# A SNAKE IN THE HOUSE

## LIVING WITH AIDS IN UGANDA

*Uganda has the largest cumulative number of reported AIDS cases of any African country. Though gravely short of resources to deal with the epidemic, the government has an open and frank policy on the problem. Outside the country, this has begun to translate into international assistance for control and prevention. Inside, it has created fertile ground for the emergence of a grass roots movement to deal with the daunting task of care and counseling of the growing number of people with AIDS.*

GERRY TOOMEY

Frail and thin, John Kasirye lies resting in the small, dim bedroom of his two-room house in Mulago village, a central neighbourhood of Kampala, the capital of Uganda. Outside his window, little children play beneath leafy banana trees, oblivious to the fact that their 32-year-old neighbour, a truck driver, has AIDS.

For people with Acquired Immune Deficiency Syndrome, the prospect of an early and painful death is tragic. What adds to the burden of thousands of Africans like Mr Kasirye is their extreme poverty, the shortage of medicine, and, perhaps worst of all, desperate worries over the fate of their children.

"Before being sick, I had four wives," laments Mr Kasirye. Three have left him, and six of his seven children have had to go and stay with a grandmother. Some of his sisters help to care for him now. His remaining wife has also tested positive for the AIDS virus.

Above the foot of Mr Kasirye's bed on a short clothes line hang half a dozen freshly washed pairs of underwear, a testament to his illness. "I can eat and drink," he continues, "and I can still walk, but I don't do so because I've been having diarrhea."

Too weak to visit the Mulago Hospital AIDS clinic even though it's not far away, Mr Kasirye is attended by a nurse, Rose Amito (not her real family name), who works for a local self-help agency, The AIDS Support Organisation, or TASO. She also has AIDS. (See "Rose of Kampala", page 9.)

Today nurse Amito is accompanied on her rounds by a West German doctor and a Canadian editor. "I used to operate my own vehicle," Mr Kasirye tells his visitors. "But I fell ill and soon didn't have the strength to change a tire." So he sold the vehicle, hoping to buy another once he was feeling better.

But Mr Kasirye's diarrhea and other symptoms persisted. He was diagnosed as having AIDS—or "slim" as the Ugandans call it. Without work, he was forced to spend the cash from the sale of the truck to support the family. The funds have run out. "I have no income and no hope now," he says in the softest of voices.

Rose Amito visits Mr Kasirye about once a week. She provides basic medication such as aspirin and antidiarrheals, plus food, soap, and kind words. Lately he has had access to the drug Imodium and to an experimental herbal treatment. Imodium helps control diarrhea caused by intestinal infections such as cryptosporidium.

But drugs are usually in short supply. "There is a tablet, Nizoral, that is very difficult to obtain," explains Ms Amito. "They used to give it free in the clinics, but now we can't get it." Nizoral is used to treat oral thrush, a fungal infection of the mouth and throat common in AIDS patients. Without the drug, says Ms Amito, patients with thrush are soon unable to eat, which further weakens them.

When Nizoral is available, it is very expensive. A full course of 20 tablets would cost about five months' salary at minimum wage. As for the drug AZT, recognized as effective against the human immunodeficiency virus (HIV) itself, it is not available in Uganda. Even if it were, it would be far too expensive for the health system to supply.

Poverty here is both personal and institutional. With the Ugandan economy in a shambles, the public health care system is underfunded and overburdened. For every 21 000 patients, for example, there is only one doctor, according to the London-based Panos Institute. In Western Europe, the figure is 470 patients per doctor.

Because salaries are so low, even the doctor who heads Mulago Hospital is forced to grow a vegetable garden to make ends meet. The flagging economy has driven some 200 Ugandan doctors and trained technical staff to seek work in Saudi Arabia and southern Africa. With no foreign exchange, the hospital has at times had to barter with other countries: pineapples in exchange for some of the 60 essential drugs it needs. And for long periods, Mulago Hospital was without running water. Staff and patients alike became water bearers.

