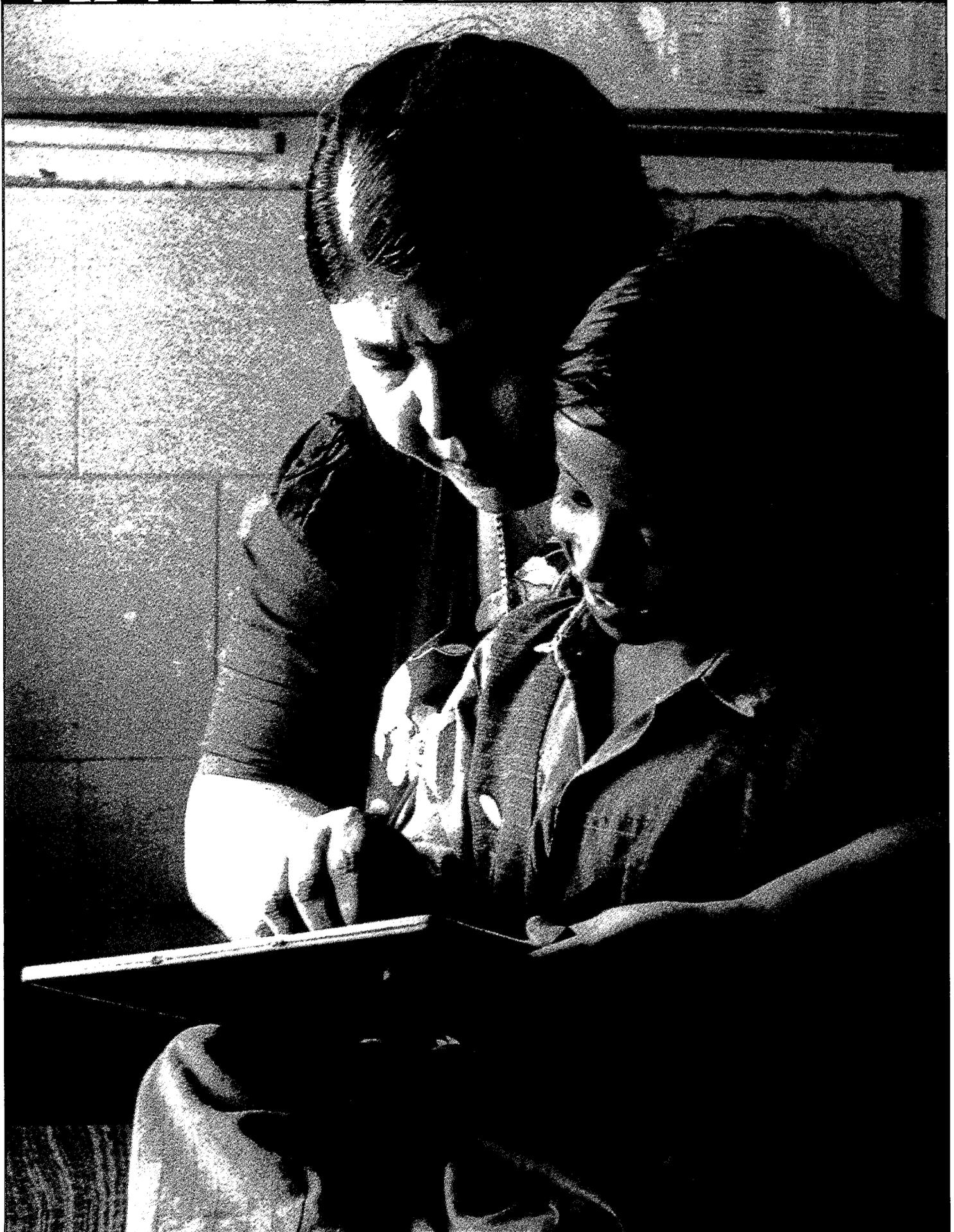


OCTOBER 1998

LINKING CARE AND PREVENTION

# IMPACT ON HIV



 **Impact**

Family Health International  
Implementing AIDS Prevention and Care (IMPACT) Project

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## Jonathan Mann: The Visionary Leader Who Linked Health and Human Rights

This first issue of *Impact on HIV* is dedicated to Dr. Jonathan Mann, who made a global impact in the field of HIV/AIDS prevention and care and on the lives of thousands of individuals around the world. Dr. Mann died in a plane crash off the coast of Nova Scotia on September 2, 1998, along with his wife, Dr. Mary Lou Clements-Mann, a prominent HIV/AIDS vaccine researcher and professor at Johns Hopkins University. Both were 51.

Dr. Mann was a visionary in the fields of international HIV/AIDS research, prevention, care, advocacy and human rights. He was the first to define HIV/AIDS as a global pandemic made up of multiple HIV epidemics spreading at different speeds through various countries and populations.

Realizing early on that HIV/AIDS was one of the most profound health challenges of our time, Dr. Mann leaped at the opportunity in 1984 to found and guide a new HIV/AIDS research program in Zaire. Under his leadership, *Projet SIDA* became known as the best HIV/AIDS research program in Africa. It was dissolved by President Mobutu Sese Seko in 1991.

Working tirelessly as the founding director of the World Health Organization's Global Programme on AIDS from 1986 to 1990, Dr. Mann mobilized international recognition of HIV/AIDS as both a public health issue and a human rights issue. He courageously challenged the world to consider HIV/AIDS as a manifestation of individual as well as societal vulnerability, inextricably linking human health with human dignity.

Dr. Mann left the World Health Organization in 1990 to become a professor of epidemiol-

ogy and international health at the Harvard School of Public Health. Two years later he was named the school's first François-Xavier Bagnoud Professor of Health and Human Rights, as well as the founding director of Harvard's FXB Center for Health and Human Rights.

Drawn by the opportunity to guide a new institution as well as to be closer to his new wife, who was based in Baltimore, Dr. Mann left Harvard to become the dean of the new School of Public Health at Allegheny University of the Health Sciences in Philadelphia, Pennsylvania, in January 1998.

A charismatic and compassionate leader, Dr. Mann often championed issues that were highly controversial. In April 1998, after receiving international criticism for a speech in which he challenged the U.S. government to speed up HIV/AIDS vaccine development, he said privately, "I think lightning rods perform a useful function, but it is not pleasant being a lightning rod!"

Dr. Mann was the senior editor of *AIDS in the World* and *AIDS in the World II*, considered to be landmark texts in the field of HIV/AIDS. A gifted writer and speaker, he held a bachelor's degree in history from Harvard College, a medical degree from Washington University in St. Louis and a master's degree in public health from the Harvard School of Public Health.

Dr. Mann and Dr. Clements-Mann were killed while en route to Geneva, Switzerland, for meetings on HIV/AIDS at the World Health Organization. He is survived by his first wife, Marie-Paule Bondat, and their three children, who work in the fields of law, health and international development.

### IMPACT in 25 Countries

U.S. Agency for International Development (USAID) missions in 25 countries and two of the agency's regional offices have requested assistance from the IMPACT (Implementing AIDS Care and Prevention) Project during its first year.

The project is working in Benin, Ethiopia, Egypt, Ghana, Madagascar, Malawi, Nigeria, Rwanda, Senegal, Tanzania and Zambia in Africa; in Bangladesh, Cambodia, India, Indonesia and the Philippines in Asia; in Brazil, the Dominican Republic, El Salvador, Honduras, Jamaica, Mexico and Nicaragua in Latin America and the Caribbean; and in the Russian Federation and the Ukraine in Eastern Europe. In addition, IMPACT is assisting USAID regional programs in Asia and the Near East and in western and central Africa.

IMPACT was established under a cooperative agreement between USAID and Family Health International (FHI) to help the agency's missions and bureaus slow the spread of HIV/AIDS and ease its social and economic impact on families, communities and nations. The project is designed to apply the lessons learned from more than a decade of HIV/AIDS prevention programs, including the USAID's flagship AIDS Control and Prevention (AIDS-CAP) Project, which FHI implemented in 45 countries from 1991 to 1997.

Like AIDSCAP, IMPACT focuses on strengthening the capacity of local private and public organizations to respond to the HIV/AIDS pandemic. However, recognizing that sustained individual behavior change is unlikely without wider social support, IMPACT emphasizes achieving prevention and care results by influencing social norms, health service delivery and public policy, as well as the beliefs and practices that put people at risk of HIV infection.

IMPACT works with dozens of nongovernmental organizations and government agencies. Technical assistance is provided in behavior change interventions, management of sexually transmitted infections, communication, counseling and testing, HIV/AIDS care and support, policy development, behavioral research, financial planning and management, private-sector leveraging, and program design, planning, monitoring and evaluation.

### HIV and Women

Scientists have discovered that women who are infected with HIV tend to have less of the virus circulating in their blood than men at the same stage of infection (as measured by CD 4 cell counts). The findings, which were presented in July at the 12th World AIDS Conference in Geneva, Switzerland, have significant implications for the treatment of HIV-positive women.

Researchers from Johns Hopkins University studied a group of 650 injection drug users over six years. They concluded that an HIV-positive woman will develop AIDS as quickly as a man with twice the amount of virus in his blood. The reasons for this gender difference are unclear, but higher levels of the hormone estrogen in women may account for the disparity.

Where possible, HIV-positive women should be prescribed antiretroviral drugs at an earlier stage of infection than men. Clinical guidelines for antiretroviral combination therapy were initially developed based on studies of white homosexual men. These guidelines received additional support from a recent study of a group of predominantly male African-American injection drug users. The Johns Hopkins study, which will be published in *The Lancet*, is the first to demonstrate the importance of gender to HIV treatment.

*Impact on HIV* is published twice a year by Family Health International's Implementing AIDS Prevention and Care (IMPACT) Project.

**IMPACT ON HIV**

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*Cover photo: Barred from attending school because of his HIV status, Ravi learns the ABCs of life at a home for AIDS orphans in Chennai, India.*

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*Dr. Manorama Pinagapany with Helen, one of three AIDS orphans she has adopted.*

# HIV Care and Prevention: An Indian NGO's Seamless Approach

BY JAYA SHREEDHAR

*An Indian AIDS service organization shows that a meaningful coalescence of care and prevention can be a cutting-edge strategy for curtailing further spread of HIV.*

A nondescript building looms over a sleepy lane in Kodambakkam, the throbbing heart of Chennai (formerly Madras), the capital city of India's southern state of Tamil Nadu. Inside, muted light from a curtained window spills over a group of children, aged 2 to 9 years, sleeping peacefully together on straw mats spread on the floor. In a room nearby, an HIV/AIDS education session is in progress, with people speaking in hushed tones so as not to awaken the children. Downstairs, a nurse gently feeds an HIV-positive woman who is too weak to feed herself. And so begins another day at the hospital that houses the Community Health Education Society (CHES), a nongovernmental AIDS service organization.

The brainchild of Dr. Manorama Pinagapany, a pediatric gastroenterologist, CHES came into being five years ago at a time when the HIV/AIDS epidemic was largely invisible in Tamil Nadu.

"I was working at the Institute of Child Health when two children from a local orphanage were brought to us with severe jaundice," relates Dr. Pinagapany. Krishnaveni, the girl, was 5 years old and Ravi, the little boy, was barely 3. The children had been tested for HIV by the orphanage and found antibody positive. "Over a period of time they became the darlings of the ward. Unfortunately, the orphanage did not want them back after they recovered. They had no place to go, and I, who had come to grow very fond of them, simply decided to take them home."

The entry of the two AIDS orphans into Dr. Pinagapany's life led to CHES's initial project, the *Ashram* (hermitage), a full-fledged shelter for people living with HIV/AIDS. CHES's primary aim was to provide care for AIDS orphans, regardless of their HIV status. To learn how to do this better, Dr. Pinagapany received informal training at the state-run Government General Hospital in Chennai.

Over time, the doctors at the General Hospital began referring destitute children and HIV-positive women to CHES. Many of the women had been abused, and some had been sold into the sex trade.

"The women required more than food and shelter," Dr. Pinagapany said. "They needed an emotional outlet of some

kind. As the orphan children at CHES needed love and physical attention, it seemed only natural to connect these two groups to fulfill each other's needs."

The *Ashram* also serves as a temporary shelter for women and their children who have become destitute because of their HIV-positive status. It has had 69 admissions to date, from Mumbai (formerly Bombay), Calcutta and other parts of Tamil Nadu as well as Chennai. The care *Ashram* residents receive includes spiritual counseling and educational support. Older members who are illiterate are taught to read and write.

Up every morning at 7, the *Ashram* children meet the day with an energetic two-lap jog around the hospital compound, enthusiastically jostling each other in a bid to finish first. Twice a week Valavan, a student volunteer, patiently teaches the children yoga, which they have come to love. Following a simple breakfast of *idlies* (steamed cakes of rice flour), they settle down to learn to read and write the English, Tamil and Hindi alphabets till lunchtime. Vijaya, a CHES worker, also teaches them simple mathematics, craft work and singing.

"They are very endearing and this never fails to evoke a response from us workers or visitors," says Geetha, a sex worker who left the sex trade to work with CHES full time. "Early in the project, a friend of mine who had looked after the children for a long time suddenly decided she would leave us, and the effect on the children was devastating. They had grown to love her so, and it took them days to recover their sense of security.

"What I earn here is not comparable to what I could earn in the sex trade," Geetha added. "But I feel wanted and respected and feel I am part of a family. I cannot buy that with money, can I?"

**Funding Dilemma** By September 1995 CHES had eight women and four orphaned children under its wing, most of whom were HIV-positive. The space to house the inmates was provided free of charge by Raasi Hospital, a private hospital owned and run by

Dr. Pinagapany. Institutional and outpatient care and counseling services were also wholly funded by the hospital, while relatives and well wishers donated food and clothing.

Gradually, the NGO realized that it could no longer sustain its work through gifts and donations. However, obtaining the requisite funding to run a shelter for AIDS orphans and HIV-positive women proved next to impossible. "Funding shelters, hospices or institutional care for people living with HIV hardly figured on the list of the donors' priorities," Dr. Pinagapany said. "We were advised to submit proposals for HIV prevention projects instead."

In September 1995, CHES received a one-year grant from the Tamil Nadu State AIDS Control Society for an intervention with female sex workers. Weeks of painstaking work with a few friendly brokers and sex workers helped the CHES staff understand the structure of the sex circuits in the coastal areas of South Chennai that were chosen for the project, named *Thozhi* (companion).

Interestingly, *Thozhi* did not start with HIV education. Again, care was offered first. Brokers and women in the sex circuits began to invite their contacts to the hospital for free medical help. There was no mention of venereal disease or AIDS. Once the women underwent a checkup and relaxed to a point where they could share their health concerns, the subject of HIV and other sexually transmitted infections (STIs) automatically came up.

**Companions** As the women began attending the hospital regularly to obtain treatment for various problems, mostly STIs, they learned how to use condoms. Those who were interested were trained as peer educators and condom suppliers.

But they learned their most valuable lessons while nursing some of the *Ashram's* residents who were dying of HIV-related illnesses. AIDS was no longer an abstract intangible, but a friend, a colleague or a relative.

Siva, a sex broker who began by bringing his employees and their friends to the hospital for free medical care, is now a full-time CHES worker. "I did not think I would stay on, but I have," he said.

His change of heart came when Siva was entrusted with the task of nursing 27-year-old Veni, a sex worker from the neighboring state of Andhra Pradesh. Veni was bedridden due to weight loss, had herpes zoster (shingles) and could not speak. "I used to talk to her every day and she would seem to understand," Siva said. "She would refuse food and eat only if I fed her.



Dr. Pinagapany examines Krishnaveni's eyes. Medical care is just part of CHES's holistic approach to helping people live with HIV/AIDS.

"Her death affected me greatly," he continued. "I have risked getting HIV-infected hundreds of times in the course of my job but have been spared. But what about the innumerable girls I procured for the profession?"

Condom use in the project area increased to 63 percent in

October 1997 from a baseline of 7 percent two years earlier. During 1997 alone, *Thozhi* reached some 700 new entrants to sex work, 150 brokers and 2,400 clients, and peer educators distributed 288,150 free condoms. The project also improved its STI care facility with financial support from the U.S. Agency for International Development's (USAID's) AIDS Prevention and Control (APAC) Project through the NGO Voluntary Health Services.

**Reaching Men** Dusk had already fallen over the narrow paths dissecting the slums into myriad patches of tiny houses when CHES field workers Raju and Muthupandian swung into action. Watched by a straggly group of adolescent boys, Raju spread a large blanket on the mud path to demarcate the dance floor. As the lyrics about AIDS set to hit film tunes pulsed out from a tape recorder, a crowd of mostly teenage boys and men collected. Male dancers from CHES's student volunteer corps, each made up to impersonate a popular film star, began dancing, accompanied by much cheering and clapping from the audience.

Between the dances, Muthupandian seized the mike to talk to the audience about STIs and HIV/AIDS, and a boisterous interaction followed. "What are the ways you can protect yourself from AIDS?" he yelled, and was answered correctly by a chorus of voices. The show usually ends with a quiz on AIDS. Prizes are handed out to the winners, and they are invited to come to CHES for further information.

Those who accept this invitation—and many do—receive counseling on safer sex and condom use and are trained as peer educators for Project *Velicham* (light). CHES developed this project for men with funding from the Tamil Nadu

State AIDS Society following complaints from the sex workers that they were often forced to agree to unprotected sex because clients refused to use condoms. *Velicham* staff have staged over 300 such programs in the slums and reached an estimated 40,000 people along the coastal areas of South Chennai.

**Reuniting Families** After reading newspaper reports that CHES was taking in people living with HIV/AIDS, a family of four from

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*AIDS was no longer  
an abstract intangible, but a friend,  
a colleague or a relative.*

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a remote district in Tamil Nadu arrived at the NGO's doorstep in early 1995. They had fled their village, following a relative's attempt to poison them.

