While preventing the spread of HIV (human immunodeficiency virus) is essential to controlling the AIDS (acquired immune deficiency syndrome) epidemic, health workers also must care for the more than 36 million people already infected with the virus. In the absence of a cure or accessible treatment to reduce damage to the immune system, providing care often means helping people living with HIV/AIDS cope with the psychological and social as well as physical burdens of a chronic and ultimately terminal illness.

In industrialized countries, approximately eight to ten years elapse from HIV infection to the development of clinical AIDS, after which people survive approximately one to five years without antiretroviral treatment. Survival times are believed to be shorter in developing countries due to malnutrition, co-infections with other diseases, and more limited access to health care. While AIDS progresses at a similar rate in women and men, in some settings sociocultural and economic factors may shorten women's survival.

People living with HIV/AIDS need access to a broad continuum of care throughout the course of the illness. Early counseling, as soon as people receive a diagnosis of HIV, can help them cope with the diagnosis and advise them on behavioral changes that will reduce future health problems and limit transmission of the disease. As HIV progresses, weakened immune systems make people susceptible to a host of opportunistic infections and illnesses. Medical care to treat these infections and to relieve other common symptoms can increase the quality of—and sometimes prolong—life for people with AIDS. Where feasible, antiretroviral drugs can slow or even reverse progression of the disease. As people with AIDS near the end of life, a combination of practical and emotional support can help them prepare for death and offer consolation to surviving family members.

Programs that provide care to people living with HIV/AIDS reinforce AIDS-prevention strategies. Their most important contribution to prevention is encouraging people to come forward for voluntary counseling and testing, at which time they can be educated about disease transmission and how to protect their sexual partners. (For a discussion of voluntary counseling and testing, see Outlook, Volume 19, Number 1.) Knowing that care is available to relieve their suffering and perhaps prolong their lives gives people an incentive to be tested. At the same time, voluntary counseling and testing provides
the ideal entry point into a broad continuum of care for people diagnosed with HIV. These programs, with ongoing input from communities, also can reduce the social barriers to testing and the stigma associated with HIV/AIDS. Finally, where it is available, treatment with antiretrovirals may actually decrease the risk of an infected person transmitting HIV by reducing viral load.7

**Barriers to Care**

People living with HIV/AIDS often must overcome sociocultural and economic barriers to get the care and support they need. The stigma associated with HIV/AIDS makes many people reluctant to admit they are infected or seek care, and can make health workers reluctant to provide care.8

Governments often have been slow to take action in part because of the long latent period before people become sick. AIDS also raises sensitive sexual issues that can be politically difficult to address, and transmission often is attributed to stigmatized groups such as sex workers, drug users, and homosexual men.9

Even if the political and social will to confront AIDS is present, the scale of the epidemic may overwhelm resources in countries where per-capita health expenditures are small and the health infrastructure is weak. HIV dramatically increases the burden on health services, especially since most victims are young adults who otherwise would require little health care. At the same time, stress and AIDS-related deaths among health care personnel reduce the number of health workers available to care for patients.3,10

While the interventions that can improve the quality of life for people living with HIV/AIDS are understood, they may not be cost-effective in every setting. Policymakers must make difficult choices, weighing HIV/AIDS against other public health concerns and balancing prevention and treatment. To guide these decisions, the World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) have defined essential care that should be universally available to people living with HIV/AIDS (see Figure 1). Other activities of greater cost and complexity should be offered where possible.

Care for people living with HIV/AIDS falls into three broad categories: (1) palliative care and social support to relieve symptoms, address nutritional and welfare needs, provide psychological support, and cope with social stigma; (2) diagnosis, treatment, and prevention of opportunistic infections and HIV-related illnesses; and (3) treatment with antiretroviral drugs.