For Uganda's 15.5 million people, the AIDS epidemic has struck just as the nation is beginning to regain its sanity and security after many years of bloody civil strife and genocide. During the regimes of Idi Amin and Milton Obote, in the 1970s and first half of the '80s, hundreds of thousands of Ugandan civilians and soldiers were slaughtered.

President Yoweri Museveni, whose rebel forces eventually defeated the government army, came to power in January 1986. He is credited with bringing a measure of peace and security to a devastated Uganda. But the economy is still plagued by a huge foreign debt, lack of foreign currency, high inflation, low wages, and impaired agricultural productivity and exports.

To this string of economic ills must be added the long-term toll of the growing AIDS epidemic. The syndrome mainly strikes a community's breadwinners—those between 15 and 40. "AIDS steals the young and most productive and loved members of the society," Dr Samuel Okware, director of the Uganda AIDS Control Programme (ACP), told an AIDS conference in Arusha, Tanzania, last September.

Uganda's AIDS program certainly has its work cut out for it. As of May 1988, the cumulative number of reported cases was 4734. By August the number had grown to 5508. But this is probably much lower than the actual number because it is only within the last year or so that a comprehensive national system for reporting AIDS cases using standardized forms has been in place.

In a June 1988 progress report, Dr Okware estimated the HIV infection rate, or "seroprevalence", at between 0 and 5 percent of rural adult Ugandans, with some areas still free of infection. Eighty-six percent of the country's population is rural.

For adults in Kampala, the infection rate is estimated at between 5 and 20 percent. In villages along trading routes, the range is 5 to 15 percent. More precise figures have come from surveys in Kampala. In one group of blood donors, the HIV infec-

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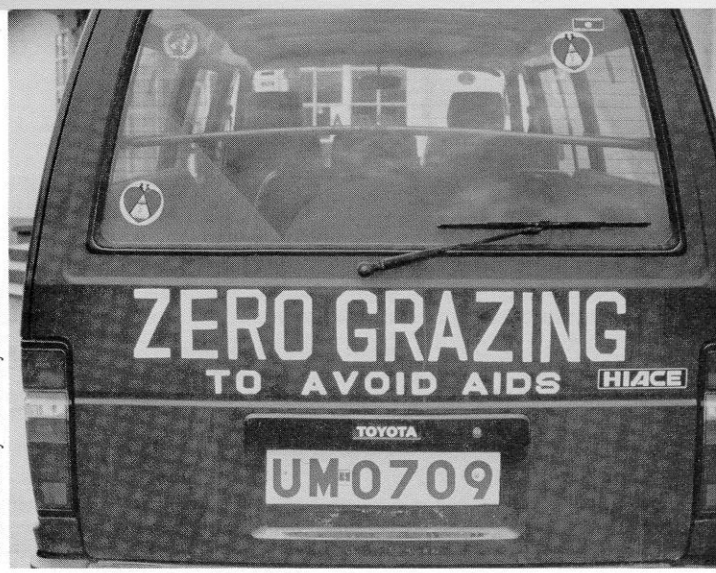


Photo: Gerry Toomey/IDRC

*Prevention motto of Uganda's AIDS Control Programme. The message is sexual fidelity.*

tion rate was 14 percent, and among women attending a prenatal clinic it was 13 percent.

Other studies cited by the London-based Panos Institute, which has been closely monitoring the AIDS pandemic, report HIV-positivity rates in Uganda of 15 to 21 percent among blood donors and 20 percent among pregnant women.

"We have found no difference in seropositivity between ethnic or religious groups," Dr Okware told the Arusha conference. "Human tragedy and misery have descended on the faces of the poor and rich alike."

While AIDS may not select its victims according to class or religion, lifestyle plays a role. Uganda ACP studies, like those from other countries, confirm an increased risk of HIV infection for those with multiple sexual partners or multiple episodes of sexually transmitted diseases such as gonorrhea.

