Their Patients, Their People

More than half of all new HIVers are African American, but only a handful of top HIV docs are black. Now these MDs are uniting to stand up for their patients-and themselves.

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I was overwhelmed," says Edith Lang, 44, of Dallas. In 1998, Lang learned not only that she was HIV positive but that her husband, a minister, had hidden his homosexual activity and serostatus. With her CD4s at 315, she landed at a clinic where her white female doctor enrolled her in a trial for the then-experimental drug Ziagen (abacavir). "Whatever I needed to do to stay alive," Lang recalls, "I'd do." But when Lang complained of aching feet and legs, the doctor prescribed neuropathy drugs—without even examining her. Afraid of "hurting people's feelings," Lang didn't object.

Instead, the clinic, which only accepted the uninsured, kicked Lang out when it learned she had a health plan. Lang landed at Dallas' Peabody Health Center, where she saw Keith Rawlings, MD, one of the nation's top HIV doctors and an expert on the disease in black people. "I was more relaxed when I saw he was black," says Lang. When Rawlings asked how she knew she had neuropathy, "I said, 'I really don't,'" she says—and added that the previous doctor hadn't examined her. "Rawlings said, 'That's like taking your car to the mechanic, and the mechanic going by what you say.'" Over the following months, Rawlings examined her frequently—and discovered that she didn't have neuropathy after all.

Four years later, Lang and Rawlings are still a strong team. "If I have a question, he has answers," says Lang. "If he doesn't, he seeks them." Says Rawlings of Lang, "I'd like to think I've been able to provide her with a high quality of medical care while being supportive of her as a person." It seems so—Rawlings even paired Lang, a Mississippi native, with a nutritionist who showed her how to cook a healthier version of her traditional soul-food diet.

Lang is among the few lucky black HIVers with a top doc who happens to be black. According to the Centers for Disease Control and Prevention (CDC), African Americans constitute 39 percent of all AIDS cases and 54 percent of new HIV infections—and have the poorest survival rate among American HIVers. However, of the nation's hundred or so doctors in the upper echelons of HIV medicine, only a handful are black.

Just as many gay HIVers prefer a gay HIV doctor, many black HIVers, gay or straight, prefer a black doc. Obviously, race isn't the only factor. "All white patients don't find any one white doctor comfortable, and not all black patients like me," says outspoken top black HIV doc Wilbert Jordan,

MD, founder of the Oasis Clinic, serving largely black South Central Los Angeles. A black doctor can, of course, be as insensitive as a white one. But many black docs may carry an innate interest in black patients' well-being that white doctors, however dedicated, lack. And many black patients perceive from a black doctor "a sensitivity that comes from having experienced the same disparities," says Rawlings.

With doctors of the same race, "[black HIVers] may be more open to discussing their life, living conditions, sexual behaviors or whatever may be impacting their ability to deal with the side effects of meds or the disease itself," says black HIVer Charles Clifton, who heads Test Positive Aware Network in Chicago. Says black doc Joseph Gathe, MD, who treats more than 4,000 patients at his clinic in a mostly black Houston neighborhood, "If you can't deal with the cultural issues, the person is never going to focus on their HIV."

Black doctors may also better calm black patients' fears over HIV meds. "Black patients think AZT kills because everybody on AZT died back in the day," says Gathe, who tells patients, "They died of AIDS—not AZT." Ditto for clinical trials, which many black people fear due to scandals like the decades-long Tuskegee experiment, in which researchers withheld syphilis treatment from hundreds of poor black men in order to study the disease's natural progression. Having a black doctor dispel myths and explain the patient protections built into modern clinical trials may be more reassuring for patients of color than hearing such news from a white doctor.

Indeed, Gathe often enrolls people of color into clinical trials for new drugs or regimens, telling patients that they offer superior care, including more frequent lab testing and closer monitoring. "I tell them, 'We can see if you gain weight, if [the drugs] mess up your period, screw up your sex life,'" he says. "I will know it sooner [if you're in a] study." But black doctor Valerie Stone, MD, senior clinician in the AIDS program at Massachusetts General Hospital, says few of her new patients want to enter trials involving random assignation to one regimen or the other but are more open to studies that merely track their progress over time.

