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 assumed he had HIV. 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 kind of woman must she be?” “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 me at all. 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 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 kind of woman must she be?” “She’s a liar. A cheat. A whore.”

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.
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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