"The good news is that there are virtually no cases between the ages of 5 and 15," said Dr Okware. That age group makes up 30 percent of the population. As for infants, the seroprevalence and disease rates are not as clear because of difficulties with diagnosis. "However, we suspect that perinatal [occurring around the time of birth] transmission in our surveillance series could be responsible for up to 10 percent of cases. (See page 10.)

The number of AIDS cases is doubling every four to six months, according to the Uganda ACP. Globally, the pandemic is spreading more slowly, with a doubling time of about one year. Assuming a six-month doubling rate in Uganda, one could expect a cumulative total of about 300 000 cases by May 1991. That equals the number of people killed during the regime of Idi Amin.

Predicting the pattern of an epidemic, though, is risky, even for experienced epidemiologists. It may be, for example, that the alarmingly short doubling time in Uganda is more a reflection of recently improved reporting of the disease than of an explosion of new cases.

But the numbers for Uganda and other East and Central African countries do point clearly to a growing epidemic. Is the current problem in Uganda simply the tip of the iceberg? "A volcano might be a better metaphor," says Dr Donald Sutherland, WHO's advisor to the Uganda AIDS Control Programme.

The Ministry of Health set up the ACP in July 1987 with WHO assistance. The program's job is to contain the volcano. Headquartered at Entebbe on Lake Victoria, a half hour's drive from Kampala, the ACP now has a staff of about 50, including four WHO experts. About 100 local health educators have also been recruited.

The ACP monitors the epidemic, provides statistics on the number of cases and infection rates, and carries out surveys and other research. It also runs a large public information and education program, screens the blood supply, operates test facilities, and helps to protect public health workers by supplying them with sterilizing equipment and gloves.

WHO's contribution to Uganda's control program is the largest of its AIDS operations in the developing world. This is not only because of Uganda's need, but also because the political climate was right, says Dr Sutherland. "Uganda has taken a remarkable attitude towards AIDS. The policy of the Ministry of Health has been to be open."

The openness of the Museveni government—toward the Ugandan public as well as foreign scientists and journalists—is remarkable in light of the negative treatment, much of it unjustified, given the African AIDS situation in the international press over the last three years.

It has often been repeated, for example, that AIDS likely originated in Africa. This view is based on, among other things, erroneous analysis in the mid-1980s of old blood samples from Kenya and Uganda. The test results indicated a high rate of HIV

## HOW AIDS IS SPREAD

The world pandemic of AIDS has several principal transmission routes. The human immunodeficiency virus (HIV) that causes the syndrome can be passed from one person to another during sexual intercourse, either vaginal or anal, heterosexual or homosexual.

HIV can also be gotten from a transfusion with contaminated blood or when intravenous drug users share hypodermic needles with an infected person. Infected mothers can pass the virus to their babies before, during and possibly after birth (though there is little evidence of transmission via breastfeeding). Ritual scarring of several people with the same knife or piercing instrument is also thought to carry the risk of HIV transmission.

In Africa, unlike Europe and North America, penetrative sex between a man and a women is by far the most common transmission route. Cases of AIDS are about equally split between men and women. Surveillance work in Uganda suggests, for example, that 80 percent of people with AIDS contracted the syndrome through a heterosexual encounter. Transmission through contaminated blood and from infected mother to child are largely responsible for the rest.

As for homosexuality, it is not generally believed to be a significant means of transmission in Africa. In one Ugandan survey, for instance, only three of 742 HIV-positive respondents said they had had homosexual relations.

For every reported case of AIDS in the world, there are likely a dozen or more people infected with the virus. Although these "seropositive" people appear healthy, they are capable of transmitting HIV to others. It is still not known what percentage of them will go on to develop full-blown AIDS or die. But one U.S. study indicates that up to 50 percent of those infected will develop the disease in 10 years. Some estimates are more pessimistic, suggesting that HIV-positivity is a death sentence, though one that may be postponed for many years. ■

infection, making it appear that Africa had harboured the AIDS virus for a long time and therefore was a likely geographical origin of the disease.

