

dosage/information sheets state their potential adverse effects. This is what most of my participants focussed on when sharing their experiences with the treatment.

As van der Geest frankly states, pharmaceuticals "are vehicles of ideologies and fashions and are thus convenient means by which globalization runs its course. If industrial goods spread the commodity ethic [...], pharmaceuticals do so par excellence, as they are the commodities most urgently needed and most invasive, especially in countries of the South" (1996:169). Praziquantel, unfortunately, falls squarely in this description. It is a highly controlled drug that is in a very high demand, therefore its value (socially and economically) increases.

According to the WHO, praziquantel was made through collaborative action between two German pharmaceutical manufacturers, Bayer and Merck (Reich et al., 1998:13). Although this collaboration was successful, Reich et al. reveal "the relationship apparently did not include a written agreement on issues of pricing or distribution methods once the product was fully developed and registered" (1998:19). This may explain why the price of the medication is not controlled. According to the International Medical Products Price Guide (last updated in 2015), the lowest price for generic praziquantel was 0.0427 US Dollars per tablet. In comparison, the South Africa Department of Health in 2015 bought praziquantel at 3.1431 US Dollars per tablet (MSH, 2016).

Although there are alternative, generic praziquantel pills, Bayer's Biltricide was the only brand recognised by the Medicines Control Council and National Department of Health that is available in South Africa, until 2019 when Merck's Cysticide was also introduced. As per Reich et al., WHO estimated in 1997 that "South Africa has a need of almost 10 million tablets, placing it 16th among the countries needing praziquantel" (1997:89). They also imply that the supply of praziquantel that is procured is significantly under the demand. Part of the reason for this is suggested to be Bayer's patent, although it expired, "it still holds a trademark registration, and evidently is, to date, the sole supplier to South Africa of praziquantel for treatment of schistosomiasis (although Merck, South Africa, produces a praziquantel-containing drug for treatment of cysticercosis)" (Reich et al., 1997:89). To this day, 25 years later, Biltricide and Cysticide are the only two praziquantel tablets available in South Africa. Reich et al. also reveal that "Bayer supplies praziquantel to the South African government at a tender price, and also supplies the private sector, offering discounts based on the volume of purchases" (1997:89).

The South African Health Products Regulatory Authority (SAHPRA), formerly known as the Medicine Control Council, plays a large role in the lack of generic, and more affordable, praziquantel in South Africa. Where other countries accept WHO-accredited generic praziquantel, South Africa requires any new generic drug to be reviewed by SAHPRA. There have not been other attempts by producers of generic praziquantel to apply through SAHPRA: this is because it is a "time-consuming, expensive, scientifically unnecessary, elaborate registration process" (Berge et al., 2011:24). Bright, a schistosomiasis medical research group that operates in KZN, holds the SAHPRA responsible for the lack of generic praziquantel stating, it requires "medical companies that manufacture generic praziquantel [to] spend money and time going through an elaborate, custom-designed scrutiny process, but WHO has approved the use so this is unnecessary" (Bright, n.d.). For instance, Leng et al. (2016) draw attention to this delay in the registration of drugs by tracing a generic version of linezolid for drug-resistant TB (DR-TB). The application was submitted for fast-track review in May 2013, however, "when a final decision on the product was still outstanding more than 16 months after its submission, activists handed over a letter addressed to the Registrar of Medicines, signed by clinicians, civil society organisations and patients with DR-TB, demanding its immediate registration" (Leng et al., 2016:352). The drug was only registered in November 2014 and a second one in March 2015 (Leng et al., 2016:352). Bright further asserts the absence of cheaper options "from year 2000 to date has left more than 10 million people with chronic problems. South Africa should allow treatment of their susceptible populations" (Bright, n.d.).