Raghu, his wife Mala and their elder son, barely aged 3, were HIV-positive. Their 2-year-old son was uninfected. "Mala, who was found to have genital warts during a routine antenatal checkup, was tested for HIV first," says

Dr. Venkateshwar K. Rammohan Rao, CHES medical officer. "We counseled them and gave Raghu the job of office assistant. Mala was extremely depressed, and we got help from psychotherapists from the Institute of Mental Health to help her handle her feelings better."

The couple's relatives visited regularly and were counseled by CHES. After a year, their families wanted the couple and their children back home.

"They saw us eating and working with them every day and realized that their fears of contagion on casual contact were baseless," says Dr. Pinagapany. "For them, seeing was believing."

The family subsequently visited CHES twice for checkups. Raghu got a job selling cloth in Wyzag, a coastal town. Mala

began to neglect her health and eventually succumbed to tuberculosis. In a letter to the CHES staff, she wrote that she would not forget CHES until her last breath.

When they received news of Mala's death, two CHES workers, Siva and Vetri, went to her village to attend the funeral. Although relatives were at the funeral in large numbers, nobody wanted to be a pallbearer. It was only when Siva and Vetri started performing the last rites without hesitation that other family members followed suit.

A few months later, Mala and Raghu's elder child was readmitted to CHES's *Ashram* with HIV-related symptoms and died. Raghu's elder brother, also HIV-positive, died

recently. This brother's HIV-positive wife lives with her two children, who are uninfected. Raghu's widowed sister also lives alone, looking after his second son. Only Raghu's younger brother is uninfected, and CHES is trying to help arrange his marriage to a female relative so that this couple can look after all the imminent orphans in their family.

"When you care for the emotionally or physically abused, it is

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*"When you care for the emotionally or physically abused, it is difficult to remain a dispassionate service provider."*

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Dr. Manorama Pinagapany holds one-year-old Helen as the children of the CHES Ashram try to amuse her. An HIV antibody test when Helen is 18 months old is expected to confirm that she is infected with the virus.

difficult to remain a dispassionate service provider," Dr. Pinagapany said. "We foster strong emotional ties between everyone here because it can make a qualitative difference to the depth to which a carer can recognize and fulfill another's needs."

**Bringing Hope** A home-based care project developed by CHES in September 1997, currently funded by the Tamil Nadu State AIDS Control Society, reaches about 120 people living with HIV/AIDS. The number of those who are too ill to come to the hospital is slowly increasing.

Staff and volunteers from all the CHES projects provide psychosocial support, medical advice and care in the homes of HIV-positive people. This helps prevent the onset of HIV-related symptoms and reduces the number of inpatient visits. Another 120 who live outside Chennai are visited periodically. Named *Vidiyal* (dawn), the project also conducts classes on yoga and meditation with help from the Chennai-based Bihar School of Yoga.

Vidiyal runs a "Hope Club," where HIV-positive people meet monthly to exchange experiences and learn about healthy living. At each meeting, the Hope Club provides a talk and a screening by a medical specialist, such as a neurologist or chest specialist.

Among CHES's more notable efforts has been a beauty contest for transsexuals, organized with guidance from the APAC Project. This unusual event, which drew widespread media attention, succeeded in promoting community acceptance of transsexuals as well as raising their own awareness and getting them involved in HIV/AIDS prevention.

"We wanted people to realize that *alis* (transsexuals) are as much a part of society as anyone else," Dr. Pinagapany explained.

CHES helped develop a self-help group for transsexuals, which will be registered as a society to enable them to improve their welfare and fight for their rights. As a positive step in this direction, CHES played a major role in convincing the collectorate of Villupuram, the traditional seat of the transsexuals' religious festivals, to allot plots of land to members of this community. Houses will be constructed on 46 plots with financial help from the Rotary clubs in the area. CHES also plans to help establish income-generating activities such as poultry farming to reduce the likelihood that transsexuals will resort to sex work.

Working with people who have been rejected by society, such as transsexuals and women and men in the sex industry, can be controversial. But unlike most Indian NGOs that help sex workers, CHES has been able to avoid the problem of police harassment. Speaking to police inspectors in the project areas before interventions began and offering education programs for police helped enlist their full cooperation.



CHES does not try to convince women or their brokers to leave the sex industry, but it has been able to offer a few alternatives. Some of the women take turns using a donated sewing machine that is kept in the CHES office. "I can make about 700 to 800 rupees a month by sewing blouses," one woman explained. "That way

I can cut five or six clients and reduce my HIV risk."

The NGO itself employs 25 sex workers and five sex brokers as full or part-time peer educators. HIV-positive people are trained in counseling to help them find jobs as counselors with other non-governmental organizations.

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*"We feel like a family because each of us understands what it feels like to be rejected, hunted or hurt by society."*

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**Care and Prevention** In order to deal with the diverse needs of its extended family, CHES has woven a web of symbiotic relationships with organizations that have skills different from its own. For example, CHES links its drug users to the T.T. Krishnamachari Hospital, a clinic specializing in detoxification programs. In turn, T.T.K Hospital obtains HIV counseling services from CHES. For HIV



Krishnaveni cradles Helen as Ravi sleeps beside her.

testing, CHES uses the testing facilities provided on payment by YRG Care, an AIDS service organization. Destitute HIV-positive women are referred to CHES by an NGO, The Banyan, that cares for destitute women, and positive women who do not need institutional medical care at CHES are referred to The Banyan. For spiritual counseling, CHES turns to a variety of Christian, Muslim and Hindu religious organizations.

The imaginary line between prevention and care is blurred at every level in each of CHES's projects, whether it be the shelter for people living with HIV, the sex worker and client interventions, or the home-based care project. Each is an organic response to the growing needs of the other. Women from *Thozhi* look after the children in the *Ashram*. Brokers and clients from *Velicham* provide home-based care, including prevention counseling, for HIV-positive people. And *Vidiyal's* HIV-positive members serve as counselors in all the projects.

"The fact that some of us have HIV and some do not, does not preoccupy us," Siva said. "We feel like a family despite such minor differences because each of us understands what it feels like to be rejected, hunted or hurt by society."

Finding funding for CHES's work remains a challenge. The NGO has no funding for its *Ashram*, and condom supplies cannot

keep pace with the demand created by CHES projects. Local schools will not admit the children of the *Ashram*, and CHES does not yet have the resources to run its own school.

Despite these obstacles, Dr. Pinagapany refuses to change her approach. "Fragmenting one's work along the clichéd lines of an AIDS proposal in order to connect to a funder's mindset may prove detrimental to the spontaneity and effectiveness of one's work," she said.

In many ways, CHES has transcended the thinking that sees care as being distinct from prevention and places it at the final stage of the spectrum in the response to HIV/AIDS. Instead of first increasing awareness of HIV—in other words, telling people that they have a problem—CHES goes to them with a solution: free medical care. CHES puts people ahead of project goals, say staff and clients, and the result is greater self-esteem, trust and openness to HIV prevention messages among those who need them most. ▣

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# Nigerian NGOs Foster a Caring Community

BY EKONG EMAH

*Community outreach workers and volunteers bring practical support and compassionate care to the homes of people living with HIV/AIDS in three Nigerian towns.*

Six years ago, a Catholic missionary from Argentina started seeing AIDS patients at the hospital where she worked in Onitsha, a town in the eastern part of Nigeria. Initially, the cases were few—one or two in a fortnight. But as Dr. Susi Coddazi became known and identified with the disease, the case profile rose.

Dr. Coddazi soon realized that the minimal hospital-based care she was able to provide was grossly inadequate. Most HIV-positive patients did not come to the hospital until they were critically ill, and many came when it was too late. When they were well enough to return home, their families did not know how to take care of them. Troubled by the suffering of her patients, she dreamed of offering them care and support in their communities.

While Dr. Coddazi was nursing this hope in Onitsha, the United States Agency for International Development (USAID) mission in Lagos and the U.S.-based nongovernmental organization (NGO) Family Health International (FHI) were also recognizing the need to help fill the gaps in care for those living with HIV/AIDS. They hoped that attention to care would also stimulate a stronger community response to the epidemic, reinforcing their efforts to promote HIV prevention through the AIDS Control and Prevention (AIDSCAP) Project.

Although most AIDSCAP funds were already committed to prevention projects, FHI had set aside money to support short-term activities and small, innovative pilot projects. In 1996 the AIDSCAP program in Nigeria used its "Rapid-Response Fund" to give Dr. Coddazi's group, the Focolare Movement, a grant for community-based HIV/AIDS care in Onitsha.

Under this pilot project, Dr. Coddazi trained outreach workers to provide care and support to people living with HIV/AIDS and their families in their homes. In just three months, the Focolare outreach workers were able to reach 20 families.

This experience was an eye-opener for all concerned, drawing attention to the needs of families affected by HIV/AIDS and to the potential for strengthening prevention efforts through a more inte-

grated approach. When USAID signed a cooperative agreement with FHI to continue HIV/AIDS activities in Nigeria after the AIDSCAP Project ended, it included an expanded commitment to community-based care. And at the conclusion of that "bridging" agreement in July 1998, the mission planned to continue and support such care projects.

**Community Care Givers** Two new community-based care projects were established with support from FHI in December 1997. The Kano state branch of the Society for Women and AIDS in Nigeria (SWAAN) began a pilot project in the northern town of Kano, while the Family Health and Population Action Committee (FAHPAC) started one in Ibadan in the west. The Focolare Movement continued its project in Onitsha, in Anambra state.

The three NGOs work in different parts of the country, but follow the same basic model. Each project is linked to a number of hospitals, where it helps train staff members in medical and nursing care and counseling for people living with HIV/AIDS. When patients are discharged from these hospitals, they are turned over to a support team of community caregivers.

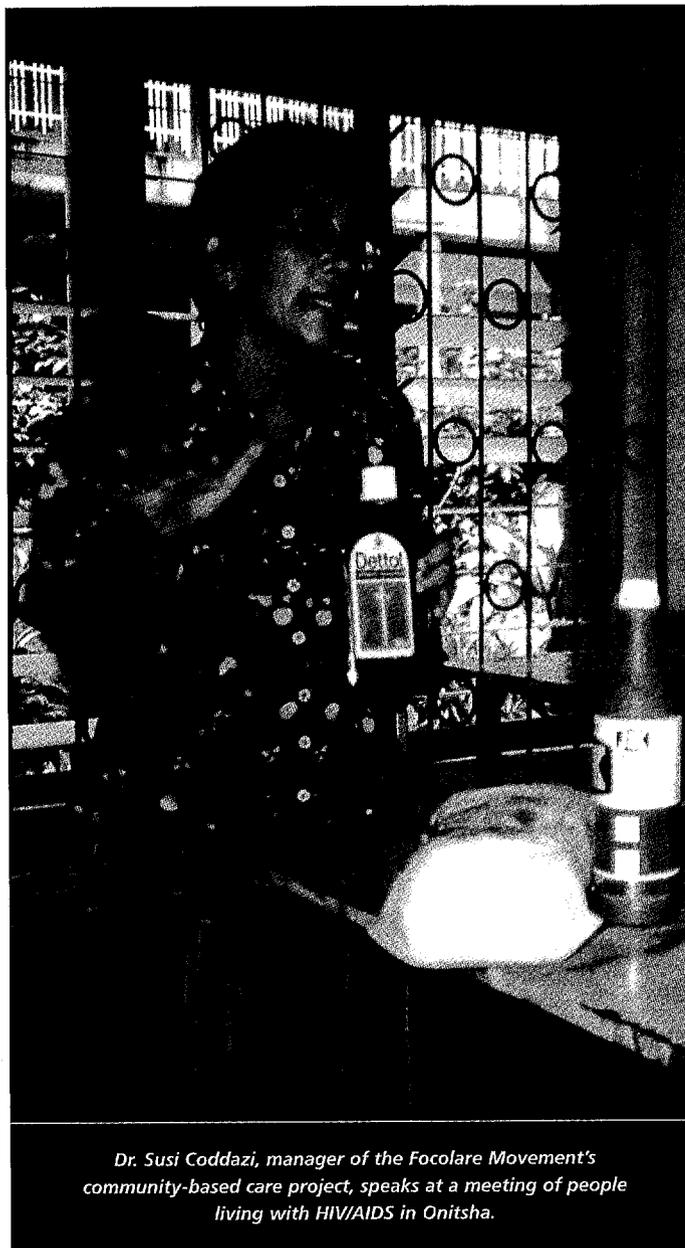
These motivated volunteers have been trained in HIV/AIDS and sexually transmitted infection (STI) education, basic hygiene, counseling, referral and nutrition. They visit people living with HIV/AIDS and their families at home and also provide counseling and nutrition education at the project offices. Support group members see an average of four families a week.

When support team members encounter difficulties, they are quick to refer clients to the more experienced counselors and health workers in the project. Health workers and volunteers also help families provide palliative care to the terminally ill, making it possible for them to spend their last days at home rather than in a hospital bed.

Dr. Lola Mabogunje, manager of the SWAAN project in Kano, reports that most of her patients with HIV/AIDS have died as a

result of tuberculosis (TB). Few families can afford drugs to treat TB, and the health care system is also unable to adequately fill this gap. FHI helped the Focolare Movement approach the German Leprosy Relief Association (GLRA), which now provides anti-TB drugs for the project, and hopes to find a similar source of the drugs for the projects in Ibadan and Kano.

If medications to treat tuberculosis and other opportunistic infections are hard to come by, most Nigerians living with HIV/AIDS can only fantasize about the antiretroviral "cocktail." Two pharmaceutical companies—Roche Nigeria Ltd. and Glaxo Wellcome—market antiretroviral drugs in Nigeria, but only the affluent can afford them. A month's supply of Hivid and Invirase from Roche, for example, costs N56,000 (U.S.\$651).



Dr. Susi Coddazi, manager of the Focolare Movement's community-based care project, speaks at a meeting of people living with HIV/AIDS in Onitsha.

SINA BALANA/FHI

**Getting Started** Starting a community-based project is a challenge under any circumstances, but it is doubly difficult in an environment of denial, stigmatization and government apathy. Such was and is still the environment in Nigeria, yet the three FHI-supported projects are thriving. After just eight months, they have reached 1,347 families.

One reason for this success is the role of the private sector NGOs and the commitment of dozens of community volunteers. Project managers say that what they look for in outreach workers and volunteers are compassion, a willingness to help without being judgmental, and a sound knowledge of the disease.

These qualities are essential because the initial phase of the work might be discouraging. "You may be alone, as the community is full of suspicion and fear for your real intentions," Dr. Coddazi said.

The first practical step involves reaching out to traditional and local authorities. The three project managers agree that it is important to make them the entry point into communities.

doctors at a hospital in Ibadan even refused to perform surgery on at least one HIV-positive man after learning of his serostatus.

It took time to convince health care providers at this hospital to refer their patients to FAHPAC for follow-up, but now they recognize that the project's services are useful and even comple-

mentary to their own work. In all three projects, these referral linkages have been strengthened by the training the projects have provided to virtually all hospital staff who counsel patients about HIV/AIDS.

**New Allies** Referrals also come from traditional healers, who once looked upon the community caregivers with suspicion.

But project staff allayed their fears by offering to help the healers protect themselves from HIV infection.

Many traditional healers are at risk because they use unsterilized equipment and do not know how to take basic precautions against exposure to HIV while treating patients. This danger was brought home to Dr. Coddazi when an HIV-positive patient

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*Now many of the traditional healers are among the converted, using universal precautions and helping to pass on accurate information about HIV/AIDS.*

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sought treatment from a traditional healer, who opened an abscess. "I realized that this traditional healer would soon be infected, and I saw the need to get in contact with him through the patient," she said.

By working with this traditional healer, Dr. Coddazi was able to bring many of the healers in the area together for a seminar on HIV/AIDS. For many of them, it was a turning point.

Before the seminar, traditional healers considered AIDS just another disease and thought its impact had been overdramatized. But Coddazi's commitment

impressed them. "If someone paid her way to come and tell us about this AIDS, then it must be true," one seminar participant reasoned. Now many of the traditional healers are among the converted, using the universal precautions Dr. Coddazi taught them and helping to pass on accurate information about HIV/AIDS and its prevention to their patients.

Since traditional healers are the first source of health care for many people throughout Nigeria, project staff in Kano and Ibadan also realized that it would be unrealistic to leave them out. Now it is not unusual for healers to seek out project staff and volunteers for information about HIV/AIDS.

**Lessons Learned** The need to involve traditional healers was only one of the many lessons the NGOs learned about community-based care during the eight-month pilot projects. Another was the importance of having a physician to provide medical care in the community.

Finding that people living with HIV who identified with the project wanted to receive medical attention in the same environment of love and compassion, the projects took measures to respond to this need. Doctors who volunteer their time help FAHPAC and SWAAN operate clinics, while a physician coordinates the Focolare Movement.

All the projects recognized the importance of involving community members from the beginning. But SWAAN found that in Kano, it also needed to recruit semiliterate men and women to visit families. Having semiliterate women on the support team was particularly important in order to reach other women.

In Moslem northern Nigeria, most men marry more than one wife and their wives are secluded in purdah, explained Dije Abdullahi, the assistant project coordinator for SWAAN/Kano. Even when educated women are available to do the work, they are regarded as being "too civilized and empowered" and in a position to corrupt other women. The semiliterate women, though empowered, are seen as harmless.

Other important lessons include the value of networking with pro-

fessional groups such as psychologists to help clients with AIDS dementia, suicidal tendencies and other difficult problems and the need for access to a reliable screening center where an antibody test can be done. With the benefit of field experience, the NGOs are using these lessons learned to strengthen their projects' linkages with community members, traditional healers and other health care professionals.

**Stigma and Denial** Overcoming the stigma associated with HIV and AIDS is one of the community-based care projects' most difficult challenges. Nigerians living with HIV/AIDS often experience discrimination, abandonment and neglect.

Stigmatization appears to vary by class in Nigeria. Upper-class families, fearing loss of social standing, tend to hide or deny the fact that a family member is HIV-positive. They may even reject a family member and withdraw financial support to avoid society's censure. Those in the lower socioeconomic classes are more likely to stand by the infected. They also shield their serostatus, but for them the fear is of losing jobs or suffering other reprisals by the privileged.

