# Women and HIV/AIDS

### **About Women's Edition**

Women's Edition is a global activity of the Population Reference Bureau (PRB) that brings together senior women editors and producers from influential media organizations around the world to examine and report on issues affecting women's health and status. Women's Edition was launched in 1993 and is currently funded by the United States Agency for International Development (USAID) through the MEASURE Communication project.

In 2000, Women's Edition members were selected from among a highly qualified group of applicants. The group represented 10 countries, and their combined audiences number an estimated 25 million.

The mission of Women's Edition is to inform policy decisions through accurate and timely media coverage that reflects women's needs and perspectives. By providing information to millions of women in developing countries on issues that affect them, Women's Edition also attempts to shape public discussion of the problems and helps women make informed decisions on matters related to their livelihood.

The Women's Edition journalists meet twice each year for week-long seminars to examine reproductive health and associated issues, to meet with experts, and to identify strategies for providing solid media coverage of the topics. The Women's Edition seminar investigated the impact on women of HIV/AIDS. Women's Edition members produced the programs and supplements in this collection following their participation in the seminar. Coverage included pullout sections in newspapers, feature stories, news reports, editorials, and talk shows.

Women's Edition also seeks to build institutional capability among media organizations. The journalists share their experiences with colleagues through their local journalism associations. They also give presentations at conferences and organize and lead training in topics they have dealt with at the seminars.

### Women's Edition Members in 2000

Gabriela Adamesteanu, 22, Romania

Harikala Adhikary, "Milijuli," and Gorkhapatra, Nepal

Thaís Aguilar, Servicio Especial para Noticias de la Mujer (SEM), Costa Rica

Sarah Akrofi-Quarcoo, Ghana Radio News, Ghana Broadcasting Corporation, and *Daily Graphic*, Ghana

Josefina (Pennie Azarcon) Dela Cruz, Sunday Inquirer Magazine, Philippine Daily Inquirer, Philippines

Lemlem Bekele Woldemichael, Radio Ethiopia, Ethiopia

Judith Hadonou-Yovo, La Chaine 2, Benin

Eunice N. Mathu, Parents, Kenya

Sathya Saran, Femina, India

Nawal Sayed Mostafa, El Akhbar, Egypt

Sara Adkins-Blanch, Women's Edition, PRB, USA

### **About PRB**

Founded in 1929, PRB is the leader in providing timely and objective information on U.S. and international population trends and their implications. PRB informs policymakers, educators, the media, and concerned citizens working in the public interest around the world through a broad range of activities. PRB is a nonprofit, nonadvocacy organization. MEASURE Communication is designed to produce accurate and timely information on population, health, and nutrition in less developed countries. The ultimate objective of MEASURE is to improve policies and programs.

# Conveying Concerns: Media Coverage of

# Women and HIV/AIDS

Preface
Women's Special Vulnerability to HIV/AIDS 6 Women and AIDS: Being Good Is Bad for Your Health 7 Are You Positive? Women at Risk 9 The Agony of Being African and Woman 10 Calling the Shots 12
Mother-to-Child Transmission13Report on AIDS14HIV/AIDS—Silence and Deafness: The Hlabisa Hospital15
Young People and HIV/AIDS16Current Problems17Are You Positive?18
Migration and HIV19Filipinos and AIDS: It Could Happen to You20HIV/AIDS—Silence and Deafness: Rural Africa22Improve Our Behavior Ourselves23
People Living with HIV or AIDS24Positive—and Carrying On25HIV/AIDS: Another Silence to Be Broken27HIV-Positive Florence: The Face of Courage and Hope29
References

### **Preface**

In many countries, HIV/AIDS represents the deadliest emergency and the greatest social, economic, and health crisis of modern times. The virus has many allies. For one thing, silence and denial have fueled its transmission. Just as cultural and religious taboos inhibit open discussion about sexual practices and preferences, including the use of contraceptives, shame and guilt have surrounded this virus that spreads mainly through sexual contact. Many governments have also been slow to acknowledge the crisis and to formulate policies and programs to halt the spread of the epidemic.

Poverty is another key ally. Those who can afford the costly anti-AIDS treatments prolong their lives, while the world's poor—the majority of whom are women¹—die in overwhelming numbers. One of the most significant challenges is the epidemic's profound impact on the lives of women, whose lack of economic autonomy and low social status often render them powerless to reject risky behaviors or to negotiate the most basic precautions against the disease. Women and girls also provide the main sources of support for the sick and dying, even when they themselves need care.

This Conveying Concerns, the fifth in a series compiled through the Women's Edition project of the Population Reference Bureau (PRB), examines the epidemic's impact on women and girls from the perspective of women journal-

ists (see description of Women's Edition on the inside front cover). In July 2000, PRB assembled senior journalists from 10 countries for a seminar to discuss women and HIV/AIDS prior to the 13th International AIDS Conference in Durban, South Africa. The journalists subsequently produced special supplements in their newspapers and magazines as well as radio programs that highlighted local and international aspects of the epidemic. Excerpts from these supplements and programs are printed here.

The articles and scripts are abridged and appear in five sections, each with an introduction. These sections represent the specific topics addressed by the journalists. The first section looks at women's special vulnerability to HIV and is followed by sections on the transmission of the virus from mother to child, young people, migrants, and people living with HIV and AIDS. The articles in this booklet were produced from various cultural perspectives. However, they all emphasize that women's economic dependence on men, as well as society's acceptance of different standards of behavior for women and men increases women's vulnerability and the burden of the epidemic on women. The articles also demonstrate that the media have a role in helping to remove the shroud of silence and denial surrounding the disease.

### Global Overview: The Changing Face of HIV/AIDS

s powerlessness and poverty place A certain groups and communities around the world at heightened risk of HIV infection, the AIDS epidemic is increasingly female, young, and poor.<sup>2</sup> Women are especially at risk because of the interplay of biological, economic, and social factors, a vulnerability that is especially acute among girls. At the end of 2000, women comprised roughly 47 percent of the more than 36 million adults living with HIV or AIDS, and more than 90 percent of infected adults were from less developed nations.<sup>3</sup> While HIV affects people of all ages, half of all newly infected people are 15 to 24 years old.4 In African countries, HIV-infected young women outnumber infected young men by 2 to 1.5

The risk for women is rising in both more developed and less developed countries, with the most dramatic challenges occurring in countries least able to cope with the epidemic. In Spain, women's share of reported AIDS cases climbed from 7 percent in 1985 to 19 percent in 1995.6 The increase has been more dramatic in Brazil. In 1986, there were 16 men with HIV/AIDS for every woman with the disease; in 1997, there were three men for every woman.<sup>7</sup> In Africa, the region hardest hit by the epidemic, 12 women have HIV for every 10 men with the virus.<sup>8</sup>

Most women with HIV or AIDS become infected during unprotected sex with their male partners. This is especially true in Africa as well as in South and Southeast Asia. Women may also become infected through intravenous drug use or through blood transfusions. In many cases, however, infection is part of a long chain of transmission that begins when husbands or

boyfriends contract the virus through intravenous drug use, relations with sex workers or other female sex partners, or by having sex with other men. This can be seen in India, where high infection rates among female sex workers and their male clients have been followed by a wave of HIV transmission among wives. 10 In many places, migration is believed to contribute significantly to the spread of infection. 11 As men and women leave their spouses and partners to work in the city or in a new country, they form new sexual networks that increase the risks of HIV transmission.

For biological reasons, the risks of contracting HIV through unprotected sex are higher for women than for men. The lining of a woman's vagina and cervix contains mucous membranes that provide a large, hospitable environment for infection. 12 The mucous membranes are thin tissues through which HIV and other viruses can pass to tiny blood vessels.<sup>13</sup> Also, infected semen typically contains a higher concentration of the virus than a woman's sexual secretions. Women are also more susceptible than men to other sexually transmitted infections (STIs), which, if not treated, multiply the risks of contracting HIV. Tearing and bleeding during intercourse, whether from coerced sex or prior genital cutting. also heighten the risk of infection. The risks of contracting HIV are even higher for younger women whose immature cervixes put up less of a barrier to infection.

At the same time, however, the high rates of HIV infection among women and girls often have less to do with biology and more to do with fundamental The AIDS epidemic is increasingly female, young, and poor.

Women's vulnerability to HIV is increased by economic or social dependence on men.

issues of power and control between women and men. Women's vulnerability to HIV infection is increased by economic or social dependence on men. As AIDS and Men editor Martin Foreman notes, it is usually men "who determine whether sex takes place and whether a condom is used."14 In situations of economic dependence, women's ability to insist on condom use becomes even more difficult. If women refuse sex or request condom use, they may risk abuse or suspicion of infidelity. They may even be abandoned or forced to leave the home. Sexual violence. including rape and sexual molestation, is a particular danger to the reproductive health of women and girls and heightens the risk of HIV infection.

