

The New York Times

Sunday, January 6, 2008

AIDS Patients Face Downside of Living Longer

By JANE GROSS

CHICAGO — John Holloway received a diagnosis of AIDS nearly two decades ago, when the disease was a speedy death sentence and treatment a distant dream.



Nicole Bengiveno/The New York Times
John Holloway, 59, survived AIDS but has more health problems than his 84-year-old father.

Yet at 59 he is alive, thanks to a cocktail of drugs that changed the course of an epidemic. But with longevity has come a host of unexpected medical conditions, which challenge the prevailing view of AIDS as a manageable, chronic disease.

Mr. Holloway, who lives in a housing complex designed for the frail elderly, suffers from complex health problems usually associated with advanced age: chronic obstructive pulmonary disease, diabetes, kidney failure, a bleeding ulcer, severe depression, rectal cancer and the lingering effects of a broken hip.

Those illnesses, more severe than his 84-year-old father's, are not what Mr. Holloway expected when lifesaving antiretroviral drugs became the standard of care in the mid-1990s.

The drugs gave Mr. Holloway back his future.

But at what cost?

That is the question, heretical to some, that is now being voiced by scientists, doctors and patients encountering a constellation of ailments showing up prematurely or in disproportionate numbers among the first wave of AIDS survivors to reach late middle age

There have been only small, inconclusive studies on the causes of aging-related health problems among AIDS patients. Without definitive research, which has just begun, that second wave of suffering could be a coincidence, although it is hard to find anyone who thinks so.

Instead, experts are coming to believe that the immune system and organs of long-term survivors took an irreversible beating before the advent of lifesaving drugs and that those very drugs then produced additional complications because of their toxicity — a one-two punch.

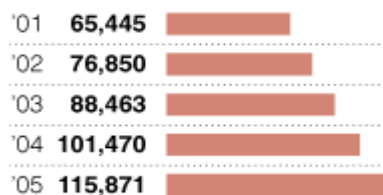
“The sum total of illnesses can become overwhelming,” said Charles A. Emlet, an associate professor at the University of Washington at Tacoma and a leading H.I.V. and aging researcher, who sees new collaborations between specialists that will improve care.

“AIDS is a very serious disease, but longtime survivors have come to grips with it,” Dr. Emlet continued, explaining that while some patients experienced unpleasant side effects from the antiretrovirals, a vast majority found a cocktail they could tolerate. “Then all of a sudden they are bombarded with a whole new round of insults, which complicate their medical regime and have the potential of being life threatening. That undermines their sense of stability and makes it much more difficult to adjust.”

The graying of the AIDS epidemic has increased interest in the connection between AIDS and cardiovascular disease, certain cancers, diabetes, osteoporosis and depression. The number of people 50 and older living with H.I.V., the virus that causes AIDS, has increased 77 percent from 2001 to 2005, according to the federal Centers for Disease Control, and they now represent more than a quarter of all cases in the United States.

Living Longer With H.I.V.

The number of people 50 and older living with H.I.V. in the United States has increased 77 percent from 2001 to 2005, and are now a quarter of all cases.



Note: Numbers are for 33 states that reported data that was acceptable by the Centers for Disease Control and Prevention.

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The most comprehensive research has come from the AIDS Community Research Initiative of America, which has studied 1,000 long-term survivors in New York City, and the Multi-Site AIDS Cohort Study, financed by the National Institutes of Health, which has followed 2,000 subjects nationwide for the past 25 years.

The Acria study, published in 2006, examined psychological, not medical, issues and found unusual rates of depression and isolation among older people with AIDS.

The Multi-Site AIDS Cohort Study, or MACS, will directly examine the intersection of AIDS and aging over the next five years. Dr. John Phair, a principal investigator for the study, which has health data from both infected and uninfected men, said “prolonged survival” coupled with the “naturally occurring health issues” of old age raised pressing research questions: “Which health issues are a direct result of aging, which are a direct result of H.I.V. and what role do H.I.V. meds play?”

The MACS investigators, and other researchers, defend the slow pace of research as a function of numbers. The first generation of AIDS patients, in the mid-1980s, had no effective treatments for a decade, and died in overwhelming numbers, leaving few survivors to study.

Those survivors, like Mr. Holloway, gaunt from chemotherapy and radiation and mostly housebound, lurch from crisis to crisis. Mr. Holloway says his adjustment strategy is simple: “Deal with it.” Still he notes, ruefully, that his father has no medical complaints other than arthritis, failing eyesight and slight hearing loss.

“I look at how gracefully he’s aged, and I wish I understood what was happening to my body,” Mr. Holloway said during a recent home visit from his case manager at the Howard Brown Health Center here, a gay, lesbian and transgender organization. The case manager, Lisa Katona, could soothe but not inform him. “Nobody’s sure what causes what,” Ms. Katona told Mr. Holloway. “You folks are the first to go through this and we’re learning as we go.”

Mr. Holloway is uncomplaining even in the face of pneumonia and a 40-pound weight loss, both associated with his cancer treatment. Has the cost been too high? He says it has not, “considering the alternatives.”

