Lethal Lottery

Treatment and care for inmates with HIV varies dramatically from prison to prison. The luck of the draw can mean life or death.

November 1, 1998 By Nina Siegal

Standing in the hospice of the California Medical Facility at Vacaville, with its brightly waxed floors and whitewashed walls and the sharp smell of pine cleaner in the air, you can forget you're in a maximum-security prison. It is quiet here, the only sounds the low murmur of a television set and the hushed voices of two inmates: a pastoral care worker and a patient.

Down the hallway and beyond the glass doors, it's another world entirely. A cacophony of sounds bounces off the walls of the prison's long, bleak central corridor, called the "main line." Pallid inmates, dressed in light blue shirts and jeans, walk jagged paths down the hall; klatches of correctional officers, clad in pressed brown and teal, are poised nearby. Inflexible but not particularly orderly, with constant talking and yelling, it seems like some form of underground military, preparing for war.

Although the hospice and prison are both antiseptic, institutional environments, it is odd to find two such seemingly opposed institutions joined together -- the focused, attentive culture of quality medical care, and the austere, forbidding and impersonal world of corrections. But it is an increasingly common juxtaposition.

Since the mid-'80s, new "tough on crime" laws have caused the nation's prison population to swell to more than 1.7 million. In the past decade, the number of incarcerated men and women has more than doubled, due in large part to mandatory drug-sentencing guidelines at both the federal and state levels. Since the percentage of inmate substance users continues to surge, more prisoners are at risk for a panoply of health problems related to drugs and the hard life of the streets. Topping the list is HIV, now one of the most common diseases among the incarcerated. Some sick inmates end up in decent hospices like Vacaville's, but the majority receive substandard care all around.

In August 1997, the Bureau of Justice Statistics (BJS) of the U.S. Department of Justice put out a special report on HIV in Prisons and Jails, using data culled in 1995. According to the survey, 24,226 state and federal prison inmates -- 2.3 percent of the total incarcerated population -- had HIV. The vast majority -- 23,404 -- were in state facilities (state prisons house the vast majority of inmates), while 822 were in federal institutions. The same report indicated that 0.5 percent of the

total U.S. prison population had AIDS, more than six times the rate of the general population, 0.08 percent.

In the past few years, prisons nationwide have been confronted with the problem of treating the growing numbers of HIV positive inmates, and most have been slow to respond to their new, complex and ever-changing needs. In some prisons, campaigns by AIDS activists and class-action lawsuits alleging gross violations of inmates' civil and constitutional rights have instigated change.

Faced with court-ordered consent decrees requiring them to improve their medical care, some prison systems, such as the Connecticut Department of Corrections, have made impressive improvements. Others, such as the Alabama Department of Corrections, remain health-care backwaters, where treatment and care are dangerously inadequate. As a result, the type of health care for those with HIV in state prisons ranges from relatively good to cruelly poor. Since inmates are often moved from one institution to another and denied access to basic information and services, such uneven care poses a significant health hazard, not just to prisoners but to the public at large as well.

The Right Stuff

What is "good" care in the prison setting? Simply put, it is the same standard of care that people with HIV on the outside deserve: access to all 11 anti-HIV drugs currently approved by the FDA, medicine for opportunistic infections and alternative therapies where appropriate.

But there are additional burdens on physicians and other health care workers who treat HIV in prisons: They must be able to help inmates comply with the complicated dosing schedules of combination regimens and to ensure that inmates get consistent treatment even if under lockdown, at parole hearings or in court, or transferred to another institution. Finding a knowledgeable doctor in a prison setting is no simple feat. Anne S. De Groot, MD, an assistant professor of medicine at Brown University Medical School who has worked in prisons for 10 years, says that there are a handful of prison doctors nationwide compassionate and interested in their patients, but otherwise the doctors inside are far from the best in their fields. "There are a lot of doctors who didn't succeed in community-based or academic-based facilities," she says. "They didn't have the people skills. So they ended up in prison, and the patients can't do anything about it."

When adequate care is not available, caregivers should help prisoners gain access to outside hospitals and infectious-diseases specialists and, when appropriate, help terminally ill prisoners get early medical release -- known as "compassionate release" -- so they won't die inside.

