

aspire to a sound analytic purchase on disease emergence—a prerequisite of effective control measures.

My intention is ecumenical and complementary. A critical framework would not aspire to supplant the methodologies of the many disciplines, from virology to molecular epidemiology, that now concern themselves with emerging diseases. "The key task for medicine," argued the pioneers Eisenberg and Kleinman almost two decades ago, "is not to diminish the role of the biomedical sciences in the theory and practice of medicine but to supplement them with an equal application of the social sciences in order to provide both a more comprehensive understanding of disease and better care of the patient. The problem is not 'too much science,' but too narrow a view of the sciences relevant to medicine."<sup>68</sup>

The rest of this book brings this biosocial framework to bear on the diseases that have wreaked such havoc on the lives of my patients. The focus is thus on the two diseases—tuberculosis and AIDS—that have caused the greatest number of deaths. Along the way, it becomes clear that malaria, typhoid, and the other plagues of the poor must be subjected to similar scrutiny. But the goal of this rethinking is never merely to come up with a better model. The goal, all along, has been to allay the unnecessary suffering caused by inequality and its embodied forms.

Paul Farmer, "Invisible Women: Class, Gender, and HIV," in *Infections and Inequalities: The Modern Plagues*, Berkeley, Los Angeles and London: University of California Press, 1999, pp. 59-93.

### 3 Invisible Women

CLASS, GENDER, AND HIV

These days, whenever someone says  
the word "women" to me, my mind  
goes blank. What "women"? What is  
this "women" thing you're talking  
about? Does that mean me? Does  
that mean my mother, my  
roommates, the white woman next  
door, the checkout clerk at the  
supermarket, my aunts in Korea,  
half the world's population?

JEEYEUN LEE, 1995A

The close of the 1980s found me sitting in a new clinic in a small village in Haiti's Central Plateau. What awaited us outside in the noisy courtyard was not entirely what we'd expected. Certainly we should have anticipated the crowd, since ours was the first facility in the region to declare a special interest in the destitute sick. And we should have expected that many would be gravely ill by the time they reached our doorstep. Granted, we did expect patients with tuberculosis. But we were nevertheless surprised by just how many rural families were affected by a disease popularly associated with overcrowded cities. We also knew, sitting in the clinic, that people with AIDS would come to us; we knew that many of them would be returning from Port-au-Prince. But why, we wondered, were so many of these patients young women?

On a trip back to the United States, I turned to the massive and expanding literature on AIDS. A search of a computerized AIDS database revealed that more than one hundred thousand references were instantaneously available. But when I restricted the search by adding the term "women" to "AIDS," I found only two thousand references. Seeking to further restrict my search by adding the word "poverty" as a third qualifier, I was informed that there were "no references meeting these specifications."

This knowledge gap was the impetus for a collective effort to review the scholarly literature, such as it was, on women and AIDS.<sup>1</sup> But it was the "invisible" suffering of the young women in the clinic courtyard that fueled both our reanalysis and a series of programs designed to remediate—or at least to ease—this suffering.

AIDS was first recognized as a distinct clinical syndrome in the summer of 1981, when physicians in California and New York noted clusterings of unusual infections and cancers in their patients, almost all of whom were young, gay men. The story has been, by now, told often. Less well known is the chronicle of the disease among women. In August, a mere two months after the first cases were reported in men, doctors identified the same syndrome in a woman.<sup>2</sup> Within a year, AIDS cases were also being registered among men and women who injected drugs, among hemophiliacs and some of their sexual partners, and among women and men from poor countries, including Haiti, who seemed to share few of the "risk factors" identified in the other patients.

Since that time, both AIDS and commentary about it have swept the globe. Never before has a single sickness been the subject of such intense and sustained scrutiny. Given the intensity of public awareness and fear of AIDS, it is not surprising that so many myths and misunderstandings about the disease have thrived and even proliferated and that fantasies and junk science have often dominated public discussions of AIDS.

The initial misunderstanding—that AIDS was a disease of men—can perhaps be attributed to historical accident: the new disease was first characterized in the technologically advanced United States, where it did, initially at least, primarily afflict men.<sup>3</sup> But from the outset of the world pandemic, it was apparent that women were also vulnerable to

AIDS; and, within in a year or two, data suggested that women were at least as likely to become infected as men.

Evidently, however, AIDS cases involving women did not count for much. In 1985, a cover story in *Discover*, a popular science magazine, dismissed the idea of a major epidemic among women. The story claimed that because the "rugged vagina," unlike the "vulnerable anus," was designed for the wear and tear of intercourse and birthing, it was unlikely that large numbers of women would ever be infected through heterosexual intercourse. AIDS, we were informed, "is now—and is likely to remain—largely the fatal price one can pay for anal intercourse."<sup>4</sup>

Such mistaken verdicts were slowly called into question. By late 1986, it was becoming clear that AIDS incidence was declining among gay men even as it was climbing among those classed as the "heterosexual exposure group."<sup>5</sup> "Suddenly," proclaimed the cover of *U.S. News and World Report* in January 1987, "the disease of *them* is the disease of *us*." The accompanying illustration depicted the "us" in question (accurately enough, as far as the journalistic stance went) as a white, yuppie couple.<sup>6</sup>

In her study of the gradual evolution of AIDS discourse in the United States, Paula Treichler discerns a "diversification" of commentary about women and AIDS in the spring of 1987.<sup>7</sup> Nonetheless, one still heard voices maintaining that women would never constitute a significant proportion of AIDS victims. *The Myth of Heterosexual AIDS*, first released in 1990, typifies that sort of thinking: "Among the great wide percentage of the nation the media calls 'the general population,' that section the media and the public health authorities has [*sic*] tried desperately to terrify, there is no epidemic. AIDS will pick off a person here and there in this group, but the original infected partner will be one of the two groups in which the disease is epidemic. Most heterosexuals will continue to have more to fear from bathtub drowning than from AIDS."<sup>8</sup>

If there is irony here, it is not the easy irony of false predictions. Even as such projections were being written, millions of women—whose partners were neither bisexual men nor intravenous drug users—had *already* been "picked off" by HIV. Even in the United States, where the epidemic among women had initially been closely linked to injection (intravenous) drug use, the proportion of women who were reported to have been exposed by a partner whose risk was not specified—in other words, not an injecting drug user and not bisexual or gay—quintupled from 1983–84

to 1989–90. In the five years preceding the publication of *The Myth of Heterosexual AIDS*, the percentage increase in annual AIDS incidence was greater among the “heterosexually acquired” exposure group than in any other.<sup>9</sup> By 1991, AIDS was the leading killer of young women in most large U.S. cities.<sup>10</sup> Rates of bathtub drowning remained low.

The mismatch between reality and representation led Paula Treichler to pose the following question in 1988: “Given the intense concern with the human body that any conceptualization of AIDS entails, how can we account for the striking silence, until very recently, on the topic of women in AIDS discourse (including biomedical journals, mainstream news publications, public health literature, women’s magazines, and the gay and feminist press)?”<sup>11</sup> In other words, why did many continue to think of AIDS as a men’s disease? More poignantly, perhaps, why were the voices of women with AIDS absent from scientific and popular commentary a full decade into the pandemic?<sup>12</sup>

One explanation is that the majority of women with AIDS had been robbed of their voices long before HIV appeared to further complicate their lives. In settings of entrenched elitism, they have been poor. In settings of entrenched racism, they have been women of color. In settings of entrenched sexism, they have been, of course, women.

