

The Burden of Shame

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Last fall, I spent four weeks working at an HIV clinic in Calcutta. The clinic was not so much an office as it was one giant room, like a rural schoolhouse. The doctors sat at the head of the room and called patients one by one from a waiting area of wooden benches. I sat with the doctors, looking out at the crowd.

"Why are most of the patients women?" I asked my preceptor.

I was taken aback by her answer. "The men have died. Most people in this country do not know about HIV. The women only get tested after their husbands fall ill or succumb to AIDS." The men are typically the first to become infected with HIV before passing it on to their wives, and thus show symptoms earlier, on average.

The patient we called next, though, was a thin, mustachioed gentleman, wearing the finest clothes he owned. He sat down and handed over the medical records he brought with him. In India, all patients with HIV carry a booklet with them tracking their CD4 lymphocyte counts (a marker of immune status) and antiretrovirals. He was not the patient; he had come as a surrogate for his wife, who was too ill to leave the house. The volume of patients was high, the afternoon was getting late, and the patient was not before us, so we refilled her medications, ignoring the reason for her absence.

I packed up to leave, and heading out I noticed this same man lingering by the exit.

"Wait," he asked with trepidation. "Will you look through these records again?" I explained that I was only a medical student, but my attempts to deflect him were unsuccessful. The records were all in English, he explained, and he just wanted someone to read them, to help him understand why his wife was so ill despite full compliance with her medications. Flipping through his wife's records, a grim tale of the last two years flashed before me. Despite an initial response to antiretrovirals, her CD4 counts kept dropping over the last year, finally bottoming out at 77. She lost a third of her body weight in six months, and one eye to Cytomegalovirus (CMV) retinitis. Still, no one made any changes to her antiretrovirals, except to add valganciclovir to her regimen. I am unsure why he trusted me. Perhaps it was because I took the time to read his wife's chart; perhaps it was because he was desperate to make someone, anyone care about his wife as she deteriorated in front of his eyes. Regardless, he asked me to come to his house in rural Calcutta, about an hour outside the city. I recognized the name of the village, as it was only ten minutes away from my uncle's house. I agreed to see him and his wife a few weeks later when I would be visiting my uncle.

I am ashamed to admit that at that time, I had made several assumptions about this man, whom I will refer to as Mr. Sen. I assumed he had HIV. I assumed he had an extramarital affair. I assumed he gave her the virus. I assumed he was showing such concern for his wife because he was consumed with guilt. I was wrong. Last year, his daughter became pregnant. On routine obstetric screening, she was found to be HIV positive, a shock to the entire family. Upon testing other family members, her mother was found to be positive for HIV antibodies, while her husband and her father both tested negative. Presumably, she contracted HIV via vertical transmission from her mother during birth. The question, then, became how did her mother get HIV in the first place 18 years ago? The assumptions I made about Mr. Sen paled in comparison to the gossip that circulated amongst the doctors while attempting to answer this question. "She got HIV and it wasn't from her husband. What kind of woman must she be?" "She must be hiding something. What did she do before she got married?" "She's a liar. A cheat. A whore."

A few weeks later, I made the journey out to my uncle's house. On a quiet Sunday evening, I walked over to the Sen household as promised. I asked neighbors until I zeroed in on a modest abode with cow dung drying on the walls. Mr. Sen came out to greet me. I took off my shoes and entered their one-room house. They lived in a communal home, sharing an outhouse and kitchen with the extended family. I sat on the edge of their bed, not quite knowing what to do next or why I was even there. Mrs. Sen, luckily, did not give me the opportunity to stammer my way through an awkward introduction.

"I'm not a bad person, you know." She spoke quickly, as if there was urgency and a need to voice her story immediately. "I know what everyone says about me. I know they think I have been unfaithful. But 20 years ago, right before I was pregnant with my daughter, I was very anemic, and I had to get iron shots. I remember they did not change needles between each patient, but I never said anything. I think that's when this happened to me."

