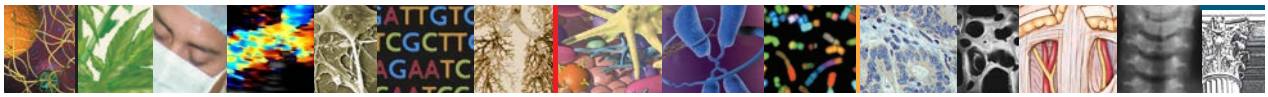

The NEW ENGLAND JOURNAL of MEDICINE

Perspective

JANUARY 22, 2015

Treating Millions for HIV — The Adherence Clubs of Khayelitsha

Edward W. Campion, M.D.

Twenty miles from the gleaming, modern buildings of Cape Town, South Africa, is the township of Khayelitsha, which was created 30 years ago under the apartheid policy of racial separation.

This immense, sprawling, crime-ridden "shacktown," the country's largest after Soweto, remains home to more than 400,000 black South Africans, many of whom work in Cape Town or its comfortable suburbs. On a sunny October morning, 15 locals, each carrying a small, green medication booklet, gather in the home of a woman who's hosting a meeting of an adherence club for HIV-positive people. Concrete houses are being built in parts of Khayelitsha, but this small, one-room home is similar to countless others jammed together along winding, dirt-path alleys: roof and walls made of corrugated steel, a dirt floor covered by linoleum and throw rugs, furnished with two beds and several simple chairs. There is a tiny refrigerator, an electric hot plate, and a small flat-screen TV, all connected to extension cords dangling from the low ceiling. The attendees chat quietly with each other in isiXhosa and then crowd in and sit down for a meeting that focuses on staying on the antiviral medications that control their HIV.

The nurse from the nearby HIV clinic weighs each patient, checks the health records, and helps to answer their questions about side effects and how to get enough medication for long holiday trips to another province. Packages from a central pharmacy are passed out, and the attendees open the big plastic bags to check that they have a full 2-month supply of the correct antivirals. The hostess, who works as a personal health care aide, is wearing a purple "I'm HIV+" T-shirt. Sitting in front of the group, she quietly urges them to keep taking their medications every day to keep the virus suppressed. She has been on treatment for years and seems to get respect from this group, which is nearly all women. And they all know that her only son was murdered in the gang violence in Khayelitsha.

The adherence-club meeting that I attended is one component of a strategy being pursued in South Africa to improve long-term compliance with antiviral treatment at lower cost than clinic visits and with less inconvenience to patients. There has been

An ART Adherence Club Meeting in a Club Member's Home.

Samantha Reinders

progress over the past decade in HIV treatment,[1,2] especially in the treatment of pregnant women. The clinic team says with pride that they no longer see heart-wrenching cases of children with AIDS. But the huge, silent epidemic goes on and on.

With 6.2 million infected, South Africa has more people with HIV than any other country. About 18% of all adults in South Africa are HIV-positive, with the highest rates found among young sexually active women. The rate among blacks is about 44 times that among the 10% of South Africans who are white. Although more than 2.4 million HIV-infected South African adults and 156,000 children are now in treatment, the epidemic continues to grow. The population of South Africa is about 20% the size of the U.S. population, but it has seven times as many new cases of HIV per year. The hope is to bend the curve downward, but that has not yet happened.

HIV-screening programs are moving to small, after-hours centers, partly in an effort to reach more men. And treatment is being initiated earlier in the course of infection. Originally, patients began receiving antiretrovirals when their CD4 T-cell count fell to 200 per cubic milliliter; now they begin at 350 per cubic milliliter, and the threshold is being moved to 500. For people receiving treatment, annual exams include measurement of the viral load — the goal being suppression to an undetectable level. Prevention initiatives stress the use of condoms as well as attaining effective antiviral suppression to prevent transmission.

Success against HIV requires affordable strategies that can achieve and maintain viral suppression, year in and year out, in millions of patients. Adherence clubs were first developed as demonstration programs by Médecins sans Frontières (MSF) as a way to reduce clinic congestion, simplify logistics, and help with motivation (see Perspective article by Ellman, pages 303–305). The clubs encourage acceptance and openness about HIV in the community, which helps with both screening and treatment. Patients appreciate this community-based approach because it means less need for transport and no more long waits in a clinic for medication refills. The providers in HIV clinics can focus on patients with medical complications, failing regimens, or coinfection with tuberculosis. Some adherence clubs have been developed specifically for young people or for men only, since those groups are the most challenging to engage and retain in treatment programs. Improved medication adherence leads to less drug resistance and longer duration of efficacy of the initial regimen, which now usually consists of tenofovir, emtricitabine, and efavirenz provided as a single-pill generic at a cost of about $8 per month.