**Palliative Care**

Palliative care does not attempt to treat HIV/AIDS. Rather it improves patients’ quality of life by treating their symptoms and offering them and their families psychological, social, and spiritual support. Ideally palliative care begins with the diagnosis of HIV and continues throughout the course of the illness, eventually helping a person die with dignity and in peace.11,12

HIV/AIDS offers special challenges to palliative care because the course of the disease and its possible complications are unpredictable and highly variable.11,13 In addition, social stigma isolates the people affected by HIV/AIDS and limits community support, while the scale of the epidemic intensifies emotional and financial stresses on families, who may lose multiple members to the disease. Comprehensive palliative care for people living with HIV/AIDS has four components:

- Relief of symptoms. Half or more of AIDS patients suffer from pain, fatigue, and weight loss. Insomnia,

<table>
<thead>
<tr>
<th>Essential Care</th>
<th>Additional Activities of Intermediate Complexity and/or Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Psychosocial support</td>
<td>• Intensified case finding and treatment for tuberculosis</td>
</tr>
<tr>
<td>• Palliative care</td>
<td>• Preventive tuberculosis therapy</td>
</tr>
<tr>
<td>• Treatment of common HIV-related infections</td>
<td>• Systemic antifungals</td>
</tr>
<tr>
<td>• Nutritional care</td>
<td>• Treatment of HIV-related malignancies</td>
</tr>
<tr>
<td>• Prevention of sexually transmitted infections</td>
<td>• Treatment of extensive herpes</td>
</tr>
<tr>
<td>• Family planning</td>
<td>• Funding of community efforts to reduce the impact of HIV infection</td>
</tr>
<tr>
<td>• Prevention of mother-to-child transmission</td>
<td>• Highly active antiretroviral therapy (HAART)</td>
</tr>
<tr>
<td>• Cotrimoxazole prophylaxis</td>
<td>• Treatment of HIV-related infections that are difficult to diagnose and/or expensive to treat</td>
</tr>
<tr>
<td>• Community activities that reduce the impact of HIV infection</td>
<td>• Advanced treatment of HIV-related malignancies</td>
</tr>
<tr>
<td></td>
<td>• Public services to reduce the economic and social impacts of HIV infection</td>
</tr>
</tbody>
</table>

Adapted from Perriens et al., 2000.10
shortness of breath, diarrhea, skin problems, fever, and depression also are common. Unfortunately, health workers may give these symptoms low priority and often lack the training and supplies to treat them.12,13

- Psychosocial support. Individual counseling, meeting with other people infected with HIV in support groups, and support from community and family members can help people accept their situation, talk about their diagnosis, and cope with anxiety and depression.10,13 Community education is important to counteract the stigma associated with HIV/AIDS.

- End-of-life care. As people with AIDS approach the end of their lives, caregivers can keep them physically comfortable with good nursing care and help them prepare for death, including making plans for dependents. End-of-life care also includes bereavement counseling for family and friends to help them say goodbye and cope with their grief.12

- Caring for caregivers. Whether AIDS caregivers are family members, community volunteers, or health workers, they need emotional support and stress management to prevent depression and burnout.14

Community-based care. When the AIDS epidemic began, sick people flooded into hospitals and health centers, occupying as many as 50 to 70 percent of beds in the hardest-hit areas and straining already-overburdened health care systems.3,13 In response to the crisis, governments, nongovernmental organizations (NGOs), and grassroots groups began developing alternative service delivery models, including outpatient AIDS clinics, outreach care, hospice care, and the option that has proven most effective: community-based care.15

Home care rooted in the community has proven more successful and more efficient than medical outreach programs.16 Community-based programs train volunteers to visit local people living with HIV/AIDS. In Zambia, community-based outreach cost only US$26 for six months of visits (compared with US$312 for outreach from medical facilities), and caregivers spent far more time with clients.3 Community volunteers are trained to offer counseling, basic nursing care, and practical advice about nutrition, hygiene, and preventive health care. They also act as a liaison with the local clinic and, where needed, may learn specialized skills such as tuberculosis treatment or pain management.14 Programs operating in some communities may find it difficult to recruit enough volunteers and donations, however.17

People living with and affected by HIV/AIDS can make a special contribution to palliative care programs. Their experience and insights ensure that services are appropriately designed and implemented; they also make effective counselors and compelling community speakers.