If it is finally recognized that AIDS poses enormous threats to poor women, this wisdom comes too late. Throughout the world, millions of women are already sick with complications of HIV infection. In the United States and in Latin America, the epidemics among women are increasing at a rate much higher than that registered among other groups: AIDS is already the leading cause of death among young African American women living in the United States.<sup>13</sup> In Mexico, the male:female ratio of HIV infection went from 25:1 in 1984 to 4:1 in 1990. In São Paulo, Brazil, positive HIV tests (seroprevalence) among pregnant women increased sixfold in the three years from 1987 to 1990.<sup>14</sup>

Similarly disturbing trends are registered elsewhere in the world, particularly in developing countries, where 90 percent of all adults and 98 percent of all children infected with HIV live.<sup>15</sup> Many sub-Saharan African nations already report more new infections among women than among men. In 1992, the United Nations Development Program estimated that “each day a further three thousand women become infected,

and five hundred infected women die. Most are between 15 and 35 years old.”<sup>16</sup> The World Health Organization has predicted that, during the course of the 365 days of the year 2000, between six and eight million women will become infected with HIV.<sup>17</sup>

Once we begin to see the extent of the problem, further questions emerge. By what mechanisms do most seropositive women come to be infected with HIV? If not all women are at high risk, which groups of women are most likely to be exposed to the virus? How are women’s risks similar—and different—in vastly different settings? Has scholarly research—whether clinical investigation, epidemiology, or social science—kept pace with the advancing AIDS pandemic? Finally, what effects have persistent misunderstandings about women and AIDS had on the allocation of resources for prevention, detection, or treatment of HIV infection?

Throughout this book, I will return to these questions. But let us begin by examining the experience of three women living with HIV. These women are from very different backgrounds: “Darlene” is an African American woman from Harlem; “Guylène” is the daughter of poor peasants from rural Haiti; “Lata” was living in a rural Indian village when, at the age of fifteen, she was sold into prostitution in Bombay. Their stories, similar in some ways and different in others, speak to many of the questions raised here.

#### DARLENE

Darlene Johnson was born in Central Harlem in 1955, one of three children born to a mother who was chronically homeless, leaving her husband and children for long periods of time.<sup>18</sup> Darlene remembered her parents having terrible fights in which her father hit her mother and her mother “cried for days.” When Darlene was five, her mother sent her to Alabama to live with her maternal grandmother.

Darlene was shuttled back to New York City when she was eleven and was left to the care of her brother, who was ten years older. Darlene’s brother, angry that this new burden narrowed his own life chances, beat her frequently. With no other means of support, Darlene lived with her abusive brother until after eleventh grade, when she married a

"hardworking man." The couple soon had two children. "No welfare," she said later. "We never did it, not even when things were hard."

Things were often hard. The couple had many problems. Chief among them was their mutual passion, not for each other but for heroin. "I didn't love him," she recalled. "He beat me, sometimes in front of the kids. It was drugs." After six years of abuse, Darlene found a way to leave. She and her children went to live with her estranged father.

A short while after moving in with her father, Darlene met her second husband. This marriage was for love. Her husband, also a heroin user, worked. They had two sons. Her two older children also loved this man, and things were looking up. Although she used heroin, Darlene insisted that it didn't interfere with taking care of her children. "It just made things smooth," she claimed.

In 1987, her stepbrother, also a heroin user, was diagnosed with AIDS. "He just died," said Darlene; no mess, no fuss. Everyone in the family was stunned. Shortly thereafter, Darlene's stepfather, whom she saw fairly frequently, had a fatal heart attack. An autopsy found that he too had been HIV-infected.

Darlene grieved, but she was determined to keep her family together. Then her husband began to have high fevers and night sweats. He refused to go to the doctor, but Darlene knew it must be AIDS. She was tortured by the memory of all the times that she, her husband, and her stepbrother had shared needles. Darlene was tested and learned that she was indeed HIV-positive.

Her husband died two months later. Alone with four children, Darlene was heartbroken; she had lost her husband, her stepbrother, and her stepfather in a single year. Two women who were her baby's godparents and who had also shared needles had become ill, and they too had died.

Darlene was not only heartbroken. She was also broke, forced to add the constant struggle to make ends meet to the struggle to overcome her grief. Her children, she recalled, kept her going. She suspected that her youngest son, sick from birth with one thing or another, was also infected. His first serious bout with pneumonia made everything clear: "I didn't know he had it till they took my baby to the hospital." Darlene was, by her own account, in a state of shock. "Too many close people" had died.

Darlene decided to set up her home to care for her son. She didn't want to abandon him in the hospital, and so she learned to do everything she

could for him. When her older children began to misbehave, cutting school and hanging out in the streets, Darlene tried to get help, to no avail. There was nothing for them. The counselors in their schools couldn't be trusted not to divulge information about her illness.

Soon the children were completely out of hand. By this time, the baby had begun to stare at Darlene as if he didn't know who she was. Crack, she explained, came to be the only way she could find to ease her pain. But, as always, there was a price to pay. She began to lose patience with her children. She yelled often; she didn't cook regular meals for them. She was relieved when they were away. No formal supports were available for her. Darlene had nothing but pain:

This social worker was telling everybody I had the virus. . . . The police came looking for me when my little son ran away, he ran away with my big son; my big son brought him home. When I came downstairs, the cops jumped all the way down the stairs. "Oh, you supposed to be in the hospital cause you got AIDS." Everybody on the street was looking at me. . . . [The social worker] told my kids' friends, their parents. A little boy was up in the fire escape, he said, "Oh, look—there's David's mother; she got AIDS."

Darlene concluded that her children were suffering and neglected. She felt they had no family; everyone had died. So she turned to the Department of Social Services and asked that her three oldest children be placed in foster care while she tried to care for the youngest, now dying of AIDS. "I just didn't want to live any more and I didn't want the kids to be running in the street, to be hungry."

The department placed the three children in separate homes. The oldest was sent to a home in the Bronx, but he ran away to live with a friend of Darlene's who wanted him and who was willing to support him. Darlene also wanted the child to be with her friend, but she knew that city authorities would never grant custody to this woman, so she said nothing. Darlene's daughter was placed with a woman whom Darlene knew to be a drug user: "They put my daughter in a house where they sell drugs, crack. My daughter watches this lady's kids." Darlene had no power to change the placement.

Her third child was placed in New Jersey with a family that Darlene likes. He is well cared for, and she expects the family to adopt him when

she dies. She is grateful for them and wants the adoption to happen. She attends family therapy sessions with this family. This son, she feels, will be all right.

Having given her children to foster care, and left alone with her youngest, Darlene found it painful to care for him. The little boy suffered terribly. His stomach became more and more distended, and he stopped responding to her. Finally one night, as he lay in bed with her, he stopped breathing. This death "took me out completely," Darlene recalled. "He was three years old. It took him six months to die." Six of the main people in her life had died in a single year.

Darlene gave in to crack completely and hit rock bottom. She lived on the streets for three months, but she was desperate "not to die that way." The children counted on seeing her. She went into the hospital to detoxify from crack and enrolled in a methadone program. Once in the program, she saw a doctor. All during the year of deaths, she had never gone to a doctor for herself. She thinks she must have been very depressed.

Darlene, too, has been diagnosed with AIDS, but mostly she worries about her two oldest children. She could have used some help with them when all the deaths began. Darlene sees the two children who live near her every day. She visits the son who lives in New Jersey every week. She says she'll see them this way until she dies. She only hopes she doesn't linger.

#### GUYLÈNE

Guylène Adrien was born in Savanette, a dusty village in the middle of Haiti's infertile Central Plateau. Like other families in the region, the Adriens fed their children by working a small plot of land and selling produce in regional markets. Like other families, the Adriens were poor; but Guylène recalled that, when she was small, they "had enough to get by." Times would get harder, however, as the eighties brought resurgent political unrest and a death in the family.

Guylène was the third of four children, a small family by Haitian standards. It was to become smaller still: Guylène's younger sister died in adolescence of cerebral malaria. Guylène's oldest sister is said to be some-

where in the Dominican Republic, where she has been living, if she is living, for over a dozen years. Guylène's other surviving sister lives with her mother and two children, working the family plot of land for ever-diminishing returns.

Guylène recounts her own conjugal history in the sad voice reserved for retrospection. When she was a teenager—"perhaps fourteen or fifteen"—a family acquaintance, Occident Dorzin, took to dropping by for visits. A fairly successful peasant farmer, Dorzin had two or three small plots of land in the area. In the course of these visits, he made it clear to Guylène that he was attracted to her. "But he was already married, and I was a child. When he placed his hand on my arm, I slapped him and swore at him and hid in the garden."

