The Challenges of Caring for Older HIV/AIDS Patients

by Archana Pyati
Minority Nurse Writer

Leopold Linton faulted the omelet he ate during a flight five years ago to Jamaica, his country of origin. He was sick to his stomach by the time he arrived at the airport in Black River on a Tuesday. By Friday, he was admitted to the hospital, where a doctor informed him he had full-blown AIDS.

While shocking, the news actually solved the mystery of why his health had deteriorated so rapidly during the previous year. He'd felt weak, lost weight, and soaked his bed sheets at night with sweat. He rarely saw his doctor, so he surmised his diabetes was out of control. His trip back home, in fact, was prompted by a gut feeling he was dying, although he didn't know why. "I might as well spend my last days where it's warm," he remembers thinking.

Linton started antiretroviral therapy in Jamaica, allowing him to return in 2010 to the Washington DC region, his home for the past 40 years. He is now happily receiving care at Whitman-Walker Health, DC's preeminent health care provider for low-income people with HIV/AIDS.

At 68, Linton received his AIDS diagnosis as a senior citizen. He joins the growing ranks of people over 50 grappling with HIV/AIDS—a population that includes long-term survivors, the newly diagnosed, and the newly infected. Thanks to groundbreaking antiretroviral drugs developed in the mid-1990's, HIV has gone from being a death sentence to a lifelong, chronic illness like diabetes, where treatment adherence can prolong life expectancy. The CDC estimates that by 2015, 50% of people with HIV in the United States will be in this age group, presenting unique challenges and opportunities for nurses.

Nurses: Front and Center

As HIV shifts from being a fatal illness to a manageable one, experts say HIV care will become a routine element of primary health care. Nurses will be on the front lines in the expanded effort to test seniors, educate them about risk factors, and motivate them to stay in treatment if they test positive.

"When it comes to retention and keeping people in care, nurses are so important," says Wayne E. Dicks, MPH, a training coordinator with the Pennsylvania/MidAtlantic AIDS Education Training Center based at Howard University. "They need to be understanding and compassionate."

Nurses, in fact, were at the heart of Whitman-Walker's restructuring of its health care delivery system five years ago. The goal was to be more medically—rather than social service—oriented, says Justin Goforth, RN, BSN, Director of the Medical Adherence Unit at Whitman-Walker Health.

During the epidemic's early days, HIV/AIDS care was palliative, focusing on getting patients basic necessities like food, shelter, and end-of-life pain medication since they weren't expected to survive. A case management system was established at Whitman-Walker, but staffed with social workers and activists who had passion for the cause but little medical training, according to Goforth, who has been HIV positive since 1992.

With the antiretroviral revolution came the need for medical expertise—especially from those who could speak in plain language to patients about comorbidities and non-infectious, age-related illnesses exacerbated by HIV and, in some cases, HIV medications. Comorbidities include heart and kidney disease, high blood pressure, cognitive impairments, depression, and non-AIDS related cancers affecting the anus, prostate, and colon.

"Every time a new comorbidity is added on and a new treatment is added on, the complexity of [a patient's] whole regimen is affected," Goforth says. "We have to sit down with them, and say, 'OK, where are we going to fit this in? Does this have any contraindications with taking it at the same time as this other med?' I'm not sure who would do this except a nurse."

In 2008, Whitman-Walker replaced their social work staff with nurse case managers, each of whom oversees a 250 to 300 patient caseload. Support staff handles referrals to benefits, food, and housing assistance. And while each Whitman-Walker client is assigned a physician, doctors only have 15-minute timeslots to see patients—enough time to prescribe medications or order labs, but not enough to talk in detail about their HIV care regimen.

"We needed nurses as case managers because we're going to need to be teaching people throughout their lifetime about what's going in their bodies and why is this treatment something they need to commit to," says Goforth. "And why they need to integrate it into their lives."

Accelerated Aging with HIV

Diagnosed in 1989, Kermit Turner is an immaculately groomed retired IT professional who hasn't let HIV slow him down. It's hard to imagine the 59-year-old has had four near-death experiences from HIV-related infections between stretches of good health.

"I'm not the rocking chair type," he says. "Yes, HIV is going on [in] your life, but HIV is not your entire life."

