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Science & Society

A case of schistosomiasis and healthcare seeking in Mwanza, Tanzania

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This article explores the cultural practices and diagnostic challenges surrounding schistosomiasis in Tanzania's Lake Zone. Mr Ezekiel's son endured years of misdiagnosis and ineffective treatments until the correct identification and treatment of his chronic urinary schistosomiasis, highlighting the need for improved healthcare access and awareness in rural African communities.

From snail data collection to storytelling

In the Lake Zone area of Tanzania, amidst the shimmering waters of Lake Victoria, lie five regions (Kagera, Mwanza, Geita, Simiyu, and Mara) where the rhythm of community life is intimately tied to its freshwater resources. Aquatic snails, while often seen as merely just another creature in the landscape, play a pivotal role in the transmission of schistosomiasis in these particular regions. But it is no wonder that many never find a diagnosis and/or treatment, and schistosomiasis remains a 'neglected' tropical disease despite being the second most important parasitic disease in the world after malaria (Box 1). Thus, this tricky and complex disease system sparked our journey of discovery and connection with the communities living in these regions.

A collaborative, international project (Figure 1A) began in inland villages of the Lake Zone regions in 2020 to understand the key discrepancies between snail densities and the parasitic cercariae released, which are critical in schistosomiasis transmission [1,2]. In addition to field surveys of snail-parasite dynamics and identifying sites for disease mitigation in small village water sources, the project included community engagement events (Figure 1B). During these meetings, we conversed with residents who shared stories of their daily lives and the challenges posed by schistosomiasis. Living in the Lake Zone area puts community members at constant risk of contracting schistosomiasis due to prolonged contact with waters that may be infested with *Schistosoma* parasites. Women, often tasked with fetching water for their households, shared anecdotes of their encounters with the snails and their awareness of the disease. One of the most prominent aspects of our interactions was the community's resilience and willingness to learn. Educational sessions on the life cycle of schistosomes and preventive measures were met with enthusiasm. Simple interventions, such as avoiding direct contact with water and using proper sanitation facilities, were discussed with the locals. One remarkable visit was to Shigala village in the Busega district of Simiyu region. During the community session at this village, the village chairperson (Ezekiel Silas Shipula, Figure 1C) shared his family's touching story about a personal encounter with schistosomiasis.

Mr Ezekiel's family story

About two decades ago, Mr Ezekiel's son was only 6 years old when he had blood in his urine. It is quite a common practice in his community to avoid health facilities when someone experiences such symptoms and instead rely on indigenous medicine. The only treatment used in Shigala village, and even beyond in Busega district, for these symptoms was a herbal

medicine from the *Ngugunu* tree (*Ziziphus mucronate* subsp. *rhodesica*). The treatment involved excavating the roots and boiling them with water for half an hour to make a juice – a process still in use across Africa [3,4]. The patient was urged to drink the herbal liquid for at least a week to cure the disease. The treatment was deemed successful then because Ezekiel's son no longer had blood in his urine. Author M.P.M. remembers the dedicated use of this type of treatment for similar symptoms in his community in Shinamwendwa village, Geita district, about 200 km from Ezekiel's village.

For almost two decades, Ezekiel's son lived seemingly free from his childhood affliction. At the age of 25, he was married, a father of two children, and had built a life for himself in the Geita region. One day, he started to feel dull pain when urinating, but he ignored it, hoping the condition would disappear on its own. But as the condition persisted for three more days, he decided to visit a local village pharmacy and was prescribed drugs for a urinary tract infection (UTI). His condition did not change despite using the medications as instructed, and so he decided to visit a health facility in Geita town. He was once again diagnosed with a UTI after laboratory tests and prescribed the same medication. He took the drugs for a week, but his health condition did not improve. However, he did notice that he experienced relief from his pain when he drank a lot of water and urinated more frequently and with more dilution. His prevailing condition of pain led him to visit Geita Regional Hospital. There, he was asked to undergo laboratory tests of blood, urine, and stool. The results indicated that a UTI was still the problem. Again, UTI drugs were prescribed for treatment, but his symptoms continued to worsen.

Having tried various treatments without success, he decided it was time to communicate his health problem to his family.