Dorzin was not so easily dissuaded, however, and eventually approached Guylène's father to ask for her hand—not in marriage, but in *plasaj*, a potentially stable form of union widespread in rural Haiti.<sup>19</sup> Before she was sixteen, Guylène moved with Dorzin, a man twenty years her senior, to a village about an hour away from her parents. She was soon pregnant. Occident's wife, who was significantly older than Guylène, was not at all pleased. Friction between the two women eventually led to dissolution of the newer union. In the interim, however, Guylène gave birth to two children, a girl and then a boy.

After the break with Dorzin, Guylène and her nursing son returned to her father's house. She remained in Savanette for five months, passing through the village of Do Kay on her way to the market in Domond or to visit her daughter, who remained in Occident's care. It was during these travels that she met a young man named Osner, who worked intermittently in Port-au-Prince as a laborer or a mechanic. One day he simply struck up a conversation with Guylène as she visited a friend in Do Kay. "Less than a month later," she recalled, "Osner sent his father to speak to my father. My father agreed." Leaving her toddler son in her parents' household, Guylène set off to try conjugal life a second time, this time in Do Kay.

The subsequent months were difficult. Guylène's father died later that year, and her son, cared for largely by her sister, was often ill. Guylène was already pregnant with her third child, and she and Osner lacked almost everything that might have made their new life together easier.

Osner did not have steady work in Port-au-Prince, although he occasionally found part-time jobs as a mechanic. After the baby was born in 1985, they decided to move to the city; Osner would find work in a garage, and Guylène would become involved in the marketplace. Failing that, she could always work as a maid. In the interim, Osner's mother would care for the baby, as Do Kay was safer than Port-au-Prince for an infant.

Osner and Guylène spent almost three years in the city. These were hard times. Port-au-Prince was wracked by political violence, especially in their neighborhood of Cité Soleil, a vast and notorious slum on the northern fringes of the city. The couple was often short of work: he worked only irregularly as a mechanic; she split her time between jobs as a maid and selling fried food on the wharf in Cité Soleil. Guylène much preferred the latter:

Whenever I had a little money, I worked for myself selling, trying to make the money last as long as I could. When we were broke, I worked in ladies' houses. . . . If the work is good, and they pay you well, or the person is not too bad, treats you well, you might stay there as long as six or seven months. But if the person treats you poorly, you won't even stay a month. Perhaps you only go for a single day and then you quit. . . . Rich women often hate poor women, so I always had trouble working for them.

When asked what she meant by decent pay, Guylène stated that the equivalent of \$20 a month was passable as long as you were able to eat something at work.

In 1987 (Darlene Johnson's year of losses), three "unhappy occurrences" came to pass in quick succession. A neighbor was shot and killed during one of the military's regular nighttime incursions into the slum; bullets pierced the thin walls of Guylène and Osner's house. A few weeks later, Guylène received word that her son had died abruptly. The cause of death was never clear. And, finally, Osner became gravely ill. It started, Guylène remembered, with weight loss and a persistent cough.

Osner returned to the clinic in Do Kay a number of times in the course of his illness, which began with pulmonary tuberculosis, a disease that we saw frequently at the clinic we'd recently founded there. In the case of a young man returning from Port-au-Prince with tuberculosis, it was routine practice to consider HIV infection in the differential diagnosis, and

we suggested it as a possibility at that time. In the clinic, Osner reported a lifetime total of seven sexual partners, including Guylène. With one exception, each of these unions had been monogamous, if short-lived.

When Osner did not respond, except transiently, to biomedical interventions, many in the village began to raise the possibility of AIDS. At his death in September 1988, it was widely believed that he had died from the new disease. As his doctors, we concurred.

Guylène subsequently returned to Savanette, to a cousin's house. She tried selling produce in local markets, but she could not support even herself, much less the child she had left in the care of Osner's mother. She was humiliated, she says, by having to ask her mother-in-law for financial assistance, even though she informed the older woman that she was pregnant with Osner's child. Finally, a full year after Osner's death, the fetus "frozen in her womb" (as she put it) began to develop. It was, she insisted, Osner's baby. (Others identified a man from her hometown of Savanette as the child's father.) She had the baby, a girl, in November of 1989. Osner's mother always referred to the child as her granddaughter.

A month after her confinement, Guylène returned to Savanette with the baby. She was unemployed; her mother and sister were barely making ends meet. Guylène and others in the household often went hungry. Believing herself to be a burden, Guylène finally went to the coastal town of Saint-Marc, where she had cousins. She worked as a servant in their house until the baby became ill; Guylène, too, felt exhausted. Since free medical care was readily available only in Do Kay, she returned again to the home of Osner's mother. Guylène and Osner's first child had already started school there, and Osner's mother allowed that she could always find food for two more.

By early June 1992, Guylène was ill: she had lost weight, and her periods had ceased. Later that month, I listened to her story with some alarm. Yes, Guylène replied, she had heard of AIDS; some even said that Osner had died from it, but she knew that was not true. After reviewing Osner's chart, I suggested that she be tested for HIV. She was leaving for Port-au-Prince, Guylène informed me, but would return for the results. The child's physical exam was unremarkable except for pallor and a slightly enlarged liver. The baby was treated, empirically, for worms and also for anemia and then sent home.

The next day, Guylène returned to Port-au-Prince. She worked a few days as a maid but found the conditions intolerable. She tried selling cigarettes and candy but remained hungry and fatigued. The city was in the throes of its worst economic depression in recent decades. "I was ready to try anything," she later noted.

Although it seemed as if things couldn't get any worse, they soon did. In the early afternoon of a sweltering summer day, Osner's mother came running to us in a panic: the baby couldn't breathe, she reported, and she was in the clinic with one of the health workers. Another doctor and I ran just as quickly back to the clinic, where we found the baby struggling for every breath. Her lips went blue as we were obtaining an X-ray. With two stethoscopes applied to her chest, we both heard her heart go still. There was nothing we could do.

The chest film gave us a clue about what had happened—it revealed that the baby's heart had been twice the expected size—but it was Guylène's laboratory results that made everything clear. Because the mother was infected with HIV, it was very likely that the baby daughter had died of HIV cardiomyopathy.

Guylène was informed of her positive serology on the day following her return. She listened impassively as I went through the likely significance of the test and made plans to repeat it. Careful physical examination and history suggested that Guylène had not yet had a serious opportunistic infection. Her chief manifestations of HIV infection at that time were severe anemia, amenorrhea, weight loss, occasional fevers, and some swelling of her lymph nodes.

Guylène began visiting the clinic regularly after the confirmation of her positive HIV serology. We spoke with her regularly—"too often," she once remarked—about HIV infection and its implications. She was placed on prophylactic isoniazid, an iron supplement and multivitamins, and also a protein supplement. Instead of returning to Port-au-Prince, Guylène rented a house with the financial aid she received through an AIDS treatment program based in the clinic.

Although Guylène experienced significant improvement in less than a month, she remained depressed and withdrawn. A young man named René had been visiting her, but Guylène discouraged him, and he disappeared—"he went to Santo Domingo, I think, because I never heard from

him again." In mid-November, however, Guylène responded to the advances of a soldier stationed in the town of Péligré. A native of a large town near the Dominican border, with a wife and two children there, the soldier had been in the region only about a month. Although residents of Péligré said that he had a regular partner there as well, Guylène insisted that she was his only partner in the region:

He saw me here, at home. He saw me only a couple of times, spoke to me only a couple of times, before announcing that he cared for me. After that, he came to visit me often. I didn't think much of it until he started staying over. I got pregnant at about the time they announced that he was being transferred back to [his home town]. He said he'd be back, but I never saw or heard from him again.

As Guylène's physicians, we had gone to some trouble to discourage unprotected sexual intercourse. We were therefore anxious to know how conversations about this subject might have figured in her decision to conceive another child, if indeed the pregnancy was the result of a decision. That Guylène understood what it meant to be an asymptomatic carrier of HIV seemed clear from a metaphor she used to describe herself: "You can be walking around big and pretty, and you've got a problem inside. When you see a house that's well built, inside it's still got ugly rocks, mud, sand—all the ugly, hidden things. What's nice on the outside might not be nice on the inside."

Guylène understood, too, that her child might well be infected with HIV, and she opted to take AZT during the latter part of her pregnancy. She understood the rationale for such a measure and even recommended it to another woman. But she was impatient with questions, tired of talking about sadness and death. "Will the baby be sick?" she remarked during a prenatal visit. "Sure, he could be sick. People are never *not* sick. I'm sick . . . he might be sick too. It's in God's hands."