Community-based care should be supported by the formal health care system. People living with HIV/AIDS need comprehensive care delivered across a continuum that extends from the home to the hospital and includes community organizations as well as the formal health care system. Above all, a strong referral system and consistent discharge-planning will link services together so that people living with HIV/AIDS can seek care at the most appropriate level and move freely between levels of care.10,15,18

The burden of everyday care falls on family members. In the later stages of HIV/AIDS, family caregivers face a long list of tasks, including helping feed, toilet, and wash the patient; cleaning and dressing sores and ulcers; administering medications; and providing comfort and company.13 Community-based care programs can give them the training and psychological support they need to do these jobs well, including a thorough grounding in infection prevention. In Thailand, for example, the Sanpatang project provides medical, emotional, and financial support to the grandmothers who traditionally fulfill the role of home caregivers.17

Helping families affected by AIDS meet basic needs for food, water, and shelter can be as important as offering nursing care and counseling. When the adults in a family become too sick to work, old people and children struggle
to make up the difference. Community volunteers can help with domestic tasks. The home-care program associated with the Church of Christ in Soweto, for instance, supplements a small group of 150 volunteers trained in counseling with about 2,000 casual volunteers who help AIDS-affected families with household chores, roof repair, raising crops, and other essential tasks.4

**Opportunistic Infections**

HIV weakens the immune system, making people vulnerable to infections and illnesses they normally would be able to resist. These opportunistic infections and malignancies are the major clinical manifestation of HIV infection and, indeed, define the illness.19 Common opportunistic infections include:

- bacterial infections such as tuberculosis, *mycobacterium avium* complex, bacterial pneumonia, and septicemia (blood poisoning);
- fungal infections such as candidiasis and cryptococcosis (cryptococcal meningitis);
- protozoal diseases such as *Pneumocystis carinii* pneumonia, toxoplasmosis, and cryptosporidiosis;
- viral diseases such as cytomegalovirus, herpes simplex, and herpes zoster; and
- malignancies such as Kaposi’s sarcoma, lymphoma, and squamous cell carcinoma.

While women are vulnerable to the same opportunistic infections as men, they face the additional risk of gynecological infections and cancers. Women living with HIV/AIDS need vigilant reproductive health care to address these risks (see box, page 5).

The pattern of opportunistic infections associated with HIV varies from one country to another, even within the developing world.4 For example, tuberculosis is the most prevalent opportunistic infection in Brazil, Congo, and Côte d’Ivoire, affecting more than 40 percent of all people living with HIV/AIDS. In Mexico, however, the prevalence of cytomegalovirus (65 to 69 percent) and *Kaposi’s sarcoma* (30 to 43 percent) is greater than that of tuberculosis (28 percent). In developed countries, *Pneumocystis carinii* pneumonia is the most prevalent opportunistic infection, with 64 percent of HIV/AIDS patients in the United States infected.22

The resources required to treat or prevent various infections also range widely, depending on the drugs required as well as the complexity and cost of diagnostic tests and monitoring.23 Some common opportunistic infections, such as oral candidiasis, can be managed by community-based programs at a cost of less than US$10 per person for a course of treatment.22 They require little equipment and rely on inexpensive, easily stored drugs. Other opportunistic illnesses, such as *Kaposi’s sarcoma* and *Pneumocystis carinii* pneumonia, require more expensive drugs and a significant investment in equipment and facilities such as laboratories and x-ray machines. There are still other opportunistic infections, like cytomegalovirus, that cost hundreds or even thousands of dollars to treat because they require specialized staff, expensive testing and drugs, and/or complex follow-up.

Policymakers often must balance the prevalence and suffering associated with each opportunistic disease against the cost of diagnosis, treatment, and prevention—frequently without complete information on either the cost or benefits of the interventions under consideration. UNAIDS recommends looking beyond the AIDS epidemic and prioritizing health needs shared by the general population—for example, controlling the spread of tuberculosis or offering pain relief for the terminally ill, no matter what their illness is.22

Managing opportunistic infections in infants and children with HIV raises special issues.24 Ensuring good...
nutrition and preventing stunting are key concerns, as is preventing Pneumocystis carinii pneumonia during the first month of life with cotrimoxazole prophylaxis. With the exception of the Bacille Calmette-Guérin vaccine, regular childhood immunizations should be given, including a second dose of measles vaccine. Early diagnosis and aggressive treatment of infections is important; more study is needed on management of persistent diarrhea.

Providers also can advise people living with HIV/AIDS on hygiene and other behaviors that reduce the risk of opportunistic infections. These include drinking only from treated water sources; washing their hands thoroughly after handling diapers, soil, and uncooked meat and produce; never eating raw or undercooked meat and eggs; and avoiding cat scratches, cat excrement, and sick animals. Unfortunately, people living in developing countries may not be able to follow all of these recommendations, for example if there is no source of clean water.