The face of AIDS is also increasingly young. The Joint United Nations Programme on HIV/AIDS (UNAIDS) calculates that half of all new HIV infections around the world occur among youth between the ages of 15 and 24.15 Girls are particularly vulnerable to the sexual transmission of HIV since they lack the information, confidence, or resources to decide on or negotiate condom use or other sexual matters. Girls are also more likely than boys to be raped or enticed into sex by someone who is older, stronger, or has more economic power. As Antigone Hodgins of the International Community of Women Living with HIV/AIDS explains, "young women face most of the issues that women do; you just have to add 10 times more difficulty...."16

Increased incidence of HIV/AIDS in young women has led to an increase in transmission of the virus from mother to child, since a baby may contract HIV during pregnancy, delivery, or breast-feeding.<sup>17</sup> Mother-to-child transmission

is by far the most common mode of HIV infection for children below the age of 15.18 Since the start of the epidemic, an estimated 4.3 million children have died of AIDS before the age of 15, well over half a million of them in 2000 alone.19 Another 1.4 million children are currently living with HIV<sup>20</sup>; most may die before they reach their teens.

Though HIV infection is not confined to the poor, poverty has contributed to its spread by creating yet another situation of vulnerability. The overwhelming majority—about 94 percent—of all people living with HIV/AIDS at the end of 2000 were in less developed regions,<sup>21</sup> where a large proportion of the poor are women.<sup>22</sup> Sub-Saharan Africa bears a disproportionate burden of the epidemic. The region is home to 70 percent of the world's adults living with HIV or AIDS.<sup>23</sup> In what has emerged as a vicious cycle, AIDS deepens the poverty of households and nations, and poverty favors the spread of the virus. With few financial assets, the poor are often politically and socially marginalized and often have limited access to health care information and services. Women living in poverty may adopt behaviors that expose them to HIV infection, including the exchange of sexual favors for food, shelter, or money to support themselves and their families.

"Breaking this cycle will require not only greatly increased investments in more effective HIV prevention and care, but also more effective measures to combat poverty," said Robert Hecht, UNAIDS Associate Director for Policy, Strategy, and Research, at the July 9-14, 2000 International AIDS Conference, held in Durban, South Africa. 24

In order to address some of the root causes of HIV's rapid spread, prevention

programs are adopting gender-sensitive approaches that consider the economic, social, and legal factors that fuel the epidemic. These programs seek to increase women's access to information and services. More importantly, however. they attempt to bring about structural changes that redress power imbalances between women and men. In the few countries that have programs on women and AIDS, the emphasis continues to be on education, counseling, partner reduction, male condom promotion, and monogamy. Unfortunately, the messages aimed at women often disregard the power imbalances that inhibit women's active use of most of these options.

Successful programs also aim to empower women economically. AIDS prevention activities are increasingly linked to programs that support women's economic independence through training activities, credit programs, saving schemes, and women's cooperatives. Other programs aim to develop communication strategies to make it easier for young people to discuss STIs. HIV/AIDS, the use of condoms, and sexual behavior. In Uganda, the government and religious leaders, as well as community development and other organizations have developed a campaign to reduce HIV infection. The Kampala-based nonprofit Straight Talk Foundation produces a weekly radio program that reaches more than 1.5 million young people, providing communication techniques for getting out of difficult sexual situations.

Other interventions engage community participation. Women from Nepal, who are sold for work in brothels in the Indian cities of Bombay, Delhi, and Calcutta, are at especially high risk of

contracting HIV. The Maiti Project in Nepal provides education, vocational training, and support and counseling for girls who either escaped their traffickers or are in danger of being sold.

On the medical front, there is much to be done. New drugs that inhibit the development of full-blown AIDS allow some people with HIV to prolong their lives and reduce transmission of HIV from mother to child. These antiretroviral drugs are costly, however, and remain unavailable to the overwhelming majority of those infected. Similarly, some progress has been made on contraceptive barrier methods—such as the female condom—that protect against HIV and other STIs and that a woman can control. However, many women in less developed countries lack access to the technology. In the meantime, the search continues for viruskilling creams, foams, or gels that would allow women to protect themselves without having to secure the cooperation of their partners.

The impact of HIV/AIDS goes beyond the lives of infected people. The disease changes community dynamics, undermines the structure of the family. and threatens the future of children. Experience shows that good information and the involvement of all levels of society are key to containing the virus. Effective strategies also require full government commitment, strong publichealth outreach, and the participation of the pharmaceutical industry. Successful country-level efforts have stressed wide access to medical care and drugs, political commitment, and responsible sexual behavior by women and men. These are key components to ending the spread of the epidemic. ■

Good
information
and the
involvement
of all levels of
society are key
to containing
the virus.

# WOMEN'S SPECIAL VULNERABILITY TO HIV/AIDS

The profound impact of HIV/AIDS on the lives of women is one of the most critical reproductive health concerns of our times. The interplay of certain social, economic, and biological factors, including policies that undermine the rights of women, heightens women's vulnerability to a disease whose most common mode of transmission worldwide is sexual contact.

Women are especially vulnerable to HIV on two counts. Anatomical differences make transmission of the virus through sexual contact far more effective from men to women than vice versa. Even more significant, though, is the fact that powerlessness, dependency, and poverty serve to diminish a woman's ability to fend off the risks.

The Platform for Action adopted by governments at the 1995 Fourth World Conference on Women in Beijing recognizes that low social status is at the root of women's vulnerability to HIV.<sup>25</sup> While individual behavior is largely responsible for the spread of the infection, preventive measures are often beyond a woman's control. Her choices are often restricted by an inability to insist on safe sex, society's acceptance of different standards of behavior for women and men, and economic dependence on men. For these reasons, married womenwhether or not they are monogamous—are the largest group of women at high risk of HIV infection.<sup>26</sup> Since most infected women are of childbearing age, they face the likelihood of infecting their children. As mothers, daughters, wives, grandmothers, sisters, and aunts, women also care for dying family members and for children orphaned by the disease.

Health experts and institutions are advocating ways to combat the virus that take into account the distinct social roles and circumstances of women and men. Governments and donor agencies are placing increased support behind women's rights groups that promote the human rights of women, including the right to have control over and decide freely and responsibly on matters related to their sexuality.

As laid out in the Beijing Platform for Action, this right includes the ability to choose safe, effective, and affordable methods of family planning, and to have access to appropriate information and health care services. Reproductive health experts widely agree on the critical need to enhance access to barrier contraceptive methods that place control in women's hands. Options include making female condoms more accessible and affordable and developing vaginal microbicides—virus-killing creams, foams, or gels. Educating boys and men to engage in responsible sexual behavior is another objective.

### Women and AIDS: Being Good Is Bad for Your Health

by Pennie Azarcon Dela Cruz

Living up to society's definition of a good woman may be hazardous to one's health, at least when it comes to AIDS. Being passive, submissive and naïve in sex matters, as well as too unquestioning of a partner's peccadilloes have made women more vulnerable to HIV, the virus that causes AIDS, experts have noted.

In this country, HIV/AIDS registrar Dr. Consorcia Lim-Quizon reveals that of the 1,390 reported cases of HIV-positive Filipinos from January 1984 to June 2000, 547 are female and 836 are male. Heterosexual contact remains the main mode of transmission, with 818 cases out of 1,390. Homosexual encounters account for 241 cases, followed by bisexual contact (71), perinatal transmission (19), blood or blood products (13), injecting drug use (6) and needle-prick injuries (3).

According to Dr. Quarraisha Abdool Karim of the South African Medical Research Council, a woman's biological makeup places her at higher risk of contracting the virus than a man for several reasons. The female genitalia has a greater exposed and mucosal surface which can suffer lacerations during sex, allowing entry points for the virus. In girls, the risk of microlesions in the genitals is greater because of the added factors of lower defenses and immaturity of vaginal tissues and cervical mucus.

Because they are economically dependent on their spouses, few women can negotiate safe sex for fear of risking violence, mistrust and recriminations, abandonment, or withdrawal of financial support. Hence, women con-

tinue to be passive and nonassertive in sexual relations.

Economic dependence also forces women to endure forced sex, early marriage, and incest, all of which might cause vaginal tearing and expose young women to HIV. For the same reason, most women accept their partners' extramarital affairs though these put them at risk. Most HIV cases are rooted in heterosexual contact involving monogamous women and their philandering husbands.

Cultural factors accelerate the risks of HIV transmission, adds Nonhlanhla Makhanya, research manager of South Africa's Health Systems Trust. "In many cultures, women are not expected to know more than their husbands. especially when it comes to sex matters," Makhanya says. She recalls interviewing long-distance truck drivers about condom use and found that the drivers would use condoms for casual sex if health educators tell them to do so. "But no, they wouldn't use one if it's their wives telling them, because they don't want their wives to think they are smarter than their husbands," says Makhanya, shaking her head.

Adds Geeta Rao Gupta of the Washington-D.C.-based International Center for Research on Women: "Many societies dictate that 'good' women are expected to be ignorant about sex and passive in sexual interaction. This makes it difficult for women to be informed about risk reduction or, even when informed, makes it difficult for them to be pro-active in negotiating safer sex."

Low social status is at the root of woman's vulnerability.

"We will not achieve progress against HIV until women gain control of their sexuality."

—Dr. Gro Harlem Brundtland, Director-General, World Health Organization Across many cultures, women are not expected to discuss or make decisions about sexuality, so suggesting condom use is out of the question. They are also expected to trust their husbands unconditionally. Feelings of love and trust often paralyze women and prevent them from perceiving the real risk, taking preventive measures, and seeking safer sexual relations.

In some societies, women cannot object to their husbands having multiple partners, because this is culturally accepted. In some cultures, men believe that sex with young virgins can cleanse them of sexually transmitted diseases (STDs) and HIV.