"When methods for testing blood for HIV antibodies improved, the early blood tests were discredited and it was accepted that AIDS was as new to Africa as it was to the United States and Europe," says a recent edition of *AIDS and the Third World,* published by the Panos Institute.

Such scientific error angered many Africans. For one thing, they felt they were being blamed for the international epidemic when in fact there was no evidence that Africa was the source. The "origins" debate flashed on and off in the international press, sometimes sparking charges of racism, and reinforcing the closed-door policies of some African governments. Uganda, though, followed a policy of openness and got on with the job of controlling the epidemic.

"We Ugandans believe that if a snake enters your house, you don't go and ask the snake where it came from," says Louis Ochero, coordinator of the ACP's information, education and communication program. "Rather, your reaction would be, 'How do I get rid of the snake?' So, in Uganda, we don't discuss the problem of where AIDS came from, we discuss how to get rid of the beast."

Whatever the metaphor—snake or volcano—the fight against AIDS is an enormous and expensive task. But, as in other countries, it is just one of a number of competing health priorities. Parasitic diseases such as malaria, sleeping sickness, and schistosomiasis, as well as acute respiratory infections, diarrhea, and malnutrition, are also serious public health hazards in Uganda. And, like AIDS, they demand attention from a beleaguered and impoverished health care system.

This helps explain a phenomenon described recently by a Canadian development worker and former research scientist who worked in Africa for several years. AIDS experts from the Northern countries, he recalls, "ran around looking very serious" at the Arusha conference. They projected a great sense of urgency over the AIDS situation in Africa because of its relative gravity in their own country.

"Would we be seeing the extraordinary Northern interest in AIDS in developing countries if the syndrome were a problem only of developing countries?" asks the Canadian, who prefers not to be named. "Malaria is a good example. It has killed millions in developing countries in this century, but has attracted a disproportionately small and hopelessly inadequate percentage of Northern research resources. The malaria catastrophe continues, and it is not unlikely that human and financial resources for the fight against malaria are being diverted to AIDS. We shouldn't be surprised if such events are viewed with some cynicism."

The Uganda AIDS Control Programme has received only minimal funding from the Ministry of Health. The money is simply not available. The government's policy of openness, however, has helped the country to attract badly needed foreign assistance, mainly from Europe.

Overall, though, funding levels are still grossly inadequate. The ACP estimates its yearly needs at about $14 million (Canadian). Donors' pledges of assistance to its first year of operation amounted to about $9 million. And only about $3.5 million of that was actually received. By comparison, Canada, with less than half as many cumulative AIDS cases as Uganda, started up its Federal Centre for AIDS with 10 times that amount—$36 million.

Cash shortfalls force the Uganda ACP to concentrate on the most critical priority—slowing the spread of the epidemic. In practice, this means concentrating on prevention work such as screening the blood supply, protecting medical workers, and educating the public. Protecting the blood supply alone eats up about a quarter of the ACP's budget.

But what about the work of counseling and caring for people like John Kasirye who are already ill with AIDS? For them, the existence of the prevention-oriented ACP is little consolation. The ACP has had to turn to church and other grass roots groups such as The AIDS Support Organisation—TASO—to at least provide moral support and basic care.

> *'HIV infection is threatening to split apart traditional family links.'*

Nurse Amito and her two foreign visitors say goodbye to John Kasirye and return on foot to the TASO headquarters at Old Mulago Hospital. As they arrive, the black sky bursts and a tropical downpour begins to beat a steady hum on the corrugated metal roof.

Inside the office, it is tea time. TASO staff and a few clients sit around the office in quiet conversation. "You can't get AIDS from this cup" reads the inscription on a steaming tea mug.

