

Patients' Perspectives: Interviews with HIV-Positive Women

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I interviewed five women about living with human immunodeficiency virus (HIV). LK, MP, FP, SP, and ML talked about their experiences with the health care system and their suggestions for doctors who treat women with HIV. While a sample of five women cannot give a sense of what all or even most women with HIV experience, the opinions and perceptions these women offered in the course of in-depth discussions provide a glimpse of some of the concerns and obstacles HIV-positive women face as patients.

Respect, Manner, and Trust

All five women felt that health care providers' attitudes toward patients and the resulting interpersonal dynamics were among the most important elements of provider/patient relationships. Most emphasized that, above all else, the essential quality of a "good doctor" is that she or he—and none seemed particularly concerned with whether her doctor was male or female—be respectful, understanding, and nonjudgmental. The manifestations of doctors' respect mentioned were often subtle, things as small as asking after children or just being attentive to a patient's words. As LK compared her relationship with her current doctor, with whom she is very satisfied, to that with doctors she's encountered in the past, she remarked, "There is a big difference. It's subtle, but big." Many focused on the importance of a personal closeness with their doctors. LK explained that the trusting relationship she and her doctor have makes her feel comfortable enough to discuss sensitive personal and medical issues. "He doesn't seem judgmental—I can ask him anything. We talk about my weight. I called him up last week and I said, 'Three of my girlfriends died last week and I'm afraid,' and he listened and said, 'That's

understandable.'" Others said similar things about their rapport with "good doctors": "She makes me feel like I'm a person and she's a person;" "I feel connected to him and respected by him. I even feel that he would respect me in my death." One woman described her doctor holding her hand after giving her her positive HIV test results, and added "It made me feel like we were going through it together."

SP, however, preferred her doctors to "keep it professional." While she reported appreciating respectful questions about her health and the health of her daughter, who is also infected, she was concerned that her doctors' manner not be too familiar. She expressed annoyance with some health care providers who offered unsolicited advice about how to live her life ("Just try to live the rest of your days happy") and asked questions she felt were rooted in nosiness ("So, did you get this through a transfusion?"), rather than concern for her health. SP also distinguished between doctors who reserved personal judgment and opinions, whom she preferred, to doctors who are "very opinionated and push their own morals and ethics."

Delivering Medical Information

While not particularly concerned about the extent of their doctors' knowledge or training (when asked what kind of doctors their favorites were, two of the women answered nurse practitioners), patients were very concerned with how their health care providers delivered medical information. Rather than simply being handed prescriptions with instructions, they wanted to know about the possible side effects of drugs and the rationales for prescribing them. A few women also mentioned that they appreciated having the decision to take or not take a drug ultimately left to them. This issue was discussed generally as well as specifically in reference to ZDV. One woman linked the lack of explanation of treatments with noncompliance: "If you walk in and you just have medications

shoved down your throat and you don't understand why you're taking them, you don't understand the benefits of taking them, and you won't complete the whole regimen."

Several women mentioned dissatisfaction with the way their initial diagnoses were handled. SP learned of her HIV status through her daughter's diagnosis, although she had not been informed that her daughter was being tested, nor had she authorized the test. SP became convinced that her daughter's doctors knew something they weren't telling her. They asked her questions, such as "You haven't by any chance slept with anyone with AIDS, have you?" but wouldn't admit to having tested her daughter. When SP herself took an HIV test, these same doctors promised to have her results by the next day, but didn't contact her until three weeks later.

A few women also mentioned that they wanted their routine blood test results explained to them. Blood work was brought up as a source of both confusion and emotional upset. As LK put it, "Getting your blood work can be very traumatic—to know what your T-cells are, what your platelets are, it's very important." SP, who gets her blood tested frequently because she is in a clinical trial, has chosen not to find out what her T-cell count is and appreciated the understanding and support of health care workers on this matter. A nurse who understood the emotions attached to these tests had initially suggested this approach, saying, "Don't play that game with yourself." Several other women mentioned instances of mishandling of the delicate matter of blood work. ML described her reaction to lab results read to her by her doctor: "Well that's good, but what does it mean?"

