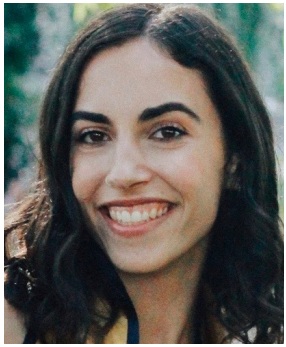
A Present for Sonia

Shira Tikofsky



Writer's Comment: After returning from a study-abroad internship at the pediatric hospital of Ghana, I could not walk away from the people I met and the experiences they shared with me. I spoke with many child-mothers who had never been given a chance to learn about sexual education, consent, or their own physiology. I wanted a platform to recognize and draw attention to the struggles faced by these women, so when Professor Herring gave us the task of writing a narrative case report describing the life story of someone who was hurt or sick, I found my opportunity. My mind jumped to the heartbreaking case of one patient in particular with whom I became especially close during my volunteer work. Sonia's story embodies many all-too-common battles experienced by women who are sex workers, HIV positive, mothers, and those who are impoverished. I feel very lucky to share her complex narrative and honor one of the most resilient woman I have ever met. A Present for Sonia.

Instructor's Comment: The single most important thing you do in medicine, working doctors tell me, is take good patient histories. For that reason, in my Writing in the Professions: Health course, I assign two case reports based on what actually happened to two people who have been hurt or sick. In the first, the tone remains cold and clinical, but the second is informal. The students explain the condition so anyone can understand it, and at the same time tell the life stories of the people involved, tasks science students are not often allowed to practice. I ask them to write like professional writers, and with some feeling. Shira's winning essay excels at all these skills, the last one especially. Like so many of our students, Shira, as an overseas volunteer, had the day-to-day reality of healthcare in the developing world brought home to her. For the details, which are wildly complex, you will have to

turn to her essay. It is easy to feel overwhelmed on such journeys, but Shira and her fellow team members did everything they could not to give in to the sense of powerlessness that should have come naturally. They allowed a better impulse take command—another important thing you do in medicine.

—Scott Herring, University Writing Program

Nurse Auntie Serwah was the angriest I had ever seen. She was furious with an HIV-positive mother who stopped taking her HIV medication while pregnant, thereby infecting her baby with the virus. After a firm scolding, she sent the mother away, took a deep breath, and remembered her other patient sitting in the corner. Both the nurses and I guessed that this petite girl with the oversized dirt speckled clothes was fifteen years old. We were shocked to discover that she was actually eighteen. Between laughs, she told me her name. This was the first time I met Sonia, a patient at the only pediatric hospital in Accra, Ghana where I was a volunteer.

When Sonia tested positive for HIV, we learned that she knew nothing about HIV or AIDS. This is not surprising, as sexual education in Ghana is very limited and the stigma of HIV often prevents it from being discussed. Accordingly, Auntie Serwah and the other HIV nurses in the hospital were determined to prevent the spread of HIV and were strong advocates of the UNAIDS board's "90-90-90" target of managing the worldwide AIDS epidemic: by 2020, ensure that 90% of HIV positive people know their status, 90% of this group is on antiretroviral medication, and 90% of people on treatment have viral suppression (UNAIDS 2014). Following this, the nurses knew that Sonia had to understand what it meant to be HIV-positive before they could move forward. Auntie Serwah was a special woman; she had mastered explaining HIV in an urgent yet clear way that minimized upsetting or scaring patients. Every day, she would deliver the same speech to the patients who landed in her office. In her speech, she always included her favorite catchphrase: "HIV is the virus, AIDS is the disease." She often elaborated, "If you take your medication, you can live as long as God wants you to live in this world." As our conversation shifted, Sonia's eyes wandered. It seemed as if there were ten other things on her mind.

In our investigation, it soon became clear that Sonia is homeless. Every day she roams the streets until men approach her and "take advantage and sleep with her when they want." Some days, she works

for a friend who pays her 80 cents to wash dishes and, with that, she can afford a meal. On these nights, he lets Sonia stay at his house but she doesn't sleep because she is always too scared to close her eyes. Instead, she forces herself to stay awake by watching TV in anticipation of random men who stumble into her friend's home and try to persuade Sonia to sleep with them. In exchange, she may receive 50 cents or a dollar, and these evenings act as her main source of income. Nurse Auntie Serwah explained that Sonia "spends everything she makes to survive without thoughts about tomorrow."

