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Patients With H.I.V. Seen as Separated By a Racial Divide

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Last January in Manhattan, at the memorial service of a colleague who died of an AIDS-related illness, Joseph Bostic lost feeling in his legs and had trouble standing. A friend, Keith Cylar, hailed a cab, crumpled some bills into the driver's palm and sent Mr. Bostic home to Brooklyn. Two months later, Mr. Bostic died of heart and kidney failure related to H.I.V., the virus that causes AIDS. Within three weeks, Mr. Cylar, too, was dead of heart disease related to the virus.

The loss of these two men -- both of them AIDS activists who had lived with H.I.V. for years -- shocked many who had nearly forgotten the days when attending funerals and memorial services was a constant, unsettling ritual. In the United States, death rates from H.I.V./AIDS have sharply dropped in the past eight years as new medications have made the disease manageable for many patients.

But among African-Americans like Mr. Bostic and Mr. Cylar, AIDS is still a killer.

In 2002, almost twice as many blacks with AIDS died compared with whites, a gap that has been increasing since 1998. Researchers say the reasons include late diagnoses and inferior care, along with complications because blacks are more likely than whites to suffer from other illnesses.

As a result, health experts say, many blacks in the United States have far more in common with their counterparts in Africa than they do with white patients.

"The area my clinic's in is essentially a suburb of the third world," said Dr. Joseph C. Gathe Jr., an infectious-disease physician in Houston and director of a nonprofit AIDS clinic. "It's a shame no one seems to know that the problem in Africa looks like the problem in inner-city Houston, Chicago and New York."

Though African-Americans make up just over 12 percent of the United States population, they accounted for 54 percent of the 40,000 new diagnoses of H.I.V./AIDS in 2002, the most recent year for which statistics were available,

according to the Centers for Disease Control and Prevention. Of the estimated 385,000 people living with AIDS, 42 percent were African-American. For them, the disease leads disproportionately to death.

Among black men ages 25 to 44, the death rate from H.I.V./AIDS was more than six times greater than for whites. For black women in the same age group, the numbers are even more startling: the death rate is more than 13 times greater than for whites. The most common method of transmission has been from infected sexual partners, followed by transmission through injected drugs.

The experiences of Mr. Cylar, who was 45, and Mr. Bostic, who was 51, help explain why managing the disease is so precarious for many African-Americans.

"Though Keith was well educated, had private health insurance, a wonderful doctor and was consistent with the dosing of his medication, he experienced in his own life what many of our clientele experience," said Charles King, who with Mr. Cylar founded Housing Works, a New York City nonprofit organization that provides services for homeless people living with H.I.V./AIDS.

"Keith had severe asthma and in childhood spent more days in bed or in the hospital than in school," said Mr. King, who was Mr. Cylar's partner for nearly 15 years. "He also dealt with many of the particular problems that occur with black gay men." Mr. Cylar endured chronic depression and had used drugs in the past as an escape from anger, Mr. King said.

"With the H.I.V., the asthma and the medications," Mr. King said, "there was not a day that Keith didn't know physical pain."

Mr. Bostic had led a troubled life: he served three prison terms for a total of 17 years, the first one for manslaughter, and ended up homeless and H.I.V. positive in 1999. Less than a year later, he turned his life around and co-founded the New York City AIDS Housing Network, a nonprofit organization in Brooklyn for low-income people living with H.I.V./AIDS.

But dealing with his disease was difficult. Mr. Bostic could barely make ends meet on his salary from the struggling organization and had health insurance only some of the time. His friends say he took H.I.V. drugs, which are expensive, off and on rather than consistently.

"Joe wasn't taking his medicine regularly," said Shirlene Cooper, a friend. "He was very intelligent, but when the medication is so toxic that it makes you sick and you can't function, you get tired of taking it."

Seeing Unequal Tracks

Dr. Daniel Kuritzkes, director of AIDS research at Brigham and Women's Hospital in Boston and associate professor of medicine at Harvard Medical School, says he believes there are two very different and unequal tracks of H.I.V. treatment and care in the United States.

"In the ideal track," Dr. Kuritzkes said, "a person discovers they are H.I.V. infected, seeks medical care, has regular follow-up and avoids complications by taking a regimen reliably, which he or she is able to tolerate. There is every expectation that this person will lead a normal life."

But others follow a more dangerous path. "These are the patients that come to the hospital with full-blown AIDS as their initial diagnosis," Dr. Kuritzkes said. "They may have limited access to care because of finances or because other social or medical problems interfere. By and large, the deaths are among this group, which tends to be African-American."

