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AIDS at the margin: Experiences and lessons from marginalized groups in India (Part I)

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In the summer of 2008, I travelled to Uttar Pradesh to observe the impact of HIV/AIDS in rural and urban areas. I journeyed from inner-city alleyways to lush rural villages. This part details my encounters with several groups of people. Their narratives coalesce in a mosaic of experiences, each a function of time and place, but not far outside the definite contours of sociocultural influence. The result is a snapshot of the impact of a devastating disease on a society and its core institutions; of chaos and uncertainty, but also of profound unity and hope.

Over the course of my observations, one overriding theme became clear: HIV/AIDS is not merely a disease of the body, but an infection that permeates rifts in the social and economic underpinnings of society. As such, the best way to learn about the social factors driving the AIDS epidemic is to study the marginalized groups whom the disease infects most frequently. The need to do so could not be more urgent—the latest UNAIDS estimates show that India has the most HIV-positive individuals of almost any country in the world.

The second part of the article lists the steps that health policy-makers and doctors specifically can take to combat further spread of this disease. Ultimately, the aim of this work is to encourage healthcare professionals to begin critically examining the socioeconomic roots of the AIDS epidemic to lead India towards solutions that remedy the disease and change society.

THE EXPERIENCES OF MARGINALIZED GROUPS

Aaliyah

Aaliyah begins speaking, hesitantly at first but soon at a quick pace. She speaks with the pronounced accent and dialect of the rural areas surrounding the city of Allahabad, where we met in a community health centre. A mother of two in her mid-thirties, she spent most of her early life in a remote interior village where she was born, married at a young age and started a family. She and her husband earned a living by growing rice on his family's land. Her husband occasionally travelled to New Delhi in search of work during the dry months.

Three years ago, Aaliyah's husband was hospitalized after suffering from a fever for several weeks. His doctors treated him for everything from tuberculosis to meningitis, but without success. After his weight dropped several kilograms, the doctors sent a blood sample to a better-equipped urban hospital. Unfortunately, the results returned too late. Three days after her husband died, Aaliyah was told that he was HIV-positive and showed typical symptoms of AIDS.

These terms, however, were completely foreign to Aaliyah. She was not alone, for awareness of the disease was virtually non-existent in her rural community, and limited even in large cities of Uttar Pradesh. Experts had long held that HIV/AIDS was a problem only in the southern parts of India and thus dedicated scant resources to fighting the disease in the northern states. Because Aaliyah herself had no formal education, she could not read the pamphlets on sexually transmitted infections available at the hospital. She was not aware of the need to have both herself and her children tested for HIV. After leaving the hospital, Aaliyah moved into her in-laws' home with her children, then 11 and 15 years of age.

Barely a year later, Aaliyah discovered that she too was HIV-positive, after experiencing symptoms similar to her husband's. She was told that she had at most 5 years to live, provided she began taking antiretroviral therapy (ART) immediately. Although this was devastating to hear, Aaliyah was even more frightened by the prohibitive cost of ART, which would quickly outpace her minimal income from subsistence farming.

By now word had reached Aaliyah's village of an incurable illness known as *mahamaari*. Aaliyah was the first in the community to contract the disease, for which she and her children suffered enormous stigma. Fearing that she was contagious, her in-laws would not eat with her or touch her clothing. They even blamed her for her husband's death, claiming she was unfaithful to him while he was away. Her children were taunted and marginalized by their schoolmates. Aaliyah and her children left the village. They moved to the home of Aaliyah's elder brother, a manual labourer living on the outskirts of the city. Aaliyah looked unsuccessfully for work while her savings diminished. She had to quit the few jobs she could find because of weakness and deteriorating health.

No one told Aaliyah that the therapy she was spending a fortune on could be obtained for free at government hospitals. It was not long before she descended into the last stages of desperation. Finding herself homeless and unable to provide for her family, she sent both her children to live with relatives and made preparations to embark on her own. It was at this moment when, by what Aaliyah calls 'an act of God', she was discovered by an outreach worker from the community health centre where she and I engaged in conversation.