Another Whitman-Walker client, Turner has battled pneumocystis pneumonia—the strain associated with early AIDS sufferers—in addition to a locked bowel and non-Hodgkin's lymphoma. In 2011, his left lung

was removed because of aspergillosis, a pulmonary disease caused by a fungus affecting people with weakened immune systems.

Turner experiences problems with vision and short-term memory. A sense of humor, he says, is an essential weapon against forgetfulness—and HIV.

“I’m the one with the Post-its about the Post-its,” Turner says.

Researchers are beginning to understand how HIV accelerates aging, and it has much to do with “immune senescence,” or aging of the immune system itself. A recent Israeli study published in the *Rambam Maimonides Medical Journal* attributed rapid aging among people with HIV to chronic inflammation of the immune system and the loss of CD4 cells, activated by the immune system to fight infections, rather than the amount of HIV virus—known as “viral load”—in a person’s blood.

Additionally, a research review published in the *Journal of NeuroVirology* found that the immune systems of HIV-infected individuals resemble those of non-infected people decades older, triggering heart disease, kidney disease, and diabetes much earlier.

In 2009, Jay Jones had a double-bypass after his chest pains and shortness of breath were misdiagnosed as asthma by an emergency room doctor. He was 48 at the time and experienced heart problems much earlier than members of his extended family with its history of heart disease. Living with HIV for 21 years, Jones, 52, tried several drug regimens, which his doctor told him were partially responsible for his coronary blockages.

“I was angry because they didn’t tell me this could be a result of taking medications,” the US Army veteran says. “I wondered if I should continue taking them.”

He continued his HIV therapy, but added blood cholesterol medication and started a more active lifestyle. His ability to surmount challenges posed by HIV, heart disease, and depression motivated him to start a second career as a minister at his son’s church in Washington, DC.

Sex and Stigma

Jones says once he’d overcome his internal stigma—for being HIV positive and same-gender loving—he was able to accept himself and the unconditional love of his former wife and children. Stigma and lack of HIV knowledge among medical staff remain powerful obstacles to HIV testing and care for people over 50.

“We’ve done an abysmal job doing sexual histories on the elderly,” says Frances Jackson, RN, BSN, MA, MSN, PhD, a professor emeritus at the Oakland University School of Nursing in Rochester, Michigan. “There’s still a level of discomfort in discussing sex lives with elderly people.”

Among the elderly, specific cultural and sexual identities must be considered. Mental health should be part of the conversation as seniors are prone to depression and feelings of isolation from their peers—especially if they test positive for HIV, experts say. Jackson says older heterosexual men and women may not use condoms because fertility is no longer a factor. Older gay men may feel rejected by younger gay men as sexual partners, leading them to recreational drug use to overcome their inhibitions, says Dicks.

“We need to do a better job with some of our questions,” he says.

Jackson suggests framing discussions about risk behaviors around what a patient’s personal goals are. “You can’t scare people into healthy behaviors,” says Jackson. “We have to meet people where they are. We have to tie it [to] what the individual wants out of their life.”

Jackson, who has practiced HIV/AIDS care for 30 years, remembers when medical staff hosed down hospital rooms where an AIDS patient had stayed. While such stories are less frequent today, the knowledge level of nurses in non-AIDS specialties feels “almost like we’re in the 1980’s again,” says Marion Smith, RN, BSN, a nurse case manager at Whitman-Walker Health.

In an oncology unit at a major urban hospital where she worked before her current position, Smith often heard nurses caution each other: “Be careful when you’re in that room because that person is positive.”

Smith says what’s needed is to normalize HIV for nurses and other medical staff no matter the context. Since HIV care is “continually evolving and changing,” health care managers need to “figure out how to keep people abreast about what’s happening,” she says.

Assumptions that seniors aren’t sexually interested or active, that they’re monogamous, that they’re heterosexual, and that they understand HIV risk factors are all barriers to testing and care, says Goforth.

“We have all this trauma instilled in us about what is HIV and we keep perpetuating that,” he says. “That keeps people . . . from thinking ‘I have good options about having a healthy life in case I am HIV positive.’”