Whether this was how she contracted HIV can never be verified, nor should it matter at this point. As doctors, we are well versed on the statistics, demographics and exposures associated with HIV infection. These epidemiological parameters have important implications for public health and aid in assessing the pre-test probability of HIV infection, but probing for the specific event leading to contraction of the virus only serves to assign blame and satisfy our lurid curiosity. However, Mrs. Sen insisted on sharing her story, because although having HIV was shameful enough for her, certain modes of transmission carried an even greater stigma.

At that moment, Mrs. Sen's daughter entered the room with her husband and other extended family. They had heard a "doctor" was at their house and rushed over to have their questions answered. Over the next half hour, I answered, in broken Bengali, questions ranging from the minutiae of how to reschedule a doctor's appointment to the complexity of how the virus causes opportunistic infections. Referring to Mrs. Sen's daughter, one of the family members asked, "How did she get HIV?" The question was innocent, but the tension amongst those that already knew the answer was palpable. I answered the question as non-specifically as possible, giving more of an overview of the different modes of transmission.

After the extended family had left, Mrs. Sen explained her trepidation. "My daughter, her husband, and my husband know I have HIV, but nobody else does." With a touch of panic in her voice, she implored, "Please don't tell them." "The other villagers, they know something is wrong," she continued. "They know I've gone blind. But they don't know why. They already stopped coming by our house. I'm afraid of what will happen if they learn the truth."

Controlling the network of people privy to her HIV diagnosis was a central theme in Mrs. Sen's life. She tried to strike a precarious balance—informing those that were affected by her disease, but hiding her illness from all others, even if they were within the family. It was exhausting for me to keep track of who knew what, and I can only imagine how difficult it must be to maintain that web of secrecy and trust.

By this time, it had been over an hour since I had been in their room, unusually long for a visitor to the Sens. It was a small community, and gossip had apparently spread that I needed to be rescued. Thinking I had been pressured into entering this house of disease, they came out of goodwill to provide me an escape. I was actually already wrapping up, so I made my exit a few minutes later. On the way back to my uncle's house, I was rebuked. "Why did you have to go in there? They aren't clean, you know." We got to a water pump, and I was made to scrub my hands thoroughly, as if I were a child caught playing in the dirt. By simply having interacted with the town pariahs, I had carried out of the house some of their stigma. I was tainted by whatever was in their air. Most importantly, I had broken the barrier they constructed out of fear and ignorance to protect themselves against this mysterious malady. The stigma I held, though, was ephemeral and easily washed away with soap and water, a luxury not afforded to this family.

The reaction of the villagers was all too common, and exactly the type of response Mrs. Sen feared. Petrified to go out and embarrassed to invite people in, Mrs. Sen had quarantined herself in her one-room home. This solution, obviously, was unsustainable, as solitude takes its own toll on the human spirit. I realized the reason I was called to their home was not to showcase the medical acumen I did not yet possess, but to serve as a human witness to her plights and a validation of her character. Before I left, she told me in a tone of resignation that now that her daughter was married, she could die peacefully. She was grateful for her husband, who continued to fight and seek medical care on her behalf, but she herself had given up, paralyzed by the indignity she would face outside the home. Even going to the doctor was embarrassing.

Thinking back to my initial prejudices, I cannot blame her. We ask patients intrusive, personal questions with the explicit guarantee of confidentiality, but also an implicit guarantee of freedom from judgment. Physicians, being human, are not immune from making presumptions about patients, whether intentional or not. We can be particularly unforgiving for diseases for which we blame the patient, ranging from obesity to depression to HIV. Rather than deny these thoughts exist, we should be cognizant of them and prevent them from affecting patient care. Mrs. Sen was so discouraged by this judgment that she delayed seeing a doctor until CMV had already consumed her eye. She hid out in her room, shedding pounds in parallel to her plummeting CD4 counts until she became so feeble and cachectic she wouldn't have been able to leave even if she wanted to. She was disappearing, both literally and figuratively. There have been such great strides in HIV research over the last thirty years that the virus itself no longer has to be a death sentence; however, the burden of shame it carries still makes it one.

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