

AIDS GOES GRAY

HIV has been with us for over two decades. Its survivors will live much longer than that--which is more than can be said for the safety net keeping them housed and healthy

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Kai Wright and LeRoy Whitfield
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LeRoy Whitfield is a Manhattan-based freelance writer. This story was produced under the George Washington Williams Fellowship for Journalists of Color, a project sponsored by the Independent Press Association.

There's not a lot of gray in Brenda Curry's worldview. At 58, she's been around the block enough times to know black from white, to tell the good guys from the bad. And one thing's for sure: Both of her ex-husbands were saints. "Neither one of those guys had other women," she wistfully recalls. "I didn't have to worry about child support. I didn't have to worry about nobody scratching at my door, wanting to throw bleach on me or something. I didn't have to worry about nothing. And I didn't even realize it, until later in life. In retrospect, you know? Shit, I had it OK!"

Even after her first marriage broke up, Curry's husband helped raise their son Kevin. Her second husband revived her spiritual life, introducing her to Jehovah's Witness. Grandma Curry had tried to raise the kids A.M.E.--"kept us in church, right on the first row so she could watch us from the choir"--but Brenda lived with her mother's mama, who drank and stirred up chaos. So she strayed from religion, and it wasn't until she met her second husband, in the 1970s, that she came back to the fold. "God is good. I had two very good men. The only thing is, we were addicts and alcoholics."

Not that they were junkies. Curry was always a little afraid of the hard stuff, and that fear tempered her, even though she'd been around drugs her whole life--parents, siblings, aunts and uncles, everyone used. That's really what she liked most about her second husband: He was unlike all the men she'd grown up with. But he left after she cut him during a drunken fight one night.

Most of Curry's life after that marriage is blurry; she remembers only the transitions, the key moments. Like meeting George--a beautiful, dark-skinned hulk of a man with enchanting hazel eyes--and moving to Connecticut to get away from the city's ceaseless hustle. Things did turn around for both of them up there--except that George kept getting bizarrely strong chest colds.

He'd cough all night long, and get winded easily. He finally ended up in the hospital for two weeks, and it was during a visit there that Curry overheard a doctor ask him something about an AIDS test.

That was one of the events that cleared out the gray for Curry. Looking back, she sees obvious signs that this guy wasn't being honest, that he knew he was sick all along and didn't tell. She quickly got a test herself, and it came back positive. So she returned to her lifelong stomping grounds on the Upper West Side, just below Harlem, to wait for death.

That was 18 years ago.

Curry and thousands like her have been kept alive long past their expected deaths by a remarkable network of AIDS service agencies and public health programs that have linked them with the medication and support they need to stay healthy. Few involved in that network's construction could have expected it to work quite so well, to keep people alive quite so long.

This has created a troubling irony. Now that the system has enabled people like Curry to live to see their sixties, can it handle the weight of its own success? And if it can, how

should doctors and patients treat the disease itself, when AIDS becomes one of a portfolio of medical crises that plague aging poor people of color? The challenge of the AIDS epidemic may no longer be staving off the death it causes, but figuring out how to live with it for the long haul.

Just a few years before Curry stood in a Connecticut hospital pondering her boyfriend's bizarre "colds," New York City and San Francisco health officials were scratching their heads over the same ailment. Pneumocystis carinii pneumonia, or PCP, lives in the air sacs through which oxygen passes from the lungs to the bloodstream. The modern immune system has long adapted to this relatively weak protozoan, and normally beats it back long before it suffocates its host. There was no fathomable reason why scores of young, otherwise healthy people should be dying from a form of pneumonia last seen in postwar European orphanages.

And it wasn't just PCP. A host of old, forgotten infections were suddenly killing people: a skin cancer last seen in elderly Mediterranean men, which had never been fatal; a herpes strain that should have been easily treated; a parasite, most often found in cat feces, that millions of people carry in their bodies without harm. It was scary stuff, which turned downright horrifying when scientists figured out these folks' immune systems had been crippled by a virus spread through sex and blood. Doctors and researchers, activists and the lovers of those killed--everyone involved saw a crisis and mobilized an emergency response.

That ethos of urgency has surrounded the AIDS epidemic ever since. We've engineered treatment, care and prevention programs meant to first and foremost stop the carnage. In 1990, activists finally convinced lawmakers of the crisis as well. They pushed through Congress a mechanism to pay for all these services, one that is today a \$2 billion program. Its name says everything: the Comprehensive AIDS Resources Emergency Act.

