

Forever Young

I FIRST MET TERRI (NOT HER REAL NAME) THE DAY I discharged her from the hospital. I had just returned to Connecticut after spending 6 weeks in rural South Africa working in an HIV clinic as an away rotation during my internal medicine residency program. Coincidentally, my first “inpatient month” as a third-year resident since my return happened to be the inpatient HIV service. As I pushed open the door to Terri’s room, I was greeted by a waif already dressed in a snug checkered jacket, skinny jeans, and a cocked newsboy hat. She perched like a pixie on the edge of her bed, exclaiming, “My sister’s waiting for me downstairs with the car running. I can’t wait to get out of here and go to the mall!” Her gruff voice clashed with the furry boots on her feet and the bubble-gum polish on her nails, but 22 years of fighting HIV had earned her each raspy note like medals in a war. So I gathered her prescriptions and sent her on her way, thinking I would never see her again. After my rotation in South Africa, it felt like a luxury to be able to provide her with all of her necessary medicines, which I thought would help her stay out of the hospital.

However, two weeks later when my team was on call, Terri was readmitted. Her abdominal pain had returned, worse than before. This time as I stepped into her room, instead of the trendy girl I had sent home, I found her 90-pound frame drowning in a hospital gown. “Can you make it quick? I really want to sleep,” she growled, shackled by layers of blankets. Hastily, I breezed through some questions, briefly examined her abdomen, then left her alone. Terri had been perinatally infected with HIV, and her mother died when Terri was 12 years old. She claimed to have taken HIV medications all her life, but the disease had weakened her body. In South Africa, I had seen patients with CD4 cell counts in the single digits, but I did not expect to see that at home. However, Terri shattered my myths, and her low CD4 cell count made her susceptible to *Mycobacterium avium-intracellulare* (MAI). This infection had caused the lymph nodes in her abdomen to enlarge, leading to unbearable pain. Two weeks ago, I had sent her home on a cocktail of seven pills a day. To me this had seemed like a reasonable regimen for someone with two complicated infections. She should have been getting better. Instead, she had returned to the hospital with even more pain than before.

During the five days of her hospital stay, no matter when I entered her room, she lay curled in a fetal position buried beneath the covers with the lights off, the blinds closed, her eyes shutting out the world. Not once did she have a visitor. Since she lived 20 miles away from the hospital, she

claimed her family and friends could not afford the trip, nor did they have the time to travel this far to see her. Once I asked if she would rather be followed up closer to home so that she could have visitors. I was surprised when she refused: “It wouldn’t make a difference anyway.” At least this way she could continue believing that they would have come if they could.

She never smiled. We tried everything. I spent one afternoon arranging for pet therapy. When the friendly dog wagged its tail outside her hospital room, she merely glanced at the animal from the door. When we found out she liked ice cream, the medical students on our team arranged for a wheelchair to take her down to the cafeteria so that she could make her own ice cream concoction at the new Moo Bella machine. They offered to rescue her from her dark hospital room and help her flee to the hospital’s healing garden. Initially, she would accept, but whenever they would come to her door equipped with wheelchair, she would postpone. We even had a medical student-turned-nun spend some time with her. When the sister left her room, her biggest accomplishment was “At least I convinced her to open the blinds.”

Directly observed therapy completely backfired with her. “Who does that nurse think she is! Waking me up, then forcing me to take all my pills at once! I’ve been doing this all my life!” Reviewing her medication records during rounds, I saw that just about every other medication had an X next to it with the phrase “Patient refused” glaring back on the computer screen. We were never sure if those records were mistakes, since Terri insisted that she took the medications after the nurse had left the room because if she didn’t stagger them, they would “drill a hole” into her stomach. But despite the medications, Terri’s pain increased. We then repeated her CT scan, which revealed that the lymph nodes in her abdomen were now larger than they were two weeks ago, prior to treatment. Since genotypic testing for HIV drug resistance had been performed before initiating her current HIV regimen two months ago, it seemed unlikely that her HIV medications were ineffective. Either she was slow to respond or, more likely, she just wasn’t taking her medications.

Despite this, Terri vowed she wanted to live. But after five days, she demanded to leave the hospital. We asked her to stay, take her medications, and regain some strength. But she insisted on leaving. “What more are you going to do for me? There is nothing left to do.” An intern on our service tried to convince her that back in the day, HIV patients would

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have to take 12 pills several times a day and that our current regimens are more convenient. Terri responded, "I know. I used to take those pills." I also went into her room later to try to convince her to stay, but she was intent on leaving. "There is nothing more you can do for me here. I just want to go home." Defeated, I slumped out of her room.

Before she left, I entered her room one last time, the blinds closed again although she was preparing to leave. "Do you mind if I sit down?" I asked. She was sitting up in the bed for the first time, combing her hair in preparation for discharge. With each stroke, the comb pulled out clumps of hair, leaving broken and brittle strands in a nest on her lap. Although I knew she had an HIV physician here, I was afraid she would have no one to turn to closer to home. As a long shot, I put myself out there. Staring down at my hands, I stammered, "Um, Terri, I was wondering if you want a doctor closer to you who could be there as your primary care doctor. Well, my clinic is close to your home. If you want, I could be one of your doctors."

Surprisingly, she looked up and seemed to register me for the first time since we met: "Okay."

Three weeks later, I was pleased to find Terri's name on my clinic schedule for 2:45 PM. My busy day in clinic somehow distracted me from thinking about Terri as I concentrated on my other patients. I encouraged one patient to stop drinking regular soda to help control her diabetes. The next patient haggled with me to reduce his exercise quota for the week, but I didn't give in. Finally, an inebriated young man begged me to treat his depression instead of helping him give up alcohol. Exhausted already, I pushed open the door to my 4:15 PM appointment when it hit me.

Terri never came.

Terri was readmitted to the hospital several times over the year, but never to my service. Fellow residents would keep me updated on how she was doing. After several months with her supposedly on treatment, Terri's repeat CD4 cell count remained in the single digits and her cultures continued to grow MAI. I felt like this was somehow my fault; that I had not tried hard enough to convince her to take her medications. I felt like I had failed her. According to her last discharge summary, she was sent home on 13 different medications, some requiring multiple doses during the day and each with several pages of side effects. Many of the medications specify abdominal pain, nausea, vomiting, and gastrointestinal discomfort as adverse effects, the same symptoms that would drive Terri to the hospital. How could I expect this young woman who had always lived with a destructive disease to comply with these increasingly complicated and unpleasant regimens? Similar to several perinatally infected adolescents I had met in South Africa, Terri understood that taking her medications would improve her immune system and keep her healthy. But like many of them, she still apparently would not take the medicines daily. Perhaps this one action provided a sense of control over her life, a life that was filled with many things that happened beyond her control. For many people in both the United States and abroad, HIV has become a well-controlled chronic disease, but for Terri and other perinatally infected young people, HIV is still capable of claiming lives.

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