**Controlling tuberculosis.** Tuberculosis is the leading cause of morbidity and mortality among people living with HIV/AIDS in developing countries. It occurs earlier in the course of HIV infection than other opportunistic infections, and research suggests that it may accelerate the progression of HIV/AIDS, increase viral load, and make people more vulnerable to other opportunistic infections; infection with HIV increases the likelihood that people will contract tuberculosis and transmit it to others. As a result, the AIDS epidemic has led to a global resurgence of tuberculosis among the general population, which is straining the ability of the health care system to respond. (For more information on tuberculosis, see Outlook, Volume 17, Number 3.)

Breaking the transmission cycle requires routinely screening and treating people with HIV for active tuberculosis, although HIV infection makes the process more difficult. Among people with both HIV and tuberculosis, half or more have disseminated tuberculosis that cannot be easily detected from just a sputum sample. Once diagnosed, however, people with HIV can be cured of tuberculosis with conventional tuberculosis treatments. The choice of treatment must take into account potential interactions with antiretrovirals and drugs used to treat other opportunistic infections, such as antifungals.

Where tuberculosis is widespread, prophylaxis has been suggested. A meta-analysis of clinical trials in Haiti, Kenya, Uganda, and the United States concluded that a course of preventive drugs cut the frequency of active tuberculosis by 70 percent and reduced mortality by 25 percent among people living with HIV/AIDS who also had positive tuberculin skin tests. The benefits of prophylaxis only appear to last about 18 months, however, probably because of re-infection.

**Cotrimoxazole prophylaxis.** WHO now recommends daily prophylaxis with the widely available antibiotic cotrimoxazole, at a cost of US$8 to US$17 a year, for adults in Africa who have symptomatic HIV or a low CD4 count (low levels of disease-fighting lymphocytes). Cotrimoxazole is used routinely in industrialized countries to prevent Pneumocystis carinii pneumonia and has the potential to prevent other opportunistic infections, including bacterial pneumonia, diarrheal diseases, septicemia, and toxoplasmosis.

Cotrimoxazole prophylaxis has proved effective among people with both HIV/AIDS and tuberculosis in Côte d’Ivoire and South Africa, although there are concerns that widespread prophylaxis will lead to resistance to the drug. In Côte d’Ivoire, cotrimoxazole was associated with a 43-percent decrease in hospital admissions and a 46-percent decrease in mortality. Another study in the same country found that cotrimoxazole led to a 43-percent decrease in mortality from Pneumocystis carinii pneumonia during the first month of life with cotrimoxazole prophylaxis. With the exception of the Bacille Calmette-Guérin vaccine, regular childhood immunizations should be given, including a second dose of measles vaccine. Early diagnosis and aggressive treatment of infections is important; more study is needed on management of persistent diarrhea.

**HIV/AIDS and Women’s Reproductive Health**

Gynecological problems are common among women living with HIV/AIDS and may be the presenting sign of immunosuppression in women. HIV/AIDS contributes to the frequency and severity of many gynecological infections, including vaginal candidiasis, herpes simplex, pelvic inflammatory disease, and genital warts. Treatments for many of these infections are relatively inexpensive, but women living with HIV/AIDS often require higher doses and longer courses of therapy; they also may suffer from more frequent recurrences. Women living with HIV/AIDS also may be at higher risk of cervical cancer. Abnormal Pap smears and cervical dysplasia are about ten times more prevalent in women living with HIV/AIDS than in women without HIV infection. They also are more likely to be infected with human papillomavirus (HPV, the primary underlying cause of cervical cancer), especially with oncogenic subtypes. When women living with HIV/AIDS do develop invasive cervical cancer, they present at more advanced stages, have metastases in unusual locations, respond poorly to standard therapy, and have higher recurrence and death rates than other women.