But as we settle into the emergency's third decade, some are beginning to wonder if we can sustain this sort of response. New drugs have brought down death rates, not by eradicating the virus from the bodies of those infected but by slowing its progression to AIDS. The troubling result is an epidemic that is growing rather than shrinking--and one that is relentlessly aging.

The number of Americans living with HIV who are over 45 years old grew by 60 percent between 1999 and 2002. In New York City, one-quarter of people living with HIV are over 50; 63 percent are over 40. "The system works," explains Dr. Stephen Karpik, research director at the AIDS Community Research Initiative of America, which has launched a series of studies on aging New Yorkers with HIV. "It gets people healthy, and they're living. But that's creating a time bomb."

For years, Curry largely avoided treating her infection. She had a series of doctors at clinics around town--"I don't trust people," she says in explaining why she clipped through them--but she preferred the concoctions of a Chinatown herbalist to meds. "She would go in the back--a little old Chinese woman--and she'd bag up these herbs," Curry recalls, laughing at the strange mix of optimism and denial that made this her treatment plan for years. "I was taking all this stuff, plus going to the store and getting other herbal pills. I wasn't reading, wasn't asking. I was just taking it. I didn't want to know."

Meanwhile, she had four bouts with PCP, two of which put her in the hospital. The last visit was a two-and-a-half month stay. "I'm 205 pounds when I go in there," she says, wincing, "and come out 145 pounds!" Now she's on a three-drug combination of medications, plus another medication for her Hepatitis B. It's more than \$20,000 worth of pills a year at market rates. If she were taking anything for her Hep C infection, that would be thousands more a year.

HIV kills by breaking into the white blood cells that organize an immune system's response to infections, taking them over and using them to copy itself. Once HIV has depleted these "T-cells," the body is incapable of mobilizing its natural defenses, and diseases that healthy people fend off instead turn fatal.

There are about 20 antiretroviral drugs available in the U.S. to fight this. Antiretrovirals work by also breaking into T-cells, then interrupting one or another stage of HIV's replication cycle. But that is a massively invasive process, and once inside the cells, the drugs often disrupt more than just HIV. People lose muscle and fat in their faces, legs and arms; develop lumps of fat in their stomachs and necks, giving them a hunchback appearance; and get nerve damage in their feet and hands, limiting motor skills. There are also many more run-of-the-mill complications, like nausea, dizziness and appetite loss.

But perhaps most troubling, the drugs complicate the conditions that already wreak havoc on the bodies of poor, middle-aged African Americans. A class of antiretrovirals called protease inhibitors is crucial to the multi-drug regimen that has brought AIDS death rates down. But protease inhibitors are also associated with high blood sugar and cholesterol levels, which means they may be inflaming the diabetes and heart disease epidemics in black neighborhoods. Meanwhile, they may also be frustrating treatment, since the AIDS drugs can make people resistant to insulin.

"A patient will be on the same insulin dose for a while and then--boom--it's suddenly harder to control the sugar," says Dr. Hilario Organista, whose virology clinic at Metropolitan Hospital sees around 75 HIV patients who are middle aged or older. "But you want to treat the HIV," he explains. "If you can treat both without side effects, then yes, that's better. Sometimes you get away with it."

The calculus can be dizzying. HIV meds also drive up the cholesterol of a patient with heart disease, so doctors give a patient additional drugs for that problem. But the

cholesterol meds can cause liver problems, which make it harder for the HIV drugs to work.

The liver and kidneys, in fact, are always a flashpoint for long-term treatment. That's where the body breaks the antiretrovirals down--which takes a lot of work. But patients who have used lots of drugs or alcohol for decades are likely to start off with a weak liver or kidneys. In such cases, you have to strike off your list of options the anti-HIV drugs that are particularly hard on those organs. That's something no HIV doc wants to do, because HIV mutates quickly, developing drug resistance. "It's a balancing act," Dr. Organista deadpans.

So far, researchers know only that there's a relationship between all of these conditions and antiretrovirals; they cannot say definitively what the ramifications are. In fact, we know very little about the long-term effects of any of the anti-HIV medications now on the market. How long will they continue to suppress the virus? Are the current side effects merely early warning signs of deeper problems they're causing?

What we do know, according to the Centers for Disease Control and Prevention, is that survival rates for those with an AIDS diagnosis are in inverse proportion to age: The older you are when you get it, the more likely you are to die from it. So, as Karpiak sums up, "When you're a treating physician, you're interested in knocking the viral load down and pushing the T-cell count up." As for what happens down the line, you worry about it when you get there.