The WHO has been running a deworming programme across the globe. The distribution of praziquantel to 'developing countries' happens in three ways. The first is "bulk sales to national governments" (Reich et al., 1998:71) which usually takes form in control programmes like National Deworming Programmes. In the case of South Africa, praziquantel is sold to the government through tendering, which according to the International Medical Products Price Guide (MSH, 2016), is reviewed every two years. The second way is through "sales to bulk suppliers, including agencies, and private and nongovernmental organizations, which then sell to national governments" (Reich et al., 1998:72). UNICEF is considered "the most important bulk supplier of praziquantel to developing countries (other than the major producers Bayer, E Merck, and Shin Poong)" (Reich et al., 1998:74), who in collaboration with WHO have programmes to prevent and control schistosomiasis and soil-transmitted helminthiasis. The World Bank has also supplied funds in the "form of long-term loan at

concessional rates for the purchase of praziquantel" (Reich et al., 1998:76). Malawi is listed by Reich et al. (1998) as one of the countries to have received assistance from the World Bank, including other Sub-Saharan African countries like Kenya, Tanzania and Zambia. The third and last way is through "direct private sector sales, either through subsidiaries, or through licensees, distributors, wholesalers, and retailers" (Reich et al., 1998:72).

Vale et al. state, "the WHO recently reported that less than one-third of individuals who required "preventive chemotherapies" received treatment" (2017:4) and according to Berge et al. (2011), South Africa has not had a mass intervention for schistosomiasis since a pilot programme between 1997 and 2000 in KZN. I spoke to schistosomiasis researchers in KZN in 2019, who confirmed that the government has not had another since.

As Whyte et al. so astutely put it, "commodification can be understood in two different senses: medicines are commodified; and in a larger sense, so is health" (2002:16). To have the luxury of access to medicine is to have power. Whyte et al. investigate the multiple ways medication can imbue power. Firstly, and most obviously, "medicines are substances with powers to transform bodies" (Whyte et al., 2002:5). Medicine is primarily supposed to cure or at least alleviate symptoms. In the context of schistosomiasis, stunted growth in children, chronic pain and fatigue (to just name a few) can be debilitating and thus affect one's ability to concentrate at school or work, or to perform physical labour. As mentioned before, schistosomiasis is a poverty trap, and without medication, this cycle will not be broken. Secondly, Whyte et al. look at the power to transform what is attributed to medicine. They state, "medicinal substances have powers to transform" (Whyte et al., 2002:5). More specifically we, as social actors, ascribe these powers to them. Here, the social and psychological ideas attached to medicine are scrutinised. As Whyte et al. explain, medicines "are supposed to do something, to change the body in a discernible way," (2002:5) otherwise they would not be deemed effective or considered medicine. However, medicine is more than a cure for one's physical health. It can also have a psychological effect, for instance, the concept of risk can also be managed by pharmaceuticals (van der Geest et al., 1996:169).

This is evident in the responses I had from my participants when I asked them if their attitude towards the disease had changed after contracting bilharzia. In my brother's case, I knew this would be a tough question to answer because he has always been an avid water sportsman and loved his time on Lake Malawi, while at the same time having the strongest aversion towards the treatment. He sheepishly responded that he would not hesitate to go back to the

Lake. My father said he had already started making some behavioural changes while we were still living in Malawi, after he began to understand how serious bilharzia is. He gave an anecdote:

> "We would sometimes, late afternoon, take those lawn chairs and put them in the water. I remember with a friend, we would sit with a beer there in the water. We would sit for hours, dead still in the shallow water. And when you got out, I remember feeling my ankles itch. I did it less when I knew what caused it. But, I mean, like windsurfing as well, we were also always in that shallow water and that didn't stop me. I did try to avoid that shallow water more, but I didn't completely avoid it."

Then, when I asked if he would change his behaviour now years after having left Malawi and all of us understanding what the consequences are of living with a bilharzia infection, he responded:

> "Well we did it that whole time and we did know what the symptoms were, and we did know what the results would be and even in Zambia, when we went back [to Malawi]. I think the only thing that we started doing was to avoid the first two or three meters in the water. Where you don't stand still. I know, when we would bring the boat back out, and when we were around the boat, I would never keep my feet still, I kept stomping around and never stood still, so that they would never get a chance."

I laughed at him and asked if it made him feel better. He also laughed at himself and said full of humour, "so that's my prevention. Yes, it made me feel better. So if I go back to The Lake, when I go in and play with the boat, and all those water sports, I won't keep my feet still." After joking further my father then said in all seriousness:

> "The thing is, I know that the Biltricide works. So all that I would do is: at The Lake, I would go in the water and then, when we come back from The Lake, I would just make sure I get the Biltricide and do two programmes of the Biltricide."