Support team members in Kano tell of a young man living with HIV/AIDS who has been abandoned by his wealthy family. They often wonder aloud why his father, who can afford antiretroviral drugs without any financial stress, chooses to consider social status at the expense of his son's well-being. But for the support team and the new family of fellow HIV-positive people he has found through SWAAN, he would have nowhere to turn.

Some wealthy men will pay for antiretroviral drugs for themselves but not for their wives. Yet in the polygamous setting in Nigeria, one infected man may have up to four wives who are exposed to the risk of infection.

Because of their social and economic dependence on men, women often have no access to information about HIV/AIDS or any means of protecting themselves from the virus. One example is a woman in Kano whose husband refused to tell her that he had tested HIV-positive. After some counseling, he consented to allow the support team to educate his wife about HIV/AIDS prevention. The woman wondered why she needed such information, but her husband kept assuring her that they meant no harm.

Trouble came when the family's eldest daughter requested information and a support team member gave her literature about HIV/AIDS. When her father found it, he rushed to Dr. Mabogunje in a fury and forbade the support team members to visit his home again. The woman still does not know her husband's serostatus, and he will not allow her to take the HIV antibody test herself.

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*Women often have no access to information about HIV/AIDS or any means of protecting themselves from the virus.*

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**AIDS Orphans** As more and more women become infected with HIV, the number of AIDS orphans is also increasing. The community-based projects are still struggling to find ways to meet orphans' needs for food, clothing, schooling and adult care.

Awelu Ibrahim is 22. His parents died of AIDS, leaving behind nine children. Soon after their mother's death, the youngest child also died.

Their mother's last wish was that the children not be separated. As the eldest, Awelu decided that he would do his utmost to fulfill that wish.

Awelu collects old iron beds, breaks them and resells them to earn enough to feed his brothers and sisters. He leaves home before 6 a.m. to trade and rushes home with whatever money he has made by 10 or 11 in the morning to give the younger ones breakfast. If he does not earn enough to buy food, the family goes hungry that day.

The burden of this responsibility is visibly aging the young man. Sometimes SWAAN/Kano comes to Awelu's aid by providing some food. But the project is not able to help buy medicine for his 5-year-old brother, who is infected with HIV. Awelu wonders how long he can continue before death comes calling.

SWAAN was able to help another 5-year-old AIDS orphan. His aunt came to project staff after his parents died, explaining that her husband refused to let the boy live with them. Members of the support team persuaded the man to take in his nephew by assuring him that the boy could not infect his own children.

**Turning the Tide** The extreme poverty of families living with HIV/AIDS is the greatest obstacle to effective community-based care. People look to the caregivers, who are largely volunteers and often have minimal income themselves, to provide virtually everything.

Poverty and a perilously weak economy have also made it difficult to involve communities in HIV/AIDS care and prevention. With many people investing considerable time in wondering how to survive each day, the epidemic is often dismissed as an unnecessary distraction. A popular saying is "Na AIDS I go chop?"—meaning the thought of AIDS will not put food on my table.

But in the areas where the community-based care projects are being implemented, the larger communities are now more concerned and prevention education has intensified. Other communities are also starting to take note. "Communities refer people to us and we get invitations from some local governments outside our project sites to address their people," said Dije Abdullahi of SWAAN/Kano.

One such invitation came from the district head of Dawakin Kudu local government in Kano state, where two women and one man with symptoms associated with AIDS had been driven from the community. A team from SWAAN educated the community leaders, who realized that they should not have expelled people just because they were HIV-positive. Others in the community are learning about ways of preventing HIV transmission.

The projects have also mobilized those living with HIV to change their behavior. Anecdotal evidence gleaned from the monthly meetings of HIV-positive people shows a resolve not to infect others.

In Onitsha, HIV-positive people have formed a support group called "Save the World." Through this group, they hope to create a support network throughout Nigeria.

Members of the group also take personal responsibility for preventing further spread of HIV. Dr. Coddazi says they believe they can make one important contribution to the future of humanity: to "keep the virus to ourselves."

**Sustaining Care** The networks of people living with HIV/AIDS associated with the projects offer some hope that a base for continuous community-based support is being developed. For many of them, this work is a lifetime commitment. Other members of the support teams, who have become role models in their communities, are also fired with a zeal to continue.

More community members, including church leaders and local officials, are beginning to wake up to the reality and challenge of HIV/AIDS. "With the important leaders in the church, the barriers are collapsing, and they are realizing that they have to help," Dr. Coddazi said.

Such community support is desperately needed throughout Nigeria, where an estimated 2.3 million people were living with HIV/AIDS by the end of 1997. Although the three FHI-supported projects collectively represent the largest single community-based care effort in the country, they are available in only three towns—a mere drop in a mighty ocean.

Even at this early stage, the three projects are looking for ways to expand and sustain their efforts. Project staff plan to ask religious groups and other prominent organizations for support now to help continue community-based care once donor support ends. "We still have to find a way of doing something because the people will keep coming," Dr. Mabogunje said. "They are our people, and we cannot tell them that we can't help them." ▣

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*Although the three FHI-supported projects collectively represent the largest single community-based care effort in the country, they are available in only three towns—a mere drop in a mighty ocean.*

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EKONG EMAH IS SENIOR PROGRAM OFFICER IN FHI'S OFFICE IN NIGERIA.



*Geoffrey Wathome and Roselyn Busaka of the Kenya Association of Professional Counselors. Counselors at the KAPC center outside Nairobi meet every week to help each other cope with the emotional strain of counseling people who test HIV-positive.*

# Study Shows Voluntary Counseling and Testing Promotes HIV Prevention

BY KATHLEEN HENRY

*The first randomized controlled trial of the prevention impact of voluntary HIV counseling and testing in non-industrialized countries reveals that providing such services can reduce HIV risk behavior.*

Simon's\* first thought after learning the results of his HIV test was of ending his own life. "After I was told that I was positive, I was frightened," he said.

But gradually, with the help of counselor Geoffrey Wathome of the Kenya Association of Professional Counselors (KAPC), Simon started looking to the future. He received treatment for a sexually transmitted infection (STI). He convinced his wife to go to counseling with him and started using condoms. "Now I do not infect anybody or reinfect myself," he said.

Making HIV counseling and testing available to men like Simon is a cost-effective way of preventing further spread of the virus, according to a three-country study sponsored by the AIDS Control and Prevention (AIDSCAP) Project of Family Health International (FHI), the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization. This randomized, controlled trial conducted at counseling centers in Kenya, Tanzania and Trinidad found that voluntary testing, combined with professional pre- and post-test counseling, encourages people to change their behavior in order to prevent HIV transmission.

"What we have for the first time is unequivocal data using the strongest possible design that counseling and testing is wanted by people, attracts high-risk people, and results in risk reduction," said Dr. Thomas Coates, director of the Center for AIDS Prevention Studies (CAPS) at the University of California at San Francisco, which was the coordinating center for the study.

**Client-centered Counseling** A neighbor told Simon about the counseling center at Kariobangi, a low-income neighborhood outside of Nairobi, where he could get a free HIV test. During his first visit, he learned about the study and agreed to participate.

Assigned through random assignment procedures to the counseling and testing arm of the study, Simon met with Wathome for a pretest counseling session and received 25 condoms, then

\*His name has been changed to preserve confidentiality.

had blood drawn for an HIV test. He would return for the results in two weeks.

Others who were assigned at random to the health information arm of the study were offered the option of receiving counseling and being tested for HIV six months after their enrollment. In the meantime, each member of this group attended a health information session that included a video about HIV/AIDS prevention and a group discussion led by a health educator. At the end of these sessions, the health educator gave each person 25 condoms and invited everyone to come back for more at any time.

Dr. Claudes Kamenga, FHI's technical monitor for the study, explained that the comparison group was given health information for ethical reasons. "These people were concerned about HIV, so we had to make sure we were not denying them crucial information," he said.

A separate video was produced for each site, using local languages, actors and settings. These videos were shown during the health information sessions in an effort to standardize the content and to ensure that the two groups received distinctly different services.

The line between health information and counseling can be a fine one, explained Dr. Kamenga, a technical officer in FHI's HIV/AIDS Prevention and Care Department. "If it's given one-on-one, health information can become counseling, depending on the background of the person giving the health information."

In fact, many health information sessions were conducted with one individual or couple because study participants often came to the counseling centers at different times.

What distinguished the counseling sessions from these one-on-one discussions, however, was the counselors' use of a culturally appropriate, client-centered counseling model. Counselors worked with each client to assess his or her own risk of acquiring or transmitting HIV and to develop a personal risk reduction plan based on the client's level of knowledge, relationships with partners, practice of HIV-risk behaviors and readiness to change.

In developing risk reduction plans, clients chose the method of prevention they believed would be most effective for them.

"A client may say, 'I have more than five sexual partners,'" Wathome explained. "After counseling, and exploring how high risk he is with more than five sexual partners, he may decide himself, 'I'm going to reduce my five sexual partners to one.' Another client may decide, 'With my five sexual partners, I will no longer have sex without condoms.' It is the client himself who makes that decision."

Clients also decided how many counseling visits they needed. Most returned for only one post-test counseling session, but others visited the counselors more often. Those returning for more than one visit usually had tested positive.

**Clients at Risk** Simon was one of 4,293 people who agreed to participate in the study at the three sites. Roughly equal numbers of men and women participated, and 27 percent enrolled as couples.

All of the sites reported some difficulty in recruiting people to participate in the study as couples. In Trinidad, only 107 couples were recruited. Many people who enrolled in the study as individuals, however, later brought partners to the center for counseling and testing.

"I think that people were testing the waters for the quality of the service," explained Dr. Colin Furlonge, principal investigator of the study in Trinidad. "If one partner felt it was good, and felt safe and comfortable, then we had many who would bring their partners along."

Overall demand for counseling and testing proved high even after the study was over. "The study sites had to continue providing counseling and testing, given that clients continued to show up at the sites beyond the recruitment period," Dr. Kamenga said.

The counseling centers used various methods to recruit participants, from television in Trinidad to word of mouth in Kenya, but all attracted people at high risk of HIV infection. HIV prevalence rates among those randomly assigned to the counseling and testing group, ranging from 21 percent in Kenya and Tanzania to 4 percent in Trinidad, were higher than those among the general population in each of the three communities.

**Confidentiality and Trust** Most participants said they had enrolled in the study because

they wanted to know their HIV status, and 82 percent of those tested returned for their results. The same percentage of all the participants returned at six months.

Although free HIV testing and STI treatment attracted participants to the study, they were not necessarily what motivated clients to return, according to Francis Kihuhu, counseling director at the KAPC site. "People came for the testing at first, but they really valued the counseling," he said.

Researchers believe the intervention succeeded in changing behavior because of the quality of the counseling. Quality assurance measures included ensuring sufficient space to guarantee privacy to counselors and clients, careful selection and training of counselors, rigorous monitoring and evaluation of the service, supportive supervision of staff

and early identification of appropriate referral systems.

"Unfortunately, in most other places, due to limited resources, all of these important aspects of HIV voluntary counseling and testing are not addressed," Dr. Kamenga said. "The results are poor quality of service, low retention of trained counselors, burnout among retained counselors, and lack of confidence in the service by the clients and the community."

Confidentiality was critical in building that confidence among study participants, according to the findings of a qualitative interview study conducted in Kenya and Tanzania as part of the counseling and testing trial. It was also what set the counseling apart from the kind of counseling participants were used to receiving from elders or health care workers.

"At every stage, staff members took time to show clients how they ensured confidentiality," Kihuhu noted. Each participant was assigned a unique number, which was used to identify all samples, test requests and interview forms. The files linking names and identification numbers were always kept in locked file cabinets, and staff members were trained in confidentiality procedures.

Counselors were able to overcome clients' initial reluctance to trust the promise of confidentiality. "Because their personal information was not released into the community, clients gained confidence in the counselor and in the counseling center," said Dr. Olga Grinstead of CAPS. "This facilitated disclosure of risk behavior, which in turn

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*"Because their personal information was not released into the community, clients gained confidence in the counselor and in the counseling center."*

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*A poster advertising the Voluntary Counseling and Testing Centre in a suburb of Port of Spain. Television proved the best medium for attracting clients to the center in Trinidad.*

facilitated the effectiveness of counseling for risk reduction.”

**Changing Behavior** Simon did not change his behavior overnight. After learning that he was HIV-positive, he decided to be monogamous and to use condoms. But at first his wife refused to use condoms because they had only one child and she wanted to have more children. It was months before Simon could muster the courage to ask his wife to go to the counseling center with him.

After Simon's wife also tested HIV-positive, they talked with counselor Wathome about how they could reduce their risk of reinfection. “Now I always use condoms with my wife,” Simon said.

Like Simon, members of both the counseling and testing and the health information groups reported changing their behavior to reduce HIV risk. Counseling and testing, however, produced more than a 50 percent greater reduction in risk behavior.

Counseling and testing and health information led to similar declines in unprotected sex with a spouse or other “primary” partner. But those who received counseling and testing were significantly more likely to report decreases in unprotected sex with any non-primary partner and with partners in commercial sex.

Counselors cite less scientific but still powerful anecdotal evidence of behavior change.

Counselor Rose Kairuthi of the KAPC in Kariobangi, Nairobi, remembers one client at high risk of infection when he enrolled in the study, a young man who said he had had 20 sex partners.

“When he came negative, he cried,” she said. “When he came back after six months, he had reduced the number of sexual partners and was still negative. At twelve months—still negative. He went around recruiting other young men to put in the study.”

Behavior change was assessed by comparing the behaviors reported by participants during interviews at enrollment and at six months. STI tests on urine samples collected at baseline and at six months confirmed the validity of this self-reported behavior. Those who reported unprotected sex with a non-primary partner were twice as likely to have a new case of STI as those who did not.



*KAPC counselor Rose Kairuthi recalls the transformation of one study participant, a young man who had had 20 sex partners before testing negative for HIV.*

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*Both groups reported changing their behavior to reduce HIV risk. Counseling and testing, however, produced more than a 50 percent reduction in risk behavior.*

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Researchers are analyzing the data collected at twelve months. Since all study participants were offered counseling and testing at six months and most chose to be tested, Dr. Kamenga noted, “the information 12 months can provide is more in terms of sustainability of the behavior change accomplished by counseling and testing.”

**Counseling Couples** Many of the couples enrolled in the study made some changes in their sex lives. Couples from both the counseling and testing and the health information

groups reported less unprotected intercourse with each other and more abstinence from sex.

Among couples, as among individuals, greater change was seen in the counseling and testing group. The difference between the two groups of couples, however, was not statistically significant.

FHI's Dr. Kamenga believes that this finding may not be as contradictory as it seems. “If you come as a couple to a health information session, that may be a starting point for you as a couple to take some action,” he explained. “Whereas if you are a single person watching a video and learning how to use condoms, it's still a challenge to initiate a discussion with a partner. So this may be one of the possible explanations why, among couples, we didn't notice a significant difference between the two study arms.”

Dr. Grinstead also points out that the couples had a lower baseline rate of risk behavior than the people enrolled as individuals. “They had less change to make,” she said.

Counselors, researchers and many study participants believe that counseling couples is even more effective than counseling individuals. Couples' counseling

was particularly effective in reducing unprotected sex when one or both partners had tested positive for HIV.

“A discordant couple may be more likely to use condoms than a couple that is concordantly HIV-negative or HIV-positive, so it's important to provide couples with that information,” Dr. Kamenga said. “And it's even more crucial for couples because there are so many decisions to be made about children and whether to have children.”

**Positive and Negative Experiences** After Simon learned that he was HIV-positive, he told his boss—a Catholic priest—in confidence. But the priest revealed his secret to all Simon's coworkers, who shunned and ridiculed him. When he could bear it no longer, Simon quit his job.

The study results suggest that Simon's experience was not typical of most participants. When asked at six months, few said they had been estranged by peers, discriminated against by employers or neglected by family members.

On the other hand, many participants reported improvements in their lives, such as strengthening of sexual relationships and increased emotional support from family, peers, employers and health professionals. Participants enrolled as couples were more likely to say that their relationships had grown stronger.

"In general, the bad experiences tend to make the news," Dr. Furlonge noted. "But one thing the study does show is that there are far more positive experiences than negative experiences."

In all three sites, participants randomly assigned to the counseling and testing group were no more likely to report negative experiences than those who had been assigned to the health information group. "Counseling and testing didn't seem to be associated with negative effects," Dr. Kamenga said.

Dr. Gloria Sangiwa, principal investigator at the Muhimbili center in Tanzania, attributes the low frequency of adverse effects among those in the counseling and testing group to the quality of the counseling and the strict confidentiality the study maintained. "Confidentiality enabled clients to control negative life events," she said.

Other researchers agree that lack of disclosure of HIV status may have helped reduce the risk of negative experiences. They are analyzing study data to determine the impact of disclosure on participants' lives.

Negative experiences were more common among those who tested positive for HIV. Of those in the counseling and testing group, HIV-positive people were more likely to

report estrangement from peers, discrimination by employers and neglect by families.

HIV-positive women enrolled as couples were five times more likely than those in the counseling and testing group as a whole to say that their marriages had broken up and more than three times more likely to have experienced physical abuse. HIV-positive women with HIV-negative spouses were at greatest risk of adverse effects, with 23 percent reporting physical abuse and 18 percent reporting marital breakup.

Dr. Sangiwa has vivid memories of the first women who told counselors they were experiencing these problems. She and her staff quickly identified an organization, the Tanzania Media Women's Association, where they could refer the two women and others in need of

more specialized counseling and legal assistance.

In addition to providing such support for clients, either directly or through referrals, Dr. Sangiwa recommends alerting counseling staff to the potential for abuse and abandonment among women who may be too ashamed to broach these subjects. "It's important that counselors are aware so they can look for this and talk to people about it," she said.

**A Valued Service** As participants in the Voluntary HIV Counseling and Testing Study, Simon and his wife received free HIV tests, counseling and STI treatment. But the time they spent receiving these services was still costly for a family with a small income.