At the International AIDS Conference in Durban, South Africa, in July 2000, several suggestions were advanced to make women less susceptible to the deadly virus, among them:

- improving girls' access to education and information to give them more economic options and prevent them from going into the sex trade;
- developing female-controlled prevention methods, like female condoms

- and microbicides (substances that act as barriers to prevent the AIDS virus from getting into the body vaginally);
- addressing the issue of desire for children by developing microbicides that are not spermicides;
- reinforcing women's economic independence by multiplying and strengthening existing training opportunities, credit programs, saving schemes and women's co-ops, and linking them to AIDS prevention activities;
- integrating STD treatment services with family planning services so women can access them without fear of social censure; and
- building safer social norms by supporting women's groups and community organizations that question dangerous behavior like child abuse, rape, sexual coercion, etc.

As Dr. Gro Harlem Brundtland,
Director-General of the WHO [World
Health Organization], puts it, "We will
not achieve progress against HIV until
women gain control of their sexuality."

### Are You Positive? Women at Risk

by Sathya Saran

It is a fact that now HIV has moved beyond gays and drug pushers and entered the bedrooms of married and faithful women who would die rather than look carnally at men other than their husbands. The Indian married woman, regardless of whether she is a blushing bride or a young mother, is at risk. And that means all of us too—you, me, and that high-profile banker across the counter.

**Fact:** Women are increasingly contracting HIV. In some African countries, there are more infected women than there are infected men. These women are wives, daughters, grandmothers, sisters, aunts, and nieces.

**Fact:** Women are becoming infected at ages significantly lower (often five to 10 years earlier) than men.

Fact: Along with teenagers and postmenopausal women, married women in their early twenties form a high statistic in the "new infection" group.

Fact: Ten years after the first woman was diagnosed as being infected with HIV in 1982, an estimated three-and-a-half million were infected, a vast majority through sexual transmission. For most women, the major risk is the fact that they are married.

Add to this other risk factors, such as their nutritional level, incidence of sexually transmitted and reproductive tract infections, lesions, inflammation and scarification in the female genital tract, and careless medical practices

that could infect a woman even on the doctor's table

### Trust no one.

A young accountant once contracted HIV from her husband. Of course, the husband did not know he was HIV positive, or perhaps did not tell her about it—probably hoping, as some of us do, that he could wish the problem away. It was at the antenatal clinic that she discovered her condition. And the dread that took hold of her as she heard the doctor say the words, like a death sentence, lived with her through labour and the first few years of the baby's life. Luckily, the child did not prove to be HIV positive. But the sword still hangs over the couple's heads.

Fact: Most women, regardless of age or socioeconomic status, get infected by errant husbands who are engaged in sex with other partners, who could include sex workers. The fact that many Indian women silently suffer from sexually transmitted infections (that increase vulnerability to HIV infection from a partner) compounds the problem and accounts for the high incidence of HIV infection among women. Also, the fear of ostracism and rejection makes many women hide or neglect their condition, even when they know that the only source of infection is the husband.

"I trusted my husband!" is the cry that is most often heard from countless HIV-positive women who are today ostracised and blamed for bringing AIDS into the home. The fear of ostracism and rejection makes many women hide or neglect their condition.

### The Agony of Being African and Woman

by Eunice N. Mathu

As the AIDS epidemic sweeps across developing nations with a vengeance, women are the most hard hit. African women are hit even harder. Research findings indicate that 55 percent of adults infected with HIV/AIDS in Africa are women. Statistics show that women and girls 15 to 24 years show the highest rates of increase.

Women in Africa are bearing the brunt of the epidemic, not only as people living with AIDS, but also as the ones caring for infected relatives, orphaned children, and others. The many malefemale inequalities also make women increasingly vulnerable to HIV infection.

It is a fact that, physiologically, women are more vulnerable than are men to HIV transmission. For African women especially, this vulnerability is heightened by social, cultural, and economic factors that place them at a disadvantage within relationships, the family, the economy, and the society at large. In total, the African woman's glaring lack of power over her body and sexual life, coupled with social and economic inequalities, make her an easy prey for contracting and living with HIV/AIDS.

World Health Organisation (WHO) statistics show that the rate of HIV infection is higher for women than for men in most African countries and that in several big cities, one out of three pregnant women has HIV. The vast majority of these women are monogamous and have been infected by their husbands. A study in Uganda found that 60 percent of HIV-positive women are married and monogamous. Thus, more often than not, HIV is brought home to the woman by her partner. Furthermore,

and to the detriment of African women, they have little say on the use of condoms. It is the men who decide whether to use condoms or not and even when sex takes place.

Once a woman is HIV positive, she faces stigmatisation. She is rejected by even her own family, regardless of whether or not it was the husband who brought the infection home. She is especially subjected to the violation of her sexual and reproductive rights. She is forced to suspend or change her sex life and will not be allowed to have children. In many instances, HIV-positive married women are abandoned by their husbands with no legal or economic recourse.

Recently, a Kenyan man ejected his HIV-positive wife from their main house to live in modestly furnished servants' quarters. The wife, a 34-year-old bank cashier, had contributed through mortgage payments to the buying of their home. However, when she tested HIV positive, the husband kicked her out. He went to court and sought estrangement from his wife, saying that her HIV status had put his life in danger. He also claimed cruelty, assault, abuse, and other matrimonial offences.

In a landmark ruling on July 31 this year [2000] that was hailed as a good precedent and practical policy statement on AIDS, three Court of Appeals judges hearing the suit ordered the husband to take back his wife. They noted that although they sympathised with the husband's fears, it would have been morally wrong for him to desert his spouse until a court decreed otherwise.

This case was, however, more the exception than the rule. Many women

Women in Africa not only live with AIDS, but also care for infected relatives and orphaned children. cannot pursue their legal rights. Often, after being widowed by AIDS, a woman loses her property to greedy relatives and finds herself abandoned by the whole family. She has to take care of her children in addition to buying drugs to manage her HIV status (if she is infected). Many such widows turn to prostitution to generate income, or they encourage their female children to take up prostitution. As is common, sex workers often cannot ensure their clients' practice of safe sex or their own.

In other cases, infected women, including single mothers, are not only faced with the task of expensive management of their status but also of caring for their children. During a recent World AIDS Day celebration, a single mother living with AIDS confessed that she had to breastfeed her baby, although doctors had warned her that in doing so, she risked infecting the child. She had no money to buy him milk. She said it

was a struggle in her slum life to raise the 600 shillings (US\$8) required for her monthly dose of AIDS drugs. She asked the crowd whether they could blame her for breastfeeding when nobody was willing to give her money to buy milk for the baby.

Various traditional practices expose African women to HIV infection. For example, early forced marriages for girls and wife inheritance create high risks of HIV infection. Widow inheritance, commonly baptised as home guardianship, is common in East and Southern Africa. In Kenya, it is common within the Luo community. When a husband dies, one of his brothers or cousins marries the widow to ensure that the children remain within the late husband's clan and that the widow and her children are provided for. If the husband died of AIDS and the woman is infected. she could pass on the virus to her guardian and children.

Early forced marriages for girls create high risks for HIV infection.

### Calling the Shots: Treating Oneself With Respect Can Give Anyone Great Respectability

by Sathya Saran

She wore a stylishly cut robe that fell to her feet, a heavy gold chain, and her hair was orange. She lives in Cape Town, South Africa, and has been a sex worker for all of 20 years.

No, she was not like the call girls we see in Hindi movies—not slinky, svelte, and rich. Rachel has always and still continues to solicit business from the street. She has a stretch of road where she operates from; and when she finds a client—and "he could be a judge, a politician, a clergyman or a tourist, and is usually white skinned"—she takes him to a room that belongs to a friend. Her fees include the rent for the room for the period her client wants to use it in her company.

"I was abused by my uncle for four to five years when I was a teenager," she revealed, "and when I finally told my aunt about it, she said I was getting too big for my boots and threw me out. Of course, it is not an excuse for the job I do, but it is a part of my life."

When a nongovernmental organization worked in her area, advocating safe sex to prevent the further spread of HIV and AIDS, Rachel took up the initiative of carrying the baton forward. Today, in her part of the city, no sex worker can indulge in unprotected sex

for payment. "If any girl does that, we gang up on her and make her leave," Rachel said. And, aware of the constant risk her profession places her at in a country where over 4.5 million people are HIV positive, Rachel keeps a stern eye on her health.

"My doctor is very proud of me," she says. "She admires the fact that I keep a close watch on my body."

Her frank eloquence and well-groomed looks belie Rachel's predicament. "I've been robbed of all my clothes and belongings five times," she says. "Each time, I have had to invest again in good clothes, and it has left me with no savings. I would love to do something else for a living; I've had enough of this life," she says, then adds, with the first hint of sadness in her voice, "but I have no choice. No savings. I cannot marry my boyfriend because he has no steady job. I have to provide for myself."

Only months ago, Rachel took her crusade as protector of the younger girls in her profession to a new plane. When three policemen beat up some young sex workers, she moved the courts against them and got a restraining order that prevented them from entering the area.

# MOTHER-TO-CHILD TRANSMISSION

Por many HIV-infected women—who may learn of their HIV-positive status only when they become pregnant—choosing whether or not to have a child is among the toughest decisions they make. Mother-to-child transmission of HIV is by far the most common mode of HIV infection for children below the age of 15.27 More than a million children are living with HIV or AIDS around the world, and more than 4 million have died since the epidemic took hold two decades ago.28 These numbers will likely rise as the number of HIV-positive women of childbearing age increases.