Two of the other participants I interviewed had the same reaction as my father. Brent responded with "fairly unconcerned" when I asked what his attitude was after contracting and treating bilharzia.

As my brother demonstrates, the side effects from the Biltricide are so severe for him, that even when he considers what he would do differently if he was reinfected, he is still reluctant

to take them. Knowing that he is very likely still infected and after his doctor urged him to take the treatment. He says:

> "The one thing I would do differently is consider taking the pills, but taking the pills will also require scheduling because, I'm reminded now it's a three times repeat of a week. So I would have to book off three weekends or so. And during a PhD second year, nearing the end stretch… it becomes such a blur of when can I do it guilt free."

What this also illustrates is the power to choose whether the adverse effects of the medication outways the symptoms of the disease in the short-term. It could also be argued that the PhD is also an excuse, as he has finished his studying and still cannot find the time to take the medication. Part of this conversation is how privilege grants access and access grants choice. This is a power that many people living in high risk areas may not have the chance to make. What is crucial to remember here is that even if these communities gain access to praziquantel, if they continue to use the same water sources, they are still at risk of a reinfection. Medication may have the power to cure, but its power will not endure without the implementation of other interventions simultaneously.

Once again, the social, political and economical systems in place uphold the status quo. Who has access to praziquantel? People like me and my participants. People who can afford private health care. Whyte, et al. state "medicines are substances" and therefore, as they elaborate, "as things they can be exchanged between social actors, they objectify meanings, they move from one meaningful setting to another" (Whyte et al., 2002:5). It is important to understand how medicine can acquire power through the meaning or importance that humans as social actors can place on an object. Here, how medicines move between people, the power that is ascribed to the people who control the medication or diagnosis and the places they are found or not found become significant in understanding the power of medicine. Lastly, "they are commodities with economic significance, and resources with political value" (Whyte et al., 2002:5). This last part is particularly important in the context of praziquantel as its power as a resource for economic gains could be the biggest contributor to its prevalence and neglect across the world, but particularly for Sub-Saharan Africa.

The networks surrounding our monsters are not only so entangled in each other, their connections are so strong they are rooted, and these roots are thick and impenetrable, rendering our monsters indestructible. In Chloe Shain's dissertation on microbiologists and their relationship with TB in the laboratory she has a chapter titled: 'This is not a wimpy

bug': wimpy humans, wimpy me (2016:16). Here she investigates the survival of TB remarking, "its ability to survive for millennia makes it a conniving agent that is not wimpy" (2016:17). Schistosomiasis is not just a survivor… it's a thriver. In the same vein, the humans are not wimpy; they are the grand architects, the master creators of these monsters; they are the agents who decide where to release them. Humans have the power. They have the tools and the knowledge to stop these monsters. The power to decide who is 'cured' and who suffers.

Conclusion

Tronto (1998) brings our attention to care's role in creating interconnections and relationships. However, these connections are not solely between humans. Kroijer and Rubow expand on this by saying, "[t]o ecologize our ethics [of care] implies the inclusion of nonhuman beings in the 'we' considered to be acting ethically" (2022:376). Attention needs to be drawn to the relationships between humans and the non-human actors that sustain these monsters. Any intervention needs to consider the impact (direct or indirect) on the environment and other actors. Is it 'care' if it is only given to those that can afford it? Is it 'care' if it means the destruction of a whole ecosystem? I argue it was the lack of care that brought us here.

However, what if the existence of one being can only result in the suffering of another? In the context of schistosomiasis, the parasite cannot survive without both its hosts, but the nature of a parasite is to deplete and inevitably destroy its host. Through a multispecies lens, one cannot separate the life of a parasite without acknowledging the suffering and death it causes. This dissertation analyses what prevention and treatment programmes have been implemented to eradicate schistosomiasis with little success. The network surrounding schistosomiasis is complex and difficult to disentangle without causing larger ecological issues. Who do you support and how do you support them without negatively affecting others? Dulcos and Criado also encountered this dilemma and thus stated, "care might require new approaches to the very idea of sacrifice" (2020:6). This sentence resonates with the current ecologies of care in Sub-Saharan Africa, in which governments and health care systems fail to provide equal access to treatment, knowledge and infrastructure, but it also sheds light on how something needs to be sacrificed in this network. If nothing is done, the hosts (humans and non-humans) die. Any intervention is ultimately designed to eradicate the parasite, however, they often cause the destruction of another species too. Who is deemed more worthy of survival?

