



## *In Their Own Words:*

### *The Current State of Women and HIV*

*This edition of “Women and HIV” presents something different. Instead of exploring a topic through our customary method of secondary research, BETA asked women with HIV, women’s HIV treatment advocates, clinicians, and researchers for their views on the current state of health in HIV positive women. We posed a single question: What do you consider to be the most important treatment or health issues facing women with HIV today?*

**Leslie Hanna**

*Recurring themes included unique problems in accessing health care, antiretroviral drug toxicities, menopause, depression, and the need for research in women. Here are some of the responses, in the words of the respondents.*

*Amy Justice, MD, PhD*

**Associate Professor of Medicine, University of Pittsburgh School of Medicine**

I think there are two major issues: helping women start and continue taking appropriate multidrug, multiclass antiretroviral therapy, and doing research to determine the degree to which treatment recommendations for men should be adjusted for women.

Access continues to be a huge issue. Women in 2002 still enter care later than men and, as a group, adhere less well to treatment than men. Today, it's not so much that providers will not or do not treat women, it's that women have real trouble with the basics of regularly accessing health care—they have trouble making and keeping appointments. Access is not something that is barred for women, but it is something that needs to be facilitated.

Drug toxicity is a huge issue we're only beginning to understand. Clearly it's a huge issue for men, too, but men and women may have different susceptibilities to many side effects. Diabetes is a good example. Women tend to have more body fat, and body fat is a predisposing factor for diabetes in the general population. What do HAART and HIV do to the picture for women? These and other questions, if answered, could improve routine monitoring—for instance, by informing better ways to use glucose and liver tests.

Liver health is a real concern. Women's livers work differently than men's. For example, we know that women are more susceptible to cirrhosis [liver scarring] when they consume the same amount of alcohol over the same amount of time, matched for weight—pound for pound—with men. We don't really know why, but the fact has been well demonstrated. Today, in HIV disease, a major cause of death is hepatitis and liver failure. Women with HIV are likely to be ethnic minorities and younger, inner-city residents with a high risk of smoking, alcohol use, and injection drug use. It's reasonable to ask whether these women might not be particularly susceptible to liver injury. This really needs to be studied.

*Anne-christine d'Adesky*

**Treatment advocate**

An issue that continues to bother me is antiretroviral dosing, and possibly overdosing, of women. Let's not forget that FDA approval [of anti-HIV drugs] has essentially all been based on dosing data gathered in male adults. There also have been a myriad of researcher observations, including published data, on differential initial viral loads and CD4 cell counts in women, and there are different patterns of drug toxicity in women as well.

*Rebecca Denison*

**Founder of WORLD (Women Organized to Respond to Life-threatening Diseases), treatment advocate, and HIV positive woman**

1. Hormones and HIV, including hormone replacement therapy (HRT) options,
2. Metabolic complications and other side effects of medications, and
3. Structured treatment interruptions.

These are high on my list today; tomorrow it will probably be something else.

*Priscilla Abercrombie, RN, NP, PhD*

**Assistant Clinical Professor, Department of Family Health Care Nursing, University of California at San Francisco (UCSF)**

I've been following women with abnormal Pap smears for many years. Nothing's changed; HPV [human papillomavirus] is still a huge problem. We're still treating it the same way, and following women very carefully over time. We're not yet sure if HAART is helping to decrease the number of abnormal Pap smears or if it's improving the status of women with cervical dysplasia [abnormal cells]. But the majority of women—at least 50%—will have an abnormal Pap smear at some point, and for most women HPV is a recurrent, persistent disease. The rates of cervical cancer have not changed, though.

Some women we've been treating for years are now entering menopause. While the signs and symptoms of menopause in HIV positive women are similar to those in HIV negative women, there are some unique treatment complications (mostly liver complications), and there are concerns about antiretroviral drug interactions and hormone replacement therapy. We need to learn more about how best to manage menopause in women with HIV who are taking HAART. [A study of HPV and HAART is currently enrolling in several cities. See page 49 for details.]

*Eve W.*

**HIV positive woman**

I am very concerned about the long-term toxicity of the antivirals. As a woman on treatment for close to ten years, I've had a hard time dealing with the side effects. Although none have been life-threatening, they started to really wear me down and scare me. On top of this, adherence became more difficult over time. I just got sick of taking the medications day after day. I felt I was pushed to start treatment all those years ago. Hopefully things are different now.