Without treatment, 25 percent to 35 percent of children born to HIV-positive women in less developed countries become infected.<sup>29</sup> A baby may contract the virus during pregnancy, labor and delivery, or as a result of breastfeeding.30 Of the infants who become infected, two-thirds are infected during pregnancy and at the time of delivery, with labor and delivery being the time of greatest risk.31 Research suggests that vaginal deliveries may increase the risks of transmission of the virus from the mother to the child.<sup>32</sup> While Caesarean sections could reduce this threat, such an option is unavailable to the majority of women worldwide who deliver their babies with the help of midwives at home, in villages, or at small health centers.

Once the baby is born, some women face yet another tough choice-whether to breastfeed their babies or provide an alternative milk formula. Given the fact that roughly one-third of mother-to-child transmissions of HIV occur through breastfeeding,33 families who have the means may provide commercial milk formulas. For millions of families with scarce resources. however, the alternatives to breast milk may be too expensive or their communities may lack the clean water and fuel necessary for the safe preparation of a milk formula. Moreover, in places where breastfeeding is common, the decision not to breastfeed a child may draw attention to the woman's HIV status and invite abuse and discrimination.

For some women, anti-AIDS drug treatment is available.<sup>34</sup> The treatment is administered late in pregnancy and during delivery and given to the infant for a period following birth. This option is also limited to those who can afford the treatment. The risk of mother-to-child transmission has been significantly lowered in high-income countries, where many HIV-positive pregnant women, in addition to taking antiretroviral drugs, later avoid breastfeeding. These measures, along with delivery of the baby by Caesarean section, have decreased mother-to-child transmission of HIV in some places.<sup>35</sup>

In addition to the provision of antiretroviral drugs, health experts stress the importance of prevention efforts, as well as appropriate counseling and testing services for women, and support for mothers and their infants, including information on infant feeding options.

Ghana Broadcasting Corporation, Ghana July 29, 2000

### **Report on AIDS**

by Sarah Akrofi-Quarcoo

**Announcer:** The fight against HIV/AIDS has become a ding-dong battle. Mother-to-child transmission, the major cause of infection among infants and children, remains one of the greatest challenges in that fight.

Correspondent Sarah Akrofi-Quarcoo:

Amid tears, Florence Ngobeni, an AIDS counselor with the Chris Hani Baragwanath Hospital in South Africa, recounted how she had lost her baby to HIV/AIDS after birth. The infant had suffered continuous bouts of diarrhea and other ailments and had finally died, leaving Florence Ngobeni with the pain and guilt that she had passed on the disease to her only child without even knowing she had it. Elizabeth Chidonza feels the same way. Elizabeth works for the United Nations in Pretoria at a project called the Greater Involvement of People Living with AIDS (GIPLA). She has a six-year-old daughter who was infected at birth.

Approximately 90 percent of the 1 million children under 15 years living with HIV/AIDS around the world acquired the virus from their mothers. In Ghana, children between 0 and 4 years constituted 2 percent of known AIDS cases in 1998. Women with AIDS included an estimated 6.6 percent of those at antenatal care clinics in major urban areas in the country and 12.4 percent at clinics outside major urban areas in 1998. All these women could have transmitted the virus to their children during pregnancy, at birth, or through breast milk.

According to the UNAIDS Report on the Global HIV/AIDS Epidemic, released

at the 13th International AIDS Conference in South Africa, transmission is reduced when HIV-positive pregnant women take antiretroviral drugs and avoid breastfeeding their newborns. These two measures, combined with delivery of the baby by Caesarean section, have dramatically decreased mother-to-child transmission. But in most cases, women only know their status through their child's ailment or death.

Apart from ignorance, there are structural and cultural problems. Dr. Efua Hesse, a pediatrician at Korle Bu Teaching Hospital, says it has been difficult to implement protocol 076 (the anti-AIDS treatment given to HIV-positive pregnant women and their babies). The treatment requires screening pregnant women with informed consent, but the hospital is not equipped to undertake the exercise. The hospital is currently not administering AZT to pregnant women. It is too expensive and beyond the reach of HIV-positive pregnant women, who are mostly of low socioeconomic status.

The stigma and shame associated with HIV do not make it easy for pregnant women who want to test for AIDS to do so. Sociocultural pressures on women to have children also make it difficult for women to opt to stay childless even when they know they have the virus. They only hope and pray that the children do not get infected. One out of every 20 people is said to be infected with AIDS in Ghana, and prevalence is high among youths. Reproductive health education and information remain the single most powerful preventive tools.

More than a million children are living with HIV or AIDS around the world.

### HIV/AIDS—Silence and Deafness: The Hlabisa Hospital

by Gabriela Adamesteanu

The way to the Hlabisa hospital in South Africa passes through an ordinary village, with round houses and cone-like ceilings and a market where people sell goods displayed on the floor: cheap clothes and sports shoes, pineapples, bunches of bananas, household tools. Unpaved roads, widely cut in the brown-reddish soil, lead to the hospital.

We pass through the waiting room, crowded with women and men, sitting on benches, waiting to see the doctor or to be admitted to the hospital. The hospital has low-ceilinged pavilions, like all the ordinary South African buildings, and the smell of disinfectants and human fluids becomes more and more pungent as we enter the maternity ward.

The maternity ward is the most visited part of the hospital. There is no evidence of the HIV-positive pregnant

women, because no tests are taken. Only pregnant teenagers—and there are many of them—have separate rooms. Early motherhood and the lack of sexual and medical knowledge are among the causes of the HIV epidemic.

According to UNAIDS, without adequate treatment for pregnant women, 15 percent to 35 percent of the children born to HIV-positive mothers are likely to have the disease. Breastfeeding also carries risks. Doctors and HIV/AIDS activists revealed the dilemma of the HIV-positive mothers: The decision to breastfeed can lead to infection, but the alternative may lead to the infant's starvation, since artificial formulas and safe drinking water are limited, if available at all. Even at Hlabisa hospital, the powdered milk is sometimes missing or is not enough, so that all the mothers then have to breastfeed their babies.

# YOUNG PEOPLE AND HIV/AIDS

The AIDS epidemic inflicts a heavy toll on young people. About 50 percent of all new HIV infections around the world occur among people ages 15 to 24, the age range within which most people begin their sexual lives. When children under the age of 14 are added, the total increases to 60 percent of new infections. The vast majority of these young people live in less developed countries where AIDS is concentrated. AIDS is concentrated.

Young people are especially vulnerable to HIV exposure because of physical, psychological, and social factors. For one thing, while youth is a time of exploring and discovering feelings and behaviors, young people often lack the social skills, services, and information necessary to avoid the risks associated with such activities as unprotected sex and illicit drug use.

The context within which young people live influences their exposure to HIV. Among the most vulnerable groups are those who live on the edges of society, including orphans, refugees, and street children, those who grow up in urban slums, or those who face isolation because of their sexual orientation.<sup>38</sup> These young people often have limited access to education, health information, and health services. Some may increase their risks by selling sex to survive; others may be abducted and sold into the sex trade. Many take up injecting drug use and expose themselves to high HIV risks by sharing needles.

The number of parents dying from AIDS also has dire consequences for young people, especially young children. Worldwide, more than 13 million children under the age of 15 have lost either a mother or both parents to AIDS, and an estimated 92 percent of these children live in sub-Saharan Africa.<sup>39</sup> Many of these AIDS orphans are forced to run households even as they grieve for dead parents and cope with the isolation and social stigma associated with the epidemic.

Individuals, groups, and governments face the challenge of breaking down the barriers for young people to seek the information, services, and supplies required to reduce the risk of infec-

tion or to treat the illness. Media campaigns, information on sexual health and on AIDS, as well as the provision of male and female condoms and other prevention services are all geared to giving young people the means and the confidence to cope with the risks.

### **Current Problems**

by Gabriela Adamesteanu

The Children's Department of the Immune Deficiency Section at the Hospital for Infectious Diseases in Romania looks impeccable on the outside. It has recently been renovated and includes a green park for the children. Inside, it is clean. There are computers, charts, a room for drawing, another filled with toys for preschool children, as well as young staff, and beds for the sick children, who are usually accompanied by their parents.

It is here that the National Anti-AIDS Committee is headquartered. It is the workplace of Dr. Adrian Streinu and his partners. A notice on the wall says that the Princess Margaret Foundation has been providing food for the children who are hospitalized here. Food from the Foundation arrives periodically, as do additional donations from other sources. I can imagine the women holding their children by the hand while a nurse enters information about each family's housing and income. They then receive the donated packages: toothpaste, rubbing alcohol, cotton, bandages, soap, and medicine.

With vulnerable immune systems, the HIV-infected children can have conditions such as anemia, tuberculosis, otitis, thrombosis, and diarrhea. Once they are hospitalized, some children become anxious and may start to have psychological problems. It is a time when the mind is affected by the physical deterioration, savs young psychiatrist Corina Jalba.

In a situation where 90 percent of the parents do not tell their children about the disease and where the more serious cases are isolated, children lose confidence in their bodies. "When the parents hide the truth, we deal with only 50 per-

cent of the information," says Jalba. If a child has pneumonia and he is told about it, the child starts to fight it.

