Women on the Verge

The needs of HIV positive women are not being addressed

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Several hundred pissed-off women on the steps of the Food and Drug Administration (FDA) last September passed a microphone around to point out that though women are the fastest growing group of people with AIDS, the FDA still restricts women's access to treatments and won't do more than "suggest" that women be included in drug trials. Eighteen percent of American AIDS cases are among women, up from 7 percent in 1985. AIDS is the fourth leading cause of death in American women between the ages of 25 and 44 and the first cause of death in 15 major cities. Women are still dying sooner after diagnosis than men because the average physician can't accept that women are at risk of infection and so misdiagnose their condition, delaying treatment. So why weren't several thousand women grabbing at that mike? Why the hell aren't HIV positive women rioting?

Waver Lynn Franklin O'Brien knows why. "Grab a cup of coffee and sit down, and I will tell you some of what's gone on with me." O'Brien, who's positive, has three daughters and seven grandchildren. In one recent month, the eldest daughter landed in jail for passing bad checks, the youngest tried to commit suicide "because her mother is dying" and the middle daughter was "abducted and brutalized by a maniac for 11 hours. She was cut more than 70 times. She's got four kids and was nine months pregnant at the time." Traumatized, that daughter, plus her four kids and an infant, moved in with O'Brien.

"Trust me on this," O'Brien says. "I know a lot of people and I don't think my life is unusually tragic. If you're going to talk about women's lives with this virus, this is the kind of story you'll hear."

If you're going to talk about women's lives with this virus, you've got to consider that 77 percent of the 14,081 AIDS cases reported among women in 1994 are among women of color even though they comprise only 21 percent of all U.S. women. You've got to consider that 75 percent of people with HIV in the U.S. end up in poverty and that half of people with AIDS currently are homeless or in danger of homelessness because they can't work and there aren't sufficient social services. Many HIV positive women have lost partners to AIDS, children to foster care and are caring for infected children. Many women don't learn about their status until they're symptomatic, then they enter a health care system that neglects and excludes them. HIV is just another problem, and not even the most immediate one.

“Why don’t women get up off their butts and do what the living-room judges think they should do? Because they really don’t know it will help,” O’Brien says. “And, second, they don’t have the time. Every woman I know, from the time she gets up to the time she lies down again, she does not have a spare minute.”

If you’re going to talk about women and this virus, you’ve got to talk about families. Because what so often the injection-drug user and the suburban wife and the inner-city teen and the corporate executive have in common, besides being positive, is that their hours are crowded with the needs of their children and families. Positive women have the same ordeals their negative sisters do: Dealing with children and housing and bills, dealing with a condescending health care system, dealing with the web of responsibilities that binds every family, dealing with the socialization issues that make women feel guilty if they tend to their own needs before someone else’s.

While hundreds of women were shouting on the steps of the FDA -- for basics such as warning labels on over-the-counter medications -- there were thousands of women like the one in the heartland who stumbled out into the sun recently with her test results after her partner had died. She learned at the same time that her six-year-old child is also positive. This woman can’t tell her employer, who is also her landlord, about her status because she’s terrified she’ll be both evicted and fired.

O’Brien understands why this woman refuses to turn to the courts for protection. “We understand better than the general public and the people who are reading your magazine. We know that women don’t have a history of getting responses from this system. They don’t believe that such a thing as fighting back exists. What are you going to tell them? Their experience makes them believe that problems can’t be undone with an argument. White men are able to organize. They think they can get a response.”

Marion Banzhaf, executive director for New Jersey Women and AIDS Network (NJWAN), agrees. She points out that gay white men knew from experience that if they pressured the system enough, they could get a reaction. “For women who are poor and women of color, the system has never worked. Why should they believe it will be any different with AIDS?”