The relationships between HIV/AIDS, cervical dysplasia (a precursor of cancer), HPV, and invasive cervical cancer are not yet clear, however. Furthermore, there is little evidence that the prevalence of invasive cervical cancer is elevated among women living with HIV/AIDS. (For more information on cervical cancer, see Outlook, Volume 18, Number 1.)
Antiretroviral Treatment

The development of antiretroviral drugs, beginning in the late 1980s with zidovudine (formerly known as AZT), offered people living with HIV/AIDS the hope of an effective treatment. While antiretrovirals do not cure the disease, they can reduce the amount of virus in the body to undetectable levels, delay the development of AIDS, reverse its effects on the immune system, and prolong survival.30 For many people in developed countries, routine use of antiretroviral therapy is transforming AIDS into a chronic disease that requires intensive medical management but allows them to lead full lives over many years. Health education is important, however, to ensure that people taking antiretrovirals understand that they can still transmit HIV and must take precautions to avoid infecting others.

The three types of antiretroviral drugs—nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, and protease inhibitors—disable the enzymes required for HIV to function and multiply.30 Because the impact of a single antiretroviral drug is short-lived, monotherapy is useful only to prevent the transmission of HIV from mother to infant (see Outlook, Volume 19, Number 1). For sustained, long-term control of HIV/AIDS, patients must take a combination of three or more antiretrovirals, from at least two of the three drug types. This type of treatment is known as highly active antiretroviral therapy (HAART).

Delivering HAART in low-resource settings. While antiretrovirals can dramatically improve the well-being of people living with HIV/AIDS, health care systems must overcome multiple obstacles to deliver them safely and effectively. HAART is complex to administer, has many adverse side effects, and may not work for everyone.30 Individuals frequently have to change the combination of drugs they take for therapy to remain effective, so multiple drug combinations must be available.30 Since people only began taking triple combinations in 1996, long-term experience with HAART is lacking.40

In low-resource settings, the lack of skilled physicians, well-equipped laboratories, and other essentials (see box at left) frequently poses a problem for provision of HAART.9 Strengthening the health infrastructure has been a necessary and successful part of the many initiatives to broaden access to HAART in developing countries around the world.7,41,42

Encouraging patient adherence to drug regimens also is essential to program success. New HAART regimens that require patients to take fewer pills less often are easing the challenges for patient adherence, although unpleasant side effects like nausea and diarrhea remain. Even with older regimens that required patients to take up to 20 pills a day following a complex timetable, programs in developing countries have achieved adherence levels equal to those in industrialized countries, where 50 to 75 percent of patients take at least 80 percent of prescribed doses.42,43 When patients skip doses, it not only undermines the effectiveness of the therapy but also encourages the development of drug-resistant strains of HIV. To increase adherence, some AIDS programs in developing countries, such as the Clinique Bon Sauveur in Haiti, are using directly observed therapy (DOT), which was first developed for tuberculosis treatment.7,44

Some additional challenges face programs working to provide effective HAART drug regimens in developing countries. There is little research on which combinations of antiretrovirals are most effective against the HIV subtypes common in the developing world—which are not the same as those prevalent in Europe and the United States.7 Also, where tuberculosis or other diseases are widespread, it is essential to consider potential drug interactions when selecting antiretrovirals.30 Some antiretrovirals require a logistical framework that may not be feasible, for example, if they require refrigeration.

International guidelines call for offering HAART to everyone with HIV who develops a symptomatic infection,
has a CD4 count below 350, or has a viral load above 30,000 RNA copies per ml.\textsuperscript{30} Where resources are limited, however, programs may choose to limit treatment to people with late-stage disease without measuring viral load. Deferring therapy is a viable strategy because HAART has the greatest impact on survival times in later stages of symptomatic HIV/AIDS disease and recovery is good even with delayed therapy.\textsuperscript{3,30} Deferring treatment also allows health workers to identify patients based on clinical signs and symptoms rather than expensive laboratory tests, as is done at the Clinique Bon Sauveur in Haiti.\textsuperscript{7,44} The later HAART is offered, however, the more opportunistic illnesses and other symptoms patients suffer.