Lynne Wilkinson, the MSF field coordinator in Khayelitsha, explains that the previously MSF-provided HIV services at 11 clinics have all been handed over to the local government health departments, along with the responsibility for ongoing funding. The support for HIV-treatment programs from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) is being phased out for South Africa because it is seen as a middle-income country,[3] though it has immense internal disparities in income and a huge economically disadvantaged population. Khayelitsha became the site of the first widespread, effective treatment of HIV in Africa at a time when the South African leadership refused to recognize the need for antiretroviral therapy and encouraged sick South Africans to treat AIDS with garlic, lemon, and beetroot. This year in the Western Cape province, 27,800 patients are receiving their HIV treatment

Distribution of Prepacked ART by Club Facilitator Fanelwa Gwashu.

Lynne Wilkinson/MSF

through adherence clubs, and the approach is being adopted in other parts of South Africa. The program offers a model for treatment in countries with far fewer resources.[1,4] Similar community models of care have been adopted in Mozambique and are being piloted by MSF in Malawi and Zimbabwe, countries with even broader treatment coverage for their HIV-infected populations but with similar challenges when it comes to maintaining patients in treatment for a lifetime.

An audio interview with Dr. Lynne Wilkinson on HIV treatment adherence is available at NEJM.org

Effective, widespread treatment of HIV in Africa was once thought to be logistically and economically impossible. Programs in multiple countries are showing that it can be done. But the problems involve attitudes as well as economics and logistics. After the adherence-club meeting in the small home in Khayelitsha, we gather outside. Someone asks our gracious host if she can take her picture for an article in a local magazine. She pauses, and for the first time she seems uncomfortable. Then she says yes to a picture but asks that her name not be used. She has worries about her employment outside Khayelitsha. "These things can get around. You cannot trust what some people out there might do."

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

This article was updated on January 29, 2015, at NEJM.org.

1. Mayosi BM, Benatar SR. Health and health care in South Africa — 20 years after Mandela. N Engl J Med 2014;371:1344-53.
2. Mayosi BM, Lawn JE, van Niekerk A, Bradshaw D, Abdool Karim SS, Coovadia HM. Health in South Africa: changes and challenges since 2009. Lancet 2012;380:2029-43.
3. Katz IT, Bassett IV, Wright AA. PEPFAR in transition — implications for HIV care in South Africa. N Engl J Med 2013;369:1385-7.
4. Farmer PE. Shattuck Lecture: chronic infectious disease and the future of health care delivery. N Engl J Med 2013;369:2424-36.

DOI: 10.1056/NEJMp1414213

Demedicalizing AIDS Prevention and Treatment in Africa

Tom Ellman, M.B., Ch.B.

At the recent World AIDS Day celebrations, national and organizational commitments to support affected communities, meet treatment and prevention targets, and expand access to antiretroviral therapy (ART) were asserted once again. Yet the reality in much of Africa suggests that AIDS is far from over.

Since 2002, ART programs have been slowly rolled out in Africa. Initially, HIV-infected people had to wait until they were seriously immunocompromised, with a CD4 T-cell count below 200 per cubic millimeter, to begin ART. The threshold was raised to 350 and then 500, as the importance of earlier initiation of treatment was recognized. Improved tools and strategies followed, as did consensus on treatment guidelines and international funding. The trajectory toward ending AIDS seemed assured, and international goals grew from "3 by 5" (treating 3 million people by 2005), to "15 by 15," to a call from the Joint United Nations Program on HIV/AIDS for "90-90-90" by 2020: 90% of people living with HIV tested, 90% receiving treatment, and 90% with an undetectable viral load.

Close examination of the HIV epidemic, however, reveals that all is not well. In South Africa, home to the world's largest ART program, for instance, 25% of patients who begin ART are lost to follow-up by a year later, and in 25% of treated patients, viral suppression is not achieved.[1] In many countries, rates of retention in treatment are worsening, the incidence of HIV infection among young women remains shockingly high,[2] men are tested and initiate treatment late in the course of infection and often not until they have advanced disease, public-sector facilities are overloaded with patients and plagued by medication stock-outs, and donor funding has flatlined for the past 6 years.[3] Perhaps most important, the activist groups that have held governments, health systems, and the international com-