Box 1. Schistosomiasis

Schistosomiasis, formerly known as bilharzia or snail fever, is caused by parasitic worms of the genus *Schistosoma*. It is one of the most neglected tropical diseases (NTDs), affecting millions of people worldwide, particularly in Africa, South America, and Asia [6]. The disease has complications that unfold in various phases (acute and chronic phases). The chronic phase can last for decades if untreated, with significant damage to the liver and bladder in the case of *Schistosoma haematobium* (or intestines in the case of *Schistosoma mansoni*), leading to liver fibrosis, cirrhosis, and intestinal blockages [7]. The urinary system is not spared, with symptoms like blood in the urine and bladder scarring, which can increase the risk of developing bladder cancer [8]. Additionally, reproductive health issues may emerge, including female genital schistosomiasis, infertility, and complications during pregnancy [8]. The disease disproportionately affects children and rural communities, where exposure to contaminated freshwater is unavoidable [7]. In general, the disease is a widespread issue, particularly in regions with limited access to clean water and proper sanitation. Families, like Mr Ezekiel's, struggle with treatment and recurring infections due to environmental and socioeconomic challenges.

He called his father, Mr Ezekiel, and explained about his ailment. His father asked him to return home to Shigala village for further treatment. So, in June 2024, Ezekiel's son left his own family in Geita,

so he could have support from his parents and siblings to cure his health problem. Mr Ezekiel communicated with a physician at Sekoutoure Mwanza Regional Hospital. The physician suggested that he meet a

urologist at Bugando Medical Centre (BMC). As booking an appointment at BMC to meet a urologist is challenging, Mr Ezekiel had to lean on his connection with the physician from Sekoutoure Mwanza Regional Hospital, and an appointment was made. Mr Ezekiel and his son had to travel 140 km from Shigala village to BMC, and it took about 2 hours to meet the urologist. Mr Ezekiel's son was subjected to ultrasound and X-ray scans, blood, urine, and stool laboratory tests as well as an examination of his urinary tract; however, the results indicated no disease. Thus, referring to the patient's history and the urologist's experiences in treatment, the patient was prescribed various drugs that he could use for a month, then, after that, he should go back to the hospital for continual monitoring. But they couldn't afford the cost of the particular drugs.

Feeling hopeless, Mr Ezekiel decided to turn to traditional treatment once again. The traditional healer claimed he could treat the condition. After one week of herbal treatment, Mr Ezekiel's son felt relief, and his health seemed to improve. He returned home to his family in Geita. However, after just another week, he experienced intense pain again. So, Mr Ezekiel asked his son to return to the traditional healer in Shigala once again to repeat the treatment. It became very clear to Mr Ezekiel's son that the liquid form of medication seemed to be most helpful, similar to when hydration was the only thing that seemed to help with his earlier repeated misdiagnosis of a UTI.

Thus, he decided to go back to a health facility and communicate that hydration was the only relief, hoping that this would finally help in seeking further treatment. But Mr Ezekiel's son continued to have several frustrating and inconclusive medical interactions. A community member in Shigala suggested that they try health facilities in the urban center of the Lake Zone,



Figure 1. Photos from the process of compiling Mr Ezekiel's story. (A) Documenting this story is one of many outcomes of an established collaboration between researchers from the National Institute for Medical Research (NIMR), Mwanza Centre, Tanzania, Emory University, USA, and the University of Amsterdam (UvA). (B) Researchers from NIMR are leading an engagement meeting with the community of Shigala village. The meeting, attended by the village chairperson, Mr Ezekiel, highlights the collaborative efforts to raise awareness about schistosomiasis within the community and learn about their experiences with its impacts. (C) Mr Ezekiel (wearing a white cap) is seen listening attentively to the NIMR facilitator while holding a brochure containing information about schistosomiasis. This interaction underscores the importance of the community and its leaders' involvement in education for combating schistosomiasis.

