

The man from the stars: a narrative approach to neglected diseases

Paolo Agostinis,¹ Teresa Michelutti,² Laura Iogna Prat,¹ Omar Simonetti³

¹Internal Medicine Unit, Sant'Antonio Abate Hospital, Azienda Sanitaria Universitaria Friuli Centrale, Tolmezzo; ²Institute of Clinical Pathology, Sant'Antonio Abate Hospital, Azienda Sanitaria Universitaria Friuli Centrale, Tolmezzo; ³Infectious Diseases Unit, University Hospital of Trieste, Italy

ABSTRACT

In this narrative medicine essay, a young migrant suffering from schistosomiasis unveils his story and his journey from Africa to the Alps. The hardships of a long voyage and the clinical history of the disease are described, combining the form of narrative medicine with a brief overview of the subject. Schistosomiasis is a neglected disease caused by a parasitic worm that lives in freshwater in subtropical and tropical regions. Such an infestation is debilitating but easy to diagnose and treat. Therefore, schistosomiasis should be suspected and recognized by doctors in every setting, as the number of international migrants, including those from sub-Saharan Africa, is growing rapidly.

Correspondence: Paolo Agostinis, Internal Medicine Unit, Sant'Antonio Abate Hospital, Azienda Sanitaria Universitaria Friuli Centrale, via Morgagni 18, 33028 Tolmezzo (UD), Italy. E-mail: paolo.agostinis@asufc.sanita.fvg.it

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Introduction

Schistosomiasis (bilharzia) is a neglected tropical disease caused by parasitic flatworms (blood flukes) of the genus *Schistosoma*. The German doctor Theodor Maximilian Bilharz (1825-1862) discovered the cause of the so-called Egyptian hematuria in 1851 while in Cairo.¹ Schistosomiasis has a high morbidity in parts of the Middle East, South America, Southeast Asia, and especially in sub-Saharan Africa. Adult schistosome parasites live in the blood vessels of their hosts, including humans, but their life cycle requires a phase of asexual reproduction in an intermediate host, a snail. Human infection occurs through contact with fresh water contaminated with cercariae, the free-swimming infective stage of schistosomes released by the snails. The characteristics of human disease depend on the species. The most prevalent species causing disease in humans are *Schistosoma haematobium*, *Schistosoma mansoni*, and *Schistosoma japonicum*. In endemic areas and low-income countries, diagnosis is often based on the microscopic detection of schistosome eggs in feces or urine.²

Case Report

Amani - one of his four names - is a 23-year-old boy from Mali. He traveled across the Ténéré and Sahara Desert, then Libya, to finally reach the island of Lampedusa, the gateway to Europe, by sea. From the Sicilian island, he arrived at the Carnic Alps in the far northeast of Italy. Within a few months, he learned Italian and the local language Friulian, spoken by half of the population of the region Friuli Venezia Giulia.³

"Do you belong to the Dogon or the Bozo people?" This unexpected question was addressed to Amani by the internist as soon as he arrived at the clinic.

A few days before, Amani was found to have a bladder mass of unknown origin by a urologist, who thus referred him to the internal medical practice for advice. Previously, urine tests on Amani, who complained of burning when urinating and abdominal pain, had identified numerous red blood cells in more than one sample.

"I soi un (I am a) Dogon, my homeland is the mountains of Bandiagara" Amani answered, mixing both Friulian and Italian, shyly smiling, surprised to hear that someone knew his country.

As a matter of fact, the internist had visited Mali to climb the smallest peak of the Man de Fatima, a natural granite block situated at the center of a large bend of the Niger River, engraved by millennial natural forces. In that exact place, filled with huge baobab and acacia trees adorned with charming weaver bird nests, he had bumped into the "Blue Men" in the Ténéré desert along with the Dogon people, an animist ethnic group who had built their dwellings on the Bandiagara cliff; the Dogon were nicknamed the "star people" and traditionally worked as blacksmiths and wood sculptors, raised goats, and grew millet and onions in tiny gardens.^{4,5}

"And what did you live on in your village?" the doctor asked Amani. "My parents farmed the land and I used to sell onions at the Mopti wharf. Then I moved to the dock and used to go fishing on my pinassa - traditional pirogue".

Mopti, a city on the Niger River, is a crossroad to Tombouctou and Dogon cliffs and a main trade center. Here, it is easy to meet all the different people settled in Mali.

The boy lay down on the bed. The internist began examining him carefully. Amani was smiling and seemed to trust the doctor who knew the difference between a Dogon and a Bozo. The doctor started palpating his belly, excavated by hardship. He then put the bell of his stethoscope on Amani's chest, which beat as rhythmically and deeply as a dundun (typical drum made of goat skin). At this point, the doctor asked the boy to take off his shoes. While entering the office, the doctor noticed he was limping, like someone who had an acacia tree thorn stuck on his sole. Amani seemed not to understand at first. He sat up on the bed, glanced at the cultural mediator who was sitting aside, brought his hands near his shoelaces and lingered. He looked again at the woman from Senegal, peacefully sitting on her chair like a guru, with her crossed arms twice as big as her thighs. She reassured Amani, inviting him to follow the instructions. The boy finally untied his shoes. On the sole of his right foot, there was a deep scar instead of a thorn. That scar did not come from any surgery or any sorcery. It meant something else, the doctor sensed. He approached it cautiously.