Even though protease inhibitors have recently become widely available in many prisons, it is difficult to determine how many inmates are on combination therapy. A 1997 report by Abt Associates Inc., a public-health research firm in Cambridge, Massachusetts, found that 90 percent of all state prison systems claimed to provide protease-based combos to their inmates, 100 percent claimed they conducted CD4 monitoring, and 80 percent claimed they administered viral load tests. But Theodore M. Hammett, the author of the study, admits that the statistics may be

misleading. “Those numbers look good, but there’s quite a bit of information showing that there are a number of problems with access,” he says. “The picture is not as rosy as it seems.”

Frederick Altice, MD, an assistant professor of medicine at Yale University, director of the college’s HIV in Prisons Program and a national expert on HIV care in prison, says the Abt numbers are more than dubious. “If a prison has just one patient on a protease inhibitor, they can say on those surveys, ’Yes, we provide it,’” Altice says. “States don’t want to say they are not providing the community standard of care. They can’t afford to, because it’s mud on their face. The real question would be, ’What percentage of inmates with HIV have access to protease inhibitors?’”

Altice conducted his own study in the Connecticut prison system and determined that 80 percent of all inmates with HIV were on protease inhibitors. But he guesses that the total would be much lower nationwide -- about 40 percent -- although he knows of no official studies.

De Groot agrees that Hammett’s numbers are too optimistic. “Institutions will tell you that they have combination therapies when saquinavir is the only protease inhibitor they have,” she says. “If you come in on Crixivan, too bad -- you get saquinavir. If you get sick from saquinavir, tough luck. Triple therapy really means having access to all 11 possible drugs, and having a qualified physician helping you to make decisions about which are the best ones for you.”

Patients on combination therapies often have debilitating side effects, ranging from nausea and dizziness to kidney stones or neuropathy. But there is an equally grave danger when those on combo-therapy fail to adhere to dosing requirements: Their virus can become resistant to entire classes of drugs, aborting future treatment options. Drug resistance is not just bad for the one patient -- it can be disastrous for the whole community because these super-resistant strains may be spread.

Fewer than 20 state prison systems -- including California, Florida, Illinois, Massachusetts, New Jersey, New York and Texas -- and the federal Bureau of Prisons (BOP) have written policies stating that they will provide the federally endorsed standard of care, according to Michael Haggerty, the executive director of the Correctional HIV Consortium in California.

Even in relatively enlightened systems, however, prison docs often have trouble ensuring that prisoners get their medications on time (and with meals if necessary), are supplied with timely refills and have access to the necessary supplements, prophylactic medications or painkillers. Judy Greenspan, chair of the HIV in Prison Committee of California Prison Focus, says she knows of no prison that adapts meal times to a prisoner’s drug-compliance needs. Only a few facilities nationwide go out of their way to provide HIV positive inmates with medically specialized diets, although some offer larger portions. And only on a case-by-case basis do prisons give inmates medication to take on their own a few hours after a meal or offer snacks for HIV drugs that must be taken with food.

Thirty-one state systems and the BOP have compassionate-release or medical-parole programs, but the process is usually long and complicated. In California, for example, a prison doctor may initiate early release if an inmate is judged to be within six months of death. The application has to

be approved by the prison counselor, the warden and the director of the Department of Corrections. A judge makes the ultimate decision, in some cases only after convening a hearing.

A Health Care Crapshoot

To generalize about HIV care in prison is hard because it is not standardized across the nation. Each state system has its own set of policies and procedures for treating inmates, and the federal prison system, too, operates under its own guidelines. Even within each state, the quality of treatment programs varies widely from facility to facility.

Most advocates agree that Alabama's prison system represents the bottom rung of AIDS care. Its 200-plus HIV positive inmates are segregated from the general population and denied access to programs. The state contracts out its medical care to a St. Louis company called Correctional Medical Systems, but according to one longtime volunteer who doesn't want to be identified, inmates have a hard time even getting CD4 counts. "You are in the system for 30 days and if you test positive, you're segregated," she says. "Then you just stay there and vegetate."

Jackie Walker, AIDS information coordinator for the ACLU's National Prison Project, agrees that Alabama's care is the nation's worst. "Being in Alabama, or being in a small county jail anywhere, are the worst places if you're a prisoner with HIV," she says. "Alabama punishes prisoners for being HIV positive. You don't have access to the work that inmates in the regular population get, you can't get educational or vocational programs, you can't get substance-abuse programs, you can't get work release."

