

## Demedicalizing AIDS prevention and treatment in Africa

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**Distribution of Prepacked ART by Club Facilitator Fanelwa Gwashu.**

province, 27,800 patients are receiving their HIV treatment through adherence clubs, and the approach is being adopted in other parts of South Africa. The program offers a model for treat-

ment in countries with far fewer resources.<sup>1,4</sup> 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.

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.

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## 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.<sup>1</sup> In many countries, rates of retention in treatment are worsening, the incidence of HIV infection among young women remains shockingly high,<sup>2</sup> 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.<sup>3</sup> Perhaps most important, the activist groups that have held governments, health systems, and the international com-



Dried-Blood-Spot Sampling Technique for Monitoring Viral Load, Thyolo, Malawi.

munity accountable are at best underfunded and at worst sidelined, jaded, and mute. South Africa's Treatment Action Campaign, which played a major role in ending denialism and starting the ART rollout in the country with the largest HIV-positive cohort, faces a major funding shortfall.<sup>4</sup> As one panelist remarked at a conference of the Southern African HIV Clinicians Society last September, "The honeymoon is over."

A major contributor to these problems is the burden placed on patients and health care facilities by the failure to simplify treatment for healthy HIV-positive people. Clinics overloaded with the healthy are unable to focus high-quality care on patients with the greatest need.

As guidelines edge closer to universal treatment for HIV-infected people regardless of CD4 count, more people can choose to receive ART before they develop symptoms. Earlier treatment represents an opportunity not only to prevent illness and

transmission but also to inform and empower people living with HIV-AIDS while reducing the burden on health care systems. Rather than seizing this opportunity by demedicalizing the provision of ART, however, programs are medicalizing HIV infection in the healthy.

In most of Africa, despite shortages of health workers, initiating ART in a healthy HIV-positive adult means the start of monthly queues at clinics and pharmacies to see overburdened medical staff. To obtain treatment, such patients face long walks to health centers or high transportation costs, hours of queuing, and poor, sometimes stigmatizing, consultation. Unlike symptomatic patients, these patients see no short-term benefit from treatment. Unsurprisingly, they often adhere poorly to ART regimens or rapidly stop them altogether. Many health care workers believe such patients should not be offered treatment, so that clinic staff can concentrate on sick patients.

The experience of Médecins sans Frontières and others suggests that the solution is not to deny people earlier treatment but rather to implement policies and strategies that reduce the burden associated with their care. Such policies and community-based models of care are already well described,<sup>5</sup> endorsed by the World Health Organization, and included in national guidelines, but theoretical commitment to them is not matched by funding.

Like other chronic disease treatments, ART is best taken at home, with pills available through repeat prescription at local pharmacies or even by mail. A viral-load test performed every 6 or 12 months can inform HIV-infected people if they're doing well and need no medical care, just as glycated hemoglobin tests inform diabetic patients.

Healthy patients require community-based adherence support backed up by robust systems for monitoring and evaluation, drug delivery, and laboratory testing. Those in need of medical care — for initiation of ART, when sick or suffering from medication side effects, or because of high viral load or low CD4 count — must be distinguished from those who are not.

Five elements of this approach are worth highlighting. First, drug delivery should be patient-centered: it should fit into patients' lives, requiring minimal time and being delinked from clinical consultation. Stable, healthy, HIV-infected people taking once-daily, low-toxicity regimens could receive refills lasting at least 3 months from a facility close to their home, with little or no queuing. Ideally, various fast-track options, including commu-

nity pharmacies, would be available. Community ART groups and adherence clubs (see the Perspective article by Campion, pages 301–303) can further minimize the burden, with one person picking up drugs for several others. Such approaches save costs and enhance retention and should become the norm rather than the exception.

Second, annual viral-load measurement should replace routine CD4 testing for stable, healthy ART recipients. Such assessment provides an objective measure of treatment effectiveness and can assuage clinicians' doubts regarding adherence. If a test on dried blood spots (with results delivered directly to patients and clinicians, by text message where possible) revealed an undetectable viral load (see photo), the patient could continue receiving “minimal-burden care,” with an annual clinic visit. A high viral load should trigger a counseling intervention to address adherence, ideally at the community level, backed up by clinical screening and regimen changes as necessary, until the virus is suppressed. It would not necessarily mean shifting the patient from low-burden care, which could further worsen adherence.

Third, monitoring and evaluation are essential for informing patients, providers, and the health system but have not been adapted to systems operating outside facility-based clinical care. The lack of a functional monitoring system leads to government and donor mistrust of community-based support and drug-delivery strategies, and investment is needed to develop integrated systems. Such systems should also support HIV-positive communities

to monitor the quality of their care and hold the government accountable for drug stock-outs or other deficiencies.

Fourth, all these activities depend on trained individuals and funded, coordinated structures operating at the community level, near where HIV-infected people live. Currently, most interventions depend on volunteers, nongovernmental organizations, or scarce and underfunded health-center outreach and community health workers. Capacity for managing support groups, promoting HIV testing and linkage to care, identifying at-risk patients, monitoring effectiveness, and supporting adherence can be established at the community level, but not without support and funding. Such services pose no threat to the health sector; rather, greater investment in community capacity should be seen as essential to population health.

Finally, independent civil-society activism, rooted in affected communities, remains critical to sustaining an effective, accountable response to HIV and health care in general. Paradoxically, with successful ART rollout has come a decline in community activism. Engagement with the strategies described here can contribute to stronger community structures, but increased funding is essential to ensure that HIV activists' voices are heard.

This approach is not a panacea. For many communities, treatment coverage remains unacceptably low. The very concept of “community” varies with the context, and community engagement does not reduce government's responsibility to provide high-quality clinical care. Efforts

to strengthen health system capacity and end the crisis in human resources for health must not be compromised. Nonetheless, a shift from facility-based medical care to shared responsibility with community-based “wellness” support could transform not just the HIV landscape but care for noncommunicable diseases and health in general.

Perhaps the threat of vast increases in the number of healthy people on ART is the impetus the health system, policymakers, and donors require to match their rhetoric with investment. Until they do, the 90-90-90 target, let alone the end of AIDS, will remain a pipe dream.

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

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