To conclude this dissertation, I want to outline the complexity of our monster actor-network once again. Here, I take a note from John Law and break it down into what he defined as the making of a good actor-network. The first is "semiotic relationality," meaning "it's a network whose elements define and shape one another" (Law, 2009:147). As one example of this, the spread of schistosomiasis positively correlated with the movement of their definitive host (humans and other mammals) and the presence of the intermediate host (snails). Conversely,

schistosomiasis impacts the mental, social, physical and economic welfare of its hosts (particularly in terms of humans). The next on his list is "heterogeneity," which refers to the "different kinds of actors" (Law, 2009:147). In this case we have the parasites, the two different hosts they need in their lifecycle, the external human actors that make decisions that impact the relationships between the hosts and parasites (namely; governments, medical professionals, developers). Thirdly, "materiality" (Law, 2009:147) refers to the role material objects have in the network, such as dams and medicine. The next element is the "insistence on process and its precariousness (all elements need to play their part moment by moment or it all comes unstuck)" (Law, 2009:147). Schistosomiasis has a very particular set of conditions it needs for it to continue its life cycle, and from the research I did, the snails similarly have a precarious set of conditions to survive. In addition, specific species of schistosomes need specific species of snails and specific species of mammals to all co-exist in the same water source. Growing up in Malawi, there was a theory that if you removed humans from Lake Malawi for only two weeks (total span of schistosome's life cycle), you could eradicate human schistosomiasis entirely. On the contrary, as mentioned above, schistosomiasis is an ancient disease that has evolved with and conquered human civilisations for millennia; it is "entangled" (physically and metaphorically) in our history and our bodies; it has withstood thousands of attempts to rid of it. Thus, a multispecied, multitargeted approach to the problem is needed.

In continuation, Law specified that there is "attention to power as an effect (it is a function of network configuration and in particular the creation of immutable mobiles)" (2009: 147). To address this, we need to understand what Law meant by the oxymoron "immutable mobile". Law and Singleton describe it as something that moves around but holds its shape, both in terms of physical or geographical shape and "in some relational and possibly functional manner where it may […] be imagined as a more or less stable network of associations" (2004:5). In conjunction, immutable mobile was created as a tool for understanding power that is held over long distances (such as currency or colonial power) and the work that went into moving scientific facts as universally applicable (Law & Singleton, 2004:5). Thus, in the context of the schistosomiasis network, there are plenty examples of power and immutable mobiles, such as schistosomiasis itself that spread across the world, debilitating communities of individuals (physically, and socio-economically), praziquantel as a physical form of Western medicine that is considered the only treatment for schistosomiasis that has the literal power to kill schistosomiasis, yet is strictly controlled by governments and pharmaceutical

companies and colonial powers who have orchestrated the war against tropical diseases and perpetuated its occurrence across the globe through landscaping developments, the trade of humans and animals, and industries contributing to climate change. As described above, this actor-network has a "large-scale political history" (Law, 2009: 147) as it moved and evolved along with the movement and evolution of human bodies (and other mammals and molluscs). It prospered in the time of slave trade across the globe, its contribution to poverty over time is still being researched and its lack of intervention in countries with high poverty is indicative of inequality, it is considered a 'poor person's disease.' Lastly, and what Law considered the most important, is how the network works and how it is held together (2009). I have only dived into some of the many connections that impact and entangle to create the phenomenon of schistosomiasis and if I had to pinpoint what holds it together, it would be our lack of interest (and thus, funding) in a very treatable (and preventable) disease that affects the lower income populations, in conjunction with our blatant disregard for our impact on the environment and multispecies relationships.

The case of schistosomiasis across the globe demonstrates how human intervention has created monsters of microscopic worms. Schistosomiasis has become a monster that lives inside other monsters; with overfishing, human's dominance over nature by rerouting water systems and 'domesticating' animals and plants; we have created a world with "nightmare creatures of a future in which only monsters can survive" (Tsing et al., 2017:M1). Bubrandt and Tsing reiterate that these glimpses of the monsters we have made "brings into focus entanglements between intensive human management and weedy refusals of planners' imagined discipline" (2018:8).