Now, two years after the birth of a son, Guylène says she is pleased that he has recently been declared free of HIV. In truth, however, she sees her life as ruined. Two of her children are dead; two others have long looked to a father or grandmother for most of their parenting. Guylène's own sisters are dead, missing, or beaten into submission by the hardness of Haiti. Few of her nephews and nieces have survived into adulthood.

Guyène assures her physicians that she is without symptoms, but she seems inhabited by a persistent lassitude.

## LATA

When Lata first entered the world somewhere in rural Maharashtra, in a small thatched hut lit only by lanterns, her mother began weeping—tears not of joy but of shame that she had brought yet another daughter into the world.<sup>20</sup> “God must not have been very happy with me that day,” she said. Lata does not know what month she was born into her untouchable *Har-ijan* family of two sisters and three brothers, but the year was 1967. Her father farmed a very small plot in Solapur, a small agricultural village. As Lata remembers it, her mother did nearly all of the remaining work:

So much of my childhood is a blur to me. I remember when my father would return home he would beat my mother for her cooking or because one of us was crying. And if he had drunk too much he would beat my sister and me, the whole time my mother running around to prepare better food or make us quiet so father could eat. It seems every day passed like this, the only difference being that father got meaner as he grew older.

Never permitted to attend school, Lata was tilling and weeding with her father by the age of six. “Years passed like this,” she remarked, examining her hands as if for traces of blisters. Her two elder sisters were married at the ages of fifteen and sixteen, respectively, and both weddings came at a heavy price to Lata’s family. One sister’s dowry totaled 10,000 rupees, almost twice her father’s earnings for that year. Predictably, both marriages forced the family to turn to the local moneylender, a man who maintained interest rates as high as 25 percent—compounded quarterly. Lata’s father, already faced with selling off more of his tiny plot in order to service his debt, lived in fear of another wedding.

Lack of rainfall during the 1982 monsoon season brought a poor harvest, leaving the family in the worst financial state it had ever experienced. “My father was drinking more every day,” recounted Lata. “Sometimes I recall him not even going out to the fields, yet forcing us to go, and

beating us more than he ever had. I know he was worried about my getting married, and when he was drunk he would curse my mother, blaming her for bringing him yet another daughter.”

In this context, the arrival of a man who would take Lata from the despair of her village life was regarded as a godsend. Like so many other *dalals* (“middlemen,” many of whom are women) who come from Bombay, Prasant had for some years been making a “decent” living in the flesh trade. As he worked a route from the villages of southern Maharashtra to the bordellos of Bombay, his scheme was identical in almost every settlement. Upon arriving in a village, Prasant would seek out a local moneylender and, often with the help of a small bribe, extract information about area families who had young daughters and heavy debt. Prasant, like other *dalals*, then approached the male heads of families, claiming to have work for their daughters as servants or seamstresses in Bombay. In Lata’s case, Prasant told her father that she would be given work as a dishwasher:

After [Prasant] arrived, my father took my mother aside and told her that jobs were available in Bombay, and this man would give him 11,000 rupees as a payment for me washing dishes and housecleaning. He said I would be able to mail money home every month and allowed to visit Solapur after six months of work. Not for one moment did anyone suspect or question what he told us.

Desperate, hungry, facing the most acute poverty his family had ever experienced, Lata’s father saw opportunity and relief in his daughter’s departure. A few hours after he and Prasant had spoken, Lata was told to pack her two cotton saris, her bangles, and sandals. She would leave for Bombay in the morning.

A frail and frightened fifteen-year-old, Lata had difficulty holding back tears as she waved goodbye. Her father’s gaze was stoic, while tears streamed down her mother’s face. It was the last time she would ever see her parents.

She remembered nothing of her trip to Bombay, although it was her first train ride. Her inability to recollect, she later suspected, was the result of a drug she had been given. The next memory she had was of a taxi in Bombay. Lata was entering the city’s red-light district. Barely awake,

she was brought to Number 27 Falkland Road, where Prasant sold her to a pimp for 15,000 rupees (about \$500). His tidy profit of 4,000 rupees was more than enough to carry him through the month.

Lata had arrived in the Kamathipura district of Bombay, and she was about to become one of its thirty thousand sex workers. Lata recalled that she came to complete consciousness in a "cage"—a cramped room full of girls putting on makeup, oiling their hair, and tightening their petticoats and blouses. Lata had no comprehension of where she was:

I saw all of these girls wearing nothing but colored blouses, makeup, and skirts, and asked the madam, "What is this?" She told me it was a place for working girls. I still didn't understand, frightened by the very clothes these women wore. . . . Sapna, the madam, told me I would be staying with her and ordered me to put on clothes that lay on the floor for me and then stand outside. I began crying and told her I couldn't stay. She slapped me hard, and I remember I couldn't stop crying. I told her to let me go, and she looked me straight in the eye and said, "You want to leave, fine. Give me 15,000 rupees and you're free. Until then, get dressed and start paying back your *kurja*."

Lata's *kurja* was her debt, the mechanism by which she was indeed trapped as if in a cage. She did not join the other girls on the street that day, nor the day after. She slept and lay in the corner of the room, pretending to be ill, eating the food she was given, and listening to the other girls call out to customers on Falkland Road. She watched the parade of men and girls in and out of the adjacent room, furnished only with a bed. On Lata's third day in Bombay, Sapna's patience had been exhausted: she ordered one of her managers to "break Lata in."

No matter how many years pass, Lata still has trouble recounting this part of her story. Arun, a manager whose main responsibility was to bring in new customers, also had the duty of making sure the girls were bringing in enough money and "working" hard. As one madam put it, "There are times when they won't listen to us, so the managers and pimps keep the girls in line." Lata recalled:

I had been sitting in the same corner for days, pretending I was not feeling well, frightened, and wishing Sapna would let me go. Finally Arun came to me and pulled me by my ear, telling me to put on the clothes and stand outside. I was a fifteen-year-old village girl and didn't even know what sex was, let alone prostitution. How could I understand

what was going on? He took me to the room with the bed and closed the door and forced me to have sex with him. Afterwards, he said, "Now do you understand?" and laughed and told me to get to work. I remember being silent while the other girls stared at me when I came out. I'm sure they knew what he did. And for the first time I began to accept that there was no way out—I was here to stay.

That day Lata, clad in a purple blouse and pink petticoat, nervously joined the thousands of prostitutes of Bombay's red-light districts. It was her first night on the streets and the beginning of a long and painful career.

Unlike most other girls, who stand in front of the cages beckoning to passing men, Lata stood quietly, receiving no business during her first three days out. The days were long: bathing at around 10 in the morning, out on Falkland Road by 11, lunch at 4 P.M., and back on the street until 2 or 3 A.M., with dinner if she was lucky. On an average day, a Bombay prostitute may see four to five customers a day. Times may vary, but generally late evening is when they are busiest. Early in the afternoon of her fourth day, Lata was finally approached:

An Arab man came and after seeing me spoke with the madam for some time and wanted to take me to the Taj Hotel for three days. I saw him give her many hundred rupee notes, and then he took me into his taxi and to the hotel. I was terrified of being alone with him; you have to remember that he was my first customer and I had no idea what to do. The first night we slept in separate beds, and the next day he took me to sari and jewelry shops, buying me clothes and gold. When he would go out in the day, he would lock me in the room. But the more he bought, the more scared I became of what he would expect. On the second night, he told me to dress in all of the clothes he bought for me. Frightened as I was, I knew that I had no choice. At that moment, I remember saying to myself, "This is now my life," truly accepting it for the first time. . . . No longer willing to fight him or my own self, I had sex with him.

Upon her return to Falkland Road, Lata settled into the routine of a Bombay prostitute. Slowly she came to know the stories of the girls in her brothel and others nearby. Although they hailed from many villages and even from Nepal, most had similar experiences. Like the others, she gave half of her daily earnings to the madam as repayment for her *kurja*. Yet Lata knew that she, and all girls sold into prostitution, had little hope of ever buying their freedom; her initial debt of 15,000 rupees was accruing

interest at a rate of 20 to 25 percent a month. If a pimp brought a customer to her, she owed him 25 percent. And in most areas, police regularly extorted money from sex workers with the threat of jail. With an average of four or five customers per day, each paying about 20 to 30 rupees, she could be left with as little as 20 rupees to cover food, clothing, and other basic needs.