Female sex workers account for 7.9% of people with HIV in the region. They are one of the key infectious populations to target for the 2020 goal of HIV eradication because they can so easily expose others to the virus (Aban 2019). While this was an obvious source of Sonia's infection, Auntie Serwah wondered aloud whether she might have contracted HIV from shared needles and gave a head nod towards the tattoo on Sonia's forearm. When I asked Sonia about her tattoo, she blushed and shyly told me it said "Elisebaby," a nickname given by her baby's father. Auntie Serwah smiled and teasingly chanted: "elliiiisseebaaaaaby," Sonia started giggling, and we all burst out laughing. Once the laughter ended, Sonia's shy smile and the look of amusement in her eyes remained, but now her fear was all I could see.

It was through this conversation I learned that eighteen-year-old Sonia had a two month-year-old son. A week prior, he tested positive for HIV while in the ER for a breathing problem. Accordingly, Sonia was tracked down through an old caregiver entrusted with Sonia's baby. Because she was hesitant to go to the hospital, the caregiver had to trick her to come in for testing by telling her the hospital had a present waiting for her. "Where is my present?" Sonia asked Auntie Serwah. "You'll get it next time you come in," she replied.

Four days later, Sonia walked into the hospital's social welfare office and a sense of relief flooded the room. We had all become attached to her case and wanted to find a fast solution to her "hand-to-mouth living." As we asked about her background, Sonia responded with conflicting, incongruent narratives. By the end of our session, we had heard at least five different stories about where she slept every night, whether she used contraceptives, and whom she slept with.

As she spoke, I noticed blood seeping through her white shirt. My eyes wandered to a deep scab above Sonia's eye, and a social worker named

Bona caught my gaze. He leaned back in his chair and whispered in my ear that Sonia's odd behavior stemmed from epilepsy. She was not taking her medication as prescribed and was experiencing avoidable symptoms such as memory lapses, odd behavior, and seizures (Adamolekun 2018). While wandering through different cities, she would often seize in the streets and fall to the ground. Sometimes people would be around to catch her, and sometimes they wouldn't. Her hand wandered to the growing red stain on her shirt; she did not know she was bleeding.

Bona explained that Sonia attributed her symptoms to spirits. They followed her, and for this reason, she refused to settle in one place and was homeless. Her only way to make the spirits dissipate was through a ritual performed by her mother. Oddly, because her mother was aware of the spirits, Sonia believed she and her child were not safe to stay with her. They lived in a small rural village, and Sonia's pregnant forty-year-old mother was a single parent to nine children and two grandchildren, without resources to provide for everyone. Therefore, she had sent Sonia away at only three years old to live with the caregiver as a house servant. This was the same woman who tracked down Sonia to bring her to the hospital. The caregiver took on the role of a mother to Sonia until she ran away at age eleven because she did something bad—I never was able to find out what it was. Six years later, Sonia showed up on the caregiver's doorstep with her three-week-old baby and disappeared five days later. From the caregiver's view, Sonia's baby was "dumped on her."

If Sonia could not stay in one place without running away, how would she take either of her medications? How could we prevent her from being taken advantage of? If she did not want her child to stay with his grandmother, could he stay with someone else in her family or the caregiver? The social workers believed that Sonia was "a risk to herself and society," as she did not understand that she was infectious and therefore did not take preventative measures of caution. She needed to begin treatment for both HIV and epilepsy and "she needed someone to watch over her" and ensure she took her medications.

Because of the negative stigma of HIV, society is quick to reject those who are HIV-positive. Although HIPAA laws do not exist in Ghana, patient confidentiality associated with HIV follows the same procedures. Clinics disclose a patient's HIV status individually and privately, even between partners. This way, the negative stigma associated with HIV is less likely to prevent patients from coming in for testing or treatment.