But even if drugs keep working without causing new problems, the longevity of the two government programs that help patients maintain access to them is also in question. The AIDS Drug Assistance Program (ADAP), which subsidizes meds for poor and near-poor people who don't qualify for Medicaid, is in its death throes.

When the first HIV drugs emerged in the late 1980s, treatment-access activists sat down with pharmaceutical companies and legislators to figure out a way to make them affordable. There was no love lost between these camps, and the best they could agree on was to create a government program that would buy drugs at discounted bulk rates, employing a formula similar to that used by Medicaid. They put off the bloody debate over bringing down the starting cost of drugs, because there was no time for such haughty principles. People were dying. "We've tended to focus on what's closest to us. And that's worked pretty well so far," says Bill Arnold, whose ADAP Working Group takes the lead in begging Congress for more money each year to keep the program from crashing. "But ADAP is at its very, very best a short-term solution."

Fifteen of the state-run ADAP programs now have waiting lists or other restrictions on assistance. New York State's remains one of the nation's most expansive, but last winter the program notified clients that they would have to begin using generics anytime they

are available. Officials have said that more drastic cost-cutting measures may be coming down the road if the budget does not stabilize.

Moreover, as people live longer, churning through drug regimens as they race to keep up with their ever-changing virus, the demand for the newest and most expensive meds will grow. The latest "salvage therapy" buzz is over a new class of antiretrovirals that cost around \$20,000 a year at market rate.

It's also unclear just what the new incarnation of Medicare will mean for aging people with HIV. Currently, those in Medicare who are poor enough to qualify for Medicaid get their drugs either for free or for a nominal co-pay of around \$1 a month. Under the new law, states will no longer be able to use their Medicaid systems to pick up this tab. Instead, Medicare will provide the drug benefit, but it will cost even the poorest seniors from \$3 to \$5 a month per prescription--a cost that will go up at what the Congressional Budget Office predicts will be a 10 percent annual rate.

But more troubling is the fact that the private insurers who will provide the new drug benefit are required to offer only one drug per class of medications. Since long-term HIV treatment means constantly mixing and matching meds--and waiting on edge for the latest, most expensive versions to hit the market--it's likely that many Medicare patients' treatment will be interrupted, or stopped altogether, when they reach for the next drug and find it's not in their plan's formulary.

On the surface, Curry leads the tidy life you'd expect of a great-grandmother. Her cozy Central Park West apartment exudes hearth--a flower-patterned tablecloth, a quilted wreath, aging photographs of army men and her own fresh-faced youth. But she got this second-floor walk-up through the city's "scatter site" housing program for homeless people with HIV. A home health aide, financed by Medicaid, stays with her from early morning until late afternoon--a service most people her age are years from thinking about.

She's been in recovery for about 10 years now, and cigarettes are the only vice she clings to. She takes the slow, deliberate drags of a mid-century diva, but the smoke comes out in puffs that are closer to sighs than exhalations. "Now I'm dealing with my grandson," she complains. "They say he murdered one and wounded three others." The 24-year-old wants to go to trial rather than plead, which she knows is a bad bet for a black kid. Plus, she'll be the one sitting in court, just like she's the one trekking out to Rikers Island now. "My son's not here to be with his son," she says with resignation, "so Grandma's going to be there."

It was Kevin's death that shocked Curry into dealing with her health. She insists there was no need for detox, that God took her addiction away with Kevin's soul. At the

funeral, as she rubbed his chest, she felt the need to drink and drug jump from her own breast.

Kevin's dad was at the funeral too, but he died from an AIDS-related illness shortly thereafter. Curry has also lost two brothers and two sisters to the virus. Her youngest sister is positive as well, living in a nursing home on the Lower East Side for people with AIDS. This is not a surprising profile for a poor black family: More than 40 percent of the city's AIDS cases are black, as are more than half of those among women.

Curry is in fact typical in many ways of middle-aged people living with the virus. But there's not a lot of hard data about her cohort--public health watchdogs and opinion-shapers in the AIDS world are just starting to notice it. Dr. Karpiak's research team recently completed a survey of 160 positive folks over 50 in New York City, with an average age of 55. Eighty-five percent of them were black or Latino, 82 percent were not working, 86 percent were on Medicaid, and 81 percent tested positive more than six years ago.

