

Olayinka Jegede-Ekpe [NIGERIA]

Yinka has broken the silence around AIDS, and confronted the stigma that puts the health of women and their newborns at risk.

The message from the Nigerian media was clear: you had to be promiscuous to contract HIV.

So when Olayinka Jegede-Ekpe's dermatologist asked if she wanted to be tested for the virus, the 19-year-old student nurse thought the suggestion ludicrous. She agreed to the test nonetheless, figuring she could eliminate it as the cause of her skin rash and move on.

"After some weeks, I found out that no one was talking to me about my results. I thought that something was wrong," she recalls. Her own doctor was traveling, and it took her several weeks of agitating before another dermatologist finally agreed to see her.

"She said, 'If people believe in God, they live. Those who do not have hope, they die.' That's how she told me," says Olayinka, who is known as "Yinka." "I went blank. I didn't hear what she was saying. I was in shock."

Yinka went to back to her bed and waited to die. She waited three days, eating nothing. "After the third day, I didn't die. I didn't believe it. I looked in the mirror. I didn't see a skeleton," she says. "I started searching for the truth."

Thus began a years-long quest, not only for truth, but for truthfulness and for critical changes in the way Nigeria deals with its HIV/AIDS epidemic.

Yinka is widely recognized as the first Nigerian to speak out publicly about her HIV-positive status, when she told her story to a newspaper a decade ago at age 19. She helped establish Nigeria's first organization for people living with HIV/AIDS; she was a member of Nigeria's National Action Committee on HIV/AIDS; and she has been influential in creating national policies to deal with a country-wide infection rate that experts put at about four percent.

But her passion is centered around women. Now 29, Yinka lives in Lagos and is executive director of the Community of Women Living with HIV/AIDS in Nigeria.

Yinka's goal is to empower women to take control of their own lives – even to help women living with HIV to have healthy babies, as she did in 2006. She encourages women who hope to become or are pregnant to learn whether they are HIV-positive so that they can take steps to protect their babies from infection.

At the time Yinka was diagnosed, AIDS was something of a joke in Nigeria, she says, even among her fellow nursing students. They didn't understand how it spread. Even her best friend in nursing school refused to eat food that she cooked, Yinka says. Another student hid the key to the toilet so she wouldn't be able to use it. "Everybody had me isolated."

But she stuck it out and after she earned her nursing degree, Yinka moved to the capital, Lagos, where she met and married her husband, who also lives with HIV. In August 2006, she gave birth to Ini. In early 2007, mother and daughter were pictured on the cover of a national magazine, *Genevieve*, which was widely commended for breaking through stereotypes.

Then, as if to illustrate the problem she was trying to resolve, the magazine's editor wrote a first-person story revealing her fear of contracting the HIV virus from Yinka at the photo shoot. She wrote that she didn't want to be "one of those AIDS PEOPLE."

The stereotype that Yinka had been fighting all those years was still very much alive. But this time, she was not the only one who was outraged. Readers rebelled. And the editor, in person and in print, apologized to the young woman who refused to remain silent.

When she was 17 and in her final year of high school, Wesam Hassan was touched by a movie about a person living with AIDS. Since then, she has been working to increase awareness of the disease in Egypt, a conservative country where sexual behavior is not a matter for public discourse and where women aren't usually on the front lines of public policy.

"Only six percent of women in Egypt have comprehensive information about HIV. It's taboo to talk about this," Wesam says. "Egypt has a good opportunity to curb the HIV virus only by increasing awareness."

With the right kind of action, she says, Egypt could dodge the epidemic that has engulfed much of sub-Saharan Africa.

Wesam began her work as a teenager, with school broadcasts that explained how HIV was transmitted. Then she went to medical school, where she made an overt statement, the kind that is unusual in Egypt, by pinning a red ribbon to her clothing. "My colleagues said this is the symbol of HIV-positive people – not the people who support them," Wesam says. "So I went to the Internet and started a search. I found that it was a symbol of supporting HIV-positive people."

That would be the first, but not nearly the last, misperception that Wesam would battle in the coming years. Now 23 and in her fifth year of medical school, she has dedicated herself to doing whatever she can to prevent AIDS among Egypt's youth and to advocating on behalf of women. Following that initial misunderstanding, Wesam decided to conduct a workshop, attended by 50 people, to raise awareness at Mansoura University. During their first presentation, she and some of her friends in the Mansoura Scientific Student Association not surprisingly focused on

misconceptions, misinformation, stigma and discrimination.

"We felt like we were really doing something, making a difference," she says. They repeated the workshop a few months later, and then began to turn their attention to youth.

Wesam attended a training program sponsored by the United Nations Population Fund (UNFPA), sought funding from another agency, and established anti-AIDS clubs in five high schools in the city of Mansoura. She personally headed the program at a girls' high school. "It was one of the turning points in my life," she says now.