"How did you get here from Mali?" he asked as soon as the examination was over, and he was busy around the ultrasound machine to start scanning his abdomen. The boy breathed in and out deeply like he was climbing the steep cliff of Bandiagara. Then he began telling his journey.

"I left Mopti and reached Niamey, the capital of Niger, by bus. Then I went to Agadez. In Agadez, I got on an old lorry with many others, and we crossed the Ténéré desert. We were squeezed, there was not even room to sit. After several days on desert tracks, starved and very thirsty, we reached the Libyan border. At every checkpoint, we had been plundered by the police and army. At every stop we had to pay a bribe to be able to proceed. They justified saying that we had no visa and that we were carrying foreign currency. At the Libyan border, the army made us get off and asked for our passports and more money. I did not have even a coin left. A soldier ordered me to raise my right leg. He grabbed a knife and stuck it in my sole. The blade got into my flesh. After crossing the border, in Al Qatrum, we were stopped again and searched by the police. I was asked to work in return for my freedom. I agreed". The doctor resumed the examination. He did not

want to know why Amani had run away from Mali, his beautiful country.

The ultrasound scan showed gross bladder polyps protruding into the lumen like boils (Figure 1). It was noon, a perfect time, thought the internist. The doctor asked the patient to stand up and jump around. Amani laughed in his face, thinking it was a joke. The doctor encouraged him, asking to expel the evil spirit nestled in his belly, and Amani was persuaded. After a couple of minutes, the doctor sent him to the bathroom with a test tube.

"Collect some pee here, please," he requested him. Amani flushed, walked out of the toilette, and gave the doctor the tube. "Your sickness is here inside" said the doctor pointing at his pink urine.

The doctor went downstairs to the lab with the tube. The urine was centrifuged at a slow speed, and then the microbiologist took a thick drop and put it on a slide. With soft and gentle moves, she put a coverslip on the slide and started turning the knobs of the microscope. After a few seconds, she was startled. There was something in the urinary sediment. There were eggs, much bigger than the red blood cells which surrounded them. These eggs were oval and had a terminal spine on one side and a lid on the other. There was a worm inside. There was no doubt that these were eggs of *Schistosoma haematobium* (Figure 2). The urologist was texted and joined the other two at the lab. He sat in front of the microscope,

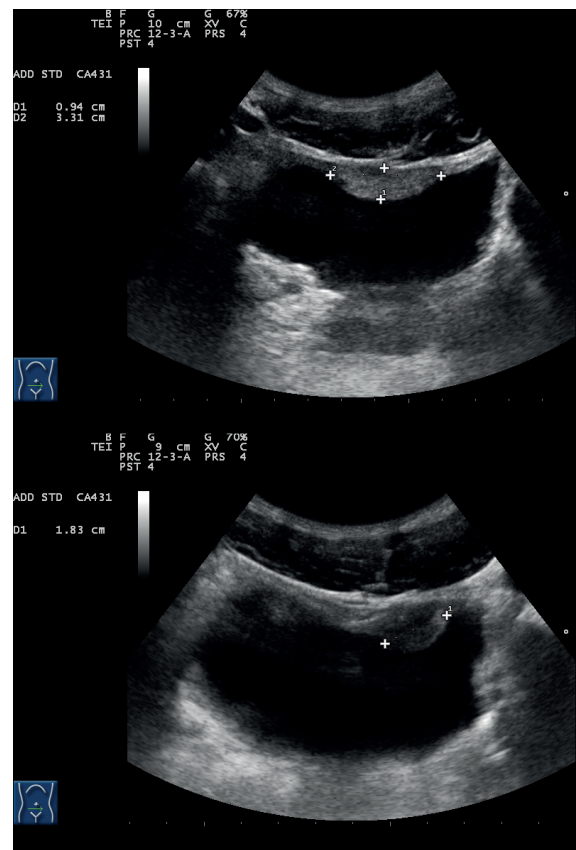


Figure 1. Amani's inflammatory polyps caused by *Schistosoma* infection. The image was taken using a convex probe and abdominal ultrasound.

happy that he guessed the right diagnosis, thus preventing Amani to undergo cystoscopy and surgery.

The internist came back to the clinic and called the patient. The cultural mediator was with him.

“You don’t have any tumor, it’s just Bilharzia” he told him. He smiled, maybe he did not understand, but looked reassured. The cultural mediator exclaimed: “Bilharzia! My siblings and I got Bilharzia as children as well”. Amani’s jumping made the eggs fall down from his bladder walls like autumn leaves in his urine well. On his right palm, Amani received four tablets of Praziquantel, which kills the worms and the evil at the root. The boy swallowed the tablets without hesitation and was sent home.