In 1988, the ACLU filed a class-action suit, Onishea v. Hopper, on behalf of the HIV positive inmates in Alabama's state system, challenging their segregation and exclusion from prison programs and activities. U.S. District Judge Robert E. Varner ruled against the prisoners twice, saying that the danger of transmission was too great to allow inmates with HIV into the general prison population. The case is in its second appeals process.

By comparison, care in New York state, with the highest proportion (10.7 percent) of HIV positive inmates -- about 7,500 of more than 70,000 prisoners -- is near the gold standard, at least on paper. It is one of the few states that has all 11 FDA-approved HIV drugs in all 69 state prisons as well as a statewide standard of care, established by the New York State AIDS Institute. Available programs include confidential testing, education, support services, one-on-one and group counseling, and transitional and pre-release counseling. Of course, even with all this, there are still many complaints about care, and the system has a long way to go before all inmates are treated adequately.

The Case of California

Mid-range in terms of quality AIDS care lies California, the state with the fourth-largest HIV positive prison population. (Only New York, Florida and Texas have more.) According to recent estimates, there are 1,300 known HIV cases in California's prison system, about 0.8 percent of the state's inmates. California is one of only three states (the others are Alabama and Mississippi) that segregate their HIV positive inmates by housing them in separate units in each prison.

By and large, the care for California inmates depends on who is in charge. For instance, Joe Bick, MD, chief medical officer at Vacaville since 1993, is credited with making its HIV care perhaps the best in the nation. Bick is assisted by a court mandate: In the late ’80s, the prison was ordered by a California judge to improve its medical care (see "Organizing Inside").

Care for the 500 HIV positive men at Vacaville is a top institutional priority, says Bick. All FDA-approved drugs are available. The clinic physicians keep charts of all meds about to expire so that patients do not have to request refills, and they clock the time it takes between an inmate’s request for a visit and when he is seen. Bick says the wait is rarely more than a week.

And there is an effort to minimize the amount of time that care is interrupted by the special circumstances of prison life. During lockdowns, or if an inmate is transferred to administrative segregation -- under lock and key 23 hours a day -- clinic staff make cell calls so inmates get treatments on time. Bick even makes it a priority to prescribe reasonable doses of pain medications, famously difficult to get in prisons because of the security risk of distribution.

Even some of the most vocal critics of HIV treatment in correctional settings concede that the medical facility is doing a good job. “I believe that Vacaville is a model for what can be done within a prison setting,” says advocate Greenspan. “I would wager that it is one of the best medical facilities for prisoners in the country.”

But Vacaville’s achievements do not translate into good care throughout the state. Just look south, to Corcoran State Prison, for a dramatically different picture of health care. Quentin Hicks, a 33-year-old inmate serving a five-year sentence for fraud, says that he has refused to start a triple-combination regimen because the average wait for refills at Corcoran is three weeks, and he knows that irregular dosing can lead to drug resistance. “If I’m going to take protease inhibitors, I want it to work,” says Hicks. “I don’t want to mess up my chances of it working in the future.”

According to a peer educator, who wanted to be identified only as CK, most inmates at Corcoran are offered just one protease inhibitor -- Crixivan -- even if they are on a different regimen when they arrive at the prison. Some report getting double-combination therapy (which is universally acknowledged as substandard). Although viral load tests should be done once every three months, prisoners at Corcoran report getting them only every six months. “My greatest concern about Corcoran is that once I got very sick, I would not receive proper care, and I would die miserably,” wrote C.K. in a medical questionnaire.

Women Do Worse

The level of care is even worse in California’s women’s prisons. There are an estimated 1,000 HIV positive inmates in the state’s four female facilities, or about 4 percent of all women prisoners. In general, women in prison are more likely to be HIV positive than male inmates; according to the BJS, nationwide 4 percent of all women prisoners are positive, compared with 2.3 percent of all men. But prisoner advocates agree that women have a harder time getting treatment than men do, and rarely have access to combination therapy. While there are four men’s facilities in the state with licensed medical care facilities, there is only one licensed medical facility for women --

the Skilled Nursing Facility at the Central California Women's Facility (CCWF) in Chowchilla, notorious for its inadequate care.