Are antiretrovirals affordable in developing countries? While HAART costs about US$10,000 to US$15,000 per person per year in industrialized countries, a combination of political pressure and marketplace competition has driven down the price of antiretrovirals by as much as 90 percent in some developing countries.\textsuperscript{7,46} As a result, a year’s supply of some basic HAART regimens may be available for as little as US$500 in some countries. Even at this price, however, HAART may not be affordable for the poorest countries hardest hit by the AIDS epidemic, given that clinical and laboratory costs more than double the cost of therapy, and treatment must continue throughout a patient’s lifetime.\textsuperscript{7,40} Of course, treatment does reduce the need for palliative care and therapy for opportunistic infections. In Brazil, for example, universal access to HAART has cut AIDS-related hospitalizations by three-quarters, saving the Ministry of Health an estimated US$422 million from 1997 to 1999.\textsuperscript{42} With HAART prices in flux, the costs and benefits of treatment must constantly be reassessed.

Lessons Learned

Low-cost palliative care and treatment of common opportunistic infections can help people living with HIV/AIDS live more comfortable, productive lives and ease the burden on their families. Universal access to cost-effective drugs that relieve common symptoms and control opportunistic infections should be a top priority for HIV/AIDS programs.\textsuperscript{3} Where financial resources and the health infrastructure permit, antiretroviral therapy can make an even more dramatic impact on the quality of life for people living with HIV/AIDS. Lessons learned from providing these services include:

- People living with HIV/AIDS need comprehensive care that addresses their emotional, spiritual, and material needs as well as medical concerns.
- By building on local traditions regarding illness and care-giving, community-based care has the potential to offer effective, affordable, and comprehensive palliative care to people living with HIV/AIDS.
- Overcoming negative community attitudes enables people living with HIV/AIDS to find needed support among their families, friends, and neighbors.
- Involving people living with HIV/AIDS in policy making and program design and implementation will ensure that services meet their needs.

As HIV/AIDS’ impact on individuals, families, and communities continues to grow, programs must strengthen their HIV/AIDS-prevention efforts in conjunction with available treatment and palliative care approaches. Efforts to prevent and to treat HIV/AIDS are most effective when they work hand in hand. Just as prevention and screening efforts (such as voluntary counseling and testing) can facilitate early and appropriate treatment, the availability of treatment regimens can strengthen prevention efforts—for example, by providing individuals with an incentive to be tested for HIV, reinforcing prevention messages, and reducing viral load and, consequently, infectiousness. By building on the synergy between treatment and prevention efforts, HIV/AIDS programs can maximize their impact on this global pandemic.

“Most important is support—counseling and reassurance that, yes, you are sick, but there are a lot of things you can do to improve your [life].”—Elly Katabira, AIDS clinic, Kampala, Uganda\textsuperscript{45}


The guest editor for this issue was Dr. Christopher J. Ellis, President of PATH. The writer for this issue was Adrienne Kols. Editorial assistance was provided by Michele Burns. Production assistance was provided by Kristin Dahlquist.

In addition to selected members of Outlook’s Advisory Board, the following individuals reviewed this issue: Dr. M. Carael, Dr. W. Cates, Dr. G. Davis, Dr. Y.D. Mukadi, Dr. G. Perkin, Dr. J. Pulweritz, and Dr. E. van Praag. Outlook appreciates their comments and suggestions.

OUTLOOK/Volume 19, Number 2

OUTLOOK

ISSN:0737-3732

Outlook is published by PATH in English and French, and is available in Chinese, Indonesian, Portuguese, Russian, and Spanish. Outlook features news on reproductive health issues of interest to developing country readers. This issue is made possible by the Bill & Melinda Gates Foundation through a grant to PATH for reproductive health activities. Content or opinions expressed in Outlook are necessarily those of Outlook's funders, individual members of the Outlook Advisory Board, or PATH. PATH is a nonprofit, international organization dedicated to improving health, especially the health of women and children. Outlook is sent at no cost to readers in developing countries. Subscriptions to interested individuals in developed countries are US$40 per year. Please make checks payable to PATH.

OUTLOOK

J. Jacqueline Serrish, Ph.D., Executive Director

4 Nickerson Street

Seattle, Washington 98109-1699 U.S.A.

Phone: 206-285-3500 Fax: 206-285-6619

E-mail: outlook@path.org

URL: http://www.path.org/resources/pub_Outlook.htm

© PROGRAM FOR APPROPRIATE TECHNOLOGY IN HEALTH (PATH), 2001. ALL RIGHTS RESERVED.

PRINTED ON RECYCLED PAPER

8 OUTLOOK/Volume 19, Number 2