Halfway across the country, Jeff, 56-year-old New Yorker who was found to have AIDS in 1987, said he asks himself that question often.

Jeff, who asked that he not be fully identified, has had one hip replacement because of a condition called avascular necrosis, the death of cells from inadequate blood supply, and needs another to avoid a wheelchair. Many experts think that avascular necrosis is caused by the steroids many early AIDS sufferers took for pneumonia.

“The virus is under control, and I should be in a state of ecstasy,” he said, “but I can’t even tie my own shoe laces and get up and down the subway stairs. ”

His bones are spongy from osteoporosis, a disorder that afflicts many postmenopausal women but rarely middle-aged men, except some with AIDS. No research has explained the unusual incidence.

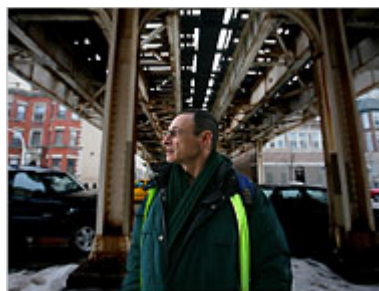
In addition, Jeff has Parkinson’s disease, which is causing tremors and memory lapses.



Donna Montanez, 58, says she has new health problems that are worse than having AIDS

He is in an AIDS support group at SAGE, a social service agency for older gay men and lesbians. His fellow group members also say they find the illnesses associated with age more taxing than the H.I.V. infection. One 69-year-old member of the group, for example, has had several heart attacks and triple bypass surgery, and his doctor predicts that heart disease is more likely to kill him than AIDS.

Cardiovascular disease and diabetes are associated with a condition called lipodystrophy, which redistributes fat, leaving the face and lower extremities wasted, the belly distended and the back humped. In addition, lipodystrophy raises cholesterol levels and causes glucose intolerance, which is especially dangerous to black people, who are already predisposed to heart disease and diabetes.



Marty Weinstein, 55, and AIDS survivor, is concerned about the physical and emotional toll connected with treating the disease

At Rivington House, a residence for AIDS patients on the Lower East Side of Manhattan, Dr. Sheree Starrett, the medical director, said that neither heart disease nor diabetes was “terribly hard to treat, except that every time you add more meds there is more chance of something else going wrong.”

Statins, for instance, which are the drug of choice for high cholesterol, are bad for people with abnormal liver function, also a greater risk among blacks. Many AIDS patients have end-stage liver disease, either from intravenous drug use or alcohol abuse. Among Dr. Starrett’s AIDS patients is 58-year-old Dominga Montanez, whose first husband died of AIDS and whose second husband is also infected.

“My liver is acting up, my diabetes is out of control and I fractured my spine” because of osteoporosis, Ms. Montanez said. “To me, the new things are worse than the AIDS.”

There are no data that compare the incidence, age of onset and cause of geriatric diseases in the general population with the long-term survivors of H.I.V. infection. But physicians and researchers say that they do not see people in their mid-50s, absent AIDS, with hip replacements associated with vascular necrosis, heart disease or diabetes related to lipodystrophy, or osteoporosis without the usual risk factors

“All we can do right now is make inferences from thing to thing to thing,” said Dr. Tom Barrett, medical director of Howard Brown. “They might have gotten some of these diseases anyway. But the rates and the timing, and the association with certain drugs, makes everyone feel this is a different problem.”

One theory about why research on AIDS and aging has barely begun is “the rapid increase in numbers,” Dr. Emler said. The federal disease centers’ most recent surveillance data, from 33 states that meet certain reporting criteria, showed that the number of people 50 and older with AIDS or H.I.V. infection was 115,871 in 2005, nearly double the 64,445 in 2001.

Another is the routine exclusion of older people from drug trials by big pharmaceutical companies. The studies are designed to measure safety and efficacy but generally not long-term side effects.

Those explanations do not satisfy Larry Kramer, founder of several AIDS advocacy groups. Mr. Kramer, 73 and a long-term survivor, said he had always suspected “it was only a matter of time before stuff like this happened” given the potency of the antiretroviral drugs. “How long will the human body be able to tolerate that constant bombardment?” he asked. “Well, we are now seeing that many bodies can’t. Once again, just as we thought we were out of the woods, sort of, we have good reason again to be really scared.”

The lack of research also limits a patient’s care. Dr. Barrett says the incidence of osteoporosis warrants routine screening. Medicare, Medicaid and private insurers, however, will not cover bone density tests for middle-aged men.

Marty Weinstein, 55 and infected since 1982, has had a pacemaker installed, has been found to have osteoporosis, and has been treated for anal cancer and medicated for severe depression — all in the last year. He also has cognitive deficits.

A former professor of psychology in Chicago, he presses his doctors about cause and effect. Sometimes they offer a hypothesis, he said, but never a certain explanation.

“I know the first concern was keeping us alive,” Mr. Weinstein said. “But now that so many people are going to live longer lives, how are we going to get them through this emotionally and physically?”