Because the researchers found their sample mainly through organizations that provide affordable services to people with HIV, the study necessarily excludes the epidemic's upper stratum--primarily white and primarily gay men who get boutique care from Chelsea's horde of HIV docs. That wasn't what Karpiak initially intended to do, but the result is an unexpected new level of insight into the use of publicly subsidized HIV/AIDS services. "These are people who have been caught by the safety net," Karpiak explains. "I don't want to give the impression that everything's fabulous, but they have faced a lot of challenges, and they ain't doing so bad. But if it were not for the AIDS groups reaching out and providing this support, by and large they would be sicker, would not be in housing, all those things."

In other words, the system is no longer responding to an emergency. It has become an indispensable part of the lives of tens of thousands of New Yorkers aging with HIV--a group that will get larger with every day that passes without a cure. If nearly two-thirds of the city's current infections are in people older than 40, soon the majority of the known local epidemic--more than 50,000 people--will be middle-aged or older. And if Karpiak's study is a reliable indicator, many of those lives will be wholly dependent on an already bursting safety net.

"I got my apartment through Harlem United," brags Linda, a 56-year-old who asked that her last name not be used. "I get all my medical here. I got my dental work here. I get my support here. I have my little stipend job--the acupuncture--and they sent me to school to do that here."

Linda's at Harlem United from 10 in the morning to three in the afternoon, every day. She does her recovery program, sees a therapist and a nutritionist, meets with a case manager, attends socials with other people who have scatter-site apartments, and even participates in a mini-worship service with a group that reads scripture and meditates together twice a week. Medically, she finds everything from her ob/gyn to her liver specialist there.

Much of what Linda gets from Harlem United resembles the "informal care" that all kinds of people depend upon to stay healthy and active. Informal care encompasses everything from counseling to changing bandages to managing medications, and would add up to about \$196 billion a year if bought on the labor market, according to a 1999 study published in the journal *Health Affairs*. It is usually provided by family and healthy friends. But just over half of Karpiak's study group is neither married nor dating. Seventy-one percent live alone. Most have family around, but it turns out they aren't typically very close. Asked who they prefer to rely upon for help with daily life problems and in crises, about half said either a friend or simply themselves--and over half said the majority of their friends are other people with HIV, people they've met at AIDS service agencies.

In AIDS parlance, they're enmeshed in "clinic culture." And the haunting question is: Can clinic culture hold up as generation after generation of HIVers join it? "These folks have got a grip on life. So the caregiving is not two or three months, like it was in the '80s," Karpiak warns. "It's a long-term thing."

The problem is one born of not only systemic successes, but personal ones. People like Curry and Linda survived long-term drug addiction and its related HIV diagnosis in part by speeding up the social weeding process that naturally occurs with aging. As people get older, their networks shrink--friends die, family members who aren't supportive fade away. But for many 50-plus HIVers, says Karpiak, staying in recovery and getting healthy meant jumpstarting that process, and isolating themselves from most of the friends and family they had.

"I used to tell everybody I loved my grandmother, I missed her," explains Curry, guffawing at her naiveté. "This shit is a lie! She was an alcoholic; she didn't do shit for us. She got all that money from the city for eight children, and what did we have to do? Eat bread with sugar on it and peanut butter for breakfast, lunch and dinner. Now where is this woman so good at?" Curry's in rapprochement with her mother, who was absent during her childhood, and keeps loose ties with her remaining siblings, but she prefers her home health aide to any of them for help. "When you deal with reality for what it is, you can brush off some of that old shit--all that pain," she says. "Get rid of it."

But the AIDS care system is already showing signs that it can't pick up the slack forever. Karpiak's survey participants were doing well, but they showed wear. Two-thirds reported depression symptoms. Seventy-nine percent said they needed more help with daily life tasks. Fifty-seven percent had an AIDS diagnosis, meaning the virus had advanced enough to cause serious medical problems.

The support they do get doesn't come cheap. Poor, middle-aged HIVers live at the intersection of the public safety net's most frayed programs. Here and around the country, Medicaid is on the brink of financial collapse, in large part because of the costs of long-term care--home health aides and nursing home costs for those who can't live on their own. It spends upwards of \$4 billion a year on people with AIDS. But the Bush

administration is currently pushing a plan that would relieve states of the federal rules that force them to provide the same array of benefits to every patient, no matter how sick or healthy. Unless they can find new money, those states will eventually be forced to cut costs by rationing their long-term care and cutting benefits for the most expensive enrollees--something the New York State legislature is already working on.