Clients in Kenya and Tanzania reported that their participation in the study cost them an average of \$U.S.2.57 to \$7.75. Lost wages were the main expense in both countries, with clients at both sites giving up a day's wages to travel to and from the site, receive services and participating in the interviews.

Despite these costs, clients said they would be willing to pay an average of \$1.64 in Kenya and \$5.11 in Tanzania for counseling and testing.

Clients overestimated how much people would actually pay, according to Dr. Michael Sweat, assistant professor of international health at the Johns

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*Was the public health benefit of counseling and testing worth the cost in countries with such limited resources? Results of the cost-effectiveness analysis suggest that the answer is yes.*

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*Peter and Anne Kanjiri at the KAPC center in Nairobi. She convinced her fiancé to go for counseling and testing before they married, and exulted when both tested negative.*

Hopkins School of Public Health, who analyzed the cost-effectiveness of the services in Kenya and Tanzania. "It seems that many people are inclined to overestimate their willingness to pay as a sign of how much they appreciate the services they received," he said.

The number of clients at the Muhimbili center in Tanzania plummeted when a fee of \$3 was instituted at the end of the study. The fee was reduced to \$1.50, and the client load rebounded. In Kenya, where clients were charged \$0.35 for counseling and testing, the fee had little effect on client access.

#### **Cost-effective Prevention**

Counseling and testing helped Simon and thousands of other people enrolled in the study, but was its public health benefit worth the cost in countries with such limited

resources? Results of the cost-effectiveness analysis suggest that the answer to this central research question is yes.

The cost of providing counseling and testing to each client—U.S.\$27 in Kenya and \$29 in Tanzania—was relatively high for countries where per capita health expenditures do not exceed \$10. Using a probability-based model of the likely number of HIV infections that did not occur as a result of the behavior change reported by participants, however, researchers estimated that the cost of averting each new case of HIV was only \$241 in Kenya and \$303 in Tanzania.

These costs are comparable to the estimated \$217 per infection averted through enhanced treatment of sexually transmitted infections in the first randomized controlled trial of that HIV prevention intervention, which was conducted in the Mwanza region of Tanzania.

Voluntary counseling and testing is much less cost-effective in areas with low HIV prevalence. In the United States, for example, one study estimated that the cost per infection averted in a setting with at least 1 percent prevalence was \$60,000.

In the study sites, voluntary counseling and testing proved most cost-effective for those who were infected with HIV. It was also more cost-effective for couples than for individuals and for women than for men. These findings reflect differences in initial risk of

HIV infection among members of these groups and in the numbers of high-risk partners they had, as well as the reductions in risk behavior that occurred after counseling and testing.

Dr. Sweat recommends that counseling and testing services target populations with high HIV prevalence by working with groups that serve those populations, such as STI clinics and camps for transport workers. This was one of the key recommendations in his recent report to the U.S. Agency for International Development (USAID) on the sustainability of the Kenyan counseling center.

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*"We have enough data to indicate that voluntary counseling and testing is an essential part of the national response to AIDS."*

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**Building a Bridge** Now that the study has ended, clients continue to receive voluntary HIV counseling and testing at the three centers. The USAID missions in Kenya and Tanzania are supporting the services in

Nairobi and Dar es Salaam, and UNAIDS funds them at the Voluntary Counseling and Testing Centre, which was established for the study in Port of Spain, Trinidad.

The study results seem to have sparked greater interest in HIV counseling and testing. A new pilot project in Zimbabwe, sponsored by the USAID mission in Harare and implemented by Population Services International and FHI, will assess a social marketing approach to counseling and testing.

Dr. Sangiwa noted that the Tanzanian national AIDS control program included recommendations for district-level counseling and testing in its latest medium-term plan for HIV/AIDS control. "Implementation will be something else, but in terms of policy, we have had an impact," she said.

Despite growing recognition of the value of counseling and testing, future support for continuing and expanding such services remains uncertain. UNAIDS Director Peter Piot believes that policymakers and program managers have a responsibility to act on the study findings.

"We have enough data to indicate that voluntary counseling and testing is an essential part of the national response to AIDS," Dr. Piot said. "As the bridge between prevention and care, the investment in counseling and testing services will go a long way in making needed care available to the invisible majority which today does not even know its HIV status." ▀

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### **FHI-UNAIDS Voluntary HIV Counseling and Testing Study**

#### **Funded by**

USAID, FHI/AIDSCAP, the World Health Organization's Global Programme on AIDS, UNAIDS and the U.S. National Institute of Mental Health

#### **Coordinating Center**

The Center for AIDS Prevention Studies,  
University of California, San Francisco

#### **Study Centers**

Kenya Association of Professional Counselors  
Nairobi, Kenya

Muhimbili University College of the Health Sciences  
Dar es Salaam, Tanzania

Queens Park Counseling Centre  
Port of Spain, Trinidad



*A Tanzanian woman cares for her HIV-positive husband. Participants in FHI's study in northeastern Tanzania, who had all recently tested positive for HIV, reported increasing emotional and economic support from spouses and other partners.*

# Study on Prevention-Care Link Yields Unexpected Results

BY KATHLEEN HENRY

*Research on AIDS care and support in northeastern Tanzania finds that voluntary counseling and testing is an important HIV prevention measure.*

When they analyzed the results of a study conducted in Tanzania to assess how care and support for HIV-positive people can contribute to prevention efforts, Tanzanian and U.S. researchers were surprised.

“Our results reinforce the importance of voluntary HIV counseling and testing, at least in the short term, and that’s not necessarily what we expected to find,” said Dr. Joan MacNeil of Family Health International (FHI), which initiated the study in 1996 through the AIDS Control and Prevention (AIDSCAP) Project.

The randomized controlled study was designed to detect any differences in behavior change reported by HIV-positive people who received continuing support from counselors and by those who received only post-test counseling and regular medical services. But researchers found minimal differences between the two groups.

Instead, the study revealed significant levels of behavior change among all study participants. Reports of two important HIV prevention measures—condom use and having fewer sex partners—increased in both the experimental and control groups during the six-month study.

Like the more extensive trial of counseling and testing sponsored by FHI and the United Nations Programme on HIV/AIDS in Kenya, Tanzania and Trinidad (see page 13), the study in Tanzania’s Tanga district showed that learning one is HIV-positive and receiving professional post-test counseling can be a powerful motivator. However, the results also indicate that this effect on behavior may be short-lived.

“Even though condoms continued to be readily available throughout the district, condom use started to decline among members of the control group between three and six months after their enrollment in the study,” said Dr. MacNeil, the associate director for care and research in FHI’s HIV/AIDS Prevention and Care Department. “This relapse into unsafe behavior suggests that additional counseling and care and support at this later point may be critical in sustaining behavior change.”

**The Tanga Study** The Tanga AIDS Working Group (TAWG), one of dozens of local groups that implement the Tanzania AIDS Project with support from FHI, offers HIV counseling and testing at centers in the towns of Tanga, Muheza and Pangani. Positive results are not uncommon in the Tanga district, where an estimated 7 percent of the adult population is infected with HIV.

Even with such high infection rates, it was not easy to find enough people who met the study criteria of being HIV-positive, sexually active, 18 to 54 years old, and not seriously ill. Counselors report that most people are reluctant to get tested for HIV and many do not want to know their serostatus. As a result, most HIV tests are performed in the hospital after people have become ill.

By early 1997, however, 154 HIV-positive people had been recruited to participate—16 more than the 138 needed to allow researchers to make statistically meaningful conclusions.

All of the study participants had received post-test counseling no more than four weeks before their enrollment. They were randomly assigned to one of two groups: a control group with access to regular health services or an experimental group that received enhanced care and support.

For this study the researchers defined enhanced care and support as the services of a trained counselor at least once a month. The counselors, all public health workers from TAWG, provided counseling, condoms and—when necessary—referral for treatment. They also visited some participants’ homes to counsel and educate family members.

Researchers and members of the TAWG agreed on this definition of care and support based on the needs of the community as well as budgetary considerations, Dr. MacNeil explained. TAWG staff members, who were spending most of their time managing AIDS-related illnesses and providing palliative care to the terminally ill, saw a need for a different kind of support for people in early stages of HIV infection.

"Since study participants were relatively healthy, we felt that counseling and education would be an appropriate level of support," Dr. MacNeil said.

All study participants were interviewed in Kiswahili at enrollment, after three months, and after six months to gather information for the study. A final round of interviews had been planned at 12 months, but the study ended after the six-month follow-up because of time and funding constraints.

Trained interviewers used a 57-item questionnaire that covered a wide range of issues, including discussing HIV with partners, HIV risk behavior and use of health services. Participants also talked about how they felt about their HIV status, its impact on their decisions about having more children, and the reactions of their families and communities.

**Women at Risk** In many African countries, women are becoming infected with HIV at faster rates than men. This high risk of HIV is partly a result of women's greater biological vulnerability to the virus, but it is compounded by social and economic pressures that make it difficult for women to refuse unwanted sex or insist on condom use.

Such pressures are evident in the Tanga district. Women enrolled in the study were more likely than men to be widowed, divorced or separated. They also were more likely to be unemployed or to work in unskilled manual labor or small businesses. Incomes were low for all study participants, but the women earned significantly less: an average monthly income of U.S.\$35, compared to \$57 a month for men.

Earlier research conducted in Tanga to provide information for HIV/AIDS prevention planning found that women working in small businesses, such as street vending or market stalls, often supplement their income by having sex with customers.

Study data suggest a high risk of HIV infection among women in monogamous relationships. At the beginning of the study, only 16 percent of the women reported having more than one sex partner in the previous three months. Forty-five percent of the women—all of whom were HIV-positive—were married or widowed. Many of them said they had sought an HIV test after learning

that a husband, partner or child was infected with the virus.

"In Tanzania, as in other parts of the world with a high prevalence of HIV, being in a marriage or a stable relationship is actually high risk for many women," Dr. MacNeil said.

**Improving Health** Proponents of voluntary counseling and testing say that early detection of HIV infection can prompt people to take better care of their health. This seems to be true in Tanga, where reports of illnesses by all participants decreased and researchers found significant increases in reported use of home care, folk healers, and medical, counseling and religious services.

"The significant decline in reported illness suggests that knowing one's serostatus can encourage those who are positive to seek care earlier for illnesses and symptoms that may be easily treated, such as diarrhea, rashes and headaches," Dr. MacNeil said.

The most striking decline was in reports of pain, burning or discharge on urination—common symptoms of sexually transmitted infection (STI). Although 35 percent of participants reported such symptoms at baseline, only 13 percent were experiencing them after six months.

The number of people seeking STI treatment after six months was also reduced, suggesting that symptoms declined because of effective treatment and preventive measures. This decline has important implications for HIV prevention because people are more likely to transmit HIV when they have an STI.

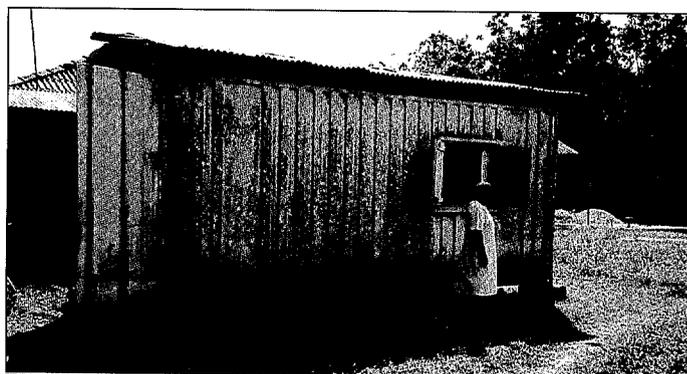
Knowledge of HIV serostatus had an impact on reproductive choice as well as reproductive health. Those reporting that they used any family planning method rose from one-fifth of all participants at the beginning of the study to almost one-half at the end as a result of increases in condom use. A substantial number of participants did not use any family planning method, however, because they wanted larger families.

**Changing Behavior** Reports of condom use for family planning and disease prevention rose dramatically in both the experimental and control groups, with most of the increase occurring during the first three months. Fidelity to one partner also increased, as

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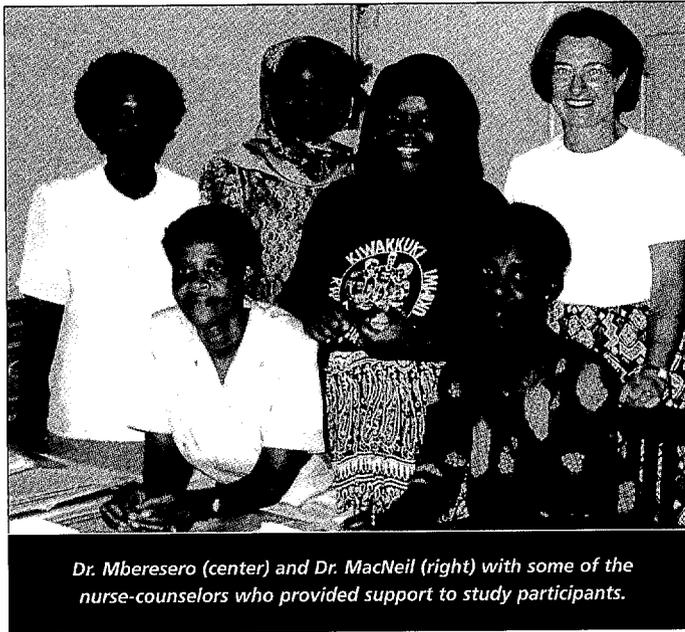
*"In Tanzania, as in other parts of the world with a high prevalence of HIV, being in a marriage or a stable relationship is actually high risk for many women."*

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An old shipping container has been refurbished to serve as a satellite office and counseling center for the Tanga AIDS Working Group in Muheza.

JOAN MACNEIL/PHI



Dr. Mberesero (center) and Dr. MacNeil (right) with some of the nurse-counselors who provided support to study participants.

TANGA AIDS WORKING GROUP

the number of people reporting more than one sex partner dropped throughout the six-month study.

Since these preventive measures were adopted by people in both groups at similar rates, the additional care and support given to one group did not appear to have played a role in reducing HIV risk behavior.

“Enhanced care and support in this early phase did not have a significant impact on behavior change, yet the study as a whole decreased risk behavior,” Dr. MacNeil said.

The researchers attribute this behavior change to the quality of the post-test counseling all participants received and the easy access to condoms and information about condoms provided by an energetic social marketing project.

Condom use did begin to decline among the control group after three months, suggesting that care and support may be more important after the initial shock of a positive test result subsides.

“Although this decline was not statistically significant, there was really a drop-off,” Dr. MacNeil said. “I would speculate that if we could have followed them at 12 and 18 months, it would have been significant.”

Also troubling was the number of people in both groups who continued to put their partners at risk of HIV and themselves at risk of reinfection. After six months, 28 of these HIV-positive individuals reported having more than one sexual partner, and many others said they had not used condoms.

Such findings are not unusual and probably reflect the difficulty most people have in accepting a positive test result, Dr. MacNeil noted. “It just takes time,” she said. “And this shows that even after the first six months, there is still a lot of work to be done.”

**Opening Up** Another important preventive measure—revealing serostatus—proved difficult for all participants. At the beginning of the study, four weeks after learning of a positive test result, only 29 of the 154 people had told anyone about it.

“Most of them wanted to get on with their lives and not even talk about HIV,” Dr. MacNeil said.

The main reason cited for telling others about a positive result was the need for support. Only a handful of people—three during the first round of interviews and two during the third round—mentioned protecting partners as a reason for revealing their status.

“Counselors emphasize the preventive aspects of knowing

one’s serostatus, but sometimes we feel that our clients were infected when they had no knowledge of AIDS and HIV,” said Dr. Firmina Mberesero, TAWG chairperson. “It takes them some time to realize their role in preventing the spread of HIV.”

The number of people who had disclosed their serostatus

increased by almost 64 percent during the study, with no significant difference between the experimental and control groups. After six months, however, 24 participants had not told anyone that they were HIV-positive, and 80 hadn’t told their spouses or other sexual partners.

“Even after six months there were a lot of problems with revealing status,” Dr. MacNeil said. “People were worried about abuse, discrimination and being abandoned.”

In fact, most responses to the news of a positive HIV test were surprisingly supportive in a community where HIV/AIDS is considered a “self-inflicted” disease and people dying of AIDS are often abandoned by all but their mothers or grandparents.

Participants in both groups also reported increasing emotional and economic support from spouses and partners. And when asked about their interactions with family members, such as eating or sleeping together and being included in discussions or cared for when ill, 91 percent of participants reported active inclusion in family life.

Although the enhanced care and support had no impact on sexual behavior, they appear to have had a positive impact on the response to HIV/AIDS in families and communities.

After the study, TAWG staff noted greater interest in HIV counseling and testing and greater support from other health care workers. “The majority of medical personnel thought that counseling was useless, but they are now in the forefront of sending clients to us,” Dr. Mberesero said.

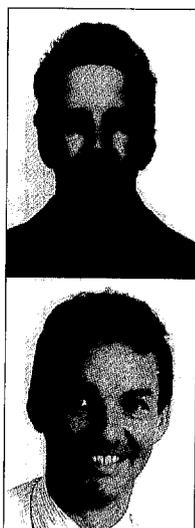
Another important sign of change is the support group formed by some of the study participants—the first of its kind in the Tanga district. Members meet to talk about their experiences and problems, visit each other, and help counsel other TAWG clients who have trouble accepting that they are HIV-positive.

Counselors believe that the study helped make community members more willing to discuss HIV/AIDS and more accepting of people living with the virus. “Ongoing care and support seem to bring people together and also bring issues out in the open,” Dr. MacNeil said. ▢

*Reports of condom use for family planning and disease prevention rose dramatically.*

## Policymaking and Antiretroviral Therapy: *A Framework for Rational Policymaking*

by Steven Forsythe and Charles Gilks



Pressured from within by a growing demand for therapies that are reducing AIDS death rates in industrialized countries and from without by offers of donor funding, policymakers in low- and middle-income countries are being forced to make decisions about providing access to antiretroviral (ARV) treatment for HIV. In some cases, they are making investments that will not be affordable, cost-effective, sustainable or equitable over the long term, which may eventually lead to the withdrawal of subsidized access in the future. Conversely, some policymakers in countries that could realistically afford to subsidize open access to ARVs incorrectly assume that these medications cannot be affordably purchased.