Especially now that it’s getting even worse. One of the organizers of the FDA demonstration, Naomi Braine, points out that “the current brutal attacks from all levels of government make it really hard for women to mobilize. When you have to work that much harder just to manage day-to-day, that wipes out a whole lot of people who had been active in the past or who would like to be active now but are using all their strength just to get what they need to survive.” She says that you can’t talk about women and AIDS without talking about Newt Gingrich and “whatever the local horror show is” in your city and state government. The population of women currently hardest hit by the virus is the same population Newt is targeting. No one knows better than these women how invisible they are to the systems of health care and government.

Women are mobilizing. But most often, their efforts are not flashy FDA demonstrations, Wall Street die-ins or back-room dealings with the highest levels of government research. They instead are

mobilizing around immediate needs: Child care, child custody, emotional and financial support.

As director of the Women and Children HIV Program at Cook County Hospital in Chicago, Dr. Mardge Cohen treats mostly poor women of color. What her patients most need has less to do with traditional medical care than with basic resources, getting out of abusive relationships, getting into recovery programs, finding a place to live, getting their kids back. “One of their issues is simply how to live in the world. How to get food, housing, clothing; issues of poverty and entitlement, the kids, but also what they’re going through with this disease. They want to know. Women who are worried about housing and kids may seem less preoccupied with clinical trials, but that doesn’t mean they don’t care about clinical trials.”

Rhoda, a 37-year-old woman with HIV, stares out the window at a fire escape and says, “The only concern I have is research.” She explains the trickle-down injustices, from the fact that AIDS research is geared toward men, to doctors who seem lost when treating women. She gets fed up with the chaos of advice from physicians who just prescribe tests or pills without specializing care to her specific needs. Rhoda tells them, "I want you to know what’s going on with me and not just give me a medication because you gave it to somebody else. *Know* me."

While Rhoda is fighting against the conveyor-belt health care system, her colleague on the Hotline, Ruth, is fighting to keep her spot in a homeless shelter for HIV positive women. A recovering injection-drug user, Ruth is 52 and -- like a lot of women -- she’s not sick enough to qualify for social services and not well enough to work full-time. She believes housing is the first concern of most HIV positive women. “You can look healthy and still not feel well. It’s scary when you don’t have enough money and don’t feel well enough to work and you’re going from month-to-month.”

Ruth then rapid-fires facts about section 8 housing, SSI and public aid structures. She’s at home with all the dry, bureaucratic jargon designed to intimidate and exhaust. Her tenacity in working the system has landed her a home, but there’s still fearfulness in her. Homelessness is a common terror on the hotline, she says. “I hear that a lot. Women saying, ’I’m getting SSI and my rent’s going up. My phone bill’s so high I can’t pay it.’ We get calls like that all the time. And if you can’t work, it’s stressful.”

National activist and educator Novella Dudley says the stress of too little food, too many bills and no place to live makes these women ill. “Women just want to cope,” Dudley says. She sighs and adds thanks that her son is grown, because she “can’t imagine being HIV positive and having small children to worry about.”

A 33-year-old white married midwestern suburban mom, Catherine Bartley has a home, but she shares with other HIV positive women this tired need “to just cope.” Having children amplifies the stress for poor or sick women, and AIDS service agencies that “don’t get it” don’t help the situation, she says. Such organizations have called Bartley to ask, “Gee, how do we get women in here?” And Bartley responds, “Do you have safe transportation? Child care? Stipends? Food? Do you meet during the day?” The point she is stressing is that women can’t just go out, leaving children and navigating dangerous neighborhoods after dark, to get to support meetings. Naomi

Braine made special arrangements to get women to the FDA demonstration because she understood that “getting to a demonstration is complicated if you have three kids, one of whom is positive.”

Betty “Jeannie” Pejko, a Native American and former injection-drug user, spoke from her home in West Chicago. She’s been positive since 1988. “Many of us have been separated, for whatever reasons, from family and children. We’d like to see all of our family and children together in front of us. Most women I know got HIV disease through IV drug use. So DCFS [Welfare] took their kids away, and whatever guy they had then is gone now, so here they are in the hardest struggle of their lives, all alone.”