The furnishings—three cabinets, three desks, and assorted chairs—have seen better days. A portrait of the late Pope Paul VI hangs on the wall. Near a window with blue and white checkered curtains is a small cabinet that holds a steel kettle, a tin of tea, and an antique telephone currently out of order. In a corner, a young woman with a sad face sits quietly reading a religious book. She is John Kasirye's wife.

"TASO sprang up among a group of volunteers who had been touched by the virus," says TASO Secretary Noerine Kaleeba, a founder of the fledgling agency and, in effect, the driving force behind it. "We want to convince the public that being infected with HIV doesn't mean you're going to die today or tomorrow."

Set up in late 1987, TASO is the only nongovernment organization in the country concerned solely with supporting and counseling families affected by AIDS. Funding comes mainly from Action Aid, a U.K.-based agency.

When a prospective TASO client is known to have had contact with an infected person and also displays clinically recognized AIDS symptoms, an AIDS test called the ELISA is administered. A confirmatory "Western Blot" test is not usually performed because of the high cost. TASO provides pre- and post-test counseling and offers clients moral support. In cases of extreme poverty, food and clothing may also be given.

Caring for people with AIDS and their families, asserts Mrs Kaleeba, is too big a task for the country's social services or the hospitals to handle. TASO can help fill the gap. "It's usually possible for NGOs to deliver services without too much bureaucracy," she says.

"HIV infection is threatening to split apart traditional family links," warns Mrs Kaleeba. In some instances, people with AIDS are brought and left to die in hospital by their relatives who are no longer able to sustain the financial drain. And sometimes families abandon those with AIDS because they fear infection.

"There are also cases where the orphans of AIDS victims have not been taken care of by the many members of the extended family, as is usually the tradition. They fear that these children may also be infectious."

Nestor B., a TASO staff member who has AIDS, says the fate of his own three children is his gravest concern. "I can face the disease for myself and accept it," says the 36-year-old former journalist who prefers not to use his family name. "My worry is that my children, since they're being discriminated against by my brothers, will not be cared for. I see a bleak future for them." Nestor and other staff are now planning a TASO program to ensure the welfare and education of orphans.

In hospital, fear has led some staff to neglect AIDS patients, reports Dr Elly Katabira, co-founder of TASO and head of a weekly out-patient clinic for AIDS patients at Mulago Hospital. Sometimes doctors thought the situation was hopeless and "many patients were sent home and not given appointments to come back."

Since the clinic opened in April 1987, Dr Katabira has used it as a kind of laboratory for him and TASO staff to learn more about the disease. It has also served as a platform for educating his fellow physicians about humane treatment of AIDS patients.

After he and Mrs Kaleeba were trained in AIDS counseling in the U.K., they visited their Ugandan clients at home. They explained that it was safe for family members to care for those with AIDS and instructed them how to do it. "I discovered that the patients were much happier—they

were smiling and cordial," says Dr Katabira.

TASO's aim is to help people to live with AIDS and to give them hope and comfort. A positive attitude and healthy living — safe sex and no alcohol, for example—are promoted as ways to extend the lifespan of clients.

As with orphans, the widows of those who die of AIDS are of special concern to TASO. Even if they wanted to, it is difficult for them to find husbands who will accept them. Poverty and prostitution are sometimes their fate. TASO is therefore encouraging widows to start up small income-generating enterprises for financial security.

"By the way," says Mrs Kaleeba. "I'm a widow. I lost my husband to HIV and because of that I've come into contact with many widows."

With help from the Uganda ACP and an Irish volunteer instructor, TASO has been busy training new counselors and expanding its service. The head office covers the greater Kampala area and, by last autumn, 10 counselors were serving 112 client families. A second AIDS clinic has also been opened in Kampala for mothers and babies with AIDS.

TASO is also expanding outside the capital. It recently opened a second branch 130 kilometres southwest of Kampala. The U.S. Agency for International Development has promised funding to set up eight more TASO branches beginning this summer.

The emphasis on training more counselors is critical since blood donors who test HIV-positive aren't normally told of their status. The Ministry of Health feels that in the absence of counseling services, it serves no useful purpose.

