

Helping the Helpers

By Judith Levine

Ten years into the epidemic, AIDS has been proclaimed a "women's issue." The media announce that women now compose the fastest-growing segment of people with AIDS, that AIDS is the largest killer of New York women between the ages of twenty-five and thirty-four. But before the doctors and bureaucrats took note, women knew AIDS. Because women, who take care of everyone, take care of people with AIDS.

Like their charges, most care givers reside at a distance from political power farther than the A train can travel. They contend with bad housing and after-the-fact health care; AIDS is just one more drive-by assassin.

"The way the crisis hits women parallels the way they've already been abused or neglected," says Amber Hollibaugh, an AIDS educator for the AIDS division of the New York City Commission on Human Rights. "Survival is already a question when the systems that aid survival are stretched to the limit." Families give out before the disease does. Social-service agencies are swamped. "All AIDS does is make it harder."

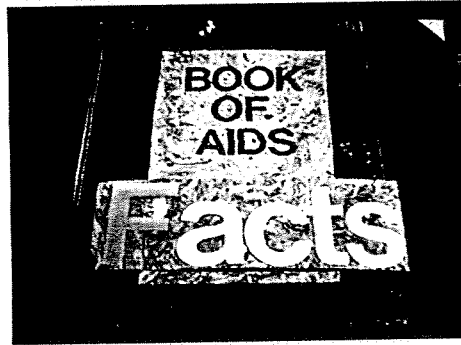
Because no one else can or will, care givers usually take care of themselves.

This is why the Women's AIDS Video Enterprise made *We Care: A Video for Care Providers of People Affected by AIDS*. WAVE's members, gathered by the Brooklyn AIDS Task Force (BATF) and including a young video maker named Alexandra Juhasz, reviewed the AIDS media and found their own stories missing. They were care givers, women of color. Invisible.

Sharon Penceal, whom friends consider the Rockaways' Mother Teresa, was taking care of a growing number of people with AIDS. "Alicia Rivera,"* in Bensonhurst, was easing the death of her cousin, the mother of three. Juanita Mohammed was "buddying a bunch of PWAs" at Woodhull hospital and showing sex-ed tapes at a women's shelter near her house in Bushwick; two local kids had gotten infected from needles they found in the street. Marcia Edwards was directing a program providing housing for 40 of the 13,000-plus homeless New Yorkers with AIDS, and the lickety-split Glenda Smith-Hasty was talking to teens for BATF. In an edgy neighborhood on the edge of Brooklyn, "Mariosol Soto"* and her recently diagnosed husband were hunkering down for the long haul.

The group met for three hours every Satur-

* Some names in this article have been changed.



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Scenes from the video: a woman with AIDS (top); separating facts from myths (center); WAVE women on-camera (bottom) day, dividing the time among a support group, AIDS education, and a video technology workshop. Inexperience made the *We Care* project challenging. But art and technology, it turned out, were the least of the group's hurdles.

There were personal strains. Death, rage, feelings of abandonment—these were tough topics to face, says Marcia, who ran the group sessions: "Rather than deal right then and there, they'd shut down or sabotage." Tension was heightened, says Alex, "because we had a serious project and there was a lot at stake." Life got in the way. "Illnesses, continual crises," she recalls. "I mean, babies falling out of windows, car accidents, heart attacks. . . . You wouldn't believe how many people died around us."

But of the original group, none quit. And in six months the tape was made—collectively written, shot, directed, and edited.

What is unique about *We Care*, aside from its subject, is that it speaks straight from urban person of color to urban person of color. Almost every face on the tape is black or brown; most are female. The pace is unhurried, the backdrops are those of the inner city: plastic chairs, cinderblock walls. Only a few professionals appear, among them an African-American doctor and a West Indian social worker.

Speakers offer information on subjects from stress reduction to funeral planning. The video makers visit people with AIDS and interview those who help them—including each other.

"We care for people—people with AIDS," begins the poem whose stanzas thread the narrative. "Why do we care? you might ask. Because people with AIDS are people like us." That connection among PWA, care giver, and viewer is reinforced throughout: "We care by treating people with dignity and respect. We care about our own well-being."

Women, accustomed to serving to the point of sacrifice, probably can't get enough of this message. "Don't feel guilty" about exhaustion or uncertainty, Glenda contributes. You're not Superperson, says Dr. Iris Davis. Sharon, gazing toward the waves, offers, "I run away from home and take a vacation at the water. . . . It cleanses my soul."