Mwanza City. While in Mwanza, they first visited a Chinese practitioner who diagnosed him with a kidney issue by conducting an ultrasound scan. However, as Mr Ezekiel could not afford the treatment prescribed, they also visited Mwananchi Hospital in Mwanza. Following the typical laboratory tests for blood, urine, and stool, this time the results corroborated the kidney problem. Seemingly, the problem had worsened since the original affliction. The doctor ordered a health checkup at BMC once again and referred them to the same urologist they had seen previously. Mr Ezekiel was reluctant to return to BMC because the previous visit had not solved his son's health problem. Instead, they returned home with the prescribed medication from Mwananchi, and once again, Mr Ezekiel's son followed the course with no avail. They decided to return to Mwananchi Hospital, where another referral was given to BMC for the same urologist due to the presence of more sophisticated diagnostic equipment. Thankfully, a different urologist was on duty, but the same procedures again yielded no significant results. As a last resort, they followed the advice of a Mr Ezekiel's sibling and decided to try Kamanga Hospital, a well-regarded private hospital known for skilled and experienced physicians.

Before the appointment, the doctor had told the patient to drink a lot of water to

help with the diagnosis. An ultrasound examination was performed at Kamanga Medics Hospital, revealing no kidney problems, but unfamiliar features were noted in the urinary bladder. The patient was asked to urinate completely and return for another ultrasound examination. The second ultrasound examination showed that urine remained in the bladder despite the patient claiming to have emptied it. After the patient's ultrasound examination the doctor started to probe various questions to his father regarding the patient, such as if he ever faced any urinary sickness like gonorrhoea or schistosomiasis. Suspecting the latter, he also asked questions about his water contact behaviors, for example participating in rice farming. Mr Ezekiel recalled when his son was suffering with blood in the urine as a child and having to rely on local herbal medication. The doctor suspected that while his son was able to quell the acute symptoms of schistosomiasis with herbal medication, the disease remained and developed into a chronic infection over the last couple of decades. He suspected that Mr Ezekiel's son had schistosome eggs lodged into his bladder, that developed into granulomas [5]. He recommended bladder surgery to remove these cysts and release the pressure on his bladder. Unfortunately, due to the cost of diagnosis and treatment, Mr Ezekiel and his son

returned home to find the necessary funds. After 3 days, they returned with the money collected by selling a cow, and Mr Ezekiel's son was admitted for surgery. The surgery was successfully performed, and he had to be discharged after 2 days due to insufficient funds to stay in the hospital. He was prescribed antibiotics and praziquantel to assist in healing and prevent reinfection with schistosomiasis.

Now, the patient is free from urinary problems. History has been made for Mr Ezekiel's family, with an incredible number of lessons for the community's better health in the future. This story underscores the treacherous path that one often takes from symptoms to treatment of schistosomiasis in the Lake Zone area of Tanzania. These stories and community-centered research that integrates local knowledge and practices are essential for sustainable and culturally appropriate solutions (Box 2). Through these collaborative efforts, we hope to make a lasting impact on the health and wellbeing of communities around the Lake Zone area of Tanzania.

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Declaration of interests

The authors declare no competing interests.

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Box 2. Schistosomiasis misdiagnosis is a global issue

The experience of Mr Ezekiel's family is mirrored time and time again across the globe. Fishermen along Lake Albert in Uganda [9], farmers in Mindoro Island in the Philippines [10], and families in Nigeria's Niger Delta [11] struggle with schistosomiasis misdiagnoses due to limited access to healthcare and low awareness of the disease. Schistosomiasis symptoms mimic other illnesses, such as UTIs and intestinal disorders, leading to delayed treatment, misattributed symptoms, and worsening health outcomes [12]. For example, female genital schistosomiasis – a neglected manifestation of the disease – is frequently mistaken for reproductive disorders, resulting in unnecessary treatments not addressing the underlying parasitic infection [13,14].

In Mr Ezekiel's family story, the use of herbal remedies (like those derived from the Ngugunu tree) highlights the resilience of communities facing barriers to accessing healthcare. Similarly, Ugandan fishermen and Philippine farmers often also turn to indigenous treatments [9,10]. However, this can also prolong the time it takes for many to seek formal medical intervention. Addressing schistosomiasis misdiagnosis requires a holistic approach: the strengthening of healthcare infrastructure, improving diagnostic accuracy [15]. Expanding education campaigns must be paired with the integration of local knowledge and livelihood needs for more effective public health outcomes for families like Mr Ezekiel's.

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