

Red and White Beads

She stared at the far wall, her eyes half open. A trail of blood ran from her nose to her bed sheets, deceptively red but no longer flowing, painted with a bold, tragic brushstroke. There was foam between her parted lips, sickly beige with a hint of maroon. I stared at the froth, waiting for new bubbles to form, but they were stagnant. I looked back at her eyes, her deep brown irises and endless black pupils. They were motionless, each fixed on a distant point. She did not blink. Her sclera, normally the “whites of the eye,” were stained an unsettling yellow. *She looks like she...surely she isn't...but had she...was she...dead?* My eyes went to her chest, searching for a rise or fall. I wanted to see it, an inhale or exhale. *Was that it? An imperceptible movement of the blanket?* No, it was only the unsteadiness of my own gaze. The blanket was still. *When was the last time someone had checked on her? It couldn't have been long.*

The clinical intern was at the foot of the bed, looking at the patient's chart. She had entered the room first, and I wasn't sure what she knew. The last time I had seen this patient, she was out in the main ward, her metal bedframe parked a yard from the nearest patient. Now she was in a private side ward, one of the only patients at Mokopane Hospital with her own room. As a public hospital in the Limpopo province of South Africa, privacy was not an affordable or expected commodity. The patient's overnight move could only mean she had turned for the worst. Having their own space, was a “privilege” most patients in Mokopane hoped to avoid.

“I feel nauseous,” the intern said.

“Is she alive?” I responded, almost embarrassed to ask the question. I felt foolish standing there, unaware if the body in front of me was occupied or vacant.

“Can you please check?” she asked. I realized she didn't know either, not for sure. But we did, we knew. We knew her eyes were not looking at the wall, but gazing beyond it, farther than we could fathom. I reached out my gloved hands. I searched for her carotid pulse, then her femoral pulse, and felt nothing. I relaxed her bent legs and covered her yellow soles with her blanket. She was gone.

I was sad, but not sad enough. My emotions were too vague, too detached, and too impersonal. I felt cognitive sadness, but not its emotional counterpart. A woman had died young and alone, from causes that were preventable. These were the tragic facts, *but who was I sad for?* She had been delirious on arrival and her wits never returned. She was a stranger to me, a person I had seen and examined, but never conversed with. I couldn't

even pronounce her name correctly. I didn't know where her family was, or if she had a family. I didn't know anything about her life, only about her death. I wished I knew more.

There was one small clue that hinted at her identity. A string of red and white beads hung around her neck. The same beads adorned her left wrist. They were simple, but beautiful. A touch of humanity in an unpleasant scene. I had been told she was a traditional healer, and these beads were the mark of her trade. *What did they mean to her? to her doctors? to me? What did they mean in the face of her death?*

She had died from acute liver failure, with bilirubin levels twenty times the upper limit of normal and a coagulation process so disrupted, it caused simultaneous clotting and bleeding in different parts of her body. She was HIV (human immunodeficiency virus) positive, but we did not know if she was taking her prescribed medication (she succumbed before her viral load and T-cell count were determined). Her viral hepatitis panel was negative, her autoimmune disease markers were not elevated, and she did not drink alcohol. She died from severe liver injury, and given her history, environment, and profession, the usual suspects for an underlying culprit were:

- 1). **Atroiza** (*The Mixed Blessing*) – a common South African brand of antiretroviral medication, also known by its mouthful name of Efavirenz, Lamivudine, and Tenofovir disoproxil fumarate. Combined in one pill, these three drugs are provided free to all HIV positive patients by the South African government. It is a lifesaving medication for many South Africans; however, Atroiza can also pack a powerful punch to the liver. In a country where a liver transplant is hard to come by, a severe adverse reaction can be deadly if not caught in time.
- 2). **Herbs** (*The Sly Guys*) – although rare, seemingly innocent mixtures of bark, leaves, and even natural supplements have been found to cause herb-induced liver injury among patients all over the world. These injuries have been attributed to a variety of factors – herbs with unknown toxicity, accidentally substituting a toxic herb for a safe one, contamination from pesticides and heavy metals, mixing herbs with alcohol...etc. Despite the ongoing expansion of primary care in South Africa, there are still many villages where a traditional healer is the only local healthcare option, especially for people who cannot afford a car or license. The use of unregulated, unstandardized, and occasionally harmful “treatments” is widespread throughout the country.
- 3). **Both** (*The Double Whammy*) – herbs and meds don't always play nicely together, and the individual effect can be hard to predict even if the ingredients in both compositions are known. Herbs and supplements can

potentiate the harmful effects of prescribed medications, hamper the liver's status as our favorite detox organ, and even mess with the kidneys, further reducing the clearance of metabolic waste.