In either case, vital decisions are being made based on severely limited information. Little is known about the extent of the demand for the drugs, the ability of governments and individuals

inhibitors), 2) providing AZT to pregnant women to prevent vertical transmission, 3) offering partial government subsidies, or 4) negotiating discounted, but unsubsidized, purchase of ARVs.

In order to evaluate the costs and benefits of each of these options and to identify creative ways of affordably subsidizing access to ARVs, policymakers need information on the demand for ARVs, the ability of those who need the drugs to pay some portion of the cost, the economic impact of the health benefits of ARVs, and the cost-effectiveness of ARVs compared to that of other drugs. They also need to evaluate their countries' overall capacity to deliver ARV therapy and effectively monitor clinical progress.<sup>1</sup> Finally, they need to assess the political and financial commitment of their own governments to sustain support for ARV therapy and the potential impact of government subsidies on health care for the impoverished.

Once this critical information has been collected, it should be assessed in the context of an objective and dynamic framework that enables policymakers to weigh issues of affordability, cost-effectiveness, sustainability and equity. Such a framework should not only allow countries to decide what is affordable now, but also to monitor how changes in drug prices and physical capacity should affect policymaking in the future.

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*It has been estimated that full public subsidization of HAART would consume 84 percent of Malawi's gross national product.*

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to pay for them, or the economic impact of various levels of public subsidy for ARVs. In such a vacuum of information, short-term political considerations, rather than a realistic assessment of what can be offered, are likely to predominate.

In deciding whether and how to provide access to ARVs, policymakers in non-industrialized countries have a number of options, ranging from full public subsidy of the three- or four-drug combination known as highly active antiretroviral therapy (HAART) to no public involvement in providing access. So far, most policymakers have opted to support more limited access by: 1) funding some ARVs (but not the more expensive protease

### **Affordability**

Although ARVs have been shown to reduce mortality and improve the quality of life of people living with HIV/AIDS in many high-income countries and some middle-income countries, the economic realities of providing access to these drugs can be overwhelming. In countries where annual public health expenditures are U.S.\$3 to \$30 per person, public provision of HAART, which can cost from \$7,000 to more than \$20,000 per person per year, is likely to be unrealistic.

In Malawi, for example, per capita income is \$180 and public health spending is only \$3 per

capita. More than 700,000 people—15 percent of the adult population—are currently living with HIV or AIDS. It has been estimated that full public subsidization of HAART would consume 84 percent of the country's gross national product.<sup>2</sup> Thus, for Malawi, access to HAART for all who need it is completely unaffordable.

In Costa Rica, where the per capita income is \$2,640, the annual purchase of \$7,000 worth of ARVs is also out of reach for most people living with HIV or AIDS. However, unlike Malawi, Costa Rica is at an early stage in the epidemic, with only about 360 people who are aware of their HIV status (out of an estimated 3,200 people living with HIV). The small number of people who require access to therapy, combined with a relatively well-financed and well-equipped health system, means that the recently enacted public policy of fully subsidizing HAART consumes only about 2 percent of the social security budget. The actual cost incurred by the Social Security Institute might be even less if one includes the economic benefits of introducing HAART, such as reductions in inpatient visits, decreased demand for drugs to treat opportunistic infections and increased labor productivity.

The countries most likely to be able to afford ARVs are those with the smallest demand (lowest HIV prevalence) and the highest level of available resources (highest per capita income). Brazil, Mexico and Costa Rica, which have initiated some public subsidization of ARV therapy, are relatively high-income, low-prevalence countries. Countries such as Zimbabwe and Malawi, which have a relatively low gross domestic product and a high HIV prevalence, have so far not pursued access to ARVs. Others, such as South Africa, are taking a middle ground by offering AZT to pregnant women. Côte d'Ivoire, Chile, Uganda and Vietnam are making ARVs available to selected centers with appropriate clinical capacity through a Joint United Nations Programme on HIV/AIDS (UNAIDS) initiative that provides discounted, but unsubsidized, access to ARVs.

In some cases ARVs may be affordable to some through partial subsidies. While partial subsidies might not be equitable, they are likely to expand the number of people who can afford ARVs. For example, it might be feasible for a government to



CRISPIN HUGHESPANOS PICTURES

subsidize 60 percent of the cost of ARVs and for individuals to pay the remaining 40 percent. Before pursuing this option, government officials must have an idea of the number of people who would take advantage of such a subsidy (their "willingness to pay" for the unsubsidized portion of the costs) and how this in turn might affect budgetary requirements. The amount that consumers are willing to pay at various prices (the elasticity of demand) will determine the total public and private resources needed when offering a subsidy for ARVs.

#### **Cost-effectiveness**

It is also necessary for policymakers to determine whether an investment in ARVs would be cost-effective. In other words, given other pressing health care needs, is it wise to invest in ARVs? While a country might find ARV therapy affordable, its policymakers might not necessarily conclude that it is a cost-effective use of limited resources.

There is growing evidence that ARVs can provide significant medical and economic benefits to a country's health care system. Data from the United States, for example, illustrate that HAART reduced AIDS-related mortality by 75

*A pharmacy in Kampala, Uganda, dispenses drugs to women, many of whom are HIV-positive.*

percent and AIDS-related morbidity by 73 percent over three years.<sup>3</sup> In the Brazilian state of São Paulo, AIDS-related mortality has declined 32 percent since protease inhibitors became available in 1996.<sup>4</sup>

Data from industrialized countries suggest that despite the high cost, the benefits achieved by averting opportunistic infections and inpatient visits may make HAART

a cost-effective option and may even produce savings. It is noted, for example, that one inpatient episode in the United States costs an average of \$7,000. Therefore, the cost of a year's supply of protease inhibitor (a type of drug that must be taken in combination with other ARVs) at an annual cost of \$6,000-\$7,000 could be completely offset if even one inpatient episode were averted.<sup>5</sup>

The cost of HAART has been

shown to be at least partially offset by reductions in inpatient hospital care and shifts toward outpatient care in the United States, Ireland and France. The CAESAR trial in Canada, Australia, Europe and South Africa showed that patients receiving lamivudine, compared to those in the placebo group, had significantly fewer hospital admissions (11 versus 6 percent), unscheduled outpatient visits (15 versus 10 percent) and prescriptions for an HIV-related illness (43 versus 30 percent).<sup>6</sup>

Despite the medical and economic benefits of ARVs in predominantly industrialized countries, many low- and middle-income countries are likely to find it more advisable to invest in less complex and costly drugs. For example, in the poorest countries, where access even to essential drugs is not assured, it is likely to be more cost-effective initially to invest in drugs to treat chronic symptoms of HIV/AIDS, such as imodium for diarrhea or non-essential antibiotics such as ceftriaxone or ciprofloxacin for septicemia, rather than in more expensive ARVs.<sup>7</sup>

While it is unlikely that countries will have the complete information necessary for performing a rigorous cost-effectiveness or cost-benefit analysis before making a decision about the public purchase of ARVs, it is imperative that they pursue a preliminary assessment of the resources necessary

to invest in such expensive drugs. Furthermore, countries should establish the mechanisms necessary to monitor the costs and benefits of such drugs once they are purchased, so that future decisions regarding longer-term commitment of resources can be more fully informed.

#### Sustainability and Capacity

Policymakers who do conclude that ARVs are both affordable and cost-effective must next determine whether such care is sustainable. Sustainability depends on the amount of time during which treatment will be necessary. Unfortunately, the duration of treatment required for patients using ARVs remains unclear. Most data indicate that patients with a few years of treatment with HAART quickly relapse if they discontinue therapy. Current estimates suggest that treatment will have to be continued for 5 to 20 years, or possibly even longer.

The impact of discontinuing ARV treatment can be devastating from both a clinical and a political perspective. A lack of politically and financially sustainable commitment to subsidizing ARVs and to the infrastructure needed to deliver

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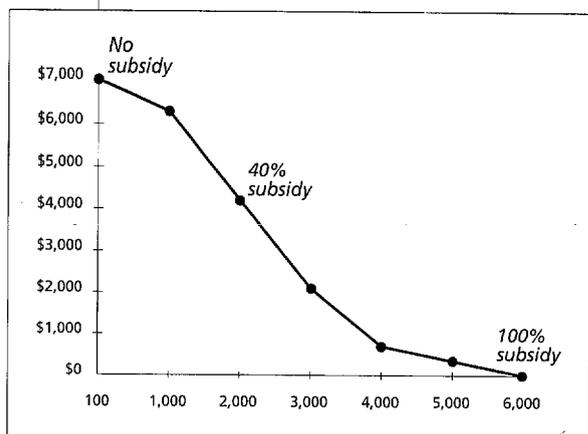
*In the poorest countries, where access even to essential drugs is not assured, it is likely to be more cost-effective initially to invest in drugs to treat chronic symptoms of HIV/AIDS.*

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them can lead to an interruption of therapy, which can cause drug resistance that could make future treatment ineffective.

Politically, offering an effective combination of drugs and then withdrawing them is probably worse than never introducing the drugs in the first place. Therefore, if governments do introduce ARVs, they must be committed to providing these drugs for the indefinite future.

In addition to the length of treatment, policymakers need to carefully review the national capacity (human and technical resources and infrastructure) necessary to administer and monitor complex and potentially toxic drug regimens.



Cost of ARVs to consumers and number of consumers who will buy them at different levels of subsidy: a hypothetical example of the elasticity of demand

Any decision to provide access to ARVs must include a realistic assessment of the ability to sustain the staff training and improvements in infrastructure required for treatment, safe drug delivery and storage, laboratory testing, patient follow-up, and treatment of drug side effects.

### Equity

The fourth consideration in selecting a policy on ARV therapy requires evaluating the equity of ARV provision. On the one hand, global equity would demand that ARVs be made available to all, regardless of whether they live in a low-income or a high-income country. Proponents of global ARV access to all argue that people should have equal access to life-saving drugs. Despite this appeal, few donors or pharmaceutical companies have been convinced that it is their responsibility to provide access to ARVs to all those cannot afford them. Donors have noted that the cost of providing these drugs at a global level is likely to be close to \$36 billion per year.<sup>2</sup>

Conversely, others maintain that a concern for equity should discourage countries from spending scarce public resources to subsidize access to expensive drugs. The argument is made that ultimately the impoverished will pay the price of subsidizing ARV access for a few (probably the most wealthy or influential) when health care resources get diverted. Such arguments against AIDS exceptionalism have also been aired within the United States.<sup>8</sup>

Policymakers must assess who the winners and losers are in any effort to subsidize access to care. They must ensure that, at the very least, the most vulnerable members of society are not made worse off by the diversion of scarce resources for ARVs, and that there are ways of encouraging equal access for those who are most in need. ▣

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## Providing Access to ARVs: What Policymakers Need to Know

### Affordability

What kind of treatment will be offered (e.g., dual nucleoside therapy alone or full HAART)? What are the indications for starting treatment? What monitoring will be appropriate, and where will clinical centers be established? What pricing mechanisms are likely to be adopted (e.g., negotiated discounts, public subsidy, donor aid)?

What is the likely demand for ARV treatment? How many HIV-seropositive people are likely to fulfill treatment requirements, and how many will be able to access treatment centers? What would be the cost of meeting that demand?

### Cost-effectiveness

What other therapeutic options or interventions could be implemented prior to ARV therapy that could also prolong quality of life (e.g., effective tuberculosis services, antifungal agents and other drugs for specific opportunistic infections, drugs for symptomatic care and pain relief, better inpatient facilities)?

### Sustainability

What kind of capacity strengthening is required to introduce and sustain effective ARV therapy (staff training and new recruits, improvements in capacity for safe drug delivery and storage, infrastructure, technical and laboratory equipment)? What would these measures cost?

### Equity

What are the equity issues that are likely to arise? What needs to be done to address them adequately? (For example, adopting indications for treatment that do not discriminate against at-risk groups such as sex workers or drug users or offering therapy in rural as well as urban areas.)

What are community health-care priorities? How does interest in HIV/AIDS care and prevention compare with concerns about other pressing health care needs, such as malaria control, safe motherhood and childhood vaccination?

# Improving Access to Antiretroviral Therapy in Latin America

BY MARGARET J. DADIAN

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*Spurred by the advocacy of people living with HIV/AIDS and their allies, a number of Latin American governments are starting new programs to finance and deliver antiretroviral medications to HIV-positive citizens.*

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In many developing regions of the world, the high cost of the new antiretroviral (ARV) drugs has been a near-unbreachable barrier to governments struggling to care for their HIV-infected citizens. In the poverty-stricken nations of sub-Saharan Africa, for example, public health programs are so underfunded that health agencies cannot afford inexpensive medications for opportunistic infections, much less the thousands of dollars it can cost to treat a single patient with ARVs.

Increasingly, though, countries with stronger economies are devising strategies to provide ARVs to those who need them. While a comprehensive combination therapy program is still beyond its means, Thailand now dispenses AZT to pregnant women with HIV to curtail perinatal transmission. Even more impressive are the efforts of several Latin American countries—including Brazil, Argentina, Colombia, Costa Rica and Mexico—that are working both individually and collectively to make ARVs a standard treatment option for their citizens. Many of the ARV programs that have emerged in the region were born of tireless advocacy by grassroots organizations seeking to convince health officials that these medications could be made affordable and accessible through government intervention.

**Improving Access, Improving Infrastructure** Brazil, burdened with a severe HIV epidemic, has created one of the most extensive ARV programs on the continent, providing double and triple combination therapy free of charge to some 58,000 people with high viral loads or full-blown AIDS. National legislation guarantees access to these medications for all affected Brazilians who are covered by the social security system (a parastatal organization that provides health care to private and public sector employees and their families) and to all HIV-positive pregnant women and their newborns. With funding from its own treasury and a World

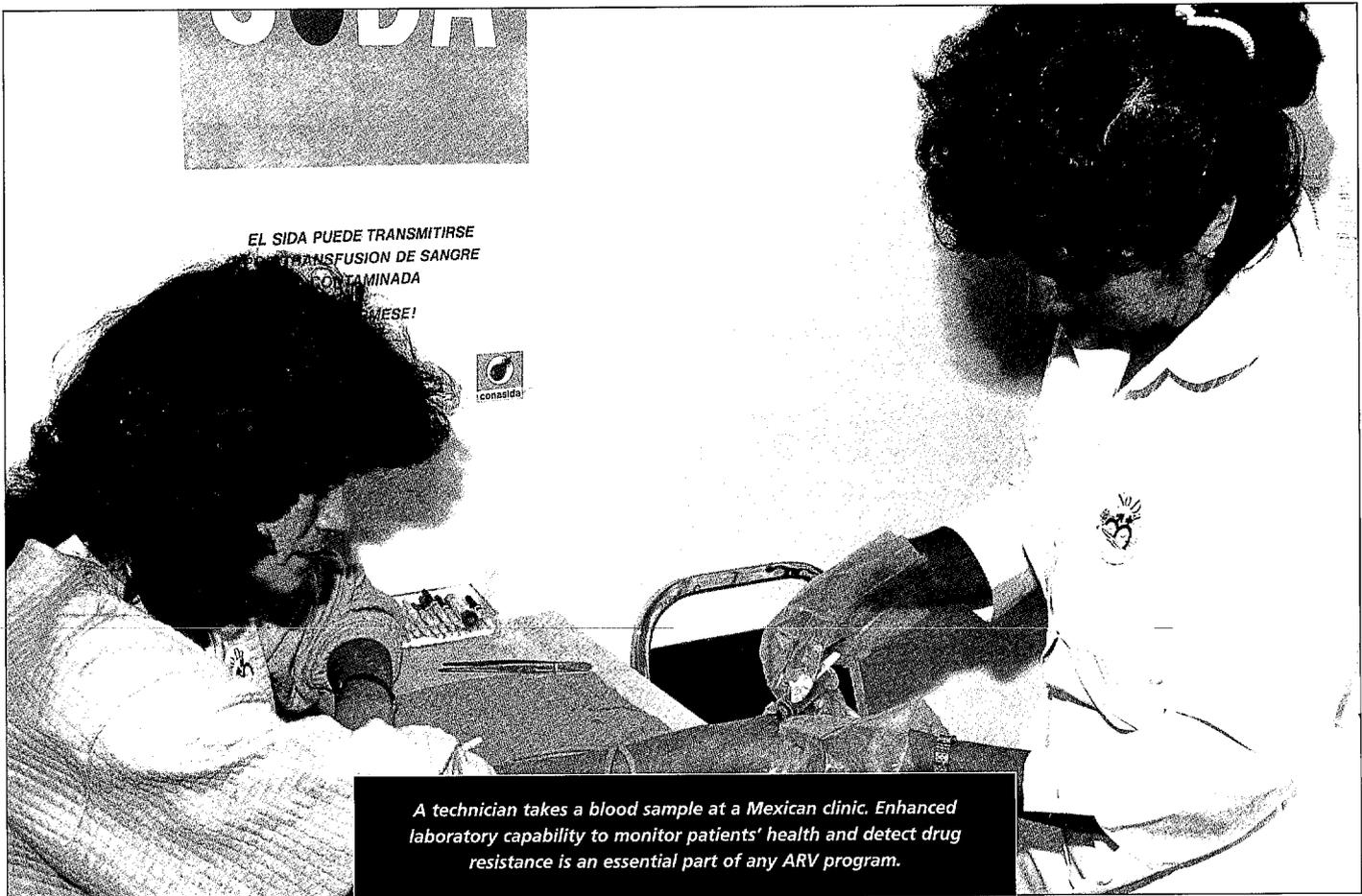
Bank loan, Brazil's projected 1998 budget for ARVs and monitoring will top \$545 million. Many credit the two-year-old program for the dramatic 32 percent decrease in AIDS-related mortality in São Paulo state—one of Brazil's highest HIV prevalence areas—between 1996 and 1997.