The Comprehensive AIDS Resources Emergency--or CARE--Act is also a perennial budgeting tightrope act. The massive and Byzantine program funds most of the services the AIDS groups provide, from primary-care physicians to support groups. But it is not an entitlement program, like Medicaid or public housing; Congress must re-up its finite funding every year. Throughout most of the program's life, a booming economy strengthened lobbyists' hands, winning them steady if hard-fought annual budget increases. But in 2002, 17 of the 51 metropolitan areas that share the money got a budget cut. A 2001 survey by the CAEAR Coalition--an umbrella group of 300-plus organizations funded by the CARE Act--found a quarter of them had waiting lists.

"I messed around with a lot of dope fiends," says Linda. "So I had always been tested, and it never showed up positive." Not until she was in detox, at age 50.

Maybe the previous tests were false negatives; maybe her luck just finally ran out. Either way, the new sober Linda immediately got into treatment and started minding her health. "I call this virus a squatter--and squatters got rights," she jokes. "So I feed it, I let it have a place to sleep, and I try not to wake it up! I take my medication and do whatever I need to do."

That includes not getting reinfected with another strain from some no-account man who won't wear a condom. But even at 56, she's finding this sort of guy hard to avoid.

Linda's a baby boomer, and her generation is still defying outdated notions about sexuality. A 1998 National Council on Aging survey of 1,300 seniors found half of the respondents were having sex at least once a month, and nearly 4 in 10 wanted more. So while the epidemic's graying is largely a result of our ability to keep people alive, it's also a sign that you're never too old for risk. Forty-four percent of newly diagnosed infections in the city each year are among people over 40.

HIV tests cannot indicate when someone actually contracted the virus, so these new diagnoses could simply be a result of late testing. But a smattering of studies have caught the attention of HIV prevention-types.

Virginia Commonwealth University researcher Dr. Christopher Coleman surveyed 130 black men who are over 45 and HIV-positive in Washington, D.C., in an effort to build data on how risky their sexual behavior is. When he asked about condom use, only a quarter of the men were willing to respond; all of those said they never use condoms. A

shocking 84 percent told Coleman they thought showering after sex reduced the chances of getting HIV. And about half had never discussed safety with their sex partners. "They always say, 'If you want to kill an act of sex, then start talking,'" Coleman explains.

Linda's got her own way of describing how guys are: "They're nasty!" Men regularly don't want to use condoms with her, though they know she's positive. One guy insisted it was O.K. because his previous two girlfriends were positive and, even though they never wrapped it, he was still negative. "He said he wanted to do all of this stuff to me, and I was just lying there listening, thinking, 'Yeah, I ain't had it like that in a long time. That'd be the dessert after the dinner!'" she recalls, laughing at her temptation. "But you can't come to Linda like that."

Navigating situations like these isn't easy at any age, says Curry, but at least positive young folks have a lot of information and support targeted at them. As great as many of the AIDS groups are, she says, most aren't ready to serve their aging clients' emotional needs. That's why she started her own support group for positive women over 50. It began at Iris House in Harlem, but Curry felt that the agency wasn't giving her enough backing. So she left that group in the hands of its members, and moved on to Harlem Directors Group, another AIDS organization, to start another. Now, she wants to team up with a friend who trains women in HIV prevention and treatment to form a new nonprofit that melds their two programs. Indeed, Curry is blooming into a full-fledged activist for HIVers over 50. Last fall, Mayor Michael Bloomberg appointed her to the community-based board that advises the city on how to spend its CARE Act funding.

Meanwhile, Curry's leaving the sex to others; she figures she's already had her two good men, and she doesn't have Linda's patience with fools. Plus, she admits, she's not sure she could navigate the emotional cliffs of disclosing her infection to every new guy she likes. "It's a damn shame you have to think like this when it comes to something God gave us to do," she complains. "It just takes away from it. So I just said, you know, when you put it all on the table, I don't need this shit."

She doesn't need a lot of stuff she once found crucial. "I'm happy now, really satisfied," she says. "I don't have to look outside to make myself feel good." She credits both her own strength and the help she's found from the AIDS safety net for getting her to this place. That's the sort of victory few could have imagined when she tested positive 18 years ago. "They should pat themselves on the back; they did a good job," Karpiak says of everyone involved in the first 20 years of fighting AIDS. "Now what?"