He returned for a follow-up visit one month later. He was doing better, the ultrasound scan confirmed that the bladder

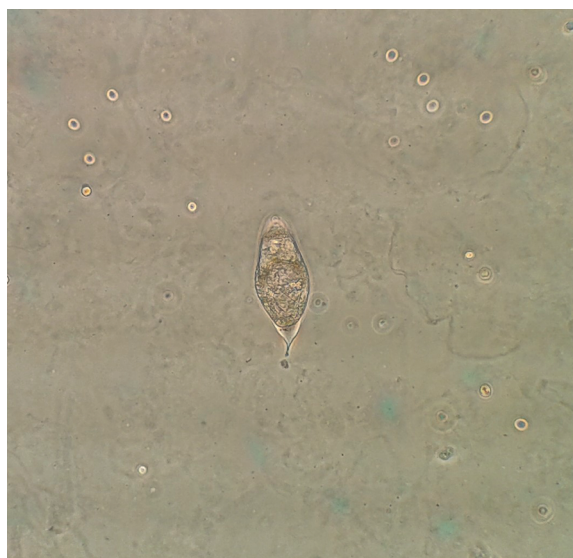


Figure 2. One egg of *Schistosoma haematobium* observed in Amani’s urine. The image was taken using a direct microscopy observation.

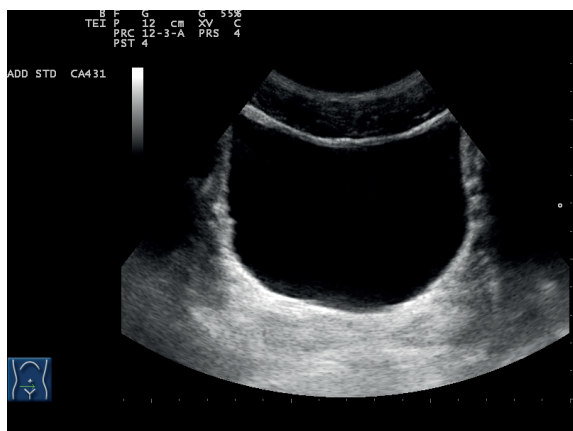


Figure 3. Amani’s regular bladder after specific treatment. The image was taken using a convex probe and abdominal ultrasound.

polyps shrank. The internist gave Amani the second dose of Praziquantel, asking him to come back in two months. Two months later, Amani entered the doctor’s office with a light pace, wearing his earphones. At the microscope, the urine analysis normalized, and no eggs or red cells were seen. The bladder scan was normal, and the polyps completely disappeared (Figure 3). Amani thanked the doctor and got dressed. He put on his jacket and earphones. A small tobacco packet came out from his left pocket, with the black words “Smoke kills” printed on it.

Discussion

For almost two centuries, the microscope had been the king of the lab.⁶ Nowadays, we have entered the era of molecular probes, and urine analysis is carried out using a small plastic colorimetric strip. Urine sediment is very rarely assessed under the microscope. Healthcare reformers, hospital managers, and dull clinicians are letting it end up like the acacia tree of Ténéré, which survived for centuries in the desert where it stood lonely, surrounded by hundreds and hundreds of sand dunes. It grew the deepest roots; it was a living lighthouse amid the desert for caravans of “Blue Men” in the northwest of Niger, and it was respected by everybody. When the Tuareg passed by the acacia tree with salt slabs on the backs of their camels, they did not dare to take a single branch to fire, nor did they allow their camels to eat a single leaf. Thereafter, the acacia tree was cut down by the lorry of a drunk Libyan driver, and it does not exist anymore. It was moved to the National Museum of Niger, in Niamey.⁷

To be diagnosed with urinary schistosomiasis, it only takes a microscope and somebody who knows the behavior of the female worm. Looking for red cells and eggs in the urinary sediment remains the gold standard, with a sensitivity of 92.5% and a specificity of 98%. The evidence still supports the benefit of conventional urine microscopy for *S. haematobium* diagnosis, as recently stated by the World Health Organization.⁸ The sensitivity of urine and serum antigen tests and real-time polymerase chain reaction assays on urine is not higher than microscopy in detecting eggs. The best performance of microscopic examination is obtained when the urine specimens are collected late in the morning or early in the afternoon and then centrifuged and filtered. The ultrasound scan can easily suggest the diagnosis showing a thickening of the bladder walls, polyps or hydroureter/hydronephrosis. Furthermore, the US scan is helpful in monitoring the medical treatment response.^{9,10}

Conclusions

Schistosomiasis infestation is debilitating but easy to diagnose and treat also in healthcare centers. The number of international migrants, including those from sub-Saharan Africa, is growing in Italy and all over the world. Moreover, climate change poses an evident challenge for emerging infectious diseases.^{11,12} Schistosomiasis should be suspected and recognized by doctors and healthcare workers in every Italian setting, as recently described and shown by Amani’s history.¹³ Moreover, recent handy and clinically relevant recommendations on schistosomiasis screening, diagnosis, and treatment have been published for non-endemic areas.¹⁴

Many recent publications have described the virtues of narrative medicine to promote medical students' development and clinical knowledge.¹⁵ It is our opinion that a narrative-based approach could be used to reach a broader audience of professionals also in the field of neglected infectious diseases in non-endemic countries.

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