You Go, Uganda

August 1, 2004 By Cindra Feuer

In April, researchers rocked the prevention world with news about Uganda, formerly Africa's hardest-hit country. They ascribed its plummeting HIV rates not to Uganda's seminal "A(bstinence), B(e faithful), C(ondom)" campaign but to the fact that people there, unlike other Africans, speak freely about the disease. On a recent trip, Cindra Feuer saw this principle flowering. She met farmers mourning multiple losses in group therapy, traditional healers exchanging treatment information, dying moms making "memory books" for their kids and traveling theater groups doing AIDS ed. While Ugandans await the agonizingly slow med rollout that began in March, they still count on the best HIV weapon they have: one another.

AMONG FRIENDS

RAKAI—Uganda's first AIDS cases were diagnosed in 1983 in the rural Rakai district. The disease blindsided farmers and fishermen, turning the region's backwater communities into apocalyptic cesspools. It is not uncommon for three generations of families to have been wiped out.

In 2001, researchers from Columbia and Johns Hopkins universities found that 21 percent of Rakai residents suffered from clinical depression. So the team organized a pioneering study: good, old-fashioned group therapy that would, they hoped, alleviate isolation, lend practical advice and foster emotional affinities. "Before the group, I spent the whole day crying, not eating," says soft-spoken Glyda Namujjuze, who lost her siblings and parents to AIDS. John Biarugaba also lost most of his relatives. "I had given up all activities: farming, rearing animals," he says. "I knew I was HIV positive, and I was doubting the group therapy."

Namujjuze and Biarugaba attended weekly, 90-minute meetings typically held at a participant's home. The women gathered indoors in barren but tidy living rooms while the men settled on benches under acacia trees. Not everyone was HIV positive, so a trained facilitator from the community initiated discussion about HIV (say, fear of testing) and general topics (generating income, for instance).

After four months, the results were profound: Of 15 groups of 12, only 6.5 percent remained clinically depressed, compared to 54.7 percent in the control group (depressed men and women who didn't participate in therapy).

"I received comfort and skills from the group," says Namujjuze. "I learned banana-beer brewing, and [the members] became like family. I can even smile now." Therapy improved Biarugaba's physical health. "The group said, 'Even though you're sick, don't spend all the time sleeping. Set

small goals,'" he says. "I started cultivating 20 trees per day with courage from the members. I feel stronger than before."

Many of those who participated still gather for sessions, and new groups have formed—the district now boasts more than 40, with plans to add youth (18 and younger) participation. Researchers hope to replicate the model throughout Uganda, Africa and elsewhere.

BOOK OF LOVE

KAMPALA—Yudaya ("God" in the Ugandan language Luganda) Nazziwa, 39, stands tall and strong. Her stature and wide smile mask her declining health—at last count she had only 130 CD4s. Like so many other ill, HIV positive women in the capital city, Nazziwa was drawn to the National Community of Women Living With HIV/AIDS (NACWOLA) and its Memory Project.

The Project helps women create scrapbooks with standardized categories like "Growing Up," "My Working Life," "My Health,"; the books were developed in 1999 as a communication tool for mothers who had difficulty disclosing their HIV status to their children. "There's a gap between mothers and children," Nazziwa says.

Nazziwa enrolled in a five-day workshop at NACWOLA's headquarters, where counselors discuss child development, parenting, disclosure and facing the prospect of dying. "Before the training, I had no time for the children," Nazziwa says. "Now I give them time, make them smile, and they have become supportive of me." Following NACWOLA's guidelines, she works on a scrapbook for each of her four children.

Each of the 40 laminated pages in Nazziwa's bursting cherry-red, looseleaf binder for her daughter Victoria, 18, focuses on one subject. On the "Growing Up" page, Nazziwa recounts her daughter's overachieving childhood. In "My Working Life," she documents her own history of selling clothes in the open market. Some of the pages hold photos of Nazziwa and her children. Others have magazine cutouts of young tykes. "I tell Victoria, 'You used to be that size,'" Nazziwa says. In-laws claimed many family photos after her husband's death.