"Brazil has worked hard to put together the kind of comprehensive system required to make a large-scale antiretroviral program successful," said Dr. Carlos del Rio, associate professor of medicine at Emory University School of Medicine and former director of Mexico's AIDS control and prevention program. "It has created national networks for drug supplies and lab facilities and put a lot of time and effort into making it all work."

As in Brazil, Argentina's ARV program owes its existence to the passage of a federal law that provides the most advanced drugs available to HIV-infected citizens through the national social security system. But the Argentinian program goes a significant step further in its creation of a special fund to pay for ARVs for those not covered by social security—street vendors, small businesspeople, the unemployed—and for low-income pregnant women. Some 11,000 HIV-positive Argentinians receive ARV therapy through these two sources and through private insurance plans.

But the process of setting up this program in Argentina was not simple. When the program first began, its managers discovered that they could not rely on the existing national drug delivery system to handle the complex job of distributing multiple therapies and to guarantee their consistent availability.

"With several expensive drugs being dispensed simultaneously, we needed a new system," said Dr. Laura Astarloa, director of Argentina's National AIDS Control Program. "We needed new computers, new computer programs, and new staff dedicated exclusively to tracking and distributing the medications, or else the program would not have succeeded."



A technician takes a blood sample at a Mexican clinic. Enhanced laboratory capability to monitor patients' health and detect drug resistance is an essential part of any ARV program.

**High Costs—and Cost-saving** In fact, infrastructure improvement can be a major expense for nations that embark on ARV programs—and it often entails much more than a more efficient distribution system. Enhanced laboratory capability is essential to follow the progress of patients who receive the medications and to determine whether virus strains have developed resistance to certain drugs. Clinic and hospital staff must receive extensive training in order to prepare patients to follow difficult drug regimens and to monitor their progress. In some countries, conditions are so poor that a complete overhaul of the infrastructure would be necessary before ARV therapy could be successfully introduced.

“Examining these issues is all part of determining the benefits of instituting an ARV program in each country,” said Dr. Rafael Mazin, regional advisor for HIV/AIDS and STDs at the Pan American Health Organization (PAHO). “How much must be invested to bring capabilities to necessary levels?”

Although they must shoulder these expenses, large countries such as Brazil and Argentina have also found ways to control some of the costs of their programs. Negotiating bulk prices with the pharmaceutical firms that manufacture ARVs helps make these drugs much more affordable. For example, Argentina now pays 33 cents for AZT pills that once cost \$2 each.

The Horizontal Technical Cooperation Group (HTCG), made up of national AIDS program directors from several Latin American countries, wants to see that kind of price break made available not only to countries that can buy in quantity but also

to smaller nations that are currently paying premium prices for their ARVs. Even though the members of the group are for the most part unable to buy these drugs together—national regulations make such joint purchases difficult unless the countries involved already collaborate in a trade agreement—the HTCG hopes to convince drug companies to offer lower prices as standard throughout the region.

“Uruguay is paying six to seven times what Argentina pays for the same medications because they have only 100 patients,” said Dr. Astarloa. “This kind of inequality should not exist between countries.”

Another proposal would create a revolving fund, administered through PAHO, that could loan money for ARV programs to Latin American countries that cannot afford the medications without financial help. But securing sufficient

seed money to get the fund started has been difficult.

“Our estimates of the amount needed to undertake this are so high that identifying potential sources for funding is a real challenge,” said Dr. Mazin.

**Involving the Private Sector** While Mexico cannot afford to consistently offer triple combination therapy to all HIV-positive citizens, Mexicans with HIV/AIDS who participate in the nation’s social security system are eligible for monotherapy or dual therapy. Pregnant women receive AZT to prevent transmission of the virus to their fetuses and newborns and, after they deliver, are eligible to receive triple therapy, as are all children under 18.

*Managers discovered that they could not rely on the existing national drug delivery system to handle the complex job of distributing multiple therapies.*

For the 50 percent of Mexicans not covered by social security, publicly funded access to ARVs has been nonexistent—but not for much longer. This year, Mexico's National AIDS Control Program worked with university researchers to develop a new funding model to cover the medication needs of HIV-positive members of this huge segment of the population. With seed money from the government, FONSIDA will operate as a nongovernmental organization, soliciting donations from a wide diversity of sources—notably, the private sector.

"We expect to involve industry, banks, community organizations and international donors in our fund-raising drive," said Dr. Griselda Hernandez, deputy director of CONASIDA, Mexico's national AIDS prevention and control program. "Perhaps we can serve as an example to other countries with limited resources that are seeking ways to expand treatment to all."

The Mexican program has made a significant investment in improving lab capacity in four states and in training medical personnel. It continues negotiations with pharmaceutical companies for lower bulk prices on drug purchases. Upgrading the national drug distribution system is also on the agenda.

"Although the program in Mexico has a way to go to reach 100 percent access, it's actually quite remarkable how much has been achieved in such a short time," said Dr. del Rio.

**The Power of Advocacy** In most of these countries, the initiative behind ARV programs grew out of the activities of advocacy organizations and support groups for people living with HIV. Although these groups are generally smaller than their counterparts in North America and Europe, they have had an enormous impact on national treatment policies in Latin America.

In Costa Rica, the national health care system did not offer combination ARV therapy when the drugs first became available. After months of negotiation between the Costa Rican social security system and a committee of nongovernmental organizations and groups representing people with HIV, activists helped an HIV-positive college student file a petition with the



An HIV-positive patient receives a hug at a clinic in Santos, Brazil. All people living with HIV/AIDS who are covered by the country's social security system are entitled to free ARV therapy.

ARMANDO WAAR/PAHO/WHO

Supreme Court asking for triple combination therapy that he could not afford but that could save his life. The justices ruled in his favor, and although he died less than a month after their decision, his courage prompted more than a dozen others to present their own petitions. Within a few weeks, the Court ordered the national social security system to develop a plan for delivery of these medications to Costa Ricans with AIDS. Activists in Panama, inspired by the victory in Costa Rica, plan to file similar petitions with the Panamanian Supreme Court.

"Advocacy is alive and well in Latin America, and it's a very

powerful force in this process," said Dr. del Rio. "Whether in Brazil or in smaller countries, the new laws and policies that guarantee access to antiretrovirals are due to the activities of these groups."

Elsewhere in Central America, resource-poor countries such as Honduras—which has more than half the reported cases of AIDS in the region—offer no ARVs to their citizens. People with HIV in Honduras who take combination therapies either pay for them themselves or are enrolled in drug trials conducted by pharmaceutical companies. Activists in Honduras continue to lobby for improve-

ments in national treatment policies and for government funding of ARV therapy.

In Nicaragua, activists have become directly involved in the treatment process itself. The country's only ARV program is operated not by the financially constrained government, but by a nongovernmental organi-

zation, the Fundación Nimehuatzin, and a team of health professionals based at a public hospital, Hospital Manolo Morales, in Managua. With support from the private sector, foundations and international donors, NGO and hospital staff have managed to provide 30 patients with ARVs. They closely track both the medical progress of the patients and all expenses to enable them to build an argument for the cost-effectiveness of ARV therapy.

"Our aim is to be able to prove to the government how important it is to provide this kind of medication and how it can cut costs in the long run," said Rita Arauz, president of Fundación Nimehuatzin. □

*"Advocacy is alive and well in Latin America, and it's a very powerful force in this process."*

# U.S. Doctors and Patients Find HAART Poses Challenges

BY MARY O'GRADY

*Debilitating side effects, demanding drug regimens and high costs are some of the barriers that limit the benefits of highly active antiretroviral therapy in the United States.*

The benefits of highly active antiretroviral therapy (HAART), the three- and four-drug combinations against HIV, have been widely publicized. In many industrialized countries, these potent drug regimens have reduced deaths from AIDS and prolonged the lives of thousands of people.

Less well-known are the formidable challenges HAART presents, including its side effects and the potential for rapid spread of drug resistance. Antiretroviral drug combinations have been available in the United States for less than three years, yet there is a rapidly growing body of knowledge about their disadvantages as well as their benefits. This knowledge may be instructive for other countries searching for ways to make antiretroviral therapy available to their HIV-positive citizens.

**Limited Options** In the countries where it is available, HAART generally includes three or four drugs in two distinct categories: nucleoside analogs and protease inhibitors. They are commonly prescribed as part of the same regimen in the United States because one or two protease inhibitors strengthen the effect of one or two nucleoside analogs. Unfortunately, protease inhibitors do not work as well with a third category of HIV drugs, non-nucleoside analogs, and they should not be taken alone.

By the end of August 1998, the U.S. Food and Drug Administration had approved four protease inhibitors—indinavir, nelfinavir, ritonavir and saquinavir—and five nucleoside analogs—didanosine (ddI), lamivudine (3TC), stavudine (D4T), zalcitabine (ddC) and zidovudine (AZT). Only two non-nucleoside analogs—nevirapine and felavirdine—had been approved for prescription use.

If one of the drugs involved in the triple or quadruple therapy is not well tolerated or if a patient's HIV infection becomes resistant to it, a whole new set of drugs must be prescribed for the regimen to be effective. Thus, with a limited number of HAART medications available on the U.S. market so far, only a few different drug

combinations are possible. HAART regimens can also fail because of lack of viral load response or poor treatment adherence.

**Resistance and Adherence** Because of its "highly active" nature, HAART can provide a symphonic response to HIV infection. If doses are missed or taken improperly, however, the crescendo falls flat. Not only does the treatment lose its potency, but also the patient's HIV infection can rapidly become resistant to the drugs involved, meaning that their HIV infection changes its chemical or genetic form to resist the effects of these drugs. Even more ominously, sexual transmission of HIV strains resistant to HAART medications has been documented and may be a growing problem.

Missing a single dose of HAART medication even twice a week can cause the development of drug-resistant HIV—a real danger because adherence to the drug regimens is difficult. Once HAART is initiated, a patient must be willing and able to take as many as 40 pills (12 is the minimum daily dosage in any currently recommended HAART regimen) and drink as many as eight glasses of water a day. The pills must be taken at several times during the day, some with food and others on an empty stomach.

A patient's ability to adhere to these complicated regimens is one of several important considerations for clinicians in determining when to begin HAART, according to Dr. Frederick Hecht, a clinician at San Francisco General Hospital Medical Center who has been treating HIV-positive patients since 1986. He noted that U.S. physicians generally prescribe HAART based on the current recommendations provided in the *Journal of the American Medical Association* by the International AIDS Society,<sup>1</sup> but they may follow these recommendations to different degrees.

"I'm slightly more conservative than the guidelines because of the long-term side effects," said Dr. Hecht, an assistant clinical professor of medicine at the University of California, San Francisco, Medical School. "I want to be clear that someone will not be at risk of developing resistance because of non-adherence."



An HIV-positive man receives medical care and emotional support in his home.

M. HALLAM/PHOTO PAPERWORK

**Side Effects** The side effects experienced by many people on HAART can readily provoke a patient to miss a dose or take a “drug holiday” from the regimented existence the treatment necessitates. Sometimes side effects are so severe that a physician must prescribe a different drug combination, involving a totally new regimen.

Most of the information available about HAART side effects is self-reported by patients because of the lack of placebo-controlled clinical research trials, according to Dr. Hecht. One study he is involved in, the Options Project, is looking at the most appropriate time for HIV-infected individuals to begin HAART, taking into account the potential side effects of this treatment. The side effects from individual drugs as well as the deleterious drug interactions reported so far are many, and vary from one individual to the next. The most common ones, however, are becoming

better documented and recognized by health care professionals.

According to Dr. Hecht, who currently treats about 100 HIV-positive patients, long-term side effects include lipodystrophy, which is a nearly complete lack of fat below the skin (or sometimes a redistribution of it to the pelvic area), and, less commonly, diabetes. After two years of HAART availability in the United States, coronary heart disease also emerged as a side effect in some patients who had lived long enough to develop it. “This makes me concerned,” he said, “especially for those who would be on treatment five to ten years.”

Common short-term side effects that Dr. Hecht has seen in his patients include medication-related nausea, fatigue, kidney stones (from indinavir) and diarrhea (from nevirapin). Patients taking ritonavir have experienced mouth numbness, loss of taste, nausea and, occasionally, vomiting.

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*This powerful therapy demands  
commitment from patients, physicians  
and health care systems.*

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**More than Drugs** HAART is not always readily available to or feasible for everyone infected with HIV, no matter where they live. This powerful therapy demands commitment from patients, physicians and health care systems.

Since HAART became available in the United States in early 1996, it has become increasingly clear that it must be prescribed and monitored by highly trained physicians and nurses who maintain the most current knowledge of all the potential side effects, drug interactions and resistance variables. Counselors who can provide emotional and psychosocial support and case managers who can identify financial assistance options are also a critical part of the HAART team wherever this form of care is attempted. In addition, such highly complex pharmaceutical treatment demands a sophisticated

health care infrastructure and delivery system to support the necessary laboratory tests, drug supplies and outpatient clinic visits.

For industrialized nations, another lesson of the experience with HAART to date might be the realization that HIV care involves much more than a technological fix. With viral strains already developing drug resistance, prevention may indeed be the best medicine against HIV. In the end, however, care is not only a basic human right, but a crucial part of the HIV prevention cycle, and it involves much more than simply dispensing medications. ▣

'CCJ Carpenter, MA Fischl, SM Hammer, et al. Antiretroviral Therapy for HIV infection in 1998: recommendations of the IAS-USA Panel. *Journal of the American Medical Association*. 1998;280:78-86.

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## Study Reveals Gaps in HIV Care in the United States

Preliminary results from the first nationally representative sample of adults living with HIV/AIDS in the United States show that less than half of them—43 percent—receive regular health care, defined as one visit to a health care provider every six months.

These results, presented at the 12th World AIDS Conference in Geneva, Switzerland, in June 1998, also indicate that slightly more than half of HIV-positive Americans have tried highly active antiretroviral therapy (HAART).

Access to the newer HIV/AIDS therapies mirrored the overall deficiencies in health care for HIV-positive adults revealed by this national HIV Cost and Services Utilization Study (HCSUS). Nevertheless, the proportion of HIV-infected adults who had tried HAART rose from 16 percent to 55 percent during 1996.

Conducted from January 1996 through July 1997, the HCSUS used two rounds of client interviews to learn about five types of care accessed during the previous six months: doctor or clinic visits, emergency room visits, hospitalizations, use of antiretroviral medications and use of prophylactic therapies.

Nearly 3,000 HIV/AIDS patients were sampled at 148 urban and 51 rural sites, chosen based on caseloads, in the 48 states in of the continental United States. Fifty-four percent of the study group consisted of individuals aged 35 to 50, with 34 percent younger than 35.

More than three out of four participants were male and almost half were men who have sex with men. Twenty-four percent were drug users, and 18 percent were heterosexuals. Nearly half the study participants were white, one-third African-American, and 15 percent Hispanic. Most were unemployed.

Study participants reflected the following categories of disease stages defined by the Centers for Disease Control and Prevention: 38 percent had clinical AIDS, 52 percent had symptomatic HIV infection and 10 percent had asymptomatic HIV infection.

Study results released in Geneva by the HCSUS Consortium,

representing the National Opinion Research Center at the University of Chicago, Harvard University, Project Hope, the University of California at San Diego, and seven other research organizations, show that the cost of HIV/AIDS treatment in the United States is \$6.7 billion a year. Forty-six percent of the total is spent on hospital costs, and 39 percent covers pharmaceuticals. The remaining 14 percent (some \$938 million) funds outpatient treatment, emergency room visits, lab costs, and other care services.

The average annual per patient cost is \$20,000, double the average annual income of nearly half of those infected with HIV in the United States.

The researchers estimate that HIV is responsible for 8 percent of the total potential years of life lost in the mainland United States. Expenditures for care of those living with HIV, however, account for less than 1 percent of total personal health costs.

The study also found that one out of five people living with HIV in the United States has no insurance to cover the cost of health care. Only thirty-two percent have private health insurance, while 48 percent are covered by the government programs Medicare or Medicaid.

HIV-positive women, African-Americans, Hispanics, drug users, and others with low socioeconomic status, no health insurance or only Medicaid have lower levels of health care.

The researchers concluded that until new strategies are identified and utilized and additional funding is allocated to provide adequate and equitable health care for all HIV-positive adults in the country, the United States will not be able to optimize health outcomes for this disease.

The HCSUS was funded by the U.S. Agency for Health Care Policy and Research, the Health Resources and Services Administration, the National Institute of Mental Health and the National Institute on Drug Abuse, among others.

# Positive with a Positive Attitude

BY GEORGE KERR III

*An HIV-positive survivor shares his often harrowing but rewarding experience with highly active antiretroviral therapy.*

October 31, 1995. I was sitting across from my counselor. She did not have to say a word. I already knew the results: I was HIV-positive. I was filled with shock, rage, hatred and fear.

Almost three years later, in July 1998, I received a call from my doctor. He told me that my viral load had dropped from over 750,000 to 650 in four months. Again I was filled with emotion—this time, excitement and relief.

The years between my first post-test counseling session and my doctor's call were difficult ones. It took all the support I could get to go through the anger, the denial, the sadness. I had to let my family and friends go through this process too. And I had to understand when some of them were not ready to accept the news.

The only experience I can offer is that of living day to day as a survivor. And the most valuable lesson I've learned is how powerful the mind and spirit are.

My experience with antiretroviral drugs shows just how important the mind and spirit can be. It also shows that these new drug combinations that some people have called an AIDS "cure" are not easy to take and don't always work.

I've been on seven different drug combinations. Some didn't affect the amount of HIV in my system, and others caused severe side effects. I'm actually running out of possibilities. I had to get FDA approval to take one of the drugs I'm on now, Sustiva, because it wasn't on the market yet. It was an experimental drug.

Even when the drugs do work, the side effects are very difficult. With some of the pills I used to take, I'd have blackout periods. I'd be walking and all of a sudden I'd be unconscious for a few seconds. Once I had to be wheeled out of my office in a chair and taken home because I couldn't even walk.