What the multispecies perspective could bring to water resource management and schistosomiasis discourses is a consideration for the greater impact that human actions have on the environment and what effects it might have on the multispecies ecosystems surrounding it. Housten et al., reiterate this by stating:

> "The concept of 'multispecies entanglement' thus takes 'connectivity thinking' further and has significant implications critiquing the conceptual problems of human exceptionalism in planning. It critiques deeply ingrained ideas about the human-centeredness of planning practices in which humans are unquestionably situated as active knowers, decision-makers and place makers (2018: 195)."

With this in mind, a holistic approach to the control in South Africa and other Sub-Saharan countries that consider all the actors in this network is needed. A single approach to the eradication of schistosomiasis has been shown to have temporary effects. Mass treatment is only feasible if generic medication is allowed into the country but does not prevent reinfection. Mass treatment also needs education programmes that may counter stigmas or misconceptions about the disease in both medical practitioners and local populations. Water sanitation programmes only work if there are no schistosomes reintroduced into the water source, therefore it requires educating the local populations on how to prevent the spread of the disease and mass treatment of the same population. Predation programmes will only work if overfishing is controlled and human infrastructure is designed and built with the connectedness of the ecosystem (environmental, human, and non-human) at the forefront of the planning. We created this monster through our acting upon nature and the subsequent neglect of it. If we are to rectify it, more 'care' is needed to prevent the creation of another, larger monster.

Like in Shain's dissertation (2016), I cannot ignore my entanglement in this monster network. I have a shared history and an active role, just like every other actor in this network (whether they are aware of it or not). Haraway's *When Species meet*, she divulges into the concept of "becoming with" multispecies beings and our interconnectedness (2008:25). Humans are never alone, not even in our own body. In the case of schistosomiasis, I did not only share my body with them, I grew up with them, I moved with them, I nurtured them, I have obsessed over them, and now that they are gone, they still shape my being; my paranoia; my education. Furthermore, through my becoming with my monsters, I became entangled with their history and the history of structural violence that created and sustains them. It has made me who I am and it has moulded this dissertation into what it has become. It is because of our shared history that I could not conduct my research in a high risk area.

Reference List

Adams, T.E. & Manning, J. 2015. Autoethnography and family research. *Journal of Family Theory & Review*. 7(4):350-366.

Adekiya, T.A., Aruleba, R.T., Oyinloye, B.E., Okosun, K.O. & Kappo, A.P. 2020. The effect of climate change and the snail-schistosome cycle in transmission and bio-control of schistosomiasis in Sub-Saharan Africa. *International Journal of Environmental Research and Public Health*. 17(1):181.

Allen, K.R. & Piercy, F.P. 2005. Feminist autoethnography. *Research methods in family therapy*. 2: 155-169.

Appleton, C. & Miranda, N. 2015. Locating bilharzia transmission sites in South Africa: guidelines for public health personnel. *Southern African Journal of Infectious Diseases*. 30(3): 78-85.

Basso, K.H. 1970. 'To Give Up on Words': Silence in Western Apache Culture. *Southwestern Journal of Anthropology.* 26(3):213–230.

Bayers (Pty) Ltd. 2021. *Patient Information Leaflet- Biltricide Tablets*. Bayer, Southern Africa.

Berge, S.T., Kabatereine, N., Gundersen, S.G., Taylor, M., Kvalsvig, J.D., Mkhize-Kwitshana, Z., Jinabhai, C. & Kjetland, E.F. 2011. Generic praziquantel in South Africa: the necessity for policy change to provide cheap, safe and effcacious schistosomiasis drugs for the poor, rural population. *Southern African Journal of Epidemiology and Infection*. *26*(1):22-25.

Bernard, H.R., 2005. *Research methods in anthropology: Qualitative and quantitative approaches*.4th ed. Rowman & Littlefield.

Bright. n.d. Bright Academy. Available: https://www.brightresearch.org/ [2022, November, 20].

Brown, H. & Kelly, A.H. 2014 'Material proximities and hotspots : towards an anthropology of viral hemorrhagic fevers. *Medical Anthropology Quarterly*. 28(2): 280-303.

