

Prologue

Into the Well and Out Again

SARASWATI¹ WAS 24 YEARS OLD AND LIVING WITH HIV/AIDS when I met her in 2004 in Namakkal, a nondescript town nestled below the Kolli Hills in the state of Tamil Nadu and the hub of the South Indian trucking industry. She told me the story of her HIV diagnosis, her pregnancy, child's birth, and early motherhood experiences.

Saraswati hailed from a nearby village, and her father, like many of the men in her village, worked as a lorry driver when she was growing up. At the age of 17, after she had completed the tenth standard of school, her marriage was arranged to her mother's brother's son—a common practice in Tamil Nadu. Her husband was 22 years old at the time of their wedding, and he too was a lorry driver who spent much of his time on the road away from home. Saraswati moved in with her husband's family after their marriage, and, to everyone's delight, within a year and a half she was pregnant and would soon give birth to her first child: a son. By the time this son was 18 months old, Saraswati was a widow.

Saraswati discovered her HIV-positive status when she went to the hospital for her first prenatal visit in the fifth month of her pregnancy and was tested for HIV, although she was not informed that the test was being done until after the fact. The medical personnel urged her husband to also be tested, but he refused. Soon afterward, Saraswati discovered that even before their marriage, her husband had been taking medicines from Majeed's Fair Pharma clinic in Kerala—medicines that Majeed claimed would cure AIDS. Armed with that knowledge, Saraswati and her parents conspired to get her husband tested on some other pretense, and it was revealed that he too was HIV-positive. Despite all this, her husband and in-laws accused her of having infected her husband.

They harassed her so vehemently that one day she climbed down the rusty steps of the ladder into the village well with the intent of drowning herself, but when she reached the bottom rung of the ladder, thoughts of the child in her womb made her reconsider and she climbed back out. Saraswati's own parents were the only others who knew of her HIV status at that time. They were supportive and wanted to rescue her from the abuse of her in-laws (even though Saraswati's father-in-law was also her mother's brother). Saraswati refused their offer, fearing that, because of her HIV status, her presence in their home would jeopardize her younger sister's marriage prospects.

Contending with the mistreatment of her in-laws was not Saraswati's only challenge. She also faced many obstacles as she sought medical care for her pregnancy and childbirth. Several doctors told her openly that they would not care for her because of her HIV status, and in other cases she found herself being referred from doctor to doctor for no apparent reason. The doctor who finally agreed to oversee her delivery only did so for an exorbitant fee, and even in that clinic the nursing staff refused to touch her or change her glucose drips for fear of being infected. The only medical practitioners who did not hesitate to treat both Saraswati and her husband were unlicensed biomedical and Ayurvedic "doctors"; they claimed that they could cure AIDS and charged high fees for their miracles.

After the birth of her son, Saraswati's doctor advised her to avoid breast-feeding because HIV can be transmitted through breast milk. Despite the financial difficulty of this and despite the shame of going against a deep-seated cultural prerogative to breast-feed, Saraswati was able to follow this advice. But Saraswati's grandmother could not bear the nagging criticism of the neighbors about Saraswati's choice to bottle-feed her baby, and the grandmother finally spilled the beans about Saraswati's HIV status to the community to justify her granddaughter's decision not to breast-feed. This only added fuel to the fire of the cruel treatment of her in-laws. When Saraswati's husband died as a result of AIDS shortly thereafter, her in-laws publicly blamed Saraswati for his death, threw her and her young son out of the house, and denied her rights to inherit her husband's property. In the end, Saraswati reluctantly moved back in with her parents, even though her sister's marriage had not yet been arranged.

When I met her, Saraswati was living with her parents and she was still battling her in-laws for her rights to a share of her husband's property in the form of cash compensation and the return of some of her jewels, which were part of her dowry. She sought help through the local *panchayat*,² the police, a "self-help" organization for women, and the courts, but all these attempts were in vain.

She was on the verge of giving up hope when a local network for people living with HIV/AIDS and a larger national network for women living with HIV/AIDS stepped in to help. A lawyer on the High Court in Chennai was offering legal services pro bono to these networks to help women living with HIV/AIDS fight against AIDS-related forms of discrimination and to gain access to what should legally be theirs. That lawyer worked with Saraswati on her inheritance claim. Furthermore, Saraswati had recently been employed as an outreach worker for one of the local HIV/AIDS support group networks. With her modest but respectable monthly salary of 4,000 rupees (US\$91),³ she became the primary breadwinner in her household, supporting her child, her mother, and her father, who was no longer working as a truck driver. When I asked her about meeting with the lawyer, she said that it was the first time in years that she had some hope, albeit guarded, for her future and for the future well-being of her son, who was now 4 years old and HIV-negative. When I asked her about her new job, she said, “I don’t try to hide my status anymore. I am able to talk freely and am free of fear. I like meeting others, and I am able to encourage others to get rid of fear and shame.”

Over the course of my research on HIV/AIDS and childbirth in Tamil Nadu from 2003 to 2008, I interviewed seventy low-income women living with HIV/AIDS. Although each woman’s story is unique, Saraswati’s experiences of her HIV diagnosis during pregnancy and the ripple effects are in many ways iconic of the experiences of most of the women I met. Throughout this book I flesh out the details of Saraswati’s narrative and of the narratives of many other women, some of whom faced far fewer challenges than Saraswati and some far greater. But this story serves as a good vantage point from which to begin to examine the social impact of HIV/AIDS and of HIV prevention and care programs on the lives of young mothers in India at the turn of the twenty-first century.