Some parents have abandoned their children since 1990-1991. The children are now the concern of the Princess Margaret Foundation, which has developed a special psychotherapy program for them. As part of the program, the children express themselves through modeling, drawing, and collage.

I can see the sculptures they have carefully made of plasticine. Some of the children are very talented, as Corina Jalba tells me. I randomly choose two pictures. One of them, created by a dying child, shows faded, reddish pink shapes next to green spots and is meant to depict children walking through the woods. The other picture is a huge butterfly with colorful spots on grey wings. The dull colors are interrupted by brighter shades. The picture has a story of its own: The butterfly stays in the hospital because it has injured a wing and its mother does not have enough money to take it home. The picture is the creation of a Gypsy child who was abandoned by his parents. Though his parents still come to see him, they have a large family and cannot afford to take care of him: the child is envious of his brothers at home.

Hospitalizations for the infections provide opportunities to learn about the disease. The child is supposed to take monthly medical treatment and see the doctor every three months. Many sick children who have been diagnosed fail to follow up with treatment, mostly because their parents are too busy or too poor to combat the disease.



The butterfly stays in the hospital because it has injured a wing and its mother does not have enough money to take it home.

### Are You Positive?

by Sathya Saran

I look long and hard at the grubby face at the car window. The girl must be about 10 or an undernourished 12 at best. In a faded frock, plastic earrings and a gay, pink satin ribbon in her hair. I cannot help wondering if she is HIV positive.

Fact: Thirty percent of the approximately 25,000 street children of Vijayawada, Andhra Pradesh, are infected with HIV. Being a major transportation hub, Vijayawada is one of 377 high-risk locations in the state and a potential HIV/AIDS transmission centre.

Sexual abuse of children is one of the highest causes of HIV infections among street children. In Mumbai, where the streets are surrogate homes to thousands of children, abuse is as common as the day. With crowded slums, migrant male labour, and a marked lack of education, the scenario as well as the figures are probably much worse.

### Young and Immortal

A car zooms past and comes to a screeching halt at the traffic lights. Levity and high spirits rise like vapour from the windows. The boys in front are dressed for the night, the girls at the back more so. What will the night bring? I look at them and wonder if any one of them is HIV positive. Will he or she, in turn, infect the others?

The car zooms off into the night. "Don't be silly," my companion tells me. "Why do you imagine the worst? More people die in road accidents and of heart attacks than of AIDS."

### **A Discriminatory Virus**

She's young and pretty, this colleague of mine, and I take her point. But I wonder

how she can think that she is safe. "Do you really think HIV affects other people?" I ask. I want to tell her that just by being a woman, she is at greater risk.

Fact: Vulnerability to sexually transmitted infections (STIs) and HIV is systematically patterned so as to render some young people more likely to become infected than others. Gender, sexuality, and age are as important as socioeconomic status and can increase the risk potential of any urban, educated young woman who is not necessarily promiscuous.

I look at my young friend. She's looking into the distance, her eyes soft with some thought. Is she thinking of her boyfriend? I wonder if, in her home, sex is a word that ever is spoken between her and her mother.

Fact: In most countries, the obstacles that make it difficult for young people to protect their sexual and reproductive health include:

- lack of access to information:
- lack of health services to meet their specific needs, as health workers seldom receive special training in issues pertinent to the sexual health of adolescents;
- hesitation among young people to seek medical help even if they are able to diagnose an STI, and a tendency to treat themselves with over-the-counter medication;
- lack of communication and advice on sexual matters within the family; and
- peer pressure that dismisses sexual abstinence as deviant behaviour.

Sexual abuse
is one of
the primary
causes of HIV
infections
among street
children.

### **MIGRATION AND HIV**

A s poverty, poor health systems, and limited information fuel HIV infection rates in some regions, recognition is increasing that migrants face greater risks of infection than less mobile populations. <sup>40</sup> As the role of migration in the spread of HIV claims increasing attention, much of the focus is on such highly mobile groups as refugees, truck drivers, traders, military and other uniformed forces, business people, airline workers, and seasonal agricultural workers. <sup>41</sup>

Migration and mobility have long been a feature of human existence, but people are moving more than ever in response to cheaper and better transportation, increased international trade, or simply the urge to better their lives. Migrants may move from rural to urban areas, from areas of poverty to countries with better opportunities, and from areas of war and conflict to areas of relative political stability. Permanent and temporary migrants, short-term visitors, and migrant workers can be found in most communities.42 UN estimates show that 120 million people voluntarily cross borders or move to cities within their own countries every year. Another 38 million people are displaced in their own countries or are refugees in foreign lands.43

Separated from family and regular sexual partners for long periods, migrants may face loneliness or even a sense of isolation in a country or region where the language and cultural practices are alien.<sup>44</sup> Such persons often become part of new peer groups, including sexual networks. Young people may also become sexually active earlier, unaware of the risks of HIV and other sexually transmitted infections. Migrants who contract the virus may also contribute to its spread when they return home.

Some refugees and migrant workers are subject to stigmatization and discrimination and suffer from an overwhelming sense of powerlessness. Many live and work in poor conditions and may even lack permission to remain in the host country. Refugee women and girls are easy targets for sexual abuse, including rape. Undocumented migrants, who live in constant fear of deportation and avoid contact with official government agencies, represent one of the most vul-

nerable groups with respect to HIV infection, as they have little access to health and welfare services. <sup>45</sup> Lacking knowledge of their rights, the women are especially vulnerable to abuse, violence, and forced prostitution.

Health workers and governments face the challenge of designing HIV prevention and care programs that do not appear to single out or stigmatize migrants. Much may therefore depend on successful community outreach programs that take into account linguistic differences and are coordinated by persons who share the same culture as the migrant community. 46 Programs may also take special note of the reasons for migration, intended length of stay in the new place of residence, socioeconomic status, and the educational level of migrants. 47

Migrants face

infection than

less mobile

bobulations.

greater risks of

### Filipinos and AIDS: It Could Happen to You

by Pennie Azarcon Dela Cruz

t particular risk for HIV are the six A million overseas Filipino workers (OFWs), the majority of whom are women, says Malu S. Marin, executive director of Achieve and Caram Asia, two nongovernmental organizations working for the welfare of Asian migrant workers. Already, 22 percent of all reported HIV cases in the Philippines are former OFWs, says Marin. This is not surprising, she adds, citing recent research by the women's group Kalayaan Inc., and Caram Asia which noted that OFWs are particularly vulnerable to HIV/AIDS because of their work circumstances abroad.

### **Vulnerable Migrants**

Titled "Breaking Borders: Bridging the Gap Between Migration and AIDS," the study shows that many migrant workers are below 30 years old and are sexually active or sexually curious. Many of the workers are single or have left their families back home. Young, alone, and socially isolated, they tend to seek comfort in intimate relationships developed while abroad, or engage in casual or paid sex.

According to the report, most young Filipino women deployed abroad are inexperienced and vulnerable to sexual abuse by their older male employers. Forced sex, because of the possibility of vaginal tearing, may facilitate entry of a sexually transmitted pathogen, including HIV. Some workers, who choose to remain in other countries despite their illegal status, are drafted into prostitution or sex trafficking where they are exposed to STDs and HIV.

While some workers indicate a moderate to high awareness of HIV/AIDS, their misconceptions about the disease hinder behavioral change, according to the findings. The view that HIV/AIDS is a foreigner's disease could lead overseas workers into thinking that risky sex is permissible with someone of the same nationality, the study said.

Compounding the misconceptions about the disease is the low incidence of condom use among migrant workers for the following reasons: the inaccessibility of condoms, uncertainty about the protection that condoms provide, and reluctance to use condoms in intimate or steady relationships.

"Among migrant workers, using condoms is an indication of the lack of trust in one's partner," the study said. Another reason cited for low condom use was that "it diminishes sexual pleasure."

Most OFWs also hesitate to seek medical help until they are convinced that they are seriously ill. The tendency is to consult family members, endure the pain, and resort to self-medication, all of which prevent the early detection of illness. Getting sick abroad also means spending money that migrant workers would rather remit home. In addition, undocumented workers do not access public services for fear of detection, arrest, and subsequent deportation. Other migrant workers would rather keep quiet about their illness as this might be used by their employer as grounds to dismiss them. Most employers, in fact, find it cheaper to send the worker home than spend money for his or her medication.

Lonely, homesick, working nonstop, and sometimes mistreated, some migrant workers compensate for their hard work by letting go—having drinking binges, engaging in paid or casual sex, spending time with their lovers.

### **Financial Crisis**

The research noted that the Asian financial crisis that began in 1997 has contributed to the vulnerability of migrant workers. To discourage foreign workers from competing with their nationals for scarce jobs, many receiving countries restrict the entry of migrants' families. Thus, for years to come, the labor market is bound to be restricted to the young and single worker, some of whom are lonely and sexually adventurous.

Another adverse effect of the Asian crisis is the shrinking of the market for domestics in those countries that no longer allow families with nonworking wives to retain a household helper. This could lead to syndicates using domestic work as enticement to lure prospective Filipino women workers abroad. Prostitution itself might be considered by women OFWs unwilling to come home despite the absence of job prospects abroad.

### **Homegrown Risks**

While millions of OFWs face the risk of HIV transmission abroad, their spouses are exposed to as much danger when they get home, says Marin. The same Kalayaan-Caram research reveals that most wives cope with their fears by denying the possibility of their husbands' casual affairs. "Their husbands are different. They are God-fearing and faithful, the women say of their spouses," says Marin. Or, she adds, the wives shrug and accept the casual affairs "as part of a man's nature and thus unavoidable."