Misjudgments about patients' levels of understanding seemed to be at the root of many painful and upsetting experiences. MP, for instance, was misinformed about HIV when she was diagnosed, but was given little basic information to correct her misconceptions. After hearing her

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positive HIV test results, she left the doctor's office not understanding the difference between HIV and AIDS and believing that she was without a doubt going to die within a few months. This initial impression left her devastated, setting off a severe bout of depression that ended in a suicide attempt and hospitalization. MP eventually got psychiatric help and since then reports that her health has improved significantly.

While some patients felt their doctors overestimated their knowledge level, others complained that some doctors underestimated patients' abilities to understand and be involved in treatment and unnecessarily accentuated the knowledge gap between providers and patients. As ML pointed out, some doctors seem to think women don't know how to take care of their HIV-infected children. "Who's up with these kids until four o'clock in the morning if they're ill? Who is sitting in the emergency room? Me, mommy. When you are not there doing your two hour check-up, I'm there 24-7, so educate me." FP commented on the arrogance of one health care worker who "pretended that she knew what was going to happen," saying that FP would probably live "about eleven more years." She contrasted that approach with that of another doctor who focused on brighter possibilities: "She said, 'You're positive, but you're healthy. Assume that, until you notice otherwise, you're healthy.' It was so helpful."

Relationship Issues

The desire for acknowledgment of sexual relationships surfaced repeatedly as an ongoing concern. The women interviewed talked about wanting to discuss sexuality with their doctors. One woman mentioned conferring with her doctor about her decision not to have sex with her husband, while another talked about being grateful for her doctor's help in entering a new relationship after her diagnosis. "She was very pro-relationship. She met with me and my partner and said 'Of course you should love each other.'" ML emphasized the need for doctors to recognize lesbians with HIV and give them appropriate treatment. "As a lesbian, it's very hard to get a doctor to understand my concerns. When I was diagnosed with herpes, they gave me a condom to go home with. They didn't

AMWA Doctors Working Against AIDS

Machelle Allen, MD

For the past six years, Machelle Allen, MD, has run a clinic at New York City's Bellevue Hospital for women who are pregnant and chemically dependent. Each time the clinic meets, she sees from 15 to 20 women who are either current or former drug users; of those, usually up to 4 or 5 are HIV positive. Most of Dr. Allen's HIV-infected patients are relatively healthy. She enjoys her role as an obstetrician/gynecologist, tending to women's health throughout their pregnancies. "I like to have an impact on a person's life and assist her in her pregnancy. It's satisfying to have a patient leave the hospital with her baby, smiling."

Dr. Allen has found herself a part of a network of providers who care for patients with HIV and refer patients to each other, a group that has made an effort to distinguish itself from the many practitioners who are still reluctant to treat people with HIV. Although Dr. Allen recognizes that many have made giant strides toward being more understanding and accepting of patients with HIV, she finds there are still many physicians who are condescending and disdainful toward HIV-positive patients or find excuses not to treat them at all.

Dr. Allen has worked with HIV-infected women since the very beginning of the epidemic (she saw the first reported case of Kaposi's sarcoma in a pregnant woman). She also worked for several years at the New York City Health Department, where she was involved with health policy regarding many reproductive issues. She believes this experience strengthened her sense of responsibility to patients' rights, a commitment she was able to act on when she returned to clinical practice. Dr. Allen worries that doctors tend to overlook patients' concerns, especially those of the patient population she sees, mostly black and Hispanic women of lower socioeconomic status. "We really have to caution ourselves about being paternalistic. Our values about who's entitled to live or procreate should not extend beyond our own lives. We don't have a right to impose them on others."

