Women, Inequality, and the Burden of HIV

Bisola O. Ojikutu, M.D., M.P.H., and Valerie E. Stone, M.D., M.P.H.

Driving through KwaZulu-Natal, South Africa, one is struck by the lush farmland and beautiful coast. Beyond this panorama, however, lie rural communities such as Umbumbulu, with its unemployment rate of 60 percent and rampant violence, where 40 percent of women seeking prenatal care are positive for the human immunodeficiency virus (HIV).1

Thandi Dlamini (not her real name) grew up in a crowded four-room house in Umbumbulu with 13 family members. As the youngest girl, she was charged with cooking, cleaning, and caring for her elders. At 19 years of age, she met her first boyfriend. From the perspective of Thandi and other women in her community, he was quite a catch—he was older, unmarried, and financially stable. She dreamed that one day he would offer to pay her lobola (bride price) and she would have her own home. Several months after meeting, he and Thandi had sexual intercourse. Thandi says this was her first sexual encounter.

Nine months later, she gave birth to a daughter, Zama. The baby had many episodes of bloody diarrhea and uncontrollable vomiting. By six months of age, Zama was clearly failing to thrive, and Thandi consented to have her tested for HIV. When the young mother returned to the hospital for the results, she was given three tragic pieces of information: she had given her daughter HIV, no treatment was available, and Zama would not live long.

Ichilo. Disgrace. Amahlioni. Shame. This is how Thandi describes her feelings after leaving the hospital. She didn’t really know what HIV was, except that it caused people to speak in hushed tones. It took months for Thandi to tell her boyfriend. Soon after hearing the news, he disappeared. Shortly after that, Zama died.

Around the same time, 9000 miles away in...
Denver, a 32-year-old black woman was sharing Thandi’s fate. In 1991, Donna Williams (not her real name) went to her doctor because of fatigue and consented to an HIV test. Weeks later, two women from the Denver Public Health Department arrived at her apartment. They informed her that she was HIV-positive and that her only option was to go to a specialty clinic at the public hospital. When she overcame her initial shock and went to the clinic, she was confronted by a sea of faces unlike her own — almost all men, many appearing near death. Terrified, she fled. A year passed before she obtained care for HIV.

Like Thandi, Donna grew up in a crowded home where she was the primary caregiver at a young age. Her mother had a series of abusive boyfriends, and in an effort to escape, Donna married an older man when she was 17 years old. During their first year of marriage, he was a good provider. Then his addiction to heroin surfaced and quickly destroyed their lives. For the next five years, he was in and out of prison, leaving his wife with their four children, unstably employed and transiently housed. After finally leaving her husband in 1987, Donna discovered that he was dying of AIDS. At the time, she was not sick and was struggling to survive as a single mother, so she did not get tested for HIV until 1991.

The differences between these two women are relatively few: native language, ethnic background, and land of birth. The list of similarities is substantially longer. Both are mothers and caregivers and both are poverty-stricken, transiently employed, and struggling to obtain basic daily requirements such as adequate housing. Both have had limited access to health care. Both have been dependent on men at some point in their lives for financial secu-
the freedom to ask questions or to demand the use of condoms. In most societies, if a woman chooses to remain single, she is choosing a life limited by poverty and instability.

Inequality between the sexes is not unique to the non-Western world. In the United States, sex-based income inequity has fueled disproportionate rates of poverty among women, and women’s options are limited as a result. Poor women, regardless of their nationality, share a fear of losing a male partner if it also means the loss of financial security. Thandi articulated it best when, in a discussion of sexual relationships with men, she noted that for many women, “it’s either that or nothing.” When “nothing” means not being able to afford food or shelter for themselves or their children, there really is no choice.

Both these women’s stories demonstrate that HIV is one small piece of a larger puzzle. As these pieces multiply and shift, health care needs are often low on the priority list. Donna is thankful that none of her children have HIV, but she has had to help each one through tumultuous circumstances. Currently, she is supporting her daughter through recovery from drug addiction. At 46, she has custody of her 5-year-old granddaughter. She is unemployed and recently had to move back to a subsidized housing project because of her limited income. Through all these difficulties, her adherence to her regimen of highly active antiretroviral therapy has been sporadic. Consequently, she has been hospitalized four times for pneumonia in the past two years.