At this writing, Lata has been in Bombay for many years. She is a well-known figure at Number 27 Falkland Road, a small brothel sandwiched between a tea stall and a large pink building brimming with Nepali girls. Proudly wearing her gold bangles, her hair always neatly oiled and braided, Lata is now a respected veteran of the red-light community. At twenty-eight years of age, she continues to see an average of four or five customers a day.

Rumors of AIDS did not reach the red-light district of Bombay until 1989 or so—surely well after the virus itself had arrived. "Back then I and other people on Falkland Road started to know about AIDS, but we did not take it seriously. Then the Indian Health Organization people came and gave us free condoms."

In 1991, Lata became one of the first sex workers to volunteer as an AIDS peer educator, and she pushes her fellow prostitutes to demand that their clients use condoms: "I tell the girls, it's your life. If he refuses to wear one, send him away. And even if he offers you one million for sex without a condom, you don't do it. But I know this is hard. There are too many hungry girls. Too many scared girls. And the madams are always watching, putting on pressure."

Preventive messages came too late for Lata, who now knows that she is infected with HIV. She continues to work as both an AIDS outreach worker and a prostitute.

#### SEX, DRUGS, AND STRUCTURAL VIOLENCE

The stories of Darlene, Guylène, and Lata—recounted in detail in order to shed light on the forces that have constrained their options—reveal both differences and commonalities. But how locally representative is each of these histories?

Darlene Johnson's experiences are all too commonplace among African American women living in poverty. As a heroin user, a habit clearly tied to a poverty structured by racism, her chances of avoiding HIV were slim, even if she had wanted to quit the drug before her diagnosis. In 1987, the year that Darlene's world was burst asunder by AIDS, only 338,365 treatment slots were available to the nation's estimated four million addicts, and most of these programs predominantly served men. As a pregnant woman, Darlene would have found it next to impossible to find treatment for her addiction.<sup>21</sup> Writing about women of color who are also addicted and living in poverty, Janet Mitchell and her co-workers point out that "access to care and services has traditionally been *marginal* for women with any one of these three criteria. Any two of these . . . essentially put women in the *extremely limited* access category. Women with all three of these characteristics fall into the *no access* category."<sup>22</sup>

In the United States, HIV has moved almost unimpeded through poor communities of color. By 1991, African Americans, who constitute approximately 12 percent of the U.S. population, accounted for 30 percent of all reported AIDS cases. During the 1980s, the cumulative incidence of AIDS was more than eleven times higher for black women than for white women. Although many early cases occurred among those who injected drugs, the epidemic is fast expanding among women with no such history. As noted earlier, AIDS is the leading cause of death among African American women of ages 25 to 44; for Latinas in this age group, it is now the third leading cause of death.<sup>23</sup> When the first multicenter study of AIDS among U.S. women was funded, almost 78 percent of the more than 1300 patients recruited were women of color.<sup>24</sup>

Understanding the contours of the U.S. epidemic is less a matter of knowing one's geography and more a matter of understanding a limited number of events and processes that range from unemployment to the destruction of housing by fires—the "synergism of plagues" discussed by Rodrick Wallace.<sup>25</sup> "Urban poverty in the United States has created the perfect machinery for the continued propagation of HIV," Robert Fullilove argues. "Inner-city poor neighborhoods often shelter a vigorous drug trade, numerous opportunities for strangers to engage in drug-mediated, unprotected sex, and numerous locations where these and other risk behaviors go virtually unchallenged."<sup>26</sup>

In Haiti, similarly, little about Guylène's story is unique. We hear a deadly monotony in the stories told by rural Haitian women with AIDS. In a study we conducted at the Clinique Bon Sauveur, where Guylène receives her care, the majority of new AIDS diagnoses are registered among women, most of them with a trajectory similar to Guylène's. As young women—or teenage girls—they had been driven to Port-au-Prince by the lure of an escape from the harshest poverty. Once in the city, each worked as a domestic, but none managed to find the financial security so elusive in the countryside. The women we interviewed were straightforward about the nonvoluntary aspect of their sexual activity: in their opinions, they had been driven into unfavorable unions by poverty.<sup>27</sup> Indeed, such testimony calls into question facile notions of "consensual sex."

Lata's painful experience also exemplifies that of hundreds of thousands of poor girls in India, Nepal, and elsewhere. It has been estimated that up to 50 percent of Bombay's prostitutes were recruited through trickery or abduction.<sup>28</sup> Although few population-based surveys have yet been conducted, it is quite likely that most of India's prostitutes have high rates of HIV infection. In the late 1980s, some seven hundred sex workers were arrested and forcibly taken to the city of Madras; 70 percent of these women were found to have antibodies to HIV. Many of them were jailed or subjected to other forms of harassment, including having their names publicly listed.<sup>29</sup>

In short, the experiences of Darlene, Guylène, and Lata are all too typical. One clear lesson we can draw from their stories is that both immediate and systemic causes of increased risk need to be elucidated. For example, heroin use and needle sharing put Darlene at increased risk of HIV infection. Sex work—or, rather, unprotected sex work—put Lata at risk. But in both Harlem and Bombay, it seems fair to assert that the decisions these women made were linked to their impoverishment and to their subordinate status as women. Furthermore, it is important to remember that Darlene and Guylène and Lata were *born* into poverty. Their attempts to escape poverty were long bets that failed—and AIDS was the ultimate form their failure took.

The stories recounted here force a difficult question: how many girls are, from birth, at inordinate risk of AIDS or some other terrible destiny? "For some women," explains the founder of an AIDS support group for

women, "HIV is the first major disaster in their lives. For many more, AIDS is just one more problem on top of many others."<sup>30</sup> In fact, attentiveness to the life stories of most women with AIDS usually reveals that it is the latest in a string of tragedies. "For poor women," as anthropologist Martha Ward describes, "AIDS is just another problem they are blamed for and have to take responsibility for. They ask, 'How am I going to take care of my family?' 'I have to put food on the table now.' 'You think AIDS is a problem! Let me tell you—I got real problems.'"<sup>31</sup>

Millions of women living in similar circumstances—but with very different psychological profiles and cultural backgrounds—can expect to meet similar fates. Their sickness is a result of structural violence: neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency. Structural violence is visited upon all those whose social status denies them access to the fruits of scientific and social progress.

If we are to present meaningful responses to AIDS, we must examine the differential political economy of risk. Structural violence means that some women are, from the outset, at high risk of HIV infection, while other women are shielded from risk. Adopting this point of view—that we can describe a political economy of risk and that this exercise helps to explain where the AIDS pandemic is moving and how quickly—we begin to see why similar stories are legion in sub-Saharan Africa and India, why they are fast becoming commonplace in Thailand and other parts of Asia. The experiences recounted here may be textbook cases of vulnerability, but their moral is deciphered only if we clearly understand that these women have been rendered vulnerable to AIDS through *social* processes—that is, through the economic, political, and cultural forces that can be shown to shape the dynamics of HIV transmission. The anthropologist Brooke Schoepf, writing from Zaire, explains how AIDS has "transformed many women's survival strategies into death strategies":

Women, who often lack access to cash, credit, land or jobs, engage in "off-the-books" activities in the informal sector. Some exchange sex for the means of subsistence. Others enter sex work at the behest of their families, to obtain cash to purchase land or building materials, to pay a brother's school fees, or to settle a debt. Still others supplement meager incomes with occasional resort to sex with multiple partners. [Whether

these women are] married or not, the deepening economic crisis propels many to seek "spare tires" or "shock absorbers" to make ends meet.<sup>32</sup>

Taken together, the dynamics of HIV infection among women and the responses to its advance reveal much about the complex relationship between power/powerlessness and sexuality. But many questions remain unanswered. For example, by what mechanisms, precisely, do social forces (such as poverty, sexism, and other forms of discrimination) become embodied as personal risk? What role does inequality per se play in promoting HIV transmission?