Mary Guinan, MD, PhD

Mary Guinan, MD, PhD, who was involved in the original Centers for Disease Control AIDS Task Force in 1981, continues to work on AIDS policy at the CDC and to provide direct care to patients with HIV. Dr. Guinan sees women (and some men) who are in the early stages of infection on an outpatient basis. Because her patients are relatively healthy, many of their problems tend to be similar to those of HIV-negative women—hormonal complaints, menstrual irregularities, concerns about menopause. She notes that many of the women patients she sees prefer to see women physicians, especially about these types of problems.

Dr. Guinan has been central to the CDC's work in research and surveillance. Her work there now focuses on preventing new infections by helping find ways to change risky behavior and by giving people, especially adolescents, reasons to stay at low risk. Dr. Guinan is hopeful about the impact of prevention efforts (see her piece this issue) and recognizes the importance of research in prevention. "We can control this epidemic if we understand people's behavior better. I am committed to getting prevention into health care and HIV into the psyche of the US population."

Mardge Cohen, MD

Mardge Cohen, MD, began the Women and Children HIV Program at Cook County Hospital in Chicago in 1988 after a patient with HIV approached her with the suggestion. Since HIV-positive women's needs weren't being met, she developed a program that provides medical and psychosocial services for women and their family members as well as HIV prevention for women and adolescents. The program has provided a wide variety of services for more than 1,100 people since 1988, including chemical dependency treatment, obstetrics/gynecology care, day care, children's health care, support groups, health education, and pastoral care, all at a single site.

One of Dr. Cohen's primary goals is to take women seriously, to incorporate their suggestions and opinions into further program design, service development, and research protocols. HIV-positive women and family members served by the program are included on advisory boards. The program also has several suggestion boxes and tries to act on advice whenever possible. For instance, they recently responded to a patient's recommendation to change the way the phone is answered to make patients more comfortable.

One of Dr. Cohen's major frustrations is that, because of a lack of a unified government response to HIV, she has had to spend much of her time piecing together funding for the clinic rather than doing her clinical work. She is also left with the feeling that she is treating the problems that result from poverty and chemical dependency while these root causes go unattended. While Dr. Cohen admits that she is sometimes overwhelmed, she blames AIDS, "a devastating disease." The clinic—the people she works with there and the women she provides care for—are sources of inspiration. "The incredible commitment from everyone who works here makes it worthwhile."

ask who my partner is. You can ask if there is a female partner and [if she has an STD] give her a regimen to go home and treat her.”

Marginalization and Contempt

Some of the women I spoke with had histories of drug use problems, compounded by poverty and, at times, homelessness. One had been a sex worker. However a person has been infected, revealing HIV infection to health care workers often results in being discriminated against as a perceived member of a stigmatized group. As LK put it, “I guess you can just tell from people’s faces what they think of you.” Sometimes, of course, they just tell you, as did the plastic surgeon who refused to operate on her abscessed arm, saying, “Frankly, the money that Medicaid will give me for this surgery wouldn’t pay my cab fare. And I don’t know if I believe you’re on drugs or you’re not. Why would I put myself at risk for you?”

Several others reported feeling contempt from health care workers as well. Horror stories included name calling and the sense that health care workers didn’t want to be near them. One woman told of nurses who pulled their hands away and a nutritionist who “ran out of the room” after learning she was HIV positive. Another spoke of health care workers who donned rubber gloves just to touch her daughter’s belly. The message that these women and their children were somehow inferior and less worthy of treatment because of the social problems related to HIV came across in many ways. A former drug user reported being denied medication for pain. By way of explanation, her nurse said, “Why would I give you demerol? You’re a drug addict.” When LK tested positive for HIV in prison, she asked the doctor, “Shouldn’t I be on AZTs or ABCs or something?” The prison doctor said that *if* she got out alive, she should see a doctor.

The women I interviewed voiced a range of concerns and preferences, some of them seemingly contradictory, such as the desire for intimacy versus the expectation of a “professional” manner, or the need for special attention versus the preference for being treated “normally.” While the needs and desires of women with HIV are as particular as the individuals who have them, underlying what

these patients wanted from their health care workers was a basic respectfulness that would translate into a positive doctor-patient relationship and, ultimately, afford women the individual attention necessary to meet their various needs. ■