“This is life,” Waver O’Brien says. She’s a client and a peer counselor at Chicago Women’s AIDS Project. “I go to group every Saturday and I sit and I listen to what life is like for women. We are all women, we are all living at the poverty level or below and we are trying to take care of ourselves. And it’s not as simple as talking about it.”

When Rebecca Denison, positive mom on the West Coast and founder of Women Organized to Respond to Life-threatening Diseases (WORLD), first started shopping for support in founding a group for women, she was told that “positive women’s lives are always in crisis. It’s not worth the headache.” Finally someone said, hell, start it anyway. And she did. She had tested positive in 1990. “And you couldn’t find another women who had HIV. You couldn’t get information unless you were in a full crisis like on the hospital table, kids screaming and the phone getting disconnected. Now if someone calls me for information, it’s like, at what point do you stop for fear of overwhelming them with numbers?,” she says.

In the years since Denison’s diagnosis, there has been a groundswell of activity on the local level and several national organizations for women with HIV besides WORLD have come into being, among them the National Women and HIV/AIDS Project and the Women’s AIDS Network. Also, older organizations like Gay Men’s Health Crisis (GMHC) have expanded to address women’s needs. “Five years ago, the women who came to GMHC thought they were the only women in the world that had HIV,” says Daniel Wolfe of GMHC. “A lot of them thought GMHC stood for Gay Men’s Health Club.” GMHC has adapted its support structure for prevention and treatment to meet the needs of women living with HIV. They have created new programs like the Child Life Project and the Lesbian AIDS Project and expanded existing programs, including adding child-custody planning to the list of legal services they provide.

While there are now more services and resources for women, Denison still thinks there’s resistance “to taking women and AIDS seriously. Some are very threatened by the issue of self-empowerment.” What also makes fund-raising and bridge-building hard, she points out, is that “it’s not always clear what hat you’re wearing. One day, somebody comes in with retinitis and we’re concerned about that. Another day, somebody’s kid is in trouble, so that becomes the issue. Then it’s clinical trials, housing or somebody doesn’t have a fax machine.”

Despite funding problems, grassroots organizing is ballooning among women’s groups. While

megaphones on a Washington doorstep might make the six o'clock news, this is where the mobilization of women is really taking place. Women at the grassroots level, in small community organizations or clinics, are doing peer outreach for no money. These elements are growing as a way of fighting back against budget cuts, says Braine. "A lot of that comes out of the need to very immediately provide services to one's community. And that's activism in my book." Civil disobedience isn't an option for women who are poor, have kids and are trying to hold their own lives together.

Peer outreach is important for all women, but perhaps mostly so among the young. In the United States, the number of 13- to 21-year-olds who became HIV positive rose 77 percent between 1991 and 1993. And the male-to-female ratio among those newly infected is two-to-one, compared to about five-to-one for adults.

When 27-year-old Jennifer McGaugh tested HIV positive in 1992 -- after probably getting infected in her early twenties -- she got no pre- or post-test counseling. She lives in the San Francisco Bay area, ground zero for safer-sex messages. And yet her infection was misdiagnosed by several doctors, including one who insisted that she had mono even after the mono test came back negative. Both times she went for HIV testing, McGaugh was told she wasn't in the "risk category," despite indicating that she'd had unprotected sex. Her circumstances were common, she says. "A lot of women I know found out by trying to get health insurance or going to donate blood."

The message persists that heterosexuals can't get infected. Melissa Marsh is a 22-year-old positive activist who just moved to Santa Cruz. "Most kids, at least in San Francisco, can run down the basics about HIV, but they can't apply it to their own lives. They haven't met anyone they know has HIV. They don't think AIDS is relevant to their lives. There's so much screwed-up stuff in young women's lives. Most young women I know are totally insecure. They're not thinking about HIV -- they're thinking they're fat or ugly or unlovable. They're so vulnerable."

That awkwardness is a basic ingredient for most girls in the mapless place between adolescence and womanhood. "Young women who are not sure of themselves are putting themselves at risk." That's what happened to Marsh. "Self-esteem is the issue for young girls. It was for me. The guy who infected me, I didn't want to have sex with and I was talking about HIV and he got mad."

