HIV Treatment Guidelines Change: But Who Cares?

April 26, 2012 By David Evans

Actually, I care quite a bit. I know others do as well, but I'd like to make a point that for a lot of people the new guidelines just don't matter--even though they should. Let me explain.

A couple of weeks ago the government committee that constructs guidelines on when and how to treat HIV published an update, particularly about when people should start treatment. Here are a couple of key things that changed:

- The guidelines subtly altered their recommendation for starting treatment with CD4 cells above 500. Where the guidelines used to say that the committee was split and that it was largely up to the provider and patient, the new guidelines say that treatment should be offered to all such individuals, but that the weight of the recommendation (which is not the strongest) should be explained.
- The committee now recommends that providers explain how treating HIV can keep people from passing on HIV to their sex partners.

There were other important changes, such as the fact that people with hepatitis C and people over 50 treatment should be considered right away no matter their CD4 count, but for this post I'd like to focus on the two I highlighted and why the change might not make much of a difference in the real world.

Some are worried that the new guidelines go too far and get way ahead of the data. In fact, there is currently no controlled study proving that starting this early is good for people. There is evidence strongly suggesting that HIV is doing silent damage every day it goes unchecked in the body and that this has long-term consequences, but for many, including guidelines experts in Europe, that's just not good enough.

I personally believe that we will eventually prove pretty conclusively that earlier treatment has benefits and there is a study ongoing right now, the START study, trying to do just that. Unfortunately, START probably won't be completed and analyzed until 2015.

I’m actually a lot more worried about the fact that we already do such a piss poor job of implementing the old guidelines that the new ones will be like those delicate flowers made out of sugar that they put on fancy cakes. They’re pretty to look at, but they crumble in your fingers if you try to do anything with them.

In fact, here’s a snippet from a study published in December 2011 by the U.S. Centers for Disease Control and Prevention (CDC):

> “In 2010…of the estimated 942,000 persons with HIV who were aware of their infection, approximately 77% were linked to care, and 51% remained in care. Among HIV-infected adults in care, 45% received prevention counseling, and 89% were prescribed ART, of whom 77% had viral suppression. Thus, an estimated 28% of all HIV-infected persons in the United States have a suppressed viral load.”

No there are no typos in there. Let me break it down:

- Only 51 percent of people who know their status stay in care.
- Just 28 percent of people who know their status have a suppressed viral load.
- Less than half of people with HIV received prevention counseling.

Now a few more pieces of information:

- Given that the average CD4 cell count at diagnosis in most urban settings is well under 500, it is safe to assume that a lot of people who should be on treatment by the old guidelines aren’t even in care at all, and of those who are in care a lot of them are not properly treated or supported in their treatment.

- Some research indicates a huge communications disconnect exists between providers and patients. It reveals that providers often say something along the lines of “You really should be on treatment, but it’s important to be ready,” and that when doctors say this their patients actually hear: “Treatment right now is optional and we’ll wait until you’re ready.”
- Random sampling indicates that a sizeable number of people who work in test centers or as case managers or as community leaders are unaware of what the guidelines say and frequently offer misinformation about both the benefits and potential side effects of treatment.
- When asked why they don’t talk about sexual risk behavior more frequently, many providers say they don’t have the comfort or the time to do so.

There are plenty of reasons that people fail to start treatment at the proper time or fall out of care, and those reasons require structural and supportive interventions to contend with them. Some of the reasons include: stigma, poverty, unstable housing, violence, mental illness, substance use, an Orwellian corrections and parole system. The list goes on.

As activists we are often very good at and spend a lot of time trying to explain how dealing with those issues is a matter of social justice--that there are certain basic dignities and rights that we must afford to people with HIV to ensure that they can live a long and meaningful life. I have long worked to ensure that HIV treatment education is delivered in a manner that recognizes those needs and rights.

People with HIV also deserve a full and accurate explanation of the benefits and risks of treatment, however, from all parties involved in their care and treatment and I also believe this is an issue of social justice. At the end of the day the decision whether to start treatment--at any CD4 count--properly resides with person who must take that treatment, but it is our duty and obligation to ensure that when a person decides they are doing so with the best information.

Trying to explain the nuances of the research on early treatment in a balanced way isn’t easy, even with people who are fairly knowledgeable about medicine. Some providers and treatment educators do it very well and others more poorly. Similarly, we have waited far too long to integrate sexual health into HIV healthcare in general and into our treatment education messages, all the while we have known for nearly a decade that an undetectable viral load was highly likely to reduce the risk for transmitting HIV.

The promise offered by the new treatment guidelines is tremendous, both for people with HIV and for society at large. I would like to ask those whose job it is to serve people with HIV to know what the guidelines say and to pledge that they will do whatever they can to make sure that those they serve also know about the guidelines and are receiving care and medical advice consistent with those guidelines. I’d also ask people who try to offer personal advice and support to the newly diagnosed through support groups or online forums to understand the guidelines well too.

The guidelines aren’t perfect. They are one set of experts’ interpretation of what the data says. There is room for debate and disagreement over whether those experts got it right and whether the benefits and the risks of treatment are adequately addressed. What I think we all can agree on is the fact that we are currently failing to ensure that all people with HIV have the full and accurate information they need to make their own treatment decisions and they deserve a lot better from us.

So to sum it up I’d like us all to pledge to do better and that really means all of us, from top government officials, doctors and leaders of AIDS organizations to the average person living with HIV. I hope you’ll take my pledge.