These scrapbooks can be as therapeutic for mothers as for children. Nazziwa's "My Health" page, which includes pictures of her looking gaunt and unhappy and written accounts of her health struggles, helps her and Victoria confront hard truths. "This is the toughest page," Nazziwa says. "It took time to write. We write with the child beside us. They say 'Mommy, you are going to die. Where will we stay? Who will pay for school fees?'"

The answers are written on pages called "Foster Parent" and "People Who Are Special to You." After scanning through them, Nazziwa hides her head in her hands, then looks up and points to a photo of two friends who are already dead. "Can you imagine," she says, "telling your child, 'This person will help you,' and then they die?"

Devastating as such moments are, the memory book gives Nazziwa and other mothers peace. They have planned for their children's well-being and enriched the mother-child bond. "Victoria

tells me, ‘You have to do the book,’” Nazziwa says.

SCHOOL TIES

BUYIJJA—Every Wednesday, about 150 women and a handful of men rise early for the arduous hike or cramped flatbed-truck ride to the Association for Promotion of Traditional Medicine (PROMETRA) in the village of Buyijja. PROMETRA has no buildings, just a shady area on a 200-acre farm that hosts more than 770 plant species. The only school of its kind on the continent, PROMETRA encourages the formal training of traditional healers, who are believed to have been born with a gift for restoring health through divine or ancestral guidance and medicinal plants. Healers accept the science behind HIV, but PROMETRA president Sekagya Yahaya says HIV perplexed them because they couldn’t fathom the cause of opportunistic infections. “That prompted them to open up their willingness to learn,” he says.

Students and teachers, many of whom are positive, trade remedies for a host of HIV-related symptoms, including diarrhea, vomiting, wasting, fevers, anorexia, pneumonia, abdominal pain, headaches, depression and mental confusion; they also address the treatment of malaria, STDs and birth control. “Some have a voice that says this plant does this and this and this,” says Kaseke Kambajwe, an eager young student.

A study conducted by THETA, a Ugandan group that promotes traditional medicine, found that herbal concoctions for diarrhea, wasting and herpes were actually more effective than some Western treatments. However, most plants have not entered comparison studies, so the government still hesitates to use them officially on a large scale.

Traditional medicine is often the only option for Ugandans: Another THETA survey reports that there is one traditional healer for every 300 to 400 patients—compared to one Western doc for every 10,000 patients. Ugandans trust their elders, and Western medicine is often cost prohibitive. “Healers are identified and commissioned by the community,” Yahaya says. “They don’t need the Ministry of Health to prove themselves.”

FACING THE MUSIC

PALLISA—Dressed in their everyday clothes—secondhands from the U.S., traditional dresses, a smattering of ASO T-shirts—the women walk barefoot onto a makeshift stage: a paprika-colored dirt floor behind a cluster of huts in the village of Pallisa. As a small group of men holding handmade instruments strike up a lively tune, the tallest woman, impersonating a philandering man, grinds against a succession of women. Each chastises and rejects him for being a casanova. The transfixed audience hangs on every slapstick move and high-pitched lyric. Soon everyone joins the commotion.

Music and dance are essential AIDS-awareness tools throughout Uganda. The country’s National Strategic Framework for HIV/AIDS includes performance as an integral educational component, and many ASOs create HIVer theater groups. Their performances are vital in rural regions, where 85 percent of Ugandans live and few have access to Internet, television or even radio. “The dance part gets people to come out,” says Moses Miro, the music director for The AIDS Support

Organization, Uganda’s largest ASO. “They need entertainment. As they watch, we give facts.”

The song messages are simple—don’t sleep around; you never can tell who has HIV—and cover an amazing range of subjects: women’s reproductive health, where to find condoms, testing, counseling, health care, battling stigma.

“People make fun of us, for they don’t know how we feel,” goes the antidiscrimination song “Let’s Fight Until the End,” Uganda’s most recognizable AIDS diddy. Its catchy refrain “You and me, let’s fight until the end” is everywhere, from tony hotels to fields in the bush. As Uganda changes, so will its songs about the disease. Anticipating the long-awaited HAART rollout, “we’re coming up with songs about antiretrovirals,” says Miro.

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