Then there's the discrimination of some white doctors, conscious or otherwise. In 2002, an Institute of Medicine review of 100-plus studies found that even among equal levels of illness, income and insurance, African Americans received inferior treatment, attributing the disparity in part to caregivers' "bias, prejudice and stereotyping." That went for HIV, too: With CD4 counts equivalent to their white counterparts', the review reported, African Americans were less likely to get HIV meds or preventive treatment for PCP pneumonia, causing more deaths. Such bias may also keep white doctors from discussing with black patients the basics of HIV progression, treatment options or the importance of treatment adherence. Adds Gathe, "In a person who is otherwise well that you're about to give expensive pills to that may make them sick, if you don't explain [the importance of adherence] so they can understand, they're not going to do it."

Gathe says he repeatedly sees the dialogue gap between white doctors and black patients: "I ask my new patients, 'How did you and your doctor decide to start these meds?'" All too often, he says, "the answer is 'He gave me a prescription and told me to take it and come back in three months.' I ask, 'Did he tell you why?' 'No.' 'Did you ask him?' 'No, I was scared to, because he

never talks to me anyway.'"

Stone works with her patients differently. "I spend time on the relationship before starting them on meds," she says, from the initial visit to discussing lab results. If it's time for meds, "I tell them all the options and the side effects. They choose the [regimen that] doesn't sound as problematic."

Her trust-building process has worked with Chris Brown (not his real name), a gay, black 31-year-old. "I was scared [of starting meds]. She calmed my fears," he says, adding that he feels comfortable enough to confide when he's missed doses. Brown might feel otherwise with a white or even straight black male doctor. "I've had a lot of bad experiences with the black heterosexual male," he says. "They tend to be very conservative and homophobic." Instead, Brown says, he got "a fabulous black woman."

It's not easy being a black HIV doctor. Often, their caseloads are more challenging than those of colleagues who treat mainly white, middle-class patients. "Go to any [meeting of HIV clinicians]," says Jordan, "and if there are 100 doctors there, I'm surprised if three are black. I have stood up and asked, 'How many of you want to see black patients? But before you raise your hand, let me describe who I'm talking about—a drug user from the inner city.' Nobody raises their hands."

Many black HIV doctors say their colleagues routinely snub them. Jordan observes that despite overwhelming numbers of black HIVers, the pharmaceutical industry invites few black docs to its advisory meetings. Stone, a 20-year veteran of HIV care who's on the faculty at Harvard med school and involved in the federal Office of AIDS Research, says, "Most of the time I am [treated with respect], but every once in a while, it's kind of like it doesn't click [with colleagues] who I am. It clicks I'm a black woman who can't really know as much as [I do]—and I get the same crap I was dealing with years ago." Most black doctors say they wish their ranks were larger—in part so they could help nonblack peers provide more culturally sensitive care. Jordan wishes for a larger nonwhite doctor population, noting, "I may miss a cultural point [about a Latino patient] if I don't have a Latino peer that I can ask questions [of]."

No wonder HIV medicine's few black stars have united. In 1999, Gathe, Jordan and Rawlings—plus Chicago's Kimberly Smith, MD; Atlanta's Harry Strothers III, MD; and Rani Lewis, MD, who recently joined Rawlings' practice—founded the nonprofit Integrated Minority AIDS Network Inc. (IMANI). The group, whose acronym means "faith" in Swahili, advocates for black patients in the crafting of HIV policy and educates clinicians and patients about HIV in black people. It sponsors symposia for black health-care providers and has conducted more than 40 training sessions everywhere from historically black medical schools to clinics in the rural South. It also pressures the organizers of major HIV meetings to include more topics about people of color on the agenda—not to mention more doctors of color among the speakers. Before IMANI, notes Stone, even HIV meetings with predominantly black audiences were headlined by few top black doctors.

Last year, most of IMANI's members plus Stone, Brooklyn's Andre Brutus, MD and DC's Luther Virgil, MD, formed the Black Clinical Research Consortium (BCRC), aiming to study how HIV and its meds affect black Americans. Stone estimates that BCRC board members combined treat more

than 6,000 HIVers of color. The group's series of studies will focus on such issues as HAART adherence, how black HIVers fare over time on different regimens and the quality of care to people of color.

As black HIV rates rise, such data are badly needed. "We have 20 years of research that has basically asked numerous questions about what happens in white men," says Rawlings. That's why BCRC is stepping forward rather than wait for the AIDS Clinical Trials Group (ACTG), the largest fed-funded body of the HIV-research establishment.