Even among medical practitioners, the lack of information about HIV/AIDS has proven to be a damper on efforts to curb HIV transmission, says Dr. Dominic L. Garcia of the AIDS Society of the Philippines, citing recent research involving 77 physicians from both public and private hospitals in three regions. "Although the Commission on Higher Education has incorporated basic HIV/AIDS education and prevention programs in the medical curriculum, these did not translate into good practice," says Dr. Garcia.

With Republic Act 8504 or the Philippine AIDS Law in place, the government has made it mandatory for all OFWs to undergo HIV/AIDS education as part of predeparture orientation (PDO). But for all the good intentions, there is hardly any attempt to monitor the implementation of the law, observes Marin. "Most PDOs consist of a 15minute video with no discussion whatsoever to link HIV/AIDS and migration. We need to get together the different migrant support groups to do preventive education throughout the migration process—from predeparture, on site, and upon return," suggests Marin. ■

Many migrant workers are below 30 years old and sexually active or sexually curious. 22, Romania July 18–24, 2000 (Translated from Romanian)

### HIV/AIDS—Silence and Deafness: Rural Africa

by Gabriela Adamesteanu

### **Rural South Africa**

When the bus stops, women and young boys stick their faces on the windows, trying to make the tourists buy their products: oranges, pineapples, and bananas, offered on trays or in plastic bags, carried on the head.

Population mobility is remarkable, especially after the political change six years ago. An estimated 60 percent of the men go to the cities for work and return to their families only once a month or a few times a year, depending on the distance. After apartheid was abolished and black people did not need a passport to work in the white districts, the social mobility increased, but, ironically, this had the effect of hastening the spread of HIV/AIDS.

As these men move away from their homes and into urban areas, many participate in drinking alcohol and visiting sex workers. Some of these sex workers are provided with condoms free of charge by various clinics or organizations, but they do not always use them.

Sometimes migrant men use condoms during casual relationships, but never with their wives at home. In this way, migration is an important risk factor for all sexually transmitted diseases.

Left alone at home with their children, some women (40 percent get pregnant before age 18) may also have casual relationships with men from the area, especially truck drivers. Thus, they are not only victims, but also agents of infections. The lack of education and money, the psychological complications (the suspicion of infidelity) make them incapable of negotiating their sexual relationships; consequently, they do not use condoms, the most common means of protection.

This is one of the conclusions reached by a team at the African Centre, a demographic center based in the city of Mtubatuba. The center opened in February 2000, is financed by the Wellcome Trust, and it focuses some of its research on the highest-risk category—adolescents. ■

Sometimes migrant men use condoms during casual relationships but never with their wives.

"Milijuli" Radio Magazine, Nepal July 25, 2000 (Translated from Nepali)

### **Improve Our Behavior Ourselves**

by Harikala Adhikary

In the village district Hlabisa in South Africa, men migrate to other parts of the country or other districts in the area for work. There, they would engage in sexual relationships with casual partners. Women living with their children at home were also known to engage in sexual relationships, especially with truck drivers, in order to generate extra income.

These situations show that the activities of both men and women could increase vulnerability to HIV. Within families, the men started to get sick, and wives and newborn infants followed. Some suffered from tuberculosis, others from diarrhea. They visited the hospital but did not find relief from the diseases. They tried traditional medicine, but the deaths did not end. No men were available for funerals. No coffins were available. Some blamed the wives for the death of family members.

Death rates increased. Even those wives who never engaged in casual sex became ill with HIV. They began to ask

for information about the disease. Until then, only a mission hospital was set up in Hlabisa. They went to this hospital frequently and began to ask what is HIV and how does it become AIDS? How does it infect? What could be done to protect children from being infected? Once they got knowledge, they started voluntary services for providing information to the others like them. They found that unprotected sexual relationships are the major cause of the spread of HIV. Now, they have become conscious and careful. They have learned.

Today, we (in Nepal) are at the same point in the epidemic as the people of Hlabisa were 10 to 15 years ago. Our men also leave the villages for work. Women look after the home and care for the children. If the men go out and engage in casual sexual relationships, society ignores their behavior. This is most harmful and destructive for us. Therefore, we have to improve our behavior ourselves.

Once they got knowledge, they started voluntary services for providing information to the others like them.

# PEOPLE LIVING WITH HIV OR AIDS

More than two decades after the start of the epidemic, HIV/AIDS still generates fear, misinformation, and the erosion of basic human rights. 48 Since the impact of the virus is greatest in poor communities, the majority of those infected must contend with the difficulties of obtaining quality health care and social services as they cope physically and mentally with a debilitating and incurable condition. Responses to the crisis in different parts of the world also starkly illustrate the divisions between the rich and the poor.

Those infected face persistent misconceptions about the virus. Many people still believe that they may fall ill through casual contact with a person who has HIV or AIDS. This fear constitutes a major obstacle to care and support for HIV/AIDS patients at home, in the community, and even at established health care facilities. To many people, HIV equals death. Few understand the difference between testing positive for the virus, yet having no symptoms, and being sick with AIDS. Someone who has HIV may be seen primarily as incurably ill even though an infected adult may be symptom free for years.

Compounding the fear of AIDS as a fatal illness is the difficulty of discussing the illness as a sexually transmitted infection. Across cultures, the shame and guilt that often accompany discussions of sexual practices, preferences, and desires also inhibit open discussions about HIV. For this reason, initial responses to the epidemic dismissed HIV/AIDS as an illness of sex workers, homosexuals, and intravenous drug users. Even now, a person living with HIV or AIDS is often seen as a moral threat to the community.

Since most HIV-infected women are of child-bearing age, the challenges for many women include the need to secure support, including foster care, for their children. Some women discover their HIV-positive status only during pregnancy and face the risk of giving birth to an infected child. In some situations, women living with HIV are forced from their homes and even blamed for the spread of the virus.

At the same time, medical breakthroughs offer little hope to the vast majority of people who have contracted the virus. Drugs that slow the progression of HIV to full-blown AIDS remain expensive and beyond the reach of most of those who need treatment. Some governments are adopting strategies to secure cheaper, generic versions of the drugs, but even these pose an economic burden to less developed countries, particularly in sub-Saharan Africa.

Policies and programs to stem the epidemic aim to promote greater access to quality health care, drugs, and treatment for those infected and to reduce HIV transmission through culturally appropriate prevention strategies. Among the approaches that promote prevention, those that stress peer support and education have proved effective and include programs that are run by youth, women, street children, refugees, and intravenous drug users. People living with HIV or AIDS are providing some of the most powerful messages against high-risk behavior.

Philippine Daily Inquirer, Sunday Inquirer Magazine, Philippines August 20, 2000

### Positive—and Carrying On

by Pennie Azarcon Dela Cruz

Pernando Feliz (not his real name) remembers exactly when his life changed drastically: "It was eight years ago, and I had been drinking with friends. Next thing I knew, I was in Ermita, where I ended up having unprotected sex with a sex worker."

Now 36, Feliz wonders if things would have been different if he had not been drunk or if he had remembered everything he had read about AIDS. "I'm not ignorant about HIV/AIDS. My friends in the U.S. would regularly send me magazines, and the company I used to work for had access to American publications. This was in the early '80s. Back then, you couldn't touch an American magazine without coming across information on the disease."

But like many other Filipinos, Feliz never gave AIDS a passing thought. "I didn't think it would happen to me. I was neither a sex worker nor an intravenous drug user, and I wasn't involved in a homosexual relationship. I was a college graduate, for Chrissake, and had a good job in a Makati firm." Indeed, he was on the fast track in his career and had just applied for a job in the United States. "I already had my visa, but part of the requirement was a drug and AIDS test."

Nothing—and nobody—prepared him for the test results. "Pretest counseling only became available in 1998, when RA 8504 (the Philippine AIDS Prevention and Control Act) was passed. Otherwise, you were on your own," he recalls. When the medical technician hesitated about giving him the results, Feliz had an inkling of what was to come. "I told him, 'Tell me

straight. I can take it." Still, when the technician confirmed that he was HIV positive, this Visayan felt his knees buckle. "I felt doubly at a loss. I'd lost my job prospect in the US, and now I was going to lose my life."

Eventually, and thanks to the post-counseling he received, Feliz realized he had a whole life ahead of him. "With proper medication, I could live a healthy life for the next 10, 20 years," he says. He also felt that he needed his family's support. Where others similarly afflicted would hesitate, Feliz immediately told his siblings, his mother, and his best friend. "My family understood and supported me because they are well-informed." Despite that, he would rather remain anonymous, "out of respect for their privacy and to spare them the stigma attached to the disease."

Indeed, as Dr. Loreto Roquero of the Department of Health (DOH) confirms, "It is often the family that is the last to know." In fact, the DOH runs Bahav Lingap at the San Lazaro compound in Sta. Cruz, Manila, as a sort of halfway home for Persons with AIDS (PWAs) until they are able to disclose their illness to their families. "Here, the protocol is to protect their privacy. We don't tell even their partners unless they agree. Even within the medical circle. there is shared medical confidentiality," says Roquero, who heads the National AIDS and STD (sexually transmitted disease) Prevention and Control Program.