Bonds, M.H., Keenan, D.C., Rohani, P. & Sachs, J.D. 2010. Poverty trap formed by the ecology of infectious diseases. *Proceedings of the Royal Society B: Biological Sciences*. 277(1685): 1185-1192.

Bubandt, N. & Tsing, A. 2018. Feral dynamics of post-industrial ruin: an introduction. *Journal of Ethnobiology*. 38(1): 1-7.

Chitsulo, L., Engels, D., Montresor, A. & Savioli, L. 2000. The global status of schistosomiasis and its control. *Acta tropica*. 77(1): 41-51.

Cui, L., Seo, H., Tabar, M., Ma, F., Wang, S. & Lee, D. 2020. August. Deterrent: Knowledge guided graph attention network for detecting healthcare misinformation. In *Proceedings of the 26th ACM SIGKDD International Conference on Knowledge Discovery & Data Mining*. Virtual Event, California, USA. 492-502.

De Certeau, M. 1984. The practices of everyday life (S.F. Rendall, trans). Berkeley. University of California Press.

De Kock, K.N. & Wolmarans, C.T. 2005. Distribution and habitats of the *Bulinus africanus* species group, snail intermediate hosts of *Schistosoma haematobium* and *S. mattheei* in South Africa. *Water SA*. *31*(1): 117-125.

Di Bella, S., Riccardi, N., Giacobbe, D.R. & Luzzati, R. 2018. History of schistosomiasis (bilharziasis) in humans: from Egyptian medical papyri to molecular biology on mummies. *Pathogens and global health*. 112(5): 268-273.

Dragojlovic, A. & Samuels, A. 2021. Tracing silences: Towards an anthropology of the unspoken and unspeakable. *History and Anthropology.* 32:4: 417-425.

Duclos, V. & Criado, T.S. 2020. Care in trouble: Ecologies of support from below and beyond. *Medical Anthropology Quarterly*. 34(2): 153-173.

Elder-Vass, D. 2015. Disassembling actor-network theory. *Philosophy of the Social Sciences*. 45(1): 100-121.

Farmer, P. 2004. An anthropology of structural violence. *Current Anthropology*. 45(3): 305-325.

Farmer, P.E., Nizeye, B., Stulac, S., and Keshavjee, S. 2006. Structural Violence and Clinical Medicine. *PLOS Medicine*. 3(10): 449.

Fisher, B., & Tronto, J. 1990. Towards a Feminist Theory of Care. In Abel, E. and Nelson, M. Eds. *Circles of Care*. Albany, N. Y. : State University of New York Press.

Grimes, J.E., Croll, D., Harrison, W.E., Utzinger, J., Freeman, M.C. & Templeton, M.R. 2014. The relationship between water, sanitation and schistosomiasis: a systematic review and meta-analysis. *PLOS Neglected Tropical Diseases*. *8*(12): 3296.

Gryseels, B., Polman, K., Clerinx, J. & Kestens, L., 2006. Human schistosomiasis. *The Lancet*. 368(9541):1106-1118.

Hall, M. 2011. *Plants as persons: A philosophical botany*. Suny Press.

Haraway, D. 2008. When Species Meet. Minneapolis, London: University of Minnesota Press.

Harshfield, E., Jemec, A., Makhado, O. & Ramarumo, E. 2009. Water purification in South Africa: reflections on curriculum development tools and best practices for implementing student-led sustainable development projects in rural communities. *International Journal for Service Learning in Engineering, Humanitarian Engineering and Social Entrepreneurship*. 4(1): 1-14.

Herbig, F. J. W. 2019. Talking dirty - effluent and sewage irreverence in South Africa: a conservation crime perspective. *Cogent Social Sciences*. 5(11):1701359.

Herbig, F., & Joubert, S. 2006. Conservation crime semantics: vision or vagary? *Acta Criminologica: Southern African Journal of Criminology*. 19(3): 87–101.

Houston, D., Hillier, J., MacCallum, D., Steele, W. & Byrne, J. 2018. Make kin, not cities! Multispecies entanglements and 'becoming-world' in planning theory. *Planning Theory*. 17(2): 190-212.

King, C.H. 2010. Parasites and poverty: the case of schistosomiasis. *Acta Tropica*. 113(2): 95-104.