I don't know which culprit was ultimately to blame for this patient's untimely death. It is possible she was taking her prescribed medication and nothing else. It is more likely, considering her vocation and culture, that she was taking a traditional treatment in addition to, or in lieu of, her Atrioza. I say that, not with a pointed finger of blame, but with recognition of reality. While at Mokopane, I saw dozens of patients admitted to the hospital with infections related to uncontrolled HIV. These patients had theoretical access to a lifetime supply of HIV medication. These daily pills would keep their immune systems robust, their lungs clear, and their lives protected. They would prevent the bloody sputum of tuberculosis, the headache and confusion of cryptococcal meningitis, and the horrific destruction of brain matter by the normally harmless JC virus. Despite this availability, many people did not take their medication, or took it for a short time and then stopped.

The woman in this story was the second patient I have seen die of acute liver failure. The second young woman whose yellow eyes stopped blinking. She was South African, at an under resourced hospital. The first was American, at a comparatively wealthy medical center. These two women lived their lives in two different worlds, died in two different worlds, and yet suffered in much the same manner. One expired in an adult sized crib in a single story brick building. The other died in a state-of-the-art bed, in a spacious room of a multi-story medical complex. One room had a crumpled brown folder and a beat-up binder holding medical records. The other had a computer on the wall with access to an electronic health record. One hospital had helicopters landing on the roof. The other had pigeons nesting on top of a broken air conditioner.

Clearly, the differences in price tags and creature comforts were great, *but what about under the surface?* *Why did these women wait to seek medical care until it was too late? Why did they fall through the cracks in the system? Why do so many patients, in South Africa and the United States, avoid the medical establishment or not follow medical advice? Can they not get to it? Do they not trust it? And why is pseudoscience so attractive?* I do not pretend to have answers to all these questions. I am not an expert on public health in the United States, much less public health in South Africa. On a small-scale and for a brief time, I was able to observe some similarities and differences between two countries, and how medical professionals address problems of compliance and patient trust.

While rotating at Mokopane Hospital for one month, I noticed a difference in the power dynamic of the patient-physician relationship between South Africa and the United States. Patients in American hospitals are being viewed as “customers” more than in previous generations, and in some cases are even labeled and treated as VIPs. They question their doctors, lodge their complaints, and ask for second opinions. Hospital administrators fear the backlash of bad patient satisfaction scores. When someone goes to a hospital in the U.S., they expect a certain degree of privacy, comfort, information, and choice. These choices range from TV channels and meal selection, to whether or not a surgical procedure or test is performed. Choices are what help patients become valued partners in their own care. (Terrifying examples of the opposite, from the Tuskegee Study of Untreated Syphilis, to the exploitation of Henrietta Lacks, resonate with U.S. healthcare providers and patients alike.)

This movement toward patient-centered healthcare and shared decision making is not exclusive to the US, nor is it absent from South Africa. However, this empowerment is aided in the U.S. by the high level of resources in our healthcare system, the availability of internet sources and online health portals for patient access, and the flexibility that most insured patients have to select their preferred providers, even if they are picking from a small network. Additionally, the idea of patient empowerment aligns well with our cultural emphasis on individuality and personal liberties. We have many problems in our healthcare system, but usually American patients have a decent idea what is happening to them and why. This does not always happen, especially for patients of lower socioeconomic backgrounds or non-English speakers, but it has at least taken root in most hospitals.

At Mokopane Hospital, patients have different expectations and less power to affect their care than I am accustomed to. This difference has material and cultural components, both more complicated than my subjective understanding. The time spent with each patient is often limited by chronic understaffing. Patient privacy is limited by available space and resources. The available treatment options are limited for the same reasons, at least in the public sector, used by 80% of the country. Outside of these material concerns, I also noticed a difference in patient mindset. Patients almost never complained, despite the absence of TVs, menus, and WiFi. They asked fewer questions than patients in the United States (perhaps due to less prompting), and seemed less concerned with personal choice. Several patients even asked permission before asking a question when they did have one. In return, the doctors were friendly and courteous to the patients, but it was a different relationship, appropriately

focused on diagnosis and care, but less focused on relationship and rapport.