Linda Cortez, incarcerated at CCWF in 1995 where she was diagnosed with AIDS, knows that all too well. Arrested in January 1994 in Riverside County for possession of an unregistered firearm and violating her parole, Cortez spent almost three years in CCWF before compassionate release sent her home in December 1996. While at CCWF, she came down with AIDS-related herpes zoster on her leg, which looked like a series of dark-red, blistering cigarette burns, but she says the doctor didn't admit her to the infirmary. The herpes spread to her eyes, and she went blind.

Brown Medical School's De Groot says that herpes zoster is a common complication of HIV that, if properly treated, should never lead to permanent disability. "If it was herpes that blinded her, that is unacceptable," says De Groot. "It could happen in Africa where there is inadequate medical care overall, but it should never have happened in the United States."

But Cortez's bad luck didn't end there. After she was returned to her old cell, she says that no one acknowledged that she couldn't see or taught her how to get around or made sure that she got breakfast -- when she was brought a breakfast tray, no one told her it was there. When she finally left prison in December 1996, Cortez weighed 92 pounds, was unable to walk and was convinced that she was about to die. "My care at Chowchilla?" said Cortez recently. "I'll put it like this: If you were dying of thirst and I stuck you in the desert with no water, how would you feel? You would die from dehydration." She paused. "To put it even more bluntly: They didn't give a fuck."

After leaving prison, Cortez was treated at the University of Southern California Medical Center in Los Angeles, where she was given AIDS meds, taught how to use her legs again and placed on an appropriate diet. Since then, she has learned how to manage her HIV herself, regained weight and begun working with the Braille Center to become self-sufficient.

In May 1995, hundreds of inmates at CCWF and the California Institute for Women (CIW) in Frontera filed a class-action lawsuit in the U.S. District Court for Eastern California against the California Department of Corrections, alleging that their rights were violated because they were provided inadequate health care, including inmates with chronic and terminal conditions such as HIV. Cynthia Chandler, director of the Women's Positive Legal Action Network, based in Oakland, California, describes the care at CCWF as "dangerously, negligently lacking. It was like watching torture in progress."

The disparity in care between Vacaville and Corcoran or CCWF brings into sharp focus the essential problem in California: It is so uneven that when an inmate is moved, it's a crapshoot as to what kind of medication, education or services they get. Chandler says that typically, when an inmate is moved from one prison to another, he or she is taken off all meds, retested for HIV and placed on an entirely new drug regimen. Medical files are routinely lost and may not show up for years.

Stories of negligence and abuse are repeated again and again across the nation. In some cases, inmates with HIV may be sent to the nearest outside hospital, whether or not it has an infectious-

disease specialist. But many inmates in state and federal prisons simply go untreated and end up in prison infirmaries or hospitals where they are left to die.

Increasingly, the final, short reprieve provided by compassionate release is unavailable, as many facilities send inmates to in-prison hospices. The Vacaville hospice, with its sparkling floors and countertops, hires inmates as pastoral care workers to comfort the dying, and the care is sensitive and timely. But now there is talk of building hospices in prisons such as CCWF, where inmates serve longer sentences. Many advocates call this trend dangerous because prisons cannot be relied upon to provide even basic services. “I worry about setting up a hospice in a prison unit with no medical care,” Greenspan says. “In a prison with no medical care, a hospice unit becomes a death camp.”

“In here you get so much attention from the most unbelievable men, but having HIV is like a case of leprosy. The men can be very cruel. My bunkie even wrote the local papers complaining he was forced to be bunked with someone with AIDS.”

-Robert Beaton, Cotton Correctional Facility, Jackson, Michigan

Every inmate is put on protease inhibitors as soon as she gets here. The sad thing is, if you refuse medications, they’re like, ’Well, if you get sick, we can’t help you.’"

-Patricia Bright, Albion Correctional Facility for Women, Albion, New York

I informed my partner that I was HIV positive, and he dealt with it very well. Yet if we had ever been caught being too intimate, I would have been placed in solitary confinement for the duration of my sentence."

-J.D. Munro-Kimble, Cotton Correctional Facility, Jackson, Michigan

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