Although many would agree that forces such as poverty and gender inequality are the strongest enhancers of risk for exposure to HIV, this subject has been neglected in both the biomedical and the social science literature on HIV infection. Let us take, as an example, an investigation of heterosexually transmitted HIV infection in "rural" Florida, conducted by Ellerbrock and co-workers. The study, published in 1992 in the *New England Journal of Medicine*, revealed that fully 5.1 percent of 1082 asymptomatic women attending a public prenatal clinic in Palm Beach County had antibodies to HIV. What risk factors might account for such high rates of infection? The researchers reported a statistically significant association between HIV infection and having used crack cocaine, having more than five sexual partners in a lifetime, or having more than two sexual partners per year of sexual activity. Also associated with seropositivity to HIV was a history of exchanging sex for money or for drugs or of having sexual intercourse with a "high-risk partner."

These associations are not surprising. How are they interpreted? The study concludes that "in communities with a high seroprevalence of HIV, like this Florida community, a sizable proportion of *all women of reproductive age* are at risk for infection through heterosexual transmission."<sup>33</sup> Is this in fact the most significant (or the most pragmatically valuable) conclusion to be drawn from such a study? In settings with an even higher seroprevalence of HIV, such as parts of New York City, it is clear that not *all* women of reproductive age are at increased risk of HIV infection; rather, *poor women*, who in the United States are often women of color, are at high risk.

A conclusion such as that drawn by the researchers is possible only if we place the "community" being studied under a Bell jar, so that both the

glittering towers of West Palm Beach and the vast fields of sugarcane—and their owners—are outside the field of analysis. But if these parts of the "community" are invisible, so too is the political economy of AIDS, for many of the women studied, like their partners, have worked in these wealthy communities or in the nearby fields. Thus, *arbitrarily constricting the social field generates the illusion of equally shared risk*. It obscures inequalities central to the advance of HIV. An equivalent exercise would be to recount Darlene's story as if Central Harlem were an island nation rather than a rich city's ghetto. Guylène's narrative would make no reference to the wealthy households in which she was forced to work. Lata's social field would be bordered by the margins of the Kamathipura district, into which no wealthy clients entered.

A closer look at the language in which Ellerbrock and co-workers couched their conclusions suggests that a meaningful discussion of risk cannot be limited to medical issues, narrowly construed. Nowhere in their article does the word "poverty" appear, even though the authors mention that over 90 percent of the women who knew the amount of their income belonged to households earning less than \$10,000 per year.<sup>34</sup> Nowhere in the article do we see the word "racism," even though in Florida, as elsewhere, the African American and Latino communities are those most affected by the epidemic. The terms "sexism," "despair," and "powerlessness" are also absent from the discussion, even though many of the women studied were pulled into the region by the possibility of jobs as servants or farmworkers. One might as easily conclude that, in Palm Beach County, it is the women who are "at risk" of attending a public prenatal clinic who are at higher risk of acquiring HIV—unemployed women of color, that is, who are more likely to have unstable sexual unions or to exchange sex for drugs or money.<sup>35</sup>

Like all societies characterized by extreme inequality or structural violence, the linked societies of Darlene, Guylène, and Lata require other kinds of violence in order to maintain the status quo, which is so unbearable for the majority. In the United States, the enormous number of African Americans in prisons reflects this violence, as do death squads in Haiti and police brutality in Bombay. Other forms of violence are more strikingly gendered. HIV and direct violence against women are intimately linked. Among sex workers, risk of assault and risk of HIV are both highest among the poorest prostitutes.<sup>36</sup> Many of the estimated four

million U.S. women who are assaulted by their male partners are also those at heightened risk for HIV. As Sally Zierler observes, "This figure, awful as it is, obscures the fact that some women are more at risk than others. For like HIV's distribution, partner violence against women follows social divisions marked by class position, and race/ethnicity, creating strata of extreme vulnerability to violence victimization."<sup>37</sup>

In an era of widespread and instantaneous communication, *symbolic violence* is also used to accomplish these ends: structural violence requires its apologists, witting or unwitting. We now turn to the role played by researchers and other opinion shapers in buttressing the myths and mystifications related to the topic of women and AIDS.

#### WOMEN AND AIDS: MYTHS AND MYSTIFICATIONS

Throughout the world, the majority of women with HIV infection are poor. They are denied access not merely to resources and services but also to symbolic capital. In her thoughtful examination of the gendering of American AIDS discourse, Paula Treichler asks, "Why were women so unprepared? And why do they continue to take it so quietly?"<sup>38</sup> She responds to her own question with a candor that is all too rare:

As evidence of AIDS in women mounted, speculations linked the disease to prostitutes, intravenous drug users, and women in the Third World (primarily Haiti and countries in central Africa). It was not that these three groups were synonymous but, rather, that their *differentness of race, class, or national origin* made speculation about transmission possible—unlike middle-class American feminists, for example. American feminists also by this point had considerable access to public forums from which to protest ways in which they were represented, while these other groups of women were, for all practical purposes, silenced categorically so far as public or biomedical discourse was concerned.<sup>39</sup>

This silencing refers to the absence of the voices of poor women in public forums ranging from conferences to published material. In truth, however, these women have not been silent; they have simply been unheard. In rural Haiti, for example, a group of poor women committed to preventing AIDS worked together in 1991 to generate a list of common

myths about women and AIDS.<sup>40</sup> The document prepared by the group referred to the following myths:

#### *AIDS Is a Disease of Men*

The data are overwhelming: AIDS was never a disease of men. Given transmission dynamics, AIDS may in fact become a disease *predominantly* afflicting women.

#### *"Heterosexual AIDS" Won't Happen*

Heterosexual AIDS has already happened. Indeed, in many parts of the world, AIDS is the leading cause of death among young women.

#### *Women's Promiscuity Causes AIDS*

Most women with AIDS do not have multiple sexual partners; they have never used i.v. drugs; they have not received tainted blood transfusions. Their major risk factor is being poor. For others, the risk is being married and unable to control not only their husbands but also what jobs their husbands have to perform to make a living.

#### *Women Are AIDS Vectors*

Women are too often perceived as agents of transmission who infect men and "innocent babies." Prostitutes have been particularly hard hit by such propaganda, but prostitutes are far more vulnerable to infection than to infecting: AIDS is an "occupational risk" of commercial sex work, especially in settings in which sex workers cannot safely demand that clients use condoms.<sup>41</sup>

#### *Condoms Are Panaceas*

Gender inequality calls into question the utility of condoms in settings in which women's ability to insist on "safe sex" is undermined by a host of less easily confronted forces. Furthermore, many HIV-positive women *choose* to conceive children, which means that barrier methods that prevent conception are not the answer for many. Woman-controlled viricidal preventive strategies are necessary, if women's wishes are to be respected.

While these were the myths deemed salient in Haiti, other, related mystifications flourish in every setting in which poor women must now add HIV to a long list of quotidian threats. In the United States, Martha Ward complains of "urban folklore" about mothers with AIDS: "Those women have food stamps. They buy alcohol or luxury items. They have

infected their innocent babies. They should use birth control, get abortions, get a job, finish school, use condoms, and say "no" to drugs."<sup>42</sup>

What many of the dominant myths and mystifications have in common is an *exaggeration of personal agency*, often through highlighting certain psychological or cultural attributes, even though it is not at all clear that these attributes are in any way related to women's risk for HIV infection. Condoms are a classic case in point. Most U.S. women at high risk of HIV infection are already aware that condoms can prevent transmission, but many of these women are unable to insist that condoms be used because their precarious situations often force poor women to rely on men. For example, a study conducted among African American women in Los Angeles showed that couples in which the woman depended on her male partner for rent money were less likely to use condoms than couples in which the woman had no such dependence.<sup>43</sup>

There is nothing wrong with underlining personal agency, but there is something unfair about using personal responsibility as a basis for assigning blame while simultaneously denying those who are being blamed the opportunity to exert agency in their lives. "A patronage that simultaneously grants 'victims' powerlessness and then assigns them blame for that powerlessness is nothing new," observes Jan Grover. "It is therefore important to make connections between the construction of AIDS victimhood and similar constructions of the poor, who also suffer the triple curse of objectification, institutionalized powerlessness, and blame for their condition."<sup>44</sup>

Although most acknowledge the link between poverty and low rates of condom use, few studies have carefully explored the association. The objectification of "the poor," as noted, is a risk run by anyone who uses the term, but striving to understand a person's material constraints does not imply a refusal to recognize the salience of personal experience. Recognizing a commonality of constraint—in addition to, say, a commonality of psychology or of culture—is an important part of unraveling the nature of risk. Indeed, failure to embed personal experience in the larger social and economic matrices in which it takes on meaning is often synonymous with intense focus on personal psychology or "deviant subcultures."

