

By Manjima Bhattacharjya

Zarina is just one of thousands of HIV–positive people caught between a government that cannot provide care and treatment to all, a private sector that is expensive and swarming with quacks, and NGOs that are driven by their own agendas.

Zarina is one amongst the thousands around us who are silently living with HIV. One of the many milling around us in malls window–shopping on a day out, rushing past us in railway stations to get home in time to cook for the family, or bargaining with the vegetable vendor while buying supplies for the week. Ordinary people living ordinary lives, and taking their HIV–positive status in their stride.



Treatment & Care Twenty–five–year–old Zarina’s story is however a little more than ordinary. At the age of 15, Mallika, as she was then called, ran away from her village in the hills of Nepal – away from a negligent father, stepmother and backbreaking hours of work in the fields – with a distant relative to take her chances with the world out there. Like many other girls before and after her, she ended up in Kamathipura, Mumbai’s red–light district, after being smuggled across the border. She remembers that night vividly: “I was given two pills that knocked me out. When I woke up I saw an incredible sight. A big monument and what I thought was a huge river. It was Haji Ali.”

After a few days in imprisonment in a room in Walkeshwar and a frightening encounter with police, goons, gharwalis and all sorts of characters, a shivering Mallika, who knew neither where she was nor understood the language around her, was taken to a new place that was to be her home for the next few years. A kothi (brothel) in Kamathipura. And thus began her new life, complete with a new name given by the gharwali. Zarina.

Life in Red

It took time for this sudden turn of events to sink in. Moreover, the red–light area wasn’t quite what she expected it to be. She says: “I saw a young girl cutting vegetables and another blowing a chulha. No gaudily dressed ladies of the night, no garish make–up. I could not believe it.”

“I tried to run away many times, I really did,” she remembers. “The gharwali told me I would have to pay her Rs 40,000 if I wanted to leave. Or I could work there for three years in which time my debt to her would be repaid. I had no choice. I didn’t see any sunlight for two years.

That became my life.”

Ek chhoti si love story

The next dramatic turn in Zarina’s life came when she fell in love with a young man from the neighbourhood. They shared a love for the silver screen, and as the young man began to take the beautiful Zarina for many matinees, their own love story began. It was accelerated by a chance discovery, after Zarina fell ill, that she was HIV–positive.

The doctor, who was personally known to the young man, told him that Zarina would not survive for more than a month if she continued in the brothel. The young man pulled all the strings he had – a contact with a hotel owner in the area who had contacts in the media, a photographer, and a social worker – and made a plan to run away with Zarina and marry her. To make sure that there would be no immediate backlash in the form of a police complaint by the gharwali, his contacts got the deputy commissioner of police himself to call the local police and ask them to ignore any such complaints.

Had things gone according to plan, Zarina and the young man would have been married on Valentine’s Day. But romance took a backseat to paperwork, and it was only on February 17 that a nikaah was performed. Soon after, not wanting to invite trouble by staying in the same area, Zarina and her husband moved to Navi Mumbai. They sold a gold chain to pay for a deposit to rent a small room in which they set up their new home.



Living with HIV Living with HIV

Meanwhile, Zarina’s illness was beginning to take its toll. Every month during her period she crumbled under a bodyache that reduced her to tears, a swollen abdomen and inexplicable white discharge. Often, it would be as frequent as once a week.

It was when she had to undergo an operation in the third month of an ectopic pregnancy a while ago that she encountered in some way the real meaning of her HIV status. Doctors at the hospital were hesitant to operate upon her when they found out her HIV status but had to do the operation. Various tests were done at this stage, including the CD4 and CD8. This was a government hospital where they considered enrolling for free treatment for HIV. However, they found that Zarina was not eligible for free treatment. According to the fine print, only patients

with a CD4 count below 200 are eligible for free treatment; those with a count above 200 have to pay for their treatment, the cost of which is about Rs 35,000 for six months. Why this differentiation amongst HIV patients? Just government policy, said the hospital. Those in the worse stages are given first preference for medicines.

With no way to challenge this logic, the couple turned to the private sector. An ayurvedic hospital in Worli was offering free medical treatment. But 'Free' once again did not really mean they could afford it. Even though they were giving the medicines free, they were required to go twice a week. Going from Navi Mumbai to Worli twice a week was not sustainable for the couple, and was not always possible given the young man's job. The medicines also seemed to have little or no effect. Instead, Zarina felt her body heated up, and she felt nauseous. After two weeks, the hospital wrote a prescription for the medication, saying that they had run out of stocks at the hospital and the patient would have to buy the medication from elsewhere with the prescription, the cost of which was Rs 600–Rs700. When this was repeated, they stopped going.



Misplaced priorities Misplaced priorities

Disillusioned with the government and then the private hospital, Zarina approached a big NGO to help her with the treatment. That one time that Zarina approached an organisation, she realised that they were after something else altogether and did not see her real requirement.

Instead, the director of the NGO was more interested in finding out who had trafficked her 10 years ago. She told Zarina: "Let's find the trafficker and put him behind bars." How will that help me, wondered Zarina. "Why should I go back to my village after all these years? My family thinks I am dead anyway; they will say, why has she come back to give us a bad name?"

Her husband is suspicious of what NGOs do with the millions of dollars worth of aid entering the country for HIV work. He says: "They get so many donations from abroad but they spend it on advertisements and travel. These NGOs will only give you information, nothing else. Only if you know them personally or are a relative they might help you with treatment."

The 60–rupee shot: The last resort

Zarina always wanted to have a family, a home, happiness. She says she enjoys being a housewife and waiting for her husband to come home from work, to cook for him. Today her dream is to have a small house of her own. She continues living her new life with a joy and

innocence that belies her difficult past, and indeed her painful HIV condition.

Zarina and her husband feel that there is really nowhere else to go in search of treatment. They do fall for the odd herbal treatment here and there. Recently, for example, Zarina tried a bottle of a 'Herbal treatment' sold to her by a lady from Nerul. Someone in the area had recommended the treatment to her, another lady who was very thin and not putting on weight. With this medicine, the appetite improved as well as sleep, leading to an overall improvement in health. Through this distributor they bought a bottle for Rs 2,500. It was a powder that had to be mixed with milk or water. Zarina tried it for a month and it did make her feel better, she says. But it was too expensive at Rs 2,500 a month and so she did not pursue it.

As of now, Zarina is not following any treatment for HIV. Instead she pays about Rs 60 to get an injection to deal with the bodyache and white discharge. She has to do this at least twice a month. Even though the doctor constantly warns her that this will harm her in the long run, and often refuses to give her the shot, she breaks down in tears and is in such visible pain that the doctor has to relent. She says that it is impossible without the injection; the pain and the swelling in her abdomen are unbearable.

Zarina is caught between a government that nit-picks about who will and will not be treated, a private sector that is expensive and swarming with quacks and alternative practitioners claiming to have found a cure for AIDS, NGOs that are more concerned about "catching the traffickers" than helping the HIV-positive. Until the system critically evaluates the imbalance towards AIDS awareness in the media as opposed to care for people living with HIV, and re-examines its policies towards HIV treatment, people like Zarina will continue to fall through the cracks and be excluded from the HIV treatment that is being made available in the country. Till then, Zarina and thousands like her will have to continue depending on dangerous 60-rupee quick-fixes for fleeting moments of relief.

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