Part of protecting his family, Feliz knew, was protecting himself. "I read a lot about Magic Johnson and the clinical studies on HIV medication in the Those infected face persistent misconceptions about the virus.

### "My family understood and supported me because they are well informed."

—Fernando Feliz (pseudonym), HIV-positive AIDS counselor U.S. When I learned that the drugs would cost from P27,000 to P40,000 (US\$700 to US\$1,000) a month, I volunteered to be part of the clinical studies at the Research Institute of Tropical Medicine." Because of limited funding, only 20 Filipino PWAs could take part in the studies, which are meant to document local experience with the drugs prior to their approval by the Bureau of Food and Drugs (BFAD).

Being on HIV medication can be a risky routine, Feliz explains. "Once started, the drugs have to be taken continuously, otherwise the virus becomes resistant and multiplies." The medication consists of a combination of such antiretroviral drugs as Saquinavir, AZT, and Zalcitabine. Feliz downs seven different capsules three times a day, or a total of 21 capsules daily. Fortunately for him, he has yet to experience the medications' side effects that range from rashes and nausea to body pains.

Feliz recalls that once, when he was assigned to do field work in Northern Luzon, he missed his medication for a whole month. The courier service that delivered his drugs could not locate him. "I was in a panic," he recounts. "It was time to ask myself what I valued more: my job or my health?" It was an easy choice. Feliz dropped his well-paying job for the more emotionally satisfying work of being an AIDS educator and counselor. He became a member of Positive Action, most of whose members are HIV positive, while the rest are volunteers, donors, and medical

practitioners. The group trained Feliz in peer counseling and has since become his main support group.

"I know just how difficult it is to cope with being HIV positive," Feliz says of his choice. "Feel ko ang sakit, ang bigat" (It's a heavy burden). The tendency is to be depressed, and depression weakens the immune system, which is what the AIDS virus attacks. A positive attitude helps; that's what I learned from a study tour in Australia," he adds, referring as much to himself as to other HIV-positive individuals.

"You cannot imagine how it felt when this dying PWA held my hand and said he wanted to hear my voice so he could die happily. It felt so good to be there for him," Feliz recounts. And his particular circumstance makes for good counseling strategy, he adds. "When people think they'll die very soon because they have the virus, I tell them, look at me! I'm robust, I'm healthy, and I've been HIV positive for eight years now. I'm proof that you have your whole life ahead of you!"

From peer counseling, Feliz now trains former overseas contract workers who became infected and have lost their jobs. "I train them to become educators because apparently, most Filipinos think AIDS is a very distant risk. I want people to know that HIV can infect anybody: health workers, NGO (nongovernmental organization) staffers, seafarers, and professionals. We must know what we're doing right and what we're doing wrong."

Servicio Especial para Noticias de la Mujer (SEM), Costa Rica July 11, 2000 (Translated from Spanish)

### HIV/AIDS: Another Silence to Be Broken

by Thais Aguilar

Jabu is just over 40. Dressed in harsh black clothing, she seeks comfort and aid from a nurse in the Hlabisa Hospital—located in the interior of the Kwazulu Natal province of South Africa, some 300 kilometers to the northeast of this city located on the Indian Ocean—because her husband died a few days before, a victim of AIDS.

She is a Zulu peasant and lives in one of the poorest and most depressed regions of this African country. Of its 41 million inhabitants, it is calculated that 3.5 million are HIV positive, most of them black, poor, and from rural areas, areas where the percentage of HIV-positive people may be as high as 50 percent.

Jabu is a living statistic. She is HIV positive and was infected by her husband, now deceased, who probably acquired HIV from a casual, unprotected sexual relationship during his tenure as a migrant worker in any of the large South African cities—Johannesburg, Cape Town, or Durban. With eight daughters and sons, Jabu is an exceptional case among her neighbors because none of her children is HIV positive.

With no way to support herself, Jabu cries from fear and desolation, leaning on the desk of the distressed nurse, who cares for HIV cases and acts as a psychologist when she has the difficult task of telling her patients whether they are HIV positive or not. Jabu does not even have one rand (local currency, 6.83 rands make one dollar) to feed her daughters and sons. She does not know what to do. She is deeply depressed and afraid because she knows that

sooner or later, she will suffer the fate of her husband, and she fears for the future of her family. As a result of her extreme poverty, she has no access to antiretroviral medications, which would allow her to extend her life some 10 more years.

Hlabisa is one of the few communities that has the luxury of having a state hospital with 300 beds and a stock of medications and palliative treatments for common diseases—malaria, diarrhea, poisonings, broken bones, and agricultural accidents of some severity—and to test whether people are HIV positive. It is a difficult task in an area where educational levels are low and living conditions modest.

### **Development Problem**

African experts argue that the high prevalence of venereal disease on this continent is perhaps one of the principal reasons for the alarming spread of HIV/AIDS. Also, the explosive combination of underdevelopment, poverty, and marginalization have provided the breeding ground where in 1999 alone, 4 million Africans joined the list of HIV-positive people, according to a global report of the Joint United Nations Programme on HIV/AIDS (UNAIDS) presented at the 13th International AIDS Conference in Durban.

Communities such as Mtubatuba, some 250 kilometers northeast of Durban, have serious problems with the prevalence of HIV, especially among those under 25 years old. Despite the high incidence of this sexually transmitted virus, it is difficult to speak about sexuality in this population and in rural

Investing in treatment and mass prevention campaigns can make a difference. areas, according to representatives of the nongovernmental African Center.

The other South Africa—the white South Africa—lives out its HIV-positive status in better conditions, as acknowledged by Edwin Cameroon, a justice of the Supreme Court of South Africa, who declared publicly at the AIDS conference that he is gay, middle-class, and HIV positive. His position did not prevent him from rubbing salt in the wound of this inequality of access to antiretroviral medications. His case and Jabu's exemplify what is happening in developed and developing countries with respect to the virus.

For him and other international activists, human rights and health go hand in hand. One human right relates to a person's well-being—not only to having access to quality public services—but to the medications that allow a good quality of life.

### A Question of Resources and Political Will

Judge Cameroon and many distinguished scientists stress that the investment of resources in treatments for those infected as well as mass prevention campaigns—including such unpopular policies as acknowledging the active sexual lives of teenagers and allowing them free access to condoms—are the factors that might make the difference.

Peter Piot, director of UNAIDS, acknowledged his organization's failures in the negotiations they have held with pharmaceutical companies and the global controls established by the World Trade Organization with mandatory and parallel import licenses.

Mandatory licenses to produce generic medications—which are equally as effective as the original ones but produced locally or regionally at a lower cost to consumers—would allow the production of antiretroviral medications at more affordable prices to developing countries such as poor African countries, explained Richard Laing, a professor from the School of Public Health at Boston University in the United States. and one of many defenders of access to low-cost medications. Parallel import licenses authorize the importation of a product without permission from the patent holder. Both mechanisms require a permit within the complicated system of international trade.

Those who support low-cost access to the antiretroviral treatment also point out the responsibility of governments to invest in purchasing them, to eliminate taxes on medications, and reduce absurd expenses—such as military expenses—to invest more in the treatment and prevention of HIV/AIDS and in health systems in general. ■

### **HIV-Positive Florence: The Face of Courage and Hope**

by Eunice N. Mathu

Tall, beautiful Florence Ngobeni, with a set of sparkling white teeth, was born 27 years ago in Alexandra, a township in Johannesburg. An only child from her mother's first marriage, her mother Julia sacrificed her for her second marriage. The man would not marry her mother with a child tugging along, so Florence was left in the care of her grandmother. Her mother was to have seven other children from this second marriage, and as a result, Florence was forgotten at her grandmother's house.

Although her grandmother, Miriam Ndlovu, was a loving and caring woman, she was a domestic worker and only went home over the weekends. Florence was left under the care of her 22- and 13-year-old uncles. The older uncle worked as a furniture deliveryman, while the younger one did not attend school. The older uncle was cruel and abusive to Florence. Although her grandmother was aware of her son's cruelty to her granddaughter, she could do nothing about it, as she depended on him for financial support.

At the age of 17, Florence met a boy who became her best friend. He convinced her to have sex with him to prove her love for him. For fear of losing her newfound friend, she started having sex with him regularly at his parents' home. The relationship lasted six months, but Florence was already pregnant. She was to lose this baby after a beating from her uncle.

It was after her mother's second husband died that Florence moved to live with her mother. However, their relationship was strained and they always fought. When her mother became pregnant with her ninth child with another man, Florence left to stay with friends and various boyfriends. She had no place to call home, and her boyfriends used sex as payment whenever they accommodated her. As a result of the unstable life Florence led, her school performance failed badly, and she failed her final exams.

At the age of 19, she was gang raped by a notorious Alexandra township gang but did not talk about it for fear of being killed by the gang. Rape was the pride of gangs in the townships then. They called it "jack-rolling." If the victims spoke of or reported the matter, their families would be attacked and even killed, and the police could not help.

At the age of 23, Florence became pregnant again, this time, with a 32year-old boyfriend. Her baby girl, Nomthunzi, "shadow" in Zulu, was born looking healthy but at the age of three months became ill. When Florence took her baby to a clinic in Johannesburg. she was tested for HIV. This was the first time that Florence was confronted with the possibility that her sexual activities could have exposed her to HIV. Tests confirmed that she was HIV positive. In great shock and denial, she went to look for the father of her child to inform him that their baby was very sick. That was December 1996, the same month that both she and her daughter were diagnosed as HIV positive. She found that her boyfriend had died a few weeks before and had already been buried. It was too much to handle and the only person she could turn to was her grandmother. She was very understanding and supportive.