The past 2 years, she recalled, were life-changing for her. With the guidance of outreach workers and resources in the city, Aaliyah reorganized her healthcare, employment, family life and, importantly, her facts. She learned that surviving for 10–15 years was not outside the realm of possibility for someone who carefully followed the ART regimen. She regained much of the weight she had lost; began taking the free government-provided ART; her children finally moved into a stable home and her son returned to school. However, the fact that she has a lifelong illness weighs heavily on Aaliyah's mind. She admits to losing hope often, but not nearly to the degree she did before finding the resources in the

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city. In a testament to human resilience, she says: 'I have had to overcome so much in life. Surely I can overcome this too.'

Seventeen men

Alfred Park is a tranquil escape from the bustling metropolis of Allahabad surrounding it. Walking paths wind through a lush tropical forest, interrupted only by small clearings with relics of India's colonial history. I visit the park looking for a group of seventeen men. Many of them are homosexuals, part of a support group for economic empowerment and peer education on sexually transmitted diseases. They agreed to meet me on the condition that I did not bring a camera or conduct any formal interviews.

Homosexuals are marginalized to the periphery of Indian society, living in constant fear and lack of social acceptance. This is surprising given that India is a progressive country by many other metrics. Nonetheless, a sustained grassroots effort has mobilized homosexuals in Allahabad and other large cities to band together in small but cohesive support groups.

This particular group is led by a volunteer peer educator, a young university student. The group members are predominantly young men who work as manual labourers, in retail employment or are unemployed. This demographic is fairly representative of the city's homosexual population, as is the most common story among them: their families grew suspicious after they were reluctant to get married; fearing sexual deviance, the family expelled them from their home, and they were homeless for several months before finding stable employment and accommodation.

These young men are even further alienated in a society where homosexuality is socially unacceptable and same-sex marriage is illegal. One young man recalled being fired from his job after his co-workers suspected he was a homosexual because he did not visit prostitutes with them. After losing his job, he resorted to commercial sex work to pay his rent.

Unlike female commercial sex workers, whose brothels are established in a red-light sector of the city, male sex workers often have sexual relations in alleyways or parks. They are at high risk for contracting HIV because they have multiple sexual partners and because they lack the bargaining power to make clients use condoms. An individual in the group who used to engage in commercial sex claimed that his clients threatened to report him to the police if he asked them to use a condom. Female sex workers, on the other hand, can remain relatively safe because brothel owners can institute a condom usage policy and protect their workers from abuse.

Moreover, encounters with law enforcement can end in disaster. In fact, the group members reveal that they were supposed to meet a day before, but had to disband because the police broke up their meeting. Several group members recall being physically or verbally harassed by the police simply for being in public places known for homosexual liaisons. For example, one young man was severely beaten for carrying a condom (a completely legal act), and the police stopped short of taking him to jail only after receiving a bribe.

Social stigma has also endangered the health of the homosexual community. Public health efforts have been obstructed because social workers cannot actively work on behalf of homosexuals in the open. Like our meeting today, they are forced to meet in secret, with constant fear of the police. As a result, the homosexual community has become insular, secretive and decentralized. Group members claim that they have special code words, phrases and body language that they use to identify other homosexuals.

This environment makes any HIV/AIDS-related intervention extremely difficult. It took several years for a network of support groups to even begin, because finding and retaining members was extremely difficult. A large portion of the homosexual community (akin to the public at large) has little awareness of HIV/AIDS or other sexually transmitted infections, and thus did not see the need to form support groups in the first place.

