It’s Time for the Community to Take Back HIV Care and Treatment

September 13, 2011 By David Evans

Have you ever seen the brilliant HBO show, *The Wire*? If you have, you’ll understand why I was incredibly pleased by a new study that’s been getting a lot of attention. Basically, researchers at the huge HIV clinic associated with Johns Hopkins University (JHU) in Baltimore--the urban epicenter of barely-contained social and legal breakdown depicted in the show--found that nearly all of their HIV-positive patients now have undetectable HIV levels.

Why is this amazing? Because the patient populations represented in the JHU clinic population--mostly inner-city, poor and disenfranchised blacks and injection drug users--typically don’t experience the same robust treatment responses seen in clinical trials, in which participants are more likely to be white and middle class.

We now have data confirming that antiretroviral (ARV) therapy can be highly effective for a huge swath of people living with HIV in the United States, regardless of gender, race, ethnicity, sexual orientation, location, infection risk group or socioeconomic situation, An astonishing finding indeed.

But here’s where things get confusing for me. What is JHU doing right that so many other HIV-treating institutions are doing wrong?

Granted, the JHU study authors point out much of the success they’re seeing in the hospital’s Moore Clinic can be attributed to the fact that ARV regimens are more effective, much better tolerated and easier to take than ever before. But there’s something else to it: JHU manages to keep an astonishing 94 percent of its HIV patients retained in care.

In effect, JHU recognizes that adherence isn’t just about taking easier, safer and more effective meds regularly, it’s also about making sure people are showing up for appointments, getting the medical and social services they need and making sure that prescriptions are filled.

But this isn’t what’s happening nationally. According to an article published in the March 15 issue of *Clinical Infectious Diseases* less than 50 percent of all people living with HIV in the U.S.--a little more than 437,000 of the 1.1 million people estimated to be infected with the virus--have been retained in clinical care. Another important statistic: While approximately 350,000 people in the U.S. meet the requirements for treatment, only 262,000 are on treatment... and even fewer are adherent or have undetectable viral loads.

We’ve known for a long time what keeps people out of care: poverty, drug abuse, mental illness, incarceration, low health literacy, younger age, immigration problems, and yes, race and ethnicity. None of which can be fixed with a lollipop and a prescription.

I’m encouraged that experts are looking more intensely at the problem of care retention--the JHU Moore Clinic boasts an multi-disciplinary approach to keep people in care--because a solution could mean the difference between a world where poor people of color continue to do worse than everyone else or a world where we erase the health disparities that have made the AIDS epidemic in the United States such a terrible social tragedy.

There have been only two controlled studies of care retention strategies published so far, and both had promising results. Several other studies are currently underway. Moreover, new technologies--especially electronic medical records--combined with enhanced surveillance and reporting could offer powerful tools to change how care is delivered and people are tracked and followed. Project Inform, the organization where I work, is looking closely at these research studies and new technologies and will be advocating strenuously for more research to document what methods work best.

There’s often a limit, however, to what a model of HIV care centered outside of the community, and community control can achieve. With a federal government focused on budget-slashing, and the average non-profit donor squeezed by a stalled economy, it’s also going to take serious time and effort on the part of many non-profit community-based organizations to find the funding and build infrastructure needed to support HIV care retention beyond what’s already being done.

I would argue, however, that there are several other types of solutions that could be implemented right now, by each one of us, with little cost. It’s time for the HIV/AIDS community to take back care and treatment.

At one time almost all HIV services were home grown and delivered with tremendous sensitivity, compassion and understanding. People flocked to the few enlightened doctors offices where they’d get better care and be treated with dignity. Those days are long over.

In some parts of the country--and perhaps JHU is a model--an efficient medical system was able to absorb the best parts of community care and compassion and combine them with the top HIV docs in the country.

My experience visiting more than 300 community based clinics and organizations over the past 20 years tells me JHU is the exception rather than the rule. There are some wonderful caring clinics and community-based organizations, but I’ve also been forced to contend with many thuggish security guards, bitchy receptionists, overworked and frustrated doctors, and nurses and case workers who act like they resent the person sitting on the other side of the desk. Frankly, it’s time to put the care back into HIV care. Here’s how...

1. If you want to make a difference in your local clinic, I would beg you to either join their community advisory board or demand the clinic institute one if it doesn't have one already. If you get on that board, insist on regular walk-throughs of the clinic and surveys of those who seek and receive care there. Demand that procedures that dehumanize people who come to the clinic--the the security guard should make you feel safe, not demean you to the point that you feel like you're in a perp walk, and the nurses, receptionists and social workers should actually look like they're glad your there--should be abolished.

   The stigma of living with HIV and mistrust of medical systems--found time and again to directly affect health outcomes--are only worsened by this kind of treatment. Also work to ensure that knowledgeable members of the community who wish to volunteer, to enhance care and guide people through the rigors of living with HIV are given space and support to do so.

2. Volunteer to provide practical and emotional support to people through the incomprehensible maze of accessing benefits. Our case managers try very hard with very little resources. Most carry a caseload that is at least twice as large as the caseloads of ten years ago, all the while knowing twice as much. If your local organizations don't have the ability to manage a volunteer program, figure out how to integrate volunteers into the work they do and insist that this be done and well supported. It takes a lot of courage and feistiness to live well and openly with HIV, two qualities that can come in handy when you hear, "No we can't do this," and have to insist that , "Oh yes we can, and we will."

3. Go back to support groups and other social activities for people with HIV, but this time for others rather than yourself. People new to their diagnosis often need a guiding hand and a warm shoulder, especially from someone who has been through similarly challenging circumstances. If your local organization doesn't have a support group then see if you can start a "buddy" program for people newly diagnosed.

4. Advocate for community-based treatment education programs. The most dedicated HIV providers have very little time to spend with their patients and often little training in educating people with lower health literacy levels. This means the provider can't always ensure that their patient fullys understand when and why HIV treatment is warranted, yet they expect their patients to adhere perfectly to therapy for the rest of their lives.??This doesn't make sense--information and understanding has long been a cornerstone of adherence-- and it doesn't have to be this way.

   Public and pharmaceutical dollars used to be available to ensure that the community could design and deliver top-notch, unbiased treatment education programs. They are needed now no less now than they were then. Please devote time to advocating that these kinds of dollars return to your community.

5. Volunteer for prison- and drug-treatment-release programs. People who've been incarcerated or been treated for substance abuse are up to four times as likely to fall out of care or fail on HIV treatment as people who haven't dealt with those same life circumstances. Those who work with formerly incarcerated individuals and people who've struggled with substance abuse challenges do heroic work and they need our support. The best of these programs work remarkably well yet they are understaffed, underfunded and overlooked. They need your practical support and your energy to advocate at the local, state and federal level.

6. Attend your local HIV care and prevention planning council meetings and insist that the councils give top funding priority to programs that offer salaries and stipends and thorough training to peer-advocates who can help people navigate the system of care--often referred to as “peer navigators.” If your local groups don’t have the resources to offer thorough training and support for peer navigators, reach out to national HIV organizations and insist that they build a national training and educational resource.

   No one understands the fear and stigma that can come with an HIV diagnosis the way that another person living with HIV can. Doctors, nurses, social workers and other professionals are vitally important, but we should remember where the most remarkable transformation in the history of patient care and treatment came from--people with HIV and the lay-people who loved and cared for them.