However, the fact that patients are given the power to share or withhold knowledge of their HIV status comes with a cost. Sonia's mother, the baby's father, and his parents all wanted custody of the child because he is "good looking," which to my surprise meant fair-skinned. The caregiver explained that this is desirable because "he will have opportunities that we don't. . . . He is not one of us, he doesn't look like us." However, none of these family members knew that Sonia or her baby was HIV-positive. The caregiver was the only one who knew the truth about their status, and she was unable to maintain custody of the child. Given the stigma surrounding HIV, I feared that no one would want to care for the child or Sonia upon learning the truth.

A custody battle erupted between Sonia's mother and the baby's father, Samiru. The social workers debated in whispers whether they should share the status of Sonia and her baby. If the family knew, Sonia and her baby could lose a "place to stay where someone cares for them and gives them medication." The baby's paternal family had already shown a strong negative reaction to Sonia's epilepsy and hid from her when she came to visit (they thought her evil spirits would also pass to them). If they knew Sonia and her child were HIV-positive, their reaction could be more severe. In addition to violating Sonia's rights, telling the family would reinforce the stigma against HIV testing due to the fear of public exposure. On the other hand, if the nurses kept Sonia's status a secret, who would make sure that Sonia took her medication and that she didn't infect others? The true battle at play was between the rights of society to be secure from HIV, the right of family members to know the truth, and the patient's rights. Ultimately, the nurses decided to reveal the HIV status of Sonia and her son to those in the custody battle.

When we met the child's extended family it became clear that Sonia's mother was not the most suitable choice for full custody of the child. When the baby was first born, Sonia and her son stayed with her mother. After three weeks, Sonia took her baby and ran away because her mother had tried to feed the infant solid foods and he became severely malnourished. She went to her second mother, the caregiver, a woman she knew that she could trust. When they arrived at the caregiver's doorstep, the baby was only made of "skin and bones." Her mother lacked the resources to provide for her nine children already, so how would she care for Sonia's baby? However, cultural barriers prevented the baby from going elsewhere even though Samiru's mother was described by the social

workers as the ideal choice.

According to cultural tradition, if a baby is born out of wedlock the child's father must pay the mother's family to customarily claim the baby as his own. Furthermore, the baby's father is supposed to pay for expenses during the mother's pregnancy. However, Samiru was not only absent during Sonia's pregnancy, but he "got Sonia pregnant before they were married." Until his debts were paid, his family could not claim custody of the baby. A separate issue at play was that the baby formula was unaffordable for all parties; it was almost nine times more expensive than the average cost of living in Ghana every month. We decided as volunteers to raise money for the rest of Baby Sonia's formula to remove it as a consideration in the final decision. Nonetheless, Samiru never paid Sonia's family the money they were owed and Sonia's mother ended up with full custody of the child. With our donation, she was able to pay for the baby's formula and with proper education from the hospital, I was happy to hear, she was "doing a good job and the baby is doing well." Sonia, on the other hand, was not doing as well. She was still controlled by her spirits and could not stay in one place, meaning she was not taking her medications.

On my last day at the hospital, Auntie Serwah took me on a tour of a nearby market and we bumped into Sonia. She was roaming the streets, and I momentarily forgot the reality of Sonia's existence outside of the hospital. I gave her a long hug, said my goodbyes, and was surprised by her disappointment that her "friends" were leaving. As I walked away, I heard a faint voice ask, "Auntie Serwah . . . when can I have my present?"

References

Aban I. 2019. In: Princess Marie Louise Children's Hospital of Ghana. [In-person interviews 2019 Aug-Sept].

Adamolekun B. 2018. Seizure Disorders. Merck manual professional version. Kenilworth (NJ): Merck Sharp and Dohme; [accessed 2019 Nov 19th] https://www.merckmanuals.com/professional/neurologic-disorders/seizure-disorders/seizure-disorders?query=epilepsy%20symptoms.

[UNAIDS] Joint United Nations Programme on HIV/AIDS. 2014. 90-90-90 An ambitious treatment target to help end the AIDS

epidemic. Geneva (Switzerland): UNAIDS; [accessed 2019 Nov 14th]; https://www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf.