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“Healthcare Access, Attitudes, and Knowledge of HIV Positive Women in Pune, India”

I spent my time in Pune, Maharashtra, India conducting fieldwork on HIV healthcare access, attitudes, and knowledge of HIV positive women in India for my senior thesis. I worked to understand their situation by interviewing 45 HIV positive Indian women, and sometimes their husbands, on their health and life experiences relating to HIV. The patients I spoke to came from a wide range in backgrounds, from rickshaw drivers to women with MBAs. Each person has faced their own set of challenges in eventually receiving HIV treatment, and many patients have told me about injustices they have suffered in both social and medical situations. I also interviewed four HIV doctors, a traditional healer who practices Ayurveda, HIV counselors, pharmacists who supply antiretroviral therapy (ART), and founders of NGOs for HIV positive people. These interviews allowed me to learn more about the situation of HIV in the state of Maharashtra and the resources available to HIV positive people. In the process, I created a safe space for HIV patients to share hardships they are rarely or never able to discuss with others because of fear of social stigma and misunderstanding, while sometimes connecting them to resources to help them cope with treatment and stigma. Conducting fieldwork on HIV healthcare access has revealed experiences ranging from dissonance and injustice to empowerment and hope.

Early on in my research I had difficulty accessing the government centers and HIV patients, and it turned out it would take several months to seek approvals from multiple government institutes in order to interview patients at the free government centers. Instead I

focused my efforts on interviewing patients at private HIV clinics and NGOs, through which I was able to interview patients who access public and private treatment for HIV. In India free healthcare is available at public government hospitals, but the conditions are crowded and understaffed. For some people spending a day each month at the hospital to pick up medicine and have tests done is a small burden for receiving free healthcare, but for others this means losing a day or two of work every month and risking being seen by someone in the community. For those who are able to pay, healthcare at private clinics is more comfortable, convenient, and private. In my interviews with HIV patients going to private doctors, many patients expressed negative attitudes towards public treatment for the lack of attention from doctors and long waiting times. Most patients who regularly received public treatment did not express these things as major complaints. The challenges experienced by HIV positive people go far beyond choosing between public and private healthcare.

One major challenge I had was when I encountered a doctor, who I will call Dr. R, who would sell ART for two to five times the cost that others sold the same medicines. When I told him other doctors' prices were much less, he said "No, impossible." I knew I needed to be well informed on ART drugs, brands, and pricing to confront Dr. R about his unfair prices. I went in search of knowledge on price determination, why and how others are able to offer much lower prices, and the exact prices for specific medicines and where they were available. I not only researched online, but also went to HIV doctors and pharmacies around the city to collect information. The next time I met Dr. R, I was well equipped with evidence on how the same ART medicines are available at much lower cost. Although making him change his prices was out of my scope of power, I was at least able to provide strong evidence and alternatives to challenge Dr. R's overpricing. It is difficult to say whether or not this difficult conversation

influenced any change in prices or Dr. R's attitudes. It is important to note that most doctors I spoke to were just and compassionate towards patients, and some even forgave patients if they were unable to pay for medicines some months.

For almost every patient I interviewed, people were tested for HIV only if they were in hospitals for other reasons, such as pneumonia, TB, pregnancy, or if their husband was terminally ill. When it comes to HIV knowledge, most patients knew very little about HIV before finding out their status. Some had never heard of HIV; others only knew the name. Just a handful of patients knew about transmission before they knew about their status. It is only when patients are fortunate enough to have a doctor who informs them on the disease and treatment that the patient is empowered with information. When patients have the right information, they have so much hope and optimism.

Most patients I interviewed have only used antiretroviral treatment, but a few patients from rural areas initially used only Ayurvedic treatment for HIV before finding out they had other options. Misconceptions or lack of knowledge and information can prevent HIV positive people from receiving proper treatment. For example, one woman from a rural town was on Ayurvedic treatment from 2002 to 2015, until a doctor in her rural town referred her to an HIV doctor in Pune. Ironically, the Ayurvedic treatment cost more than ART at the private clinic. Several patients said they had seen advertisements in newspapers or signs on the streets in their hometowns advertising a cure for HIV, and the Ayurvedic doctor I interviewed said that his treatment can cure HIV. These are dangerous misconceptions that can cost HIV positive people their lives.

The experiences of HIV positive women in India were a manifestation of the public policies and healthcare system. For example, one woman who I will call Riya, found out she was

HIV positive during pregnancy in the late nineties. She aborted her child because no treatment for preventing transmission was accessible to her. Although treatment for HIV and for preventing mother to child transmission existed, it was not available to most people in developing countries because of patent laws that kept the cost of the drugs high and inaccessible. This resulted in over 10 million preventable deaths, including the death of Riya's husband in 2001. It was not until patent law changed, generic HIV drugs were produced, and government centers began providing free treatment that Riya began HIV treatment. Through changes in global policy and the national healthcare system, the life of Riya and lives of millions of others improved.

Riya's experiences contrast with the experiences of another woman, who I will call Shweta, who found out she had HIV in 2004 during her third trimester of pregnancy. The only thing she knew about HIV was that people died from it, but when treatment and support became available to Shweta, her entire outlook changed. Today she lives happily with her 12-year-old son who is HIV negative because Shweta was able to access treatment in time to save her child and herself. This narrative is not unique to Shweta. Through the HIV positive women I worked with in India, I witnessed that when they had the right support, treatment, and knowledge, these women were empowered and full of life. In the same way that doctors were able to renew the lives of women like Shweta, I too want to empower patients and alleviate their suffering through healthcare. I appreciate the men and women who opened up to me and shared their experiences and hardships, and I want to do more for them and people affected by HIV and other diseases.

Listening to the difficulties and injustices many HIV patients experience has been both engaging and emotional work that gives me even more reason to pursue a career in medicine and public health. Although this summer I was only able to provide emotional support and

information to HIV patients, I hope to return to India to treat and provide care for marginalized populations affected by disease after medical school. Already, I have established strong connections with HIV doctors with whom I can see myself continuing to work even after this research is complete. I look forward to continuing this research as I write my senior thesis. I will be sharing my findings and senior thesis with the doctors and NGOs I worked with in Pune. I hope my research can be useful to the doctors and NGOs, as they may reveal experiences and knowledge gaps in HIV positive people in Maharashtra that can be addressed.