Florence advises
patients to
make their HIV
status known in
order to stop the
spread of the
disease.

Word had already spread in the township that Florence had HIV and that her child was dying from AIDS. People used to come to her grandmother's house to see a child with AIDS. Her boyfriend's family accused her of having infected him with the disease.

Florence only heard of sexually transmitted diseases and HIV when she was 19—almost three years after she had been sexually active. Neither her mother, nor her grandmother, nor the uncles who took care of her had mentioned sex or sexuality to her.

Today, Florence is an active member of NAPWA, South Africa's National Association of People Living with AIDS, which was founded in 1994. She is also a board member of the Townships AIDS Project in Soweto. She also works with numerous nongovernmental and UN organisations on AIDS projects. She is a spokesperson for people infected with HIV, comforting them and striving to prevent others, especially young people, from becoming infected.

Florence works as a counselor in the Prenatal HIV Research Unit at Chris Hani Baragwanath Hospital in Soweto. As a counselor, she sees many HIV-infected people each day. Sharing her personal experiences during counseling

sessions has helped both her patients and herself. She encourages them to find the courage to report cases of rape and violence and to address issues of gender power by inviting their partners for counseling. She also advises them of the importance of making known their status in order to stop the spread of the disease and to give a face to HIV/AIDS.

Disclosure remains an important issue for discussion during counseling, as it is often difficult for somebody with HIV to talk about his or her status. Many people go into denial when their status is disclosed. Often, men become aggressive, fighting with their partners and blaming them. Many women are afraid of disclosing their status to their husbands for fear of being beaten up or even thrown out of the matrimonial home. In some cases, fear of community hostility and of being shunned by friends makes it difficult for people with HIV to come out. Florence has a way of talking to her patients during counseling that makes the burden of disclosure lighter. She knows through her own experience that with acceptance and disclosure comes the first step toward personal healing.

### References

- 1. See, for example, United Nations Development Fund for Women (UNIFEM), *Progress of the World's Women 2000: UNIFEM Biennial Report* (New York: UNIFEM, 2000).
- Adriana Gómez and Deborah Meacham, eds., Women, Vulnerability, and HIV/AIDS: A Human Rights Perspective (Santiago, Chile: Latin American and Caribbean Women's Health Network, 1998): 2.
- Joint United Nations Programme on HIV/AIDS (UNAIDS), "AIDS Epidemic Update: December 2000" (Geneva: UNAIDS, December 2000): 3.
- UNAIDS, "1999 World AIDS Campaign" (www.unaids.org/wac/1999/eng/facts%2De.htm, accessed March 6, 2001).
- World Health Organization (WHO), Fact Sheet 10, "Women and HIV and Mother-to-Child Transmission" (www.who.int/HIV\_AIDS/Nursesmidwivesfs/fact-sheet-10/index.html, accessed February 9, 2001).
- 6. Avert, "Women, HIV and AIDS" (www.avert.org/womenaid.htm, accessed June 12, 2000).
- 7. Ibid
- 8. UNAIDS, Report on the Global HIV/AIDS Epidemic: June 2000 (Geneva: UNAIDS, June 2000): 11.
- 9. WHO, Fact Sheet No. 242, "Women and HIV/AIDS" (Geneva: WHO, June 2000).
- 10. UNAIDS, Report on the Global HIV/AIDS Epidemic: June 2000 (Geneva: UNAIDS, 2000): 13.
- 11. HIVInSite, "Monitoring the AIDS Pandemic, Part II" (http://hivinsite.ucsf.edu/social/un/2098.3cee.html, accessed January 24, 2001).
- Chris Jennings, Understanding and Preventing AIDS: A Book for Everyone (Cambridge, MA: Health Alert Press, 1996).
- 13. Ibid.
- Martin Foreman, ed., AIDS and Men: Taking Risks or Taking Responsibility? (London: Panos/Zed Books, 1998).
- 15. UNAIDS, "1999 World AIDS Campaign."
- HIVInSite, "Young Women in HIV Crisis: Press Release from the International Community of Women Living with HIV/AIDS for World AIDS Day," December 1, 1998. (http://hivinsite.ucsf.edu/topics/adolescents/2098.3f8d.html, accessed March 6, 2001).
- 17. Family Health International (FHI), "Preventing Mother-to-Child Transmission of HIV," Impact on HIV Vol. 1, No. 1 (October 1998).
- 18. UNAIDS, "AIDS 5 Years Since ICPD: Emerging Issues and Challenges for Women, Young People, and Infants" (Geneva: UNAIDS, 1999): 6.
- 19. UNAIDS, "AIDS Epidemic Update: December 2000": 3.
- 20. Ibid.
- 21. Ibid.
- 22. See, for example, UNIFEM, Progress of the World's Women 2000: UNIFEM Biennial Report.
- 23. UNAIDS, "AIDS Epidemic Update: December 2000": 5.
- 24. The World Bank Group, press release, "AIDS Blunts Economic Growth, Worsens Poverty in Hard-Hit Countries" (Durban: June 11, 2000).
- United Nations, Platform for Action and the Beijing Declaration, Fourth World Conference on Women, Beijing, China, 4-15 September 1995 (New York: United Nations, 1996): 60.
- Julie Hamblin and Elizabeth Reid, "Women, the HIV Epidemic and Human Rights: A Tragic Imperative" (New York: UNDP HIV and Development Programme, 1991): 5.
- 27. UNAIDS, "AIDS 5 Years Since ICPD: Emerging Issues and Challenges for Women, Young People, and Infants": 6.
- 28. UNAIDS, "AIDS Epidemic Update: December 2000": 3.
- 29. UNAIDS, "AIDS 5 Years Since ICPD: Emerging Issues and Challenges for Women, Young People, and Infants": 6.
- 30. Ibid.
- 31. WHO, Fact Sheet 10, "Women and HIV and Mother-to-Child Transmission" (www.who.int/HIV\_AIDS/Nursesmidwivesfs/fact-sheet-10/index.html, accessed February 9, 2001).
- 32. Ibid.
- 33. Ibid.
- 34. Ibid.
- 35. UNAIDS, Report on the Global HIV/AIDS Epidemic: June 2000: 81.
- 36. UNAIDS, "AIDS Epidemic Update: December 1998" (UNAIDS: Geneva, December 1998): 10.

- 37. Population Reference Bureau (PRB), The World's Youth 2000 (Washington: PRB, 2000): 1.
- 38. HIVInSite, "World AIDS Campaign with Young People" (http://hivinsite.ucsf.edu/social/un/2098.3f71.html, accessed January 29, 2001).
- 39. UNAIDS, Report on the Global HIV/AIDS Epidemic: June 2000: 6.
- 40. United Nations Educational, Scientific, and Cultural Organisation (UNESCO) and UNAIDS, *Migrant Populations and HIV/AIDS* (Geneva: UNESCO and UNAIDS, June 2000): i.
- 41. HIVInSite, "Monitoring the AIDS Pandemic, Part II."
- 42. Broad definition of migrants taken from UNAIDS discussion paper developed for the second ad hoc thematic meeting in New Delhi, "Migration and HIV/AIDS" (Geneva: UNAIDS Programme Coordinating Board, October 28, 1998).
- 43. Ibid.
- 44. Mary Haour-Knipe, "Migration and HIV/AIDS in Europe" (Geneva: International Organization for Migration (IOM) and the University Institute of Social and Preventive Medicine, October 2000): 4.
- 45. Ibid: 1.
- 46. Ibid: 9-10.
- 47. Ibid.
- 48. World Health Organisation (WHO), Fact Sheet 6, "HIV/AIDS: Fear, Stigma and Isolation" (www.who.int/HIV\_AIDS/ Nursesmidwivesfs/fact-sheet-6/index.html, accessed February 9, 2001).

### **Acknowledgments**

This booklet is one of an occasional series on population, reproductive health, and gender issues produced by the Population Reference Bureau with funding from the U.S. Agency for International Development (USAID) under the MEASURE *Communication* project (HRN-A-00-98-000001-00).

Yvette Collymore of PRB wrote the overview for each section and compiled and edited the articles. Heather Lilley of PRB created the design. Justine Sass and Sara Adkins-Blanch of PRB co-authored the global overview. Several other PRB staff members also contributed to the editing and review process. Thanks are due to the following colleagues who reviewed drafts of the publication and offered valuable comments: Adriana Gómez of the Latin American and Caribbean Women's Health Network; Ellen Weiss of Horizons/International Center for Research on Women; and Ellen Starbird, Michal Avni, Gabrielle Bushman, and Linda Sussman of USAID.

PRB appreciates the cooperation of the editors who participate in the Women's Edition project and whose media organizations are represented in this booklet. Responsibility for the facts and interpretations presented in the excerpted articles belongs to the individual authors.

The booklet was printed by McArdle Printing Company, Inc.

© August 2001 Population Reference Bureau





## Population Reference Bureau MEASURE Communication

1875 Connecticut Ave., NW, Suite 520 Washington, DC 20009 USA Telephone: (202) 483-1100

Fax: (202) 328-3937 E-mail: measure@prb.org

or popref@prb.org

Website: www.measurecommunication.org

or www.prb.org