Krøijer, S. & Rubow, C. 2022. Introduction: enchanted ecologies and ethics of care. *Environmental Humanities*. 14(2): 375-384.

Landmann, J. 2013. *Twentieth century borrowings from French to English: Their reception and development*. Cambridge Scholars Publishing.

Latour, B. 1996. On actor-network theory: A few clarifications. *Soziale Welt*. 47:369-381.

Law, J. 2009. Actor network theory and material semiotics. In *The New Blackwell Companion to Social Theory*. B. S. Turner, Ed. Wiley-Blackwell. 141-158.

Law, J. & Singleton, V. 2005. Object lessons. *Organization*. 12(3): 331-355.

Leng, H.M.J., Sanders, D. & Pollock, A.M. 2016. The impact of the Medicines Control Council backlog and fast-track review system on access to innovative and new generic and biosimilar medicines of public health importance in South Africa: in practice-issues in public health. *South African Medical Journal*. 106(4): 350-353.

Lothe, A., Zulu, N., Øyhus, A.O., Kjetland, E.F. & Taylor, M. 2018. Treating schistosomiasis among South African high school pupils in an endemic area, a qualitative study. *BMC Infectious Diseases*. 18(1): 1-10.

Maphumulo, A., Mahomed, O., Vennervald, B., Gundersen, S.G., Taylor, M. & Kjetland, E.F. 2020. The cost of a school based mass treatment of schistosomiasis in Ugu District, KwaZulu Natal, South Africa in 2012. *Plos one*. 15(6):1-13.

Manderson, L. 1998. Applying medical anthropology in the control of infectious disease. *Tropical Medicine & International Health*. 3(12): 1020-1027.

McMahon, J.E. & Kolstrup, N. 1979. Praziquantel: a new schistosomicide against *Schistosoma haematobium*. *Br Med J*. 2(6202):1396-1398.

MSH (Management Sciences for Health). 2016. International Medical Products Price Guide, 2015 Edition. (Updated annually.) Medford, Mass.: MSH.

"Monster". *Merriam-Webster's Dictionary*. 2022. Merriam-Webster, Springfield, Massachusetts, Available: http://www.merriam-webster.com/dictionary/monster. [2022, November, 10]

"Monstres Sacres". *Collins Dictionary*. 2022. HarperCollins, Glascow, Available: https://www.collinsdictionary.com/dictionary/english/monstre-sacre. [2022, November, 10]

The National Department of Health, South Africa: Essential Drugs Programme. 2020. Primary Healthcare Standard Treatment Guideline and Essential Medicine List. 7th ed. South African National Department of Health.

National Water Act, No. 36 of 1998. 1998. Government gazette. 398(19182). 26 August. Government notice no. 1091. Cape Town: Government Printer. Available; https://www.dws.gov.za/Documents/Legislature/nw_act/NWA.pdf [2022, November, 10].

Nelwan, M.L. 2019. Schistosomiasis: life cycle, diagnosis, and control. *Current Therapeutic Research*. 91:5-9.

Olliaro, P., Delgado-Romero, P. & Keiser, J. 2014. The little we know about the pharmacokinetics and pharmacodynamics of praziquantel (racemate and R-enantiomer). *Journal of Antimicrobial Chemotherapy*. 69(4): 863-870.

Olsen, A., Ørnbjerg, N., & Winkel, K. Eds. *A success story in Danish development aid: DBL (1964-2012)*. Copenhagen: DBL - under funding from the Danish International Development Agency (Danida).

Petryna, A., Lakoff, A. & Kleinman, A. Eds. 2006. *Global Pharmaceuticals: Ethics, Markets, Practices*. Duke University Press.

Randjelovic, A., Frønæs, S.G., Munsami, M., Kvalsvig, J.D., Zulu, S.G., Gagai, S., Maphumulo, A., Sandvik, L., Gundersen, S.G., Kjetland, E.F., & Taylor, M. 2015. A study of hurdles in mass treatment of schistosomiasis in KwaZulu-Natal, *South African Family Practice*. 57:(2):57-61.

Reich, M.R., Govindaraj, R., Dumbaugh, K., Yang, B.M., Brinkmann, A., & El-Saharty, S. 1998. *International strategies for tropical disease treatments: Experiences with praziquantel* (No. WHO/DAP/CTD/98.5). World Health Organization.