Along similar lines, I found the information provided to the patients by the team was often brief and centered on the plan going forward, not the process that gave birth to the plan. Things like “We’re going to start you on Tb treatment today,” rather than “One of your tests showed a chemical in your urine found in the tuberculosis bacteria. Because of that, we would like to start you on treatment today, while we wait for your sputum results.” On a couple occasions, I stayed behind my intern, just to answer a patient question or to tell them a little bit more about what was happening to them. This wasn’t always possible, as not every patient spoke fluent English and I spoke about as much Sepedi as a fruit-fly. When I was able to communicate with them directly, the patients really seemed to appreciate the quick morsel of our reasoning.

Noting this difference in how the patients and doctors interacted at Mokopane, led me to think about the use of pseudo-treatments and reliance on traditional healers in South Africa. Many of the patients I saw came from small villages plagued by unemployment and poverty. Few of these patients had extensive education, and many lacked access to computers, the internet, and reliable transportation to get to appointments. A striking number were HIV positive, but did not adequately understand what the disease meant, that it was a chronic condition, and that they must remain on their medication even after they felt well again. For many patients in these villages and townships, a formal relationship with medicine was absent. *Why take your medicine when you feel healthy? Why see the doctor when you live down the street from a healer you have known since birth?* Someone who knows about Sunday’s sermon, your sick cow, and your disagreements with your family seems more dependable than an anonymous doctor. As people, we like to stick with what we know...and who we know.

These cultural and environmental barriers made interactions with patients who sought medical help even more important. These were opportunities to treat, but also to educate people on what HIV was, how it spread, and why it was so important to stay on treatment. It is an opportunity to introduce a piece of our world into their world and pull the two together.

Dr. Daniel Mokumo, the chief medical officer at Mokopane Hospital, is a charismatic and compassionate young man, who can hold a conversation on everything from public health efforts to the works of Plato. During a Wednesday morning Grand Rounds, Danny (as he insists on being called) spoke of his goals to “improve the patient experience” at Mokopane. During the meeting, he lamented that “Communication and debriefing is not enough”

and “patients don’t feel cared for.” He then mentioned the family of a patient who had died in the hospital. They had been confused about what had happened to their loved one and hadn’t realized how serious her situation had been. Danny concluded, “Families can be alleviated of a little of that suffering if we sit and talk with them and explain...we’re not doing that enough.”

Danny went on to directly address “pseudotherapies”, something I had been thinking about since I saw those red and white beads. He stressed the importance of respecting patient beliefs without compromising their care. “We should allow traditional healers to visit patients in the hospital, just like pastors or chaplains. They can visit the patient and say their prayers, but we cannot let them give patients anything to eat or drink while they’re here.” I found great wisdom in Dr. Mokumo’s approach. He recognized scolding a patient’s beliefs was not likely to change their behavior. He advocated for patient centered care, for a balance between patient autonomy and non-maleficence. It can be a hard balance to find, and that’s true on both sides of the Atlantic.

In the United States, skepticism towards science, medicine, and research has been gaining a stronger foothold and a louder voice. For many upper and middle-class Americans, it is not a lack of available information or adherence to traditions that is breeding this mistrust. Rather, the overwhelming availability of alternate opinions is the driving force. Anecdotal evidence, emotional appeal, and misplaced hope are being capitalized on, sometimes with good intentions and sometimes without. Internet conspiracies and anti-vaccine blogs, cure-all-promises from magic “stem cell” injections, and other snake oil peddlers are flexing pseudoscience muscles throughout the United States. The public trust and approval of the American medical system seems to have nose dived in the past few decades. In an era where patients have more power, they also have more power to make alternate choices, some helpful, some neutral, and some harmful. *So what do we do?*

Success against pseudoscience starts with listening and a genuine desire to understand the viewpoint of the person needing care. It doesn’t matter if the patient is a black farmer from Sekgakgapeng that attributes his illness to evil spirits, or a white influencer from Iowa City who thinks aromatherapy can cure scoliosis, all people have underlying assumptions that are important to their care. Unless we uncover these assumptions, it is hard to anticipate where the treatment process may break down. We won’t always agree with our patients or understand their actions, but we should always try to respect them and address their concerns, however outlandish they may seem to us. Given the chance, we should always ask about the red and white beads.