With TASO now building its cohort of counselors, more and more cases of AIDS and seropositive individuals are being referred to it for counseling by hospitals. "The environment is now right for people to be told they are positive," says Dr Edison Mworozi, who is conducting research on mother-to-child transmission of AIDS.

In Uganda and other countries, both North and South, the medical and moral support of AIDS patients and their families has so far taken a back seat to prevention and control efforts. But as the pandemic grows, the number of people with AIDS will grow and, along with it, the need for direct support.

Organizations such as TASO are charting new waters. Their experience and expertise should be of increasing value to other countries and other support groups in the years to come. No country is too small to offer something in the fight against the AIDS pandemic, says Dr Okware of the ACP. And no country is big enough to have the complete solution to the AIDS problem. ■

*Editor's note: John Kasirye, a TASO client, died of AIDS last October. He was 32.*

# *ROSE OF KAMPALA*

## *LIVING WITH AIDS*

*Rose and TASO client, William, a 23-year-old student with AIDS in the village of Kabalagala. She brings soap, eggs, simple medication, and friendly encouragement.*

Photo: Gerry Toomey/IDRC

Rose Amito, a 29-year-old Ugandan nurse, has AIDS. Last year, after learning she was in the first stages of the disease, she joined the staff of The AIDS Support Organisation (TASO), a fledgling self-help group based in the capital city, Kampala.

For 10 years, beginning in 1977, Ms Amito worked as a registered nurse, first at a hospital in Eastern Uganda, then for the Institute of Public Administration in Kampala. In 1987 she decided to leave her nursing job to pursue a career as a midwife. She enrolled in a training program at the Mulago Nurses' Training School, but in March 1988, she fell very ill.

"I had fever and joint pains, especially in my knees," she recalls. "I wasn't able to move easily so I walked with a stick supporting me. And I had a cough which was not responding to treatment." She was admitted to hospital and, suspected of having AIDS, was given blood tests for HIV. "I spent two weeks in hospital and during that time, I was really ill and feeling so bad. There was no counseling available. It was terrible." She was discharged without knowing the results of her tests because they had not yet come back from the lab.

Back at the nurses' training school, she was shunned by other trainees because of her AIDS-related body rash. In the dormitory she shared with 20 other women, beds had been moved a "safe" distance away. Friends she used to take tea with avoided her.

She felt too weak to do her midwifery work and, besides, patients didn't appreciate it when she held their hand. She dropped out of school and went to live with her younger sister, who was more understanding of the problem.

"I was referred to TASO where I found colleagues—friends who had the same problem." During a visit to a local AIDS clinic, her fears about her blood test were confirmed when she saw a simple inscription on her case sheet: HIV positive.

"At TASO, they comforted me and assured me that I wouldn't die immediately. I told them I wanted to go back home even though I knew very well that if I did so nobody else would bother about me and I would die there. So they discouraged me from leaving and told me *their* personal stories. They asked me to keep reporting back for the next few days.

"Each time I came to TASO I felt more at home. Because I was a nurse, they asked me if I could stay with them and care for some of the people who had been referred to TASO who really needed help. Some had open sores, others suffered headaches, and such things. I accepted their request and stayed on. So I have been dispensing the few drugs that the ACP (AIDS Control Programme) has assisted us with.

"At times I take sick friends home to stay with me in the small room I share with my sister because TASO doesn't have any place where we can admit them. One woman has some sores that need dressing but she can't do it herself because she is so weak. Here is somebody you know is very ill and maybe there is no treatment. But she needs someone by her side to at least comfort her and to do small things like give her a sponge bath.

"If these patients are taken to hospital, nobody is willing to touch them. Once somebody sees you've got a rash like mine, they keep away from you and leave you lying there. The hospital staff aren't very well informed about AIDS. But since TASO started holding workshops for them, there has been some slight attitude change." ■