Granted, times are changing: According to the ACTG's Daniel Kuritzkes, MD, as of 2003, black HIVers made up 32 percent of all ACTG trial participants. (Latinos made up 17 percent, said Kuritzkes.) And Smith says she will cochair ACTG's new Underrepresented Populations Committee. But Cornelius Baker, black executive director of DC's HIVer-serving Whitman-Walker Clinic, says, "Hiring one black lead investigator or scientist won't overcome the years of distrust an organization has built." (Kuritzkes says the racial breakdown of ACTG's investigators "isn't tabulated," though he claims the group has "a fair number of Hispanic investigators and a smaller number of African Americans.")

Stone credits Community Programs for Clinical Research on AIDS (CPCRA), a newer trials group, with having done "an excellent job" of enrolling people of color but notes that the group conducts a small percentage of all HIV research. And while drugmakers are enrolling more blacks, she says, increasingly, enrollees are from outside the U.S., with genetics that may yield data inapplicable to African Americans.

The stakes in the numbers game are high. When statistically significant percentages of minority groups—preferably near the percentages found in the real HIV population, says Stone—are included in studies, the results can be invaluable. An ACTG sub-study contained 50 black participants out of 137 and found that 20 percent of the black HIVers metabolized Sustiva (efavirenz) more slowly than usual, causing more side effects. "I don't think it means black folks shouldn't use Sustiva," says Smith, winner of ACTG's 2003 Young Investigator of the Year Award. "I think different groups may metabolize drugs differently."

Other research suggests that HIV or HIV meds may act differently depending on gender or race, but until studies enroll ample numbers of black HIVers, research will uncover more questions than answers. BCRC wants to change that.

Behind the unified mission of IMANI and BCRC's brain trust are human beings, of course—each uniquely driven to specialize in HIV. Gathe trained in infectious diseases before the disease that would be called AIDS emerged, in the early 1980s. While he was studying PCP pneumonia, a supervising physician told him, "You'll never see one of these cases in your entire career." Before long, he was inundated with AIDS patients—and doctors needing his expertise.

Also trained in the pre-AIDS 1970s, Jordan dedicated his early work to the first person he diagnosed with the disease, a childhood friend and closeted bisexual abandoned by his friends and angry wife. Witnessing homophobia and AIDS-phobia has led him to fight bigotry—once

confronting a church deaconess who had kicked out her gay grandson at gunpoint. “I said to her, ‘Tell me what it means when you claim to be touched by a loving God and put your grandchild out.’”

Becoming a parent gave inspiration to Rawlings, who says he asked himself, “If this was going to be the public-health issue of my generation, then was I, as a father, going to do something about it or sit on the sidelines?” Stone says she has lost several acquaintances to AIDS, including a Yale medical-school classmate, and that treating a closeted bisexual black man for HIV while in med school opened her eyes to the ways shame and stigma often undermine HIVers’ care. Smith says she chose HIV care to “offer services to people many doctors didn’t want anything to do with.”

Those people often come to them not just with HIV but drug or alcohol addiction, homelessness, joblessness, domestic violence and other problems. The doctors say they get down on the system, not their patients. “It’s outrageous that racial disparities in care cause black people to die from HIV,” fumes Stone. Docs also worry about their patients’ high rates of diabetes, heart disease and hepatitis C.

Yet they’re proud that, in many cases, they’ve helped turn HIV “from a death sentence to one of full lives and smiling faces,” as Gathe puts it. Several docs say they believe a higher spirit guides their work. “God put me here and steered me to take care of this epidemic,” says Gathe.

And as for Edith Lang? With Rawlings’ help, she took a drug holiday for two years—and of course there’s that new heart-healthy soul-food diet. She even looks forward to doctor visits. “I feel safe with him,” she says. “My family wanted me to move home to Mississippi, but I wouldn’t have a Dr. Rawlings down there. If something isn’t broke, why fix it?”

Top Black MDs

Don’t see one near you? Call the nearest and ask for a referral.

Andre Brutus
Brooklyn, NY
718.240.5438

Joseph Gathe
Houston, TX
713.526.9821

Wilbert Jordan
Los Angeles, CA
310.668.4213

Helena Kwakwa
Philadelphia, PA
215.989.3851

Keith Rawlings
Dallas, TX
214.421.7848

Robert Scott
Oakland, CA
510.663.7979

Kimberly Smith
Chicago, IL
312.942.5865

Valerie Stone
Boston, MA
617.267.0900

Harry Strothers III
Atlanta, GA
404.752.1000

Anita Vaughn
Newark, NJ
973.733.5300

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