I have what's called neuropathy in my left hand. I feel tingling and numbness, and sometimes the pain is so bad I can't use it. There are times when I have a problem simply picking up a book with it. Sometimes I can do it, but other times the pain that goes through my hand is so bad that all I can do is cry. And I am not one to cry.

Neuropathy is a very common side effect. Other common side effects that I have experienced are headaches, upset stomach, diarrhea and loss of balance.

I take 38 pills a day. That's eight different medicines a day, including two allergy medicines and a multivitamin. When I have a side effect, I take more.

All but one of the medicines have to be taken with food. One of the side effects of these medicines is nausea. But even when I don't have the appetite to eat, I have to force myself to eat in order to take the pills. They are all pills, so I need fresh water to take them too.

One of the medicines must be taken on an empty stomach. I take four tablets dissolved in water first thing in the morning. Then I take ten pills at 10 a.m. and another nine at 4 p.m. Before I go to bed I take 15 more pills.

It took me a couple of years to learn to take these medicines the way I am supposed to. I was saying, yes, I'm taking my pills, but in all honesty, I wasn't always. I was not brought up to take pills—I rarely took even an aspirin. So taking all these pills was a difficult new process I had to learn.

I started with AZT. I think the biggest reason AZT didn't work for me is that I went in with a negative attitude. I thought, I'm going to get all these side effects. And I did. I experience some side effects with the pills I'm taking now, including the neuropathy in my hand. But I'm learning that with a positive attitude, I'm able to overcome the side effects, or at least live with them.

For example, whenever I start feeling ill, I remember a walk I took with my parents in the spring when the cherry blossom trees were starting to bloom. I try to remember that feeling—how gorgeous it was, and how at peace I was with myself. And that helps tremendously—not just mentally, but physically.

I remember one time in particular, when I was walking and I tripped and scraped my hand. It really hurt. But I made myself think of the cherry blossoms, and then my hand didn't hurt any more. If I had sat down and looked at my hand, it probably would

have hurt for a couple of days. But I didn't let the pain affect my mind. I took it away from the pain.

Of course this is not going to work every time. I still have pain in my hand, no matter how much I think about cherry blossoms. But there are times when you can overcome pain. Most of the time you can. You just have to keep trying until it works.

I realize that I am very fortunate to have access to antiretrovirals and even experimental drugs for HIV. But in my opinion, the most important factor in improving my health has been a positive attitude.

Adopting a positive attitude has made a direct difference in my life. Now HIV is making me take care of not only my body, but also my mind and spirit.

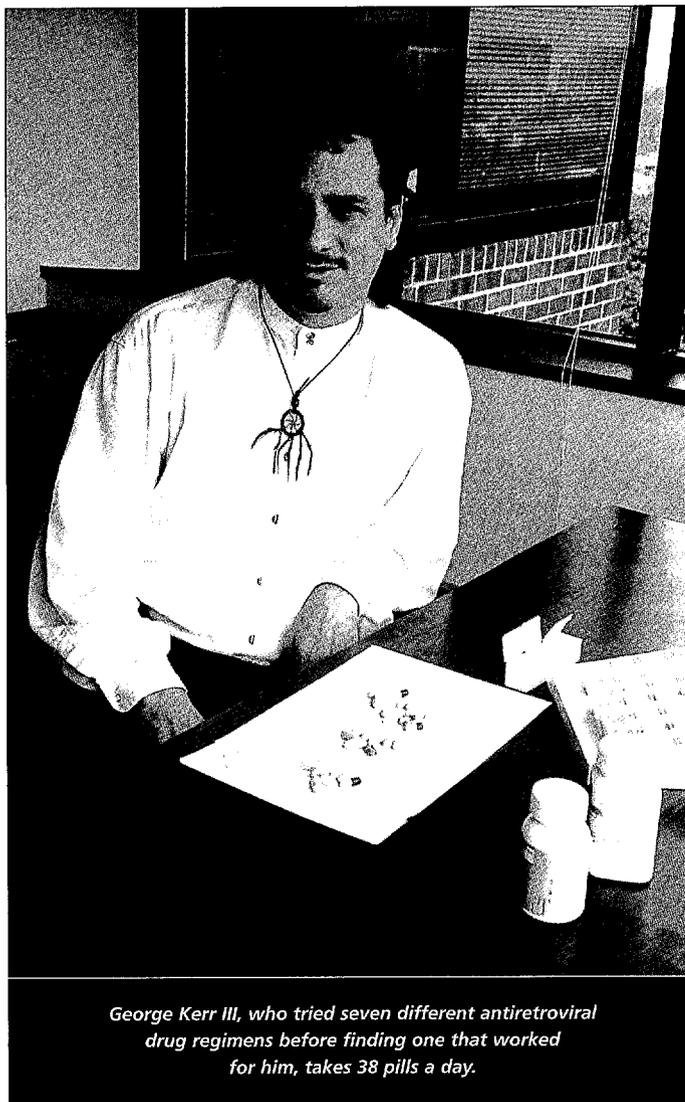
It took me three years to learn just how powerful the mind and spirit are. I think the turning point was when I had a lymph node removed from my neck. They removed a mass the size of a tennis ball. Fortunately, it wasn't cancerous. But that was a real eye-opener for me. And I think that was when I stepped over the line and started to take an active role in making my HIV status a positive rather than a negative.

What helps me most is meditation, the support of family and friends, and reading—a lot of reading. Through reading, I've learned how to use meditation to conquer pain and I've been inspired by the success stories of other HIV-positive people.

The biggest success of my life so far has been riding my bike 350 miles from Raleigh, North Carolina, to Washington, D.C., last year in an "AIDS Ride" to raise money for HIV/AIDS care and support programs. I wore a jersey that said "Positive Pedaler" on the back, and I got so much support from the people in all the towns we went through. And seeing other people out there—all age groups, all genders, all races—for a cause that affected me directly was so uplifting.

When I started to train for the ride, I hadn't ridden a bike since I was a child. I couldn't even change a tire. So I never thought I could do the whole thing. But getting out there and proving to myself that I could do it was a wonderful feeling. When I grow old, that's one thing I will always remember.

Of course everyone doesn't need to go out and bike 350 miles. But regular exercise and good nutrition can help keep you healthy. Just getting out and walking every day can make a big difference.



George Kerr III, who tried seven different antiretroviral drug regimens before finding one that worked for him, takes 38 pills a day.

MARY O'GRADY/FPHI

And you can use that time to meditate and relax, to concentrate on the positive things in your life.

Being at peace with myself helps me maintain a positive attitude as well. Many of us are told that we are being punished by a higher power. Once we realize that that isn't true, we can let spirituality back into our lives.

My daily inspiration is a quote that I have posted above my desk at work: "By being open about my status, I found it served more people than just myself. And that attitude has kept me alive."

I count myself extremely lucky because I can be very open about my HIV status with my friends and coworkers. And I enjoy talking about it because I like educating people. That edu-

cation is three-fold: teaching people who are positive how this can be a good experience, talking to caretakers about how to care for those who are positive, and helping people who are negative understand how important it is to stay negative.

To all of them I say: "How we protect and care for ourselves matters now. Our positive attitudes and behavior matter now." ▣

GEORGE KERR III IS AN ADMINISTRATIVE SERVICES ASSISTANT IN FHI'S HIV/AIDS PREVENTION AND CARE DEPARTMENT IN ARLINGTON, VIRGINIA.

### George Kerr's Medication List

March 26, 1998  
(excluding allergy medications)

Meds	7am	10am	4pm	Bed
<b>Fortovase</b> (200mg) With food		6 Tabs	6 Tabs	6 Tabs
<b>DDI</b> in H <sub>2</sub> O W/O food	4 Tabs			
<b>Hydroxyurea</b> (500mg) With food		1 Tab		1 Tab
<b>Sustiva</b> (200mg) With food				3 Tabs
<b>Bactrim,DS</b> (800/160) With food			1 Tab	
<b>Lamictal</b> (100mg) With food				1 Tab

# Practical Nutritional Advice Helps People Live Longer with HIV

BY KATHLEEN HENRY

*An NGO run by people living with HIV/AIDS in Zimbabwe teaches others who are HIV-positive how to improve their health by eating nutritious traditional foods.*

If your granny didn't eat or drink it, you shouldn't either.

This simple rule of thumb and other practical advice on nutrition from The Centre in Zimbabwe has helped hundreds of HIV-positive people live longer, healthier lives.

What it means, explains Centre director Lynde Francis, is reverting to the foods used before colonization and avoiding low-fiber Western diets that are high in fat, sugar and stimulants, which have harmful effects on the immune system.

"Where there is a traditional cuisine, that is the one people should adopt," she said. "The only exception is where the staple is a potato or cassava or yams—what we call ground produce. Then they need to supplement it with unrefined grains."

In Zimbabwe, for example, a traditional staple is *sadza*, a stiff porridge made from ground maize, millet or sorghum.

Centre staff show clients that a nutritious diet is effective and affordable. "When you tell people that they can stay healthier by eating well, their faces fall because they think that's expensive," Francis said. "But in most developing countries, to eat healthy is almost always cheaper."

In fact, when Centre staff compare the cost of buying food for a nutritious traditional diet to a client's regular shopping bill, the savings are substantial. They recommend that clients use these savings to buy vitamins to strengthen their bodies' natural resistance to infection.

Francis noted that scientific papers on nutrition tend to focus on parenteral feeding, supplementation with micronutrients, and other high-tech interventions that are irrelevant to most people in low- and middle-income countries, rather than food.

Centre staff show people that they "don't need Western packets of protein powder," Francis said. They do so by translating nutritional theory into useful information, suggesting foods that are available and affordable to people with limited incomes and explaining the health benefits of a nutritious diet in clear, understandable terms.

This advice is provided through individual counseling, group education sessions and training workshops. Until last year, when

a grant from the Canadian Public Health Association's Southern African AIDS Training Service enabled The Centre to open an office, these services were offered from Francis' home in Harare, the country's largest city.

The Centre's materials include sample menus and meal plans, lists of foods to eat and foods to avoid, and guidance on the best foods and vitamins to take during various illnesses, such as diarrhea, herpes or shingles attacks, and thrush. Its "Golden Rules of Eating for Health" emphasize the importance of unrefined, unprocessed indigenous foods, clean water, and small, frequent meals.

This is good advice for anyone, but for people living with HIV/AIDS, it is a survival strategy.

Francis and the other six staff members at The Centre know this first-hand. All HIV-positive, they do not take antiretroviral drugs. Instead, they practice what they preach and share what they have learned about diet and natural remedies with others.

"I thought the best thing I could do was helping other people not to have the kind of experience I had when I was diagnosed with HIV in 1986 and there was nothing—no support or information and absolutely no hope," Francis said.

Since it was founded in 1991, The Centre has worked directly with more than 700 clients, in addition to reaching hundreds more through training workshops and educational awareness sessions at workplaces. Of those 700-plus clients, only 68 have died.

This relatively low mortality rate has been achieved without antiretroviral treatment or—in many cases—other drugs. Like most people in countries with limited resources, many Centre clients have little or no access to any medical intervention.

"For many people, good nutrition is the only therapy available," Francis said. "The good news is, it's available, affordable, effective and—importantly—enjoyable, with no adverse side effects like drugs." ▮

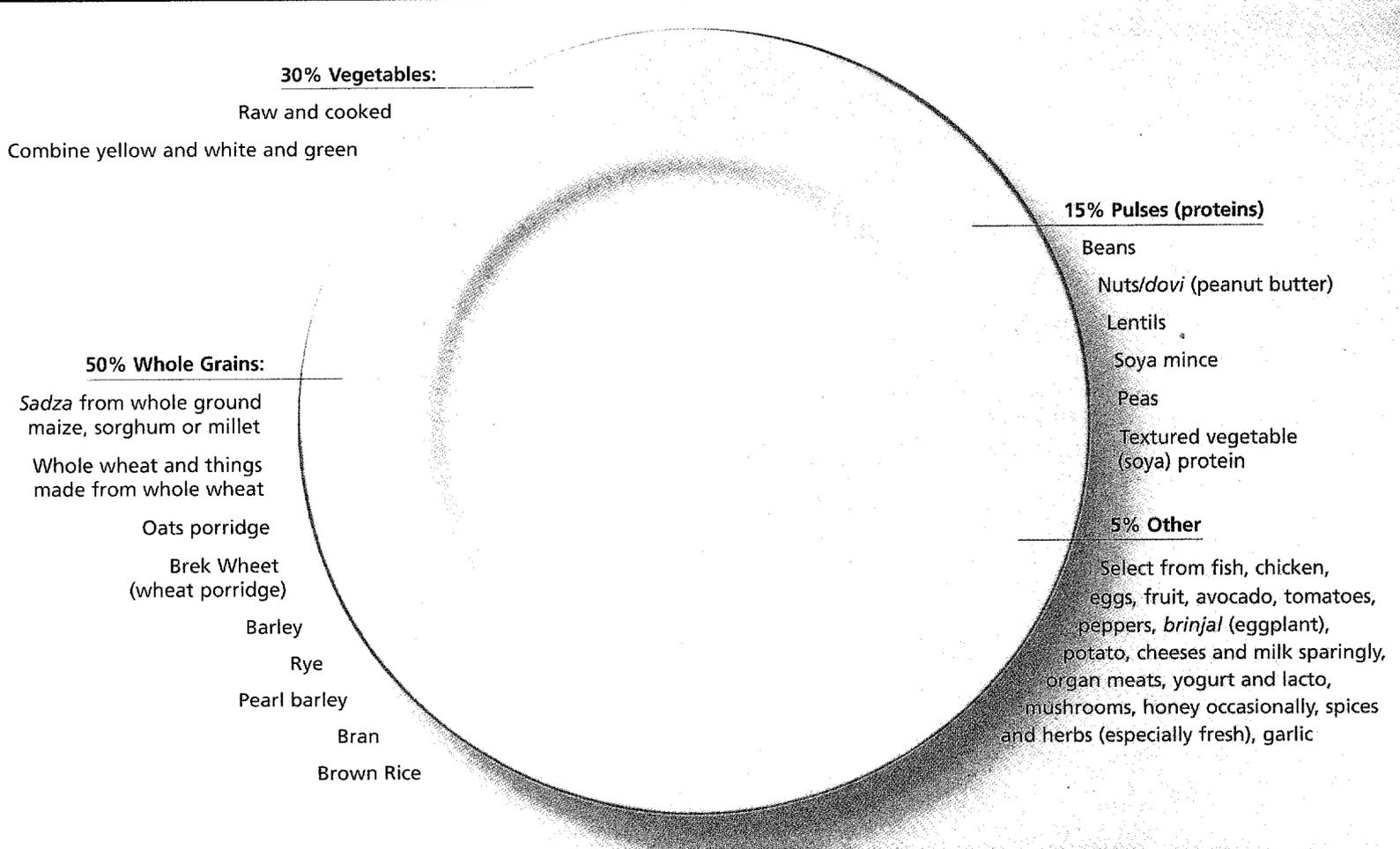
FOR MORE INFORMATION, CONTACT THE CENTRE, 21A VAN PRAAGH AVENUE, MILTON PARK, HARARE, ZIMBABWE.

## Golden Rules of Eating for Health

- Eat whole (unrefined) foods
- Eat natural (unprocessed) foods
- Eat indigenous (not imported) and in-season foods
- Drink clean water (if not bore-hole, boil for 10 minutes or filter)
- Eat little and often: five times daily (every three hours)

## Healthy Combinations: Putting Together a Well-Balanced Meal

35



### Foods to Avoid

Sugar and all food containing sugar: this includes cool drinks, cakes, sweets and cookies

Cooking oil (except olive oil or cold pressed oils). Heating oil to cook with it destroys any goodness—use for salads only.

Red meat and pork (liver and kidney are best if you crave nyama [meat])

Strong tea and coffee (rooibos tea, herb, fruit and bush tea, and decaffeinated coffee are substitutes)

Alcohol and tobacco (do not go into smoky places)

Fats should be used sparingly and not at all with diarrhea.

Tinned, processed and refined foods

### Sample Menu

**7 am**  
Good breakfast (porridge with lacto and fruit)

**10 am**  
Snack (biscuits and banana)

**1 pm**  
Lunch (whole wheat sandwich with egg and salad)

**4 pm**  
Snack (small yogurt or some nuts and fruits)

**7 pm**  
Supper (sadza, beans and vegetables)

Always combine pulses and grains at the same meal.

Adapted from educational materials produced by The Centre, Harare, Zimbabwe.



*For mothers in low-income countries,  
the risk of transmitting HIV in breast milk  
poses an agonizing dilemma.*

# Preventing Mother-to-Child Transmission of HIV

BY JOAN MACNEIL

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*Antiretroviral therapy and alternatives to breast milk can reduce mother-to-child transmission of HIV, but they are not realistic options for most mothers living with the virus.*

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Since the beginning of the HIV pandemic, almost 3 million children have died of AIDS. Another million children were estimated to be living with the disease at the end of 1997, half of them infected last year alone.

Most HIV-positive children acquire the virus from their mothers in the uterus, during labor and delivery, or through breast milk. Their numbers will continue to rise as the number of HIV-positive women of childbearing age increases. In a growing number of countries, HIV has already become the single greatest cause of child death, undermining decades of progress in child survival.

The majority of children infected with HIV live in low- and middle-income countries. This gap in mother-to-child HIV transmission between industrialized and non-industrialized countries continues to widen. For example, in France and the United States fewer than 5 percent of children born to HIV-positive women in 1997 were infected with the virus. In non-industrialized countries, the average was between 25 percent and 35 percent.<sup>1</sup> There are two major reasons for this difference—access to drugs for reducing mother-to-child transmission and breast-feeding practices.

**AZT and Access** Four years ago research in the United States and Europe showed that giving an antiretroviral drug, Zidovudine (AZT), to pregnant women during pregnancy and delivery and to their infants after birth could cut HIV transmission from mother to child by as much as two-thirds.<sup>2</sup> This quickly became common practice in industrialized countries.

That particular regimen of AZT has not been available to women in resource-constrained settings, however, because of its complexity and cost. It is difficult to administer, involving regular drug taking over several months and intravenous administration during delivery. It is also prohibitively expensive, at approximately U.S.\$800 per pregnancy.