Among the myriad mystifications that obscure the nature of women's risk, three are recurrent and important. One is the *focus on local factors and*

*local actors to the exclusion of broader analyses* that would implicate powerful forces and powerful actors outside the field of view. A second is the *conflation of structural violence and cultural difference*. A third, centrally related to the others, is the *absence of serious consideration of social class*.<sup>45</sup> These are not infrequently the mechanisms by which personal agency is exaggerated in both scholarly and popular commentary. To cite Brooke Schoepf again: "The structure of the wider political economy establishes the situations and restricts the options that people can choose as a means of survival. A focus on 'sub-cultures,' as on individual behaviors, tends to obscure the underlying causes of social interaction."<sup>46</sup>

These expedient erasures and exaggerations are buttressed, rather than challenged or exposed, by research published in a host of key journals. For example, a review of the ever-enlarging epidemiologic literature reveals that although racism, sexism, and powerlessness go unmentioned, we usually *do* find mention of culture.<sup>47</sup>

An example is a study conducted by Nyamathi and co-workers in the Los Angeles area among 1173 women ages 18 to 75. Half were African Americans; half were called "Latinas" and described as either "high-aculturated" or "low-aculturated." Recruited through homeless shelters or drug-treatment programs, all of these women had histories of using drugs, being the sexual partner of an injecting drug user, being homeless, or having a sexually transmitted disease. Some had histories of sex work; some had multiple sexual partners. A survey administered to these women revealed that "African-American and Latina women were equally knowledgeable about AIDS symptomatology; the etiologic agent of AIDS; and behaviors known to reduce risk of HIV infection, such as using condoms and cleaning works used by intravenous drug users."<sup>48</sup> Greater differences existed in how much the women knew about modes of transmission, but the women tended to *overestimate* transmissibility, not to underestimate it.

In a sense, then, what the researchers found was that ignorance about HIV was not really the issue for these women. What put them at risk was something other than cognitive deficits. But the researchers' interpretation of their findings, published in the influential *American Journal of Public Health*, was not in keeping with the data: "These findings suggest the need for culturally sensitive education programs that cover common

problems relating to drug use and unprotected sex and, in addition, offer sessions for women of different ethnic groups to address problematic areas of concern.<sup>49</sup> Was this truly a key implication of the research? By the researchers' own standards, these women were by and large *fully aware* of transmission of HIV through injection drug use and unprotected sex. Moreover, the more a woman had used drugs or had multiple sexual partners, the more likely she was to perceive herself, correctly, as being at increased risk of HIV infection.

By insisting that "culturally sensitive education programs" have a large role to play in protecting poor women from AIDS, the authors are suggesting, all evidence to the contrary, that ignorance of the facts is centrally related to high HIV risk and that, consequently, the way to diminish risk is to increase knowledge. Through this cognitivist legerdemain, we have expediently moved the locus of the problem—and thus the focus of the interventions—away from certain features of an inequalitarian society and toward the women deemed "at risk." The problem is with the women; thus the interventions should change the women.

The cost of all this desocialization might well be significant, for cognitivist, behaviorist, or culturist assumptions often privilege effects over cause. Immodest claims of causality, and even undue focus on the psychological or cultural peculiarities of those with AIDS, are not only intellectual errors; they also serve to deflect attention away from the real engines of the AIDS pandemic. Thus, when the *éminences grises* of sexually transmitted disease control examine the possibilities for effective AIDS control in developing countries, their list of suggested interventions ranges from public lectures to "long-term psychotherapy for HIV-positive individuals" and "group therapy for commercial sex workers."<sup>50</sup>

Similar themes are widely echoed in a society known for its obsession with individualism. It is not surprising, then, to hear the same exaggerations of agency even from those most committed to preventing AIDS. Often we hear about a certain community's "denial" of risk or about the epidemic of "low self-esteem" among those living with HIV infection. These cultural and psychological factors are then granted etiologic power: they are construed as the *source* of increased risk rather than the *effects* of structural violence.

Sadly, if predictably, the same calculus of causality occurs in the comments of those afflicted by AIDS. The founder of one group for women

living with HIV infection put it this way: "Low self-esteem is a significant 'co-factor' that led many women to be at risk of acquiring HIV."<sup>51</sup> Surely there exist important co-factors for "low self-esteem"—and poverty (otherwise known in post-welfare America as hunger, joblessness, and homelessness) is the obvious leader among them. Other variations on this theme of inequality, including racism and sexism, are also high on the list.

Such immodest claims of psychological and moral causality expediently divert attention away from structural violence. No wonder, then, that U.S. Republicans and their friends among the Democrats are so eager to advance the same hypotheses. In the recently promulgated "Personal Responsibility Act," AFDC recipients are called to work a minimum of thirty-five hours per week in a designated "work slot." Since these women have, apparently unlike the authors of the act, more than a passing knowledge of math, they know that, with a median disbursement of \$366 per month and an hourly wage in such "slots" of well under \$3, they will be unable to assemble the funds necessary to provide day care—let alone health care and safe housing—for their children. Even in cities with a modest cost of living, a single mother of two children would need an hourly wage of \$10 in order to cross the poverty line.<sup>52</sup> We are left to surmise that these women's infants and toddlers will buy and prepare their own formula and meals. As Valerie Polakow, who recently interviewed scores of single American mothers, bitterly notes, this experience should give these babies an early lesson in the importance of personal responsibility. "As their rhetoric against won't-work mothers and promiscuous teens escalates," concludes Polakow, "it advances the pernicious idea that poverty is a private affair, that destitution and homelessness are simply products of bad personal choices."<sup>53</sup>

From typhoid to tuberculosis and AIDS, blaming the victim is a recurrent theme in the history of epidemic disease.<sup>54</sup> In case after case, analysis can lead researchers to focus either on the patients' shortcomings (failure to drink pure water, failure to use condoms, ignorance about public health and hygiene) or on the conditions that structure people's risk (lack of access to potable water, lack of economic opportunities for women, unfair distribution of the world's resources). The results are not indifferent. One of the chief benefits of choosing to see illness in global-systemic terms is that it encourages physicians (and others concerned to protect or

promote health) to make common cause with people who are both poor and sick. In addition, analyses that resolutely embed personal experience in the larger social fields in which experience takes on meaning have far more explanatory power in examining epidemics of infectious disease—particularly those that, like AIDS, move along the fault lines of our inter-linked societies.

The most frequently encountered and easily circulated theories about women and AIDS are far more likely to include punitive images of women as purveyors of infection—prostitutes, for example, or mothers who “contaminate” their innocent offspring—than to include images of homelessness, barriers to medical care, a social service network that doesn’t work, and an absence of jobs and housing. Dominant readings are likely to suggest that women with AIDS have had large numbers of sexual partners, but are less likely to show how girls like Lata are abducted into the flesh trade, and even less likely to reveal how political and structural violence—for example, the increasing landlessness among the rural poor and the gearing of economies to favor exports—come to be important in the AIDS pandemic today.

For women most at risk of HIV infection, life choices are limited by racism, sexism, political violence, and grinding poverty. It is a wonder, then, that discussions of AIDS so rarely focus on these issues. Complex indeed are the mechanisms by which such structural violence can be effaced and the apparent significance of personal choice (or cultural difference) inflated. But when dominant myths about women and AIDS are contrasted with the experiences of Darlene and Guylène and Lata, we are forced to call into question many of these understandings.

#### WHAT IS TO BE DONE?

As I described earlier, a group of poor women in rural Haiti, some of them living with HIV, met in 1991 to consider AIDS and its effects on their communities. They agreed that, although many were infected with HIV through means well beyond their own control, not enough had been done to educate the people in the region. How could they join forces to make up for this deficiency?