Increasingly, however, homosexual young men are not content to live at the periphery of society. Thus, they form support groups who collect monthly contributions in a small bank account and form a pool to give each other small loans. Members use these group loans to start their own small business, go to school or pay their rent. The support group is also a perfect environment for peer educators to educate members about sexually transmitted infections and condom usage, and also to connect them with important resources. For example, one member of the group has begun studying in a university because the peer educator helped him through the examinations. When I ask the peer educator how he finds time to pursue his own studies, earn money to support himself, and help the members of this group, he responds, 'They are just seventeen men. They have only each other and me. So what choice do I have?'

The doctor and the drug addicts

Our crowded car comes to a sudden halt along a nondescript side street. We exit the car and enter a web of alleyways between slum dwellings. We are looking for an HIV/AIDS outreach clinic that serves injecting drug users (IDUs), many of whom live in slum areas. 'Come inside!' calls a voice that seems to come from inside a brick wall. Upon closer inspection, I see a narrow entrance to a small room, where a man in a white laboratory coat is seated below a ceiling fan. 'I'm Dr Chatterjee!' he says.

I enter the room, which is actually the clinic we have been looking for. Dr Chatterjee is the clinic's physician, pharmacist and administrator. He shows me a thick ledger of patients who visit the clinic; although he is assigned to serve drug users, his patients include many of the destitute residents of the surrounding slums. 'The government hospitals', he explains, 'are too far away. Also we have a rapport with the people here.'

Meanwhile, our team members re-stock the clinic. The most vital supplies are sterile syringes for the clinic's needle exchange programme. Our team also delivers condoms and informational pamphlets for the dispensary attached to the clinic. Both the needle exchange and condom distribution programmes are vital to fighting the spread of HIV, which is transmitted both sexually and through blood.

I ask Dr Chatterjee what motivated him to leave his post in a large government hospital for this isolated part of the city in an alleyway clinic. Drug users, he replies, rarely visit large hospitals. Thus, locally situated 'micro-clinics' are often the only ones to make contact with them.

Coincidentally, one of Dr Chatterjee's long-time patients visits while our team is at the clinic. His arms are clean of the abscesses that usually mark drug users. He drives a rickshaw, which even in the heat does not make him sweat. He introduces himself as Ram Singh; he is in his mid-forties, married and has 5 children. He has visited the clinic for several years, though he never confessed to using drugs until Dr Chatterjee gained his trust by obtaining tuberculosis treatment for his daughter.

Two years ago, Ram Singh suffered precipitous weight loss, fever and nausea. He was found to be HIV-positive and started on ART immediately. After receiving a check-up, Ram Singh

exchanges several used syringes for fresh ones from the dispensary. After a brief conversation and a cup of tea, he pedals away on his rickshaw.

As it turns out, there are an estimated 2000 IDUs like Ram Singh in Allahabad alone, only 500 of whom are linked to the network of government healthcare services. More importantly, IDUs are contracting HIV at a rate several times as high as that of the general population. Preliminary studies in Allahabad estimate that 1 in every 50 IDUs has HIV. The rapid spread of HIV among IDUs is due to the sharing and reuse of syringes, as well as other risk-seeking behaviour.

Our final stop was the Allahabad railway station, where we sought out homeless IDUs living along the train tracks. Upon our arrival, several individuals recognized our team members and approached us: rickshaw drivers, railway employees, homeless men and many others. Most of them, like Ram Singh, did not fit the stereotypes of drug users. One was a 10-year-old boy who ran away from his home and ended up in Allahabad by sneaking onto a train. His peers encouraged him to take inhalants ranging from rubber cement to cheaply available drugs; he will probably start using injectable drugs and become one of their customers. The boy's companion, a young man in his mid-twenties, reported that he has been injecting drugs for several years. Two years ago, while under the influence of drugs, he injured one of his legs and must now use crutches permanently. He and the young boy make money by picking pockets, collecting recyclable waste, and refilling empty water bottles and reselling them. When I asked them why they trusted us enough to come out in the open, the young man replied, 'Do you know Dr Chatterjee? We trust him, and so we trust you.'

(To be concluded)

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The names of all the people I spoke to have been changed.