I would say the most important thing is to develop medications that are less toxic and easier to take for the long term. Also, women need to be educated about their options, so they can decide if and when they should start medications and be fully aware of what they are getting into—side effects and all.

One last thing that is important to me as an HIV positive woman is that HIV did not take away my right to have a child. Women should not give up on having a family if that is what they want.

*Maureen Shannon, MS, FNP, CNM*

**Associate Clinical Professor, Department of Family Health Care Nursing, UCSF**

There are multiple issues because there are so many different women with HIV disease who have acquired the virus in different ways, and because it's a very complicated disease. There are some major themes, though.

First, although things have changed, there is still a strong stigma associated with this disease, especially for women. It's still so shameful to have HIV/AIDS that some women delay seeking services or treatment just for that reason. By trying to conceal their status, they'll end up receiving suboptimal care. Even in the San Francisco Bay Area, let alone the rest of the world, there's a prevailing attitude toward women of, "What did you do to get this disease?" Many women today do not tell their families or their coworkers or neighbors. Stigma may be subtler in the U.S., but I've known positive women who give birth to babies they hope are HIV negative, who then have to go to a pediatrician—and the judging begins, or so it's perceived. Just having to discuss the babies' HIV-related concerns reflects on the mom, and it's not like discussing diabetes or herpes. It's just not.

Another important issue for women, and one that affects access, is the amount of violence that so many women experience, especially at the hands of intimate partners. This includes both psychological and physical threats. HIV positive women also have a very high rate of past childhood abuse, including sexual assault and molestation. As providers we're more aware of this today than we were earlier in the epidemic, but clinicians still do not screen for violence as much as they should. Yet doing so can make a huge difference when making treatment decisions. For example, you have to be very careful when interpreting depression in women—is it related to HIV? to medication side effects? to current violence, or a childhood history of sexual assault? Women living with violence or with a history of violence often have a condition similar to post-traumatic stress disorder, but since they're not often screened for any of this, they don't often receive the appropriate care. Such women often self-medicate, too, and it's important for us as providers to know why. Violence also impacts women's entry into care and adherence to care. We discuss safety

plans on a regular basis with many of our women clients—for instance, do they have a supply of medications and a suitcase ready to go in case they need to leave a dangerous situation in a hurry? Finally, women with so much violence in their lives also may end up spending time in jail or otherwise incarcerated, which has implications for access to medicines.

A somewhat related issue is the lack of mental health services. Women with HIV have a high rate of depression and chronic stress, along with abuse. In general, there aren't a lot of psychological services available for anyone these days, but what does exist tends to be focused on people with severe mental illness. It would be great to have services available to women earlier in challenging situations—during periods of new or significant stress—to teach coping and problem-solving skills. Instead, we tend to throw drugs at people and hope for the best, i.e., without providing counseling. We don't hesitate to order an expensive CT scan, but we don't generally support psychological needs and services.

*Grace McComsey, MD*

**Assistant Professor of Medicine and Pediatrics, Case Western Reserve University School of Medicine**

Several things come to mind. The most important thing is probably the fact that we need studies focused on women. If we want answers to questions about women, we cannot get the data we need from men. This is true whether you're talking about antiretroviral treatments or side effects.

Here in Cleveland we are beginning a study that involves two months of complicated treatment, requiring participants to be seen frequently, to use study medications that need to be taken three times daily, and at study's end to have muscle and fat biopsies. This is a study that might have been difficult to enroll anyone in, yet we have so far enrolled 60% women (18 of 30 total). We also have more women than men on the waiting list.

How have we enrolled so many women? What works is not mysterious: we simply spend the time necessary to explain and discuss what the study is trying to achieve and why it's important. When women understand that there are more complications in women than in men, and once they understand the purpose and benefits of the study to themselves and to HIV medicine, they are usually very interested in participating. I also give talks at different community groups and forums, some of which are focused on women. In the days following a talk, women have tracked me down at the clinic, asking for more information and how to enroll. So our efforts to educate about special issues relating to women have sometimes yielded very good results.

**Leslie Hanna is the former editor of BETA.**