In order to desensitize discussions about AIDS in a country in which open dialogue about sex is frowned upon, Wesam and her colleagues have turned to the theater and a radio station that targets young people. The infection rate in Egypt appears to be minuscule – less than one-tenth of a percent of the population – but Wesam says she considers the number suspect.

"People are afraid to get tested" because of social and religious constraints, she says. In her six years of working to prevent HIV/AIDS, Wesam has only met one Egyptian who acknowledged having contracted the disease.

At a global training workshop in 2007, she met many women living with HIV, and Wesam came away with a profound appreciation for them and their work. All the women were advocates like her, but AIDS had touched them in a much more personal way.

"They are amazing," she says. "They are inspiring me. They are teaching me strength. They taught me that all communities are like each other. We are all the same."



Wesam Hassan [EGYPT]

Working with youth is critical, Wesam believes, since "Egypt has a good opportunity to curb HIV by increasing awareness."



Jemimah Nindo Atieno [KENYA]

To protect Kenya's future, Jemimah helps the 4,000 teachers known to have HIV — and countless others who don't know they are infected.

At 25, Jemimah Nindo Atieno had a new husband and a flourishing career teaching in the largest boys' high school in Kenya. A year later, she gave birth to a baby boy. Then, after a two month illness, her husband died. His doctors did not tell her what took his life.

Though Jemimah was raising a toddler on her own, she said she had extra time on her hands and wanted to be "useful." So, she began helping a growing segment of students in her school — boys who had been orphaned by AIDS.

Jemimah also joined a widow support group at St. Stephen's Cathedral, an Anglican church in Kisumu, Kenya. "Most of the issues we were discussing were related to HIV/AIDS, but no one wanted to talk about it because there was stigma in the church," she says. "We decided to break the silence."

All 30 women in the group underwent training to counsel people infected with HIV or affected by AIDS. Jemimah volunteered at a new church counseling center — never dreaming that she was living with HIV herself.

At the high school where she taught, she started an AIDS club, and worked to help students cope with a problem that often remained hidden from society. It was only when she applied for a visa to leave the country for an educational program that she was tested for HIV. Though she had no outward symptoms, her blood count was poor and she was placed on emergency medication.

"If I hadn't been tested, I might have just collapsed and died," says Jemimah.

Unlike so many people in Kenya and around the world, Jemimah had a ready-made support group: the widows of St. Stephen's. When she ran out of money for medication and her health deteriorated rapidly, the women

pitched in financially. Her husband's colleagues helped, too.

Once her health improved, Jemimah turned her attention to breaking down stigma.

"I decided I needed to disclose my status," she says. "I started with the students in class, slowly — the HIV club — then the principal of the school, who was very, very supportive." She joined a network of HIV-positive teachers and began speaking on behalf of people living with HIV in Kenya and worldwide.

Now 40, Jemimah lives in Nairobi and works for the Teachers Service Commission, which supports the 4,000 Kenyan teachers who are known to be HIV-positive and countless others who have not discovered or disclosed their status, she says. She offers counseling and social support to teachers and other employees living with HIV and AIDS, and works with them to live openly and fully. She facilitates support groups comprised primarily of widowed women teachers who are living with HIV. Her biggest challenge, she says, is fighting the stigma and discrimination that prevent these widows from participating fully in society.

Jemimah says the vast majority of the teachers who have disclosed their HIV-positive status are women. Women comprise nearly two-thirds of those living with HIV in Kenya, and take care of ailing parents, children, husbands, and friends, she says. Even young girls with older brothers tend to take responsibility for sick parents, she notes, adding, "So girls need to be empowered."

With more empowerment, Jemimah believes that women and girls can make a difference in communities affected by AIDS. "They will challenge the cultural norms," she says.

"When you educate women, you educate a community," she says

This publication profiles an inspiring group of women who participated in an **Advancing Women's Leadership and Advocacy for AIDS Action** workshop. The initiative equips and empowers a growing cadre of women worldwide with the knowledge and skills to advance the global response to AIDS. Partners include the Centre for Development and Population Activities (CEDPA), International Center for Research on Women (ICRW), International Community of Women Living with HIV/AIDS (ICW), National Minority AIDS Council (NMAC) and the UNAIDS-led Global Coalition on Women and AIDS. The initiative is made possible through a generous grant by the Ford Foundation.

CREDITS: PROFILES WRITTEN BY JODI ENDA. PHOTOS BY MAX TAYLOR PHOTOGRAPHY. DESIGN BY EASON ASSOCIATES, INC., WASHINGTON, DC.
©CEDPA/GCWA/ICRW/ICW/NMAC, 2008