Self-respect, coupled with solidarity with people with AIDS, goes beyond the emotional, says

Alex. It is political: it seizes authority, redefines expertise. "When the women liked something in a video, it was because the participants were 'real,'" she explains. "They used that word to differentiate from 'experts,' the white newscaster figures who are very distanced. It has something to do with proximity. . . . That is a real expertise—people who actually have something to do with AIDS, as opposed to a scientist, who talks about it as if he were listing facts." Says Marisol: "It wasn't like it was a skit that we had rehearsed. It was something that just came out of us and how we felt within ourselves, you know, to share with other people."

Do viewers relate to these representations of their own lives, or do they find them disappointing compared with, say, *Fresh Prince of Bel Air*? Clearly the tape doesn't grab you as commercial TV does. While *We Care* has received accolades at the Whitney Museum, as well as schools and social-service agencies, it has had equivocal success in clinic waiting rooms, where it can't compete with the hubbub.

But when *We Care* fails to reach viewers, the problem may be less one of style than of the ignorance surrounding AIDS. "They're horrible-looking people. . . . They got no kinda texture about their skin," says a man on-screen.

Ignorance often masks fear. To identify with *We Care*—to say, "That is me"—involves acknowledging one's own risk, facing the perceived social contagion of AIDS. "There's a lot of things out there that let them know the facts," says Marisol, "but they're still in this little world that no, it can't be me, or I don't want to deal with that. At one time, I even felt that way. It was like, it can never be me, and it can never be one of my loved ones. Sure enough, it could."

Only a handful of viewers at *We Care*'s dozens of screenings and discussions have revealed themselves to be HIV-positive. Few admit even to knowing a PWA. Says Glenda: "People are scared of the stigma."

At the Reverend Benhur Goodridge's Universal Help in Life Church in East New York, where I went with Juanita, the audience—two women in their twenties, with seven small, impeccably dressed children—arrived an hour late.

"Okay, so what can you tell us about AIDS we don't already know?" one woman challenged. She dozed as the TV flickered atop the shoescuffed pulpit. Maybe the minister's presence was inhibiting, but neither Juanita's wisecracking lecture nor *We Care* itself provoked comment. Afterward, they thanked Juanita politely and left.

Did the women learn from the tape? Do they see themselves as care givers, which they obviously are? From the couple of questions they asked Juanita privately, it was hard to tell.

Another afternoon, I met Juanita at the cheerful Chelsea headquarters of Nontraditional Employment for Women (NEW), a program that trains women, most from backgrounds similar to the two parishioners', for jobs in the trades.

This audience took in *We Care* hungrily, augmenting it with grisly and gleeful tales of their own, from their spotty sex education to their adventures in condom use.

The NEW women, like those in WAVE, have taken a big step on their own behalf, challenging allegations about their race, gender, and class. They are already empowered. Affirming themselves as care givers is just another step.

But Amber Hollibaugh insists that the tape is not "inappropriate" for women like those at the church. Sensitive AIDS media put forward questions about health care, sexuality, and poverty "that are much deeper than what they appear to be presenting," she says. "The power of a tape like this is that something in it lingers longer than the practical information."

Immediate response isn't the only gauge of success, she adds: "It can take years for any of us to get hold of large enough chunks of information and consciousness to change our lives. A good AIDS film should be one more piece to hook into to get an idea of how not to give up."

We Care has changed lives. Having moved beyond isolated coping to collective accomplishment, the "girls" remain committed to one another. Juanita now thinks of herself as a filmmaker and a feminist. When Alicia screened *We Care* at the Borough of Manhattan Community College, she was invited to apply for a job as an AIDS counselor, then was disqualified because she lacked a B.A. Still, "it gave me a lot of confidence," says Alicia, who has gained the poise and perspective of an organizer. "No matter how the people may react," she says, "you know that nothing you say is going to come back empty. . . . At one point in their lives, these people are going to think, 'Wow, I remember I learned this from that AIDS workshop,' or they'll be able to help somebody else."

In other ways, things haven't changed. Marisol asked that I not use her real name, lest her daughter be shunned at school. She worries that next time, her own HIV test may come up positive. "Who will take care of me?" she asks. "Who will take care of my kids?"

Meanwhile, requests for *We Care* pile up in Glenda's cubby at BATF. Hundreds of copies have been mailed, and the tape will be screened on WNET's *Independent Focus* this season. But if the tape fires up legions of care givers, they'll be a frustrated army. "Women can receive education and information," says Marie-Lucie Brutus, project director of the Women and AIDS Resource Network, "but when they go to find the services—the clinics, the lawyers, the dental care, the home-visit nurses—all these will be severely curtailed by budget cuts."

If trends continue, by the year 2000 almost every family in the South Bronx, Harlem, and Bushwick will have lost several members to AIDS.

JUDITH LEVINE IS A CONTRIBUTING EDITOR OF THIS MAGAZINE.

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