Richards, R., 2008. Writing the othered self: autoethnography and the problem of objectification in writing about illness and disability. *Qualitative Health Research*. 18(12): 1717-1728.

Shain, C. 2016. 'They are my babies': piecing together my meetings with mycobacterium tuberculosis and the scientists who care for it. MA. Dissertation. University of Cape Town.

Sokolow, S.H., Huttinger, E., Jouanard, N., Hsieh, M.H., Lafferty, K.D., Kuris, A.M., Riveau, G., Senghor, S., Thiam, C., N'Diaye, A. & Faye, D.S. 2015. Reduced transmission of human schistosomiasis after restoration of a native river prawn that preys on the snail

intermediate host. Proceedings of the National Academy of Sciences. 112(31): 9650-9655.

Solomon, N. 2022. The Kuils River multiple: versions of an urban river on the edge of Cape Town, South Africa. Ph.D. Thesis. University of Cape Town. Available: https://open.uct.ac.za/bitstream/handle/11427/36562/thesis_hum_2022_solomon%20nikiwe.pdf?sequence=1&isAllowed=y

Stauffer Jr, J.R., Madsen, H., Konings, A., Bloch, P., Ferreri, C.P., Likongwe, J., McKaye, K.R. & Black, K.E. 2007. Taxonomy: a precursor to understanding ecological interactions among schistosomes, snail hosts, and snail-eating fishes. *Transactions of the American Fisheries Society*. 136(4): 1136-1145.

Tronto, J.C. 1998. An ethic of care. *Generations: Journal of the American Society on Aging*, 22(3): 15-20.

Tsing, A. 2012. Unruly Edges: Mushrooms as Companion Species For Donna Haraway. *Environmental Humanities*. 1(1): 141-154.

Tsing, A.L., Bubandt, N., Gan, E. & Swanson, H.A. Eds. 2017. *Arts of living on a damaged planet: Ghosts and Monsters of the Anthropocene*. University of Minnesota Press.

Vale, N., Gouveia, M.J., Rinaldi, G., Brindley, P.J., Gärtner, F. & Correia da Costa, J.M. 2017. Praziquantel for schistosomiasis: single-drug metabolism revisited, mode of action, and resistance. *Antimicrobial Agents and Chemotherapy*. 61(5): 1-16.

Van der Geest, S., Whyte, S.R. & Hardon, A. 1996. The anthropology of pharmaceuticals: a biographical approach. *Annual review of anthropology*. 25(1): 153-178.

Webster, B.L., Alharbi, M.H., Kayuni, S., Makaula, P., Halstead, F., Christiansen, R., Juziwelo, L., Stanton, M.C., LaCourse, E.J., Rollinson, D. & Kalua, K. 2019. Schistosome interactions within the *Schistosoma haematobium* group, Malawi. *Emerging Infectious Diseases*, 25(6): 1245-1247.

WHO (World Health Organisation). 2022. Available: https://www.who.int/health-topics/schistosomiasis#tab=tab_1 [2022, November, 1].

World Health Organization. 2021. Diagnostic target product profiles for monitoring, evaluation and surveillance of schistosomiasis control programmes. Available:

https://apps.who.int/iris/bitstream/handle/10665/344813/9789240031104-eng.pdf?sequence=1

Worldometers.info. 2022. Dover, Delaware, U.S.A. Available: https://www.worldometers.info/population/countries-in-africa-by-population/

Whyte, S.R. 1988. *The Power of Medicines in East Africa. In The Context of Medicines in Developing Countries: Studies in Pharmaceutical Anthropology*, edited by S. Van der Geest & S.R. Whyte, Eds. Dordrecht: Kluwer.

Whyte, S.R., Van der Geest, S. & Hardon, A. 2002. *Social Lives of Medicines*. Cambridge University Press. 3-193.

Wildman, S.M. and Davis, A.D. 1994. Language and silence: Making systems of privilege visible. *Santa Clara L. Review.* 35:881.

Wu, X.H., Wang, X.H., Utzinger, J. & Kun, Y. 2007. Spatio-temporal correlation between human and bovine schistosomiasis in China: insight from three national sampling surveys. *Geospatial Health*. 2(1):75-84.