Recognizing that most women in non-industrialized countries would not even have the opportunity to consider a drug regimen

that must be taken throughout the last trimester because they have limited or no access to antenatal care, researchers set out to evaluate a more feasible course of therapy. They chose a shorter course of oral AZT administered throughout the last days of pregnancy and during labor and delivery—the time when most mother-to-child transmission appears to occur.

Trials of this short course of AZT, sponsored by the ministries of public health in Thailand and Côte d'Ivoire and the U.S. Centers for Disease Control and Prevention, began in 1996. This year, the results from Thailand showed that the shorter regimen reduced mother-to-child transmission by half.<sup>3</sup>

Both the reduced course of AZT and the HIV testing and counseling that must precede it are beyond the grasp of many HIV-infected pregnant women. But these results have triggered interest among governments and international donors in making this method of preventing maternal-child HIV transmission more widely available. The manufacturer of zidovudine, Glaxo Wellcome, recently agreed to reduce the price for women in low- and middle-income countries, and the Joint United Nations Programme on HIV/AIDS (UNAIDS) is working with governments to provide access to short-course AZT in 11 African, Asian and Latin American nations.

The cost of this therapy still poses a barrier for governments trying to expand access and for individuals who may try to buy it through private health care providers. The discounted price of U.S.\$50 is many times the per capita health expenditure of most non-industrialized countries, and it does not include the additional cost of antenatal HIV counseling and testing and baseline laboratory tests. These costs raise questions of long-term sustainability after subsidies are reduced or eliminated.

Another critical question rarely mentioned in the debate or the research on AZT and maternal-child transmission is how to maintain the health and well-being of HIV-positive mothers. One of the many contradictions of preventing mother-to-child HIV transmis-

sion is that while short-course AZT decreases child mortality, it has no known impact on the health of the mother.

After short-course AZT treatment, HIV-positive mothers are still faced with the burden of their own infection and the likelihood that they will die from AIDS before their infants grow up. Preserving the health of HIV-positive mothers after they give birth should also become a priority, for their own sake and to ensure the continued survival of their infants.

**Breast-feeding Dilemma** Providing short-course AZT therapy to breast-feeding mothers may not be effective because the infants who escaped HIV infection during pregnancy and delivery may become infected through breast milk. Up to one-third of all mother-to-child HIV transmission is due to breast-feeding.

For mothers in resource-constrained countries, this risk poses an agonizing dilemma. By choosing artificial feeding, a woman may avoid passing on HIV to her child. But where the water supply is unsafe, she may also expose her child to other deadly diseases. Research results suggest that in populations with high levels of infant mortality (usually due to infectious diseases), the risk of child death is actually lower if mothers with HIV breast-feed their infants.

Even when an HIV-positive woman knows she can bottle-feed her child safely, there are other disadvantages to artificial feeding. The most formidable obstacle is cost. For example, a year's supply of artificial milk for an infant will cost a Vietnamese family more than the country's per capita annual income. In addition, since prolonged breast-feeding has a naturally contraceptive effect, a woman who does not breast-feed may become pregnant again, repeating the dilemma. And if bottle-feeding becomes a badge of HIV status, a woman who decides not to breast-feed may risk loss of confidentiality and social rejection.

In the absence of clear guidance, mothers who know or suspect that they are HIV-positive must weigh the odds of infecting their babies with HIV, with its certain mortality, against risking infection and possibly infant death by feeding their babies formula mixed with water that may be contaminated.

Given the importance of breast-feeding for child health

and the increasing prevalence of HIV infection around the world, health policymakers and service providers have struggled to develop appropriate and feasible guidelines on breast-feeding for HIV-positive mothers. This has proved to be extraordinarily difficult for a number of reasons.

First and foremost, most mothers do not know their HIV status. In non-industrialized countries, nine out of ten HIV-positive women are unaware that they are infected. Therefore, broader promotion of bottle-feeding could do more harm than good because it might encourage women who are HIV-negative to needlessly seek alternatives to breast-feeding.

On the other hand, more specific guidance is difficult because it is still not possible to compare the risk of HIV acquisition from breast-feeding with the risk of infant and child morbidity and mortality from unsafe artificial feeding in various settings. Researchers' attempts to determine these risks using mathematical models have been constrained by the limited information available, including a lack of consensus on the mechanisms and timing of HIV transmission through breast-feeding.

Early policy guidance to HIV-infected mothers in industrialized countries (where safe and affordable alternatives to breast milk usually exist and HIV counseling and testing are widely available) advised them to avoid breast-feeding. Consequently, very few HIV-positive mothers in these countries chose to breast-feed their children, and few children were infected from breast-feeding. At the same time, mothers in non-industrialized countries were being advised to continue breast-feeding.<sup>4</sup>

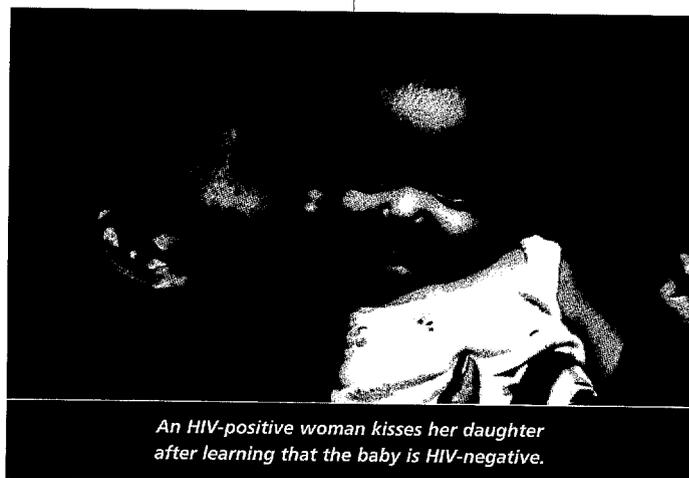
Recently, however, UNAIDS changed its guidelines from wholesale support of breastfeeding for HIV-positive mothers to supporting breast-feeding as the best method of feeding only for infants whose mothers are HIV-negative or whose mothers do not know their HIV status.<sup>5</sup>

The new guidelines emphasize the importance of supporting HIV-positive mothers in their right to choose an infant feeding method appropriate to their needs. They say that mothers who decide not to breast-feed must be ensured access to safe and sufficient quantities of nutritionally adequate breast milk substitutes—a costly and problematic recom-

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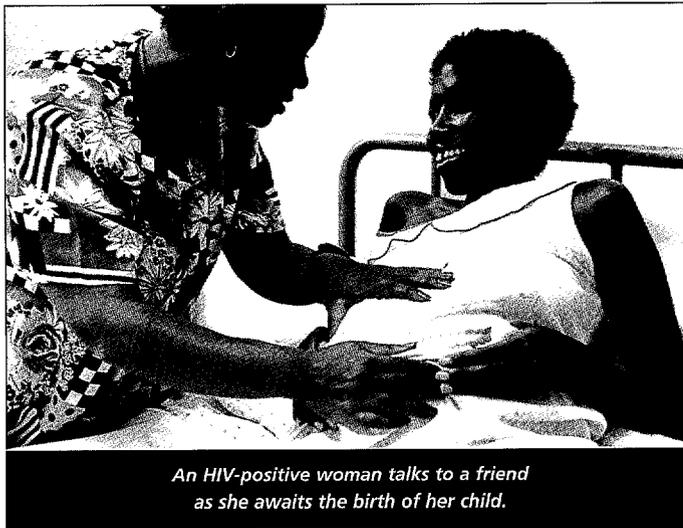
*After short-course AZT treatment, HIV-positive mothers are still faced with the burden of their own infection and the likelihood that they will die from AIDS before their infants grow up.*

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*An HIV-positive woman kisses her daughter after learning that the baby is HIV-negative.*

ANNIE BUNGEROTH/PIANOS PICTURES



An HIV-positive woman talks to a friend as she awaits the birth of her child.

GISELE WULFSOHN/PANOS PICTURES

mentation in many settings. They also call for improved access to antenatal services and voluntary, confidential HIV counseling and testing for pregnant women.

Without such services, women will not be able to make an informed choice about whether or not to breast-feed their children. Through counseling, both women and men of reproductive age can be informed of the implications of their HIV status for the health and welfare of their children. Women who are aware of their HIV-positive status need the best available information on the risk of HIV transmission through breast-feeding and on the risks and possible advantages of other methods of infant feeding. And women who are HIV-negative need to know that if they become infected after they begin breast-feeding, they are at heightened risk of passing on the virus in their breast milk because of the high concentrations of HIV in a person's blood early in infection.

**Unanswered Questions** In the search for more effective and feasible ways of preventing mother-to-child transmission of HIV, many questions remain. Little is known about the interaction between short-course AZT treatment and breast-feeding, the potential of more affordable alternatives to AZT and bottle-feeding, or the impact of the fear of maternal-child transmission.

As efforts to expand access to short-course therapy begin, there is some concern that this drug regimen may actually increase the amount of HIV in a person's system during breast-feeding, reducing its efficacy in breast-feeding populations. This concern is based on observations of a rebound effect on viral load in some adults after they stop taking AZT and on the fact that short-course therapy ends just before breast-feeding begins.

Continuing AZT treatment during the breast-feeding period might reduce the risk of HIV transmission through breast milk, but no research has examined this question. If AZT was found to have a protective effect during breast-feeding, it would increase the rationale for countries to expand access to the drug for HIV-positive pregnant women. Otherwise, HIV transmission through breast-feeding will weaken the effect of AZT on child mortality.

Research is also needed to assess more affordable and feasible ways of preventing mother-to-child HIV transmission. For example, little is known about promising options for reducing the risk of HIV transmission through breast milk, such as adding Vitamin A to the diets of HIV-positive mothers and treating other maternal infections.

Even less is known about the psychological, sociological and possibly even immunological impact of the choices HIV-positive mothers must make. We do not know how the fear of infecting a young infant through breast-feeding—a practice with deep cultural, emotional and psychological roots that is universal in many countries—

affects women, families and society. We also do not know what toll the fear of infecting an unborn child takes on women and their families, particularly in cultures where children are highly valued and a woman's identity is closely associated with child-

bearing. These fears may play a role not only in decisions about treatment or infant feeding, but also in HIV transmission itself.

**Protecting Women and Children** Two interventions have been shown to reduce the risk of mother-to-child transmission: antiretroviral therapy for HIV-positive pregnant women and alternatives to breast-feeding. Another important—and often overlooked—option is primary prevention, or prevention of HIV in women of childbearing age.

The role of primary prevention in preventing HIV in children adds urgency to the need for policies and programs to reduce women's vulnerability to HIV. Practical measures to prevent HIV infection in women and men should include providing information about HIV/AIDS and its prevention, promoting safer sex and ensuring access to reproductive health services that include family planning and treatment for sexually transmitted infections.

It is encouraging that effective methods to limit mother-child transmission have been identified, but discouraging that, for the most part, they are too complicated and costly for universal use in the countries where they are most needed. Further research to answer the many unanswered questions and to develop simpler approaches is critical. Meanwhile, the most effective mechanism we have to prevent mother-to-child transmission remains prevention of the initial HIV infection in women. □

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- <sup>5</sup>UNAIDS, WHO and UNICEF. 1998. Consensus statement on infant feeding and HIV. Geneva: World Health Organization.

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## AIDSCAP PROJECT PUBLICATIONS

The following publications, published at the end of the AIDS Control and Prevention (AIDSCAP) Project (1991-1997), are available from FHI's HIV/AIDS Prevention and Care Department:

**AIDS Control and Prevention Project Final Report** This two-volume report highlights the accomplishments and results of the world's largest international HIV/AIDS prevention effort. Volume I contains detailed information about AIDSCAP regional programs and the technical and program strategies used to support them. Volume 2 contains summaries of individual country programs and activities.

**HIV Risk Behavioral Surveillance Surveys (BSS): Methodology and Issues in Monitoring HIV Risk Behaviors** This report summarizes the recommendations from an international workshop, "HIV Risk Behavioral Surveillance: Country Lessons, Lessons Learned, and Recommendations for the Future," held in Bangkok, Thailand, August 11-14, 1997.

**The Female Condom: From Research to the Marketplace** This report presents consensus recommendations from a two-day conference held May 1-2, 1997, in Arlington, Virginia, to develop strategies for making female condoms available to women worldwide.

## SPECIAL REPORTS

**Making Prevention Work: Global Lessons Learned from the AIDS Control and Prevention (AIDSCAP) Project, 1991-1997** This report presents AIDSCAP lessons learned in the areas of behavior change communication, sexually transmitted disease prevention and treatment, condom social marketing, policy development, behavioral research, program evaluation and capacity building. It also describes the project's experience in building gender-sensitive initiatives, integrating care and support into HIV/AIDS programs, and targeting mobile populations for HIV/AIDS prevention.

**Meeting the Challenge of the HIV/AIDS Epidemic in the Dominican Republic. The AIDSCAP Response, 1992-1997** This special report shares the accomplishments and lessons learned of the AIDSCAP program in the Dominican Republic, which reached and influenced thousands of people in the workplace, adolescents, young adults, women, and men who have sex with men.

**The Tanzania AIDS Project: Building Capacity, Saving Lives. The AIDSCAP Response, 1993-1997** This special report describes the accomplishments and lessons learned of the Tanzania AIDS Project and presents its unique "cluster" strategy as a global model for HIV prevention programming in resource-poor settings.

## BCC HANDBOOKS

**HIV/AIDS Care and Support Projects: Using Behavior Change Communication Techniques to Design and Implement Care and Support Projects** This handbook outlines how to design care and support interventions, select target audiences and use effective communication approaches. It also addresses confidentiality and supporting people living with HIV/AIDS.

**Policy and Advocacy in HIV/AIDS Prevention: Strategies for Enhancing Prevention Interventions** Written for program managers and policy advocates of HIV prevention, this handbook offers suggestions for making policy an effective component of HIV/AIDS programming.

**Partnership with the Media: Working with the Media for HIV/AIDS Prevention** This handbook provides readers with a strategy and practical suggestions for forming a long-lasting partnership with the media to inform people about HIV/AIDS and its prevention. Available in English and French.

## SYNOPSIS SERIES

**Regional Accomplishments and Lessons Learned** This booklet discusses the accomplishments and lessons learned of AIDSCAP's HIV/AIDS prevention programs in Latin America and the Caribbean.

**Capacity Building** This booklet provides a theoretical framework and practical strategies for enhancing the ability of individ-

uals, organizations and institutions to design, manage, evaluate and sustain HIV/AIDS prevention programs.

#### **Civil-Military Collaboration**

This booklet introduces key issues in civil-military collaboration for HIV/AIDS prevention and provides suggestions for integrated prevention planning.

#### **Religious-Based Initiatives**

A collaborative production of AIDSCAP's Latin America and Caribbean Regional Office and MAP International, this booklet outlines strategies for collaboration between religious and health organizations on HIV/AIDS prevention and describes model interventions in Latin America, where religious-based initiatives are filling a strategic niche in HIV/AIDS programming.

Other booklets in the Synopsis Series include **Gender-Sensitive Initiatives, The HIV/AIDS Multidimensional Model, Behavioral Research and STD Syndromic Management.**

#### **Ordering Information**

All publications are in English unless otherwise specified. Single copies are available free of charge. Organizations from industrialized countries are asked to pay shipping charges (please include a DHL or Federal Express account number with your request). To order these publications, contact Information Programs, Family Health International, 2101 Wilson Boulevard, Suite 700, Arlington, Virginia 22201, USA. Phone: (703) 516-9779; Fax: (703) 516-9781.

## **OTHER RESOURCES**

#### **Positive Development**

Healthlink Worldwide (formerly AHRTAG). This 144-page manual was developed by and for people living with HIV/AIDS to increase the confidence and skills of those wishing to establish self-help groups to advocate change. It contains step-by-step instructions, training exercises and case studies addressing important topics such as project development, fundraising, working with the media and campaigning. The manual also lists additional resources and organizations that can offer more information. Single copies are free to indigenous organizations in developing countries with no access to Sterling or U.S. dollar currencies. For others the cost is 15 pounds or U.S.\$30, which includes postage. Contact Healthlink Worldwide at Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB, United Kingdom. Fax: (44 171) 242-0041; e-mail: [publications@healthlink.org.uk](mailto:publications@healthlink.org.uk).

#### **AVERT: A Tool for Estimating Intervention Effects on the Reduction of HIV**

**Transmission** Family Health International. AVERT is a computer program designed to estimate the impact of prevention interventions on HIV transmission. The estimates of HIV infections averted that it produces can also be used to carry out cost-effectiveness analyses of intervention programs that were tailored for specific target populations in defined epidemiological settings. The program is easy to use: with only a brief intro-

duction, a computer-literate user with some background in epidemiology can learn to operate AVERT within about an hour. The manual accompanying the AVERT software includes complete instructions for operation and a tutorial with practical examples of applications. Computer requirements: IBM-compatible PC with DOS 3.1 or higher (or equivalent OS) and 1.6MB disk space. To receive a free copy of the AVERT program and manual, contact Dr. Thomas Rehle at Family Health International, HIV/AIDS Prevention and Care Department, 2101 Wilson Boulevard, Suite 700, Arlington, VA 22201, USA. Fax: (703) 516-9781; e-mail: [trehle@fhi.org](mailto:trehle@fhi.org).

#### **Care and Support for People with HIV/AIDS in Resource-Poor Settings**

Department for International Development (DFID). This 192-page publication, part of DFID's series on sexual health and health care, helps planners and policymakers identify strategies for HIV/AIDS care and support activities that maximize limited financial and human resources. The monograph is also useful for individuals who need basic information about HIV/AIDS care and support issues, including cost-effectiveness analysis, gender, and health sector reform. To request a copy, contact International Family Health, Parchment House, 13 Northburgh Street, London EC1V 0AH, United Kingdom. Tel: (44 171) 336-6677; Fax: (44 171) 336-6688; e-mail: [infor@ifh.org.uk](mailto:infor@ifh.org.uk).