Written materials would have limited utility in a setting of nearly universal illiteracy, and the military government had just taken control of many of the area’s radio stations. In the end, these women—who had never had electricity in their homes and had never owned televisions—decided to produce a videotape that told a story very similar to Guylène’s. They then worked with a community-based organization to acquire a portable generator, a video projector, and a screen. Condom demonstrations and community discussion accompanied each showing of the video.

Proud of their success, the women subsequently spoke of their experience at a number of meetings and conferences held in rural Haiti. At one of these conferences, a Haitian physician (herself not unsympathetic to the trials of the women who’d made the video) listened to a presentation by one of the women and saw the video. During the discussion, the doctor faced the project participant, who had proudly introduced herself as a *malerez*, a “poor woman,” and asked, “So what? In other words, if we are manifestly failing to prevent HIV transmission in this region, what is the significance of your project?”

The *malerez* did not hesitate in answering: “Doctor, when all around you liars are the only cocks crowing, telling the truth is a victory.” Telling the truth about the nature of women’s risk would be no mean feat in the current climate.

A second, and related, set of tasks concerns prevention. Making condoms readily available is an altogether insufficient response. Getting the right message across remains a priority and always will, as HIV is unlikely to be eradicated soon. Adolescents everywhere in the world simply must learn about sexually transmitted diseases before becoming sexually active. Universal HIV education needs to become part of growing up, which might also help to attenuate AIDS-related stigma. Clearly such efforts will need to be different in different settings, but the universal finality (and obstinacy) of AIDS has changed the way we think about sexuality and sexism. Teenagers throughout the world need to learn about the relationship between HIV transmission and social forces such as poverty and gender inequality.

A third set of activities might target specific groups of those at risk for HIV infection. In northern Tanzania, for example, improving the quality

and accessibility of treatment for sexually transmitted infections reduced the incidence of HIV by 42 percent.<sup>55</sup> Injecting drug users need ready access to drug-treatment programs, but we also know that needle-exchange efforts can decrease the incidence of new infections even in the absence of adequate drug treatment.<sup>56</sup>

Stopping exploitative prostitution would require addressing poverty, gender inequality, and racism, but in the absence of serious societal programs with such aims, public health authorities can make a priority of protecting, rather than punishing, sex workers.<sup>57</sup> Commercial sex workers benefit from high-quality medical care, especially when it is provided with the well-being of the prostitutes—rather than that of their clients—in mind. “It is important,” notes one advocate, “that a full range of health care services, including health care for their children and not just STD services, be made more accessible—and more acceptable—to prostitutes.”<sup>58</sup> Attacking AIDS-related stigma will require an attack against the scapegoating of sex workers, gays, and other groups.

For women already living with HIV disease, improved clinical services are critical. This means, among other things, educating health care professionals about women and AIDS.<sup>59</sup> HIV infection is underrecognized in women, with many cases diagnosed during pregnancy—or at autopsy. When AIDS case definitions were changed to include, among other conditions, invasive cervical cancer, the number of AIDS diagnoses in U.S. women doubled in a single year.<sup>60</sup>

Further improving services implies removing the barriers that currently prevent poor women, regardless of their HIV status, from obtaining much-needed resources. These resources range from access to certain medications to safe housing. Although we lack extensive data, research currently under way in the urban United States suggests that, in one large cohort of women, the majority of patients with advanced HIV disease were not receiving prophylaxis to prevent the most common opportunistic infections, to say nothing of antiretroviral therapy. In the same cohort, most women did not have secure housing; almost 20 percent stated that they had “no safe place to live.”<sup>61</sup> Attention to matters such as these could, in principle, prolong the lives of millions of women already infected, in both rich and poor countries.<sup>62</sup>

Finally, it is important to recall that women are also affected by AIDS in indirect ways, for it is women who bear the brunt of caring for the sick, regardless of age or gender.<sup>63</sup> For this reason, improving the quality of care for *all people* living with AIDS will improve the lives of the women who care for them.

Through these three sets of tasks alone—that is, setting the record straight, rethinking prevention activities, and improving the array of services available to women and to all persons with AIDS—we can do much to strengthen the hand of women living in poverty. With perseverance and commitment, such measures might eventually result in slowing the rate of HIV transmission to poor women. Indeed, evidence suggests that the recently registered drop in AIDS deaths is attributable to more effective therapy.<sup>64</sup> Patients receiving highly active antiretroviral therapy often have undetectable viral loads; transmission is much less likely when viral burden is low.<sup>65</sup>

As important as these AIDS-focused activities are, they largely address only the symptoms of a deeper ill. Endeavors focused on AIDS, though crucial, must be linked to efforts to empower poor women. The much-abused term “empower” is not meant vaguely here; empowerment is not a matter of self-esteem or even of parliamentary representation. Those choosing to make common cause with poor women must help them gain control over their own lives. Control of lives is related to control of land, systems of production, and the formal political and legal structures in which lives are enmeshed. In each of these arenas, poor people overall are already laboring at a vast disadvantage; the voices of poor women in particular are almost unheard.

The occurrence of HIV in the wealthy countries, where even those living in poverty control more resources than women like Guylène and Lata, reminds us that *HIV tracks along steep gradients of power*. In many settings, HIV risks are enhanced not so much by poverty in and of itself but by inequality. Increasingly, what people with AIDS share are not personal or psychological attributes. They do not share culture or language or a certain racial identity. They do not share sexual preference or an absolute income bracket. What they share, rather, is a *social position*—the bottom rung of the ladder in inegalitarian societies. Writing from Bombay, Sarthak Das underlines similarities in the experiences of the untouchable

castes of India and poor people of color in U.S. cities: "We need only replace the categories of 'Black' and 'Hispanic' with the low-caste, untouchable titles of *Harijan* and *Sudra* in order to observe a parallel epidemiological pattern on the subcontinent."<sup>66</sup>

The trials of women like Guylène and Lata pose challenges to women—and, of course, to all people of good will—in the rich countries. Can we somehow lessen the huge and growing disparities that characterize our world? Within rich countries, the struggles of women like Darlene Johnson are even more of a rebuke, challenging facile notions of sisterhood and solidarity. Unlike Guylène and Lata, Darlene lives within a mile of a world-class medical center. At key points in her experience, however, that center might as well have been half a world away. Without insurance, Darlene did not have ready access to it.

The rapidly growing literature on women and AIDS is well stocked with pieties about solidarity, but the progress of the disease among women seems to take particular advantage of the lack of solidarity among the members of an AIDS-affected society. When solidarity fails, the reasons are often less about color and more about class. A working-class lesbian writes that "HIV makes a mockery of pretend unity and sisterhood." Those most affected, she notes, are women of color and poor white women, many of whom are "struggling with long histories of shooting drugs or fucking men for the money to get those drugs. These are not the women usually identified as the women the feminist movement or the lesbian movement most value and try to organize to create a progressive political agenda."<sup>67</sup> One of the contributors to *Listen Up*, a recently published collection of feminist essays, concurs: "Many feminists seem to find the issues of class the most difficult to address; we are always faced with the fundamental inequalities inherent in late-twentieth-century multinational capitalism and our unavoidable implication in its structures."<sup>68</sup>

This is why efforts to promote pragmatic solidarity—that is, a solidarity that acknowledges and responds to the material needs of the destitute sick—must engage not only local inequalities but also global ones. The medical and social analysts whose work I prize most highly aim to link a deep concern for pragmatic interventions—projects designed to prevent or better treat complications of HIV infection—with more utopian aspi-

rations. If indeed inequality is an important co-factor in this pandemic, then stopping AIDS will require a more ambitious agenda, one that calls for the fundamental transformation of our world. What is at stake in these tasks is well expressed by anthropologist and activist Brooke Schoepf: "Unless the underlying struggles of millions to survive in the midst of poverty, powerlessness, and hopelessness are addressed, and the meanings of AIDS understood in the context of gender relations, HIV will continue to spread."<sup>69</sup>

In embracing a pessimism of the intellect, a certain optimism of the spirit is permitted. To paraphrase Patricia Hill Collins: as surely as HIV may be linked to oppression, so too are the conditions of oppression inherently unstable.<sup>70</sup>