According to a new survey from the Kaiser Family Foundation, African-Americans are more likely to say they have been tested for H.I.V. in the past year than Latinos or whites. But some research has shown that they are also more likely to learn that they are infected at a later stage, when the disease is harder to treat.

Jay, who asked to be identified only by his middle name because acquaintances do not know he is infected with H.I.V., says he believes he contracted the virus in the late 1980's from a dirty heroin needle. But his condition was not diagnosed for another six years, after he contracted a case of shingles so severe that he had to be carried up and down the stairs of his home.

"I had so much heroin and cocaine in my body that I couldn't feel anything, so I had no idea if I was sick or not," said Jay, 54, who says he has been off drugs for 11 years and now owns a small business in Chicago.

Once they do find out they have been infected with the virus, African-Americans receive life-sustaining treatment less often than whites, according to several research studies. Part of the problem is tied to an inability to pay: African-Americans with H.I.V./AIDS are more likely to be uninsured or underinsured than whites. According to the government AIDS Drug Assistance Program, antiviral drugs cost at least an average of \$12,000 a year per patient.

In June, the Bush administration announced that it was moving \$20 million into the AIDS Drug Assistance Program, which helps obtain medications for those who cannot pay for them. But the National Alliance of State and Territorial AIDS Directors and other organizations believe that 10 times that much money is needed to close the gap.

Even when insurance and income are the same, evidence is mounting that blacks receive lower-quality medical care than whites. A study two years ago by the Institute of Medicine, an independent research group, found that African-Americans were less likely to be given the most sophisticated treatments for H.I.V. than whites, even when money was not a factor.

Effects of Other Illnesses

For those who do get the care and medication that they need, other medical problems -- and the medications needed to treat them -- can get in the way of H.I.V. treatment. African-Americans have a shorter life expectancy than whites and higher rates of cardiovascular disease, diabetes, stroke, some forms of cancer, sexually transmitted infections, asthma and other illnesses.

"African-Americans have a higher incidence of common illnesses other than H.I.V., so the reality is that most of the people who I see with H.I.V. don't have H.I.V. as the only thing wrong with them," said Dr. Kimberly Y. Smith, an assistant professor of medicine at Rush University Medical Center in Chicago and an attending physician at an outpatient H.I.V. clinic. "We have more hypertension, diabetes and cardiovascular disease, and at younger ages. This makes treatment more complex."

Karen, a black woman who contracted H.I.V. from a former boyfriend, says she laughed when she first heard AIDS referred to as a manageable disease. Since the virus was diagnosed in her in 1992, she has battled numerous side effects of antiretroviral medication, including kidney stones, weight loss and severe nausea. She has also required surgery to remove her appendix, gall bladder and an ovarian cyst, and she takes medication to control endometriosis.

She says she is poor and struggles to pay for her medication. "I am trying to stay positive with this disease and with these drugs, but I'm losing organs right and left," said Karen, 42, who is a single mother and lives in a city in the Northeast. She asked that her last name and city not be identified to protect the privacy of her son.

"Sometimes it's hard for me to stay on the medications, because I feel better when I'm off the drugs," she said. "I've had stomach pain so bad that I couldn't get out of bed and I could eat only baby food. The pain of the kidney

stones was like giving birth to triplets. I've got so many things wrong with me that I'm like a carnival ride. I know that the drugs are working, and I don't mean to sound ungrateful. But it is a struggle to stay on them because of how it affects your quality of life."

Part of a Struggle

Those who treat AIDS patients and others who are infected with the virus are acutely aware of that struggle. Phill Wilson, director of the Black AIDS Institute in Los Angeles and a friend of Mr. Bostic and Mr. Cylar, said he was stricken by their deaths. Mr. Wilson was infected with H.I.V. in the mid-1980's. "Black people are continuing to die of AIDS though you don't hear much about it," he said, "and every time another one of us dies, it feels like you are one less person closer to being the one who is next."

Dr. Valerie E. Stone, a physician at Massachusetts General Hospital in Boston who has treated H.I.V./AIDS patients for the past two decades, sees the toll among her patients. She says she is increasingly alarmed about the death rates among blacks.

"In 1994, I remember being burned out, because 27 of my 90 to 100 patients died in one year," said Dr. Stone, who is also an associate professor of medicine at Harvard Medical School. "But then the new potent combination regimens came on the scene and everything changed. These medicines made such a difference that by 1997 we didn't have a single person die of H.I.V. in our program. There was tremendous hope for change."

"However, it is now clear that management of this very complex disease is much more difficult than just taking pills, particularly for my African-American patients who often have very difficult life challenges," she said. "So now when I go to these international AIDS meetings and hear that the problem is solved here, I get incredibly angry. This epidemic is out of control in the black community. There is no magic bullet."

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