Marsh was one of the youngest women to come out and be vocal about her status. She helped to start special programs for youths on the West coast. She says that when she tested positive "there weren't a lot of role models, a lot of young women who were openly positive, so I decided to step out."

What both these young women see is that young women who aren't sure of themselves are putting themselves at risk. "And the more sex they have, the more they're in denial," Marsh says. That's why she's committed to working with 14- to 18-year-old girls. These young women don't know anything about their bodies, Marsh says; they don't realize people with HIV look just like them. Safer-sex billboards aren't enough, even better sex education isn't enough, Marsh argues. The basic approach to prevention education has to change. "Not just about HIV, but about

sexuality and our bodies. Everything. HIV plays into many issues. Young people need to be taught very basic things, like loving your bodies. The problem with education is that we've taken it out of context."

Women of all ages need to be armed with information -- especially when dealing with a health care system that has always trivialized them. Like McGaugh, Novella Dudley was misdiagnosed for two years. Despairing and sick, she finally saw a psychiatrist. A main reason that women with HIV seem to die faster than positive men is because their infection is much further along when they are first diagnosed. Better care for women means better information: For themselves, for the people who are treating them, for the public at large. "Education is empowering and that's what we need to do -- empower people," Novella Dudley says.

While facilitating support groups, Catherine Bartley is often winded by the questions of newly diagnosed women: What are CD4 cells? What is a Pap smear? Why do I need one? "Their questions are so basic, it's hard to believe." Dudley finds the same thing. That's why she stresses information and education, which she says are as vital for herself and the women she knows as having a home and making fun trips to thrift stores.

It's with this in mind that Rebecca Denison has created the HIV University -- an eight-week training program with a curriculum designed by positive women.

"Positive women want instructors who will assume they don't know anything so nobody will be made to feel stupid. Everyone will come to the table as equals," she explains. There will be sessions on anatomy and physiology, HIV and the course of HIV disease progression, clinical trials, safer sex, relationships, working the benefits system, how to deal with society. "Everything you need to know and can't learn in a hospital clinic," Denison says. And the courses are structured so that women uncomfortable with reading materials won't be intimidated or excluded.

Every idea becomes real like this is a victory. "Women are definitely getting over issues of stigmatization, isolation and punitive approaches toward women -- around childbearing, childrearing and sterilization. That those problems are all being addressed defines a movement," Mardge Cohen says.

Marian Banzhaf agrees. "What women are seeing is that if you're willing to disclose your status, you can make a difference." She tells the story of one HIV positive African American woman Banzhaf encouraged to work for NJWAN's Project Act. It was the woman's first contact with other women who were positive. Afterward she told Banzhaf the greatest benefit of that contact was that "I lost that 'why me?' shit."

Ruth says isolation is a big topic on the hotline. "A lot of people do have a concern about coming out," she says, "because of the 'sneezing in a crowded room' bit." Of course, many men also feel the shame factor. "But shame is compounded in women because they feel they've done something to deserve this and because their children may lose a mom," says Martina Clarke of the International Community of Women Living with HIV and AIDS.

The best ways to treat the shame factor is for more women to step forward and reach out to one another. Becky Trotter, in Missouri, is an HIV positive lesbian who says she's been threatened by the Ku Klux Klan, had her car vandalized, had "AIDS FAG" painted on her windows. She talks while looking out at her front lawn, scorched by an attempt to burn her house down. She has to drive three hours to find a doctor who'll see her. She hasn't moved because she wants "other women out there in the same position to think that holding your ground is worth it. I haven't left because I care."

Gay white men addressed the stigma issue by fighting for their civil rights. It's also the first step for HIV positive women. Some women are at a stage in the epidemic occupied by gay men in the early '80s -- slowly opening their eyes to a devastation quickening around the edges of their lives. But now, leaders are emerging and sleeves are being rolled up for the coming political and social battles. Becky Trotter can't even relate to the shame factor anymore. "After you get a diagnosis for HIV, nothing else seems as scary."

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