After Zama’s death, Thandi gave birth to a second daughter — who is also HIV-positive. Luckily, through the support of a benefactor, this child has access to the same medications that would be used to treat her in the United States. Thandi’s life revolves around ensuring that her daughter takes her medications and stays well. Her greatest concern is that she and her daughter will never have financial security. She is training to become an HIV counselor because she would like to help other women obtain and benefit from HIV treatment, but she has no income and is therefore still dependent on a boyfriend for support.

The lives of these and many other women with HIV infection are mired in adverse circumstances. HIV adds to the overwhelming burden that they must bear. Here in the United States, there are disparities between the sexes in the care received for HIV infection — partly because of the complexity of these women’s lives, but also because they are frequently uninsured or underinsured and because they
are often forced to seek care in systems that are not structured to meet their needs. For example, many HIV clinics have inflexible and inconvenient hours, long waiting times, and few staff members from the same racial or ethnic groups as the patients.

As antiretroviral medications become more widely available in the developing world, a major challenge will be finding ways not simply to dole out medications but also to simultaneously address the broader context. In both Thandi’s world and Donna’s, cultural, economic, and social structures must be changed to allow women more viable life options. Throughout the world, physicians can assist in this process by advocating a multidisciplinary approach to treatment and prevention that would address women’s life circumstances along with their medical needs. Only when such change has been effected will HIV-infected women be able to obtain and benefit optimally from appropriate treatment, and only then will uninfected women be able to protect themselves from HIV infection and secure their own well-being.


---

Individual Rights versus the Public’s Health — 100 Years after Jacobson v. Massachusetts

Wendy E. Parmet, J.D., Richard A. Goodman, M.D., J.D., M.P.H., and Amy Farber, Ph.D.

We have on our statute book a law that compels . . . a man to offer up his body to pollution and filth and disease; that compels him to submit to a barbarous ceremonial of blood-poisoning, and virtually to say to a sick calf, “Thou art my savior: in thee do I trust. . . .”


Upon the principle of self-defense, of paramount necessity, a community has the right to protect itself against an epidemic of disease which threatens the safety of its members.

— Supreme Court of the United States, Jacobson v. Massachusetts, 197 U.S. 11 (1905)

On February 20, 1905, ruling in Jacobson v. Massachusetts, the U.S. Supreme Court upheld the right of the city of Cambridge, Massachusetts, to mandate vaccination against smallpox. Rejecting the contention that mandatory vaccination violated an individual’s rights to due process and equal protection as guaranteed by the 14th Amendment of the Constitution, the Court held that states may limit individual liberty in the service of well-established public health interventions. For 100 years, this seminal opinion has served as the constitutional foundation for state actions limiting liberty in the name of public health. Today, as physicians, policymakers, and public health officials contemplate the use of law to protect the public from emerging and reemerging infectious diseases as well as chronic diseases and other threats, it is instructive to revisit Jacobson and consider the lessons offered by the facts behind the case.

The case arose from a 1902 outbreak of smallpox. The Cambridge Board of Health voted, pursuant to a state statute, to require the vaccination of all residents who had not been vaccinated since March 1897. On March 15, 1902, Reverend Hennings Jacobson refused to be vaccinated. He was convicted and fined $5. His conviction was upheld by both the trial courts and the state’s Supreme Judicial Court.

Writing for the U.S. Supreme Court, Justice John Marshall Harlan noted that the defendant was concerned about the safety of vaccination. The Court,

Ms. Parmet is a professor of law at Northeastern University School of Law, Boston; Dr. Goodman is the codirector of the Public Health Law Program, Centers for Disease Control and Prevention, Atlanta; Dr. Farber is a student at Northeastern University School of Law and a research fellow at the Department of Social Medicine, Harvard Medical School, Boston.