

Chapter 3



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In Peru, a mother who is HIV-positive kisses her daughter after learning that the child is HIV-negative.

TREATMENT

Recommendation: Ensure equal and universal access to treatment

The need for increased and equitable access to AIDS treatment cannot be overstated. In sub-Saharan Africa alone, it is estimated that only about 3 per cent of people in need of antiretroviral treatment (ART) received it in 2003.¹ Of the 1 million people receiving AIDS treatment worldwide, the overwhelming majority live in wealthy countries. Without concerted prevention efforts, the numbers needing ART will only grow.

The '3 by 5' initiative, created by the World Health Organization (WHO) and UNAIDS, which aims to provide HIV/AIDS treatment to 3 million people by the end of 2005, has made it possible to imagine a world in which HIV is no longer necessarily a death sentence in developing regions. But the challenge is literally of global proportions.

The promise of '3 by 5' and its expansion to all those in need (estimated at an additional 3 million as of 2004) can only be reached if treatment efforts are coupled with prevention and are based on knowledge of the conditions in regions where HIV has been most devastating. That means understanding the different problems men and women face when it comes to prevention and treatment, and the ways in which women have been affected differently.

The Challenges of Accessing Treatment

Recent experiences in Southern Africa point to the issues that affect women's access to treatment. Throughout the region, only one eligible person in 25,000 is receiving drug treatment. Most of them are educated men living in urban areas, where health services are generally better and more available than in rural areas. However, where testing and treatment are offered through public health clinics and reproductive health centres in Southern Africa, women have greater access.²

Nevertheless, women are not always able to use the services that are available. In Zambia, for example, the Government was able to dramatically reduce the monthly cost of ART from \$64 to \$8 per month after receiving support from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Given that well over half—some reports put it as high as 70 per cent—of the 870,000 Zambians living with HIV/AIDS are women, officials expected to see a majority of women receiving ART. Instead, men began showing up in much greater numbers. In one rural town, of the 40 people on ART, only three were women.³

Zambian women reported various reasons for not accessing treatment, including:

- **Discrimination:** Where money was limited, families often chose to pay for medication for the men in the household rather than the women;
- **Property rights:** One couple, who could only afford treatment for one of them told reporters that if the husband died, his family would inherit his land and his wife would have no way to support their children. If the wife died, he would still have the land;

Bringing Treatment Home: Every morning and evening a group of women and a few men, many of them HIV-positive, fan out over the villages of the central region of Haiti bringing ART to more than 650 AIDS patients. These *'accompagneurs'* distribute twice-daily dosages of antiretroviral drugs and provide other medications as needed, some food and a shoulder to lean on. For many patients, it is their first experience of sustained health care. Although renewed conflict and natural disasters in Haiti may make it more difficult to reach patients, the *accompagneurs* continue to make their rounds as part of the HIV Equity Initiative (HEI), a joint programme between Haitian and US NGOs.

Based on the DOTS (directly observed therapy, short-course) method, first developed for TB patients, the *accompagneur* system brings health care to the patient rather than the other way around. Fuelled as much by hope as by money, the Initiative provides treatment for opportunistic diseases to the overwhelming majority of its 6,500 HIV patients and ART to the 10 per cent with AIDS. Without money for more sophisticated testing, the Initiative's protocol for providing ART is also based primarily on direct observation: patients with visible conditions such as wasting or severe diarrhoea receive therapy.

The *accompagneurs* factor women's caring responsibilities into their treatment in various ways, including by providing money to help pay school fees when possible. They also try to be aware of the circumstances under which the women became infected. "We realize that gender inequality is at the root of a lot of infectious diseases, including HIV/AIDS, because of the limited ways women can protect themselves," said Dr. Joia Mukherjee of Partners in Health, the US NGO that, along with the Haitian organization Zanmi Lasante, runs HEI. "Many women we see were domestic servants when they were young girls and were abused by their employers. Others had to do sex work for food or security," said Dr. Mukherjee. Many of them came home to their villages to die, she added, but thanks to HEI, they are still alive.

Sources: Mukherjee, J.S. et al., *Tackling HIV in Resource-Poor Countries*, *BMJ*, vol. 327, 8 November 2003; Joia S. Mukherjee, "HIV-1 Care in Resource-Poor Settings: A View From Haiti," *The Lancet*, vol. 362, 20 September 2003; and interviews

- **Poverty:** More women than men lacked the money to pay for monthly medication.⁴

Transportation is another major factor limiting women's access to treatment. A study in Rwanda found that many women who were receiving medication for opportunistic diseases had to stop because they could not afford transportation to the hospital.⁵

In Botswana, on the other hand, where treatment is available through the public health system to anyone who needs it, women have been utilizing testing and treatment services at greater rates than men. In the capital of Gaborone, some 57 per cent of the patients on ART are women.⁶ Observers believe this is because women have access through reproductive health services and are more comfortable in health-care settings. Nevertheless, the overall numbers remain low, most likely because of the stigma attached to HIV/AIDS. Only 11,000 people were on ART in Botswana at the end of 2003.⁷

Even in countries with more established treatment and prevention programmes, men's and women's differing health-care needs can get ignored in the struggle to provide care on a large scale. Brazil has universal health care and runs one of the world's most successful anti-HIV programmes. Rates of infection are down, with 7,361 new infections registered in the first nine months of 2001, compared with 23,742 cases registered in 1997.⁸ The campaign started out by focusing on urban men who had relations with other men, since they were the largest HIV-positive population in the early years of the epidemic. As the demographics changed, so did treatment programmes and now women have access to prevention and treatment services in urban areas.

Nevertheless, many rural women are still underserved. "The programme was not developed with their special needs in mind," said Astrid Bant, UNIFEM regional adviser for HIV/AIDS in Brazil. "There are a few clinics in rural areas, but it is hard for women to leave their families to travel by bus to a place with a clinic. In rural areas, women don't have the same mobility as men." Bant estimates that a fraction of the people living with HIV in rural areas are registered with the national health programme and receiving treatment. The rest, the majority of whom she and many others believe are women, never make it to testing facilities. "In some states, 90 per cent of pregnant women don't go for prenatal care because it is too far off. So you're not bringing women into prenatal care and therefore you're not testing them and introducing them to HIV programmes."

Making Treatment Gender Equitable

Many advocates have already begun thinking about how to ensure that women have equal access to HIV/AIDS treatment. Recent guidelines produced by NGOs and international organizations on how to distribute medication equitably all start from the perspective that access to ART is a human right that should be available to anyone who needs it. Until full coverage is achieved, life and death choices will be made only slightly more bearable if they are based on as broad a range of criteria as possible. WHO has described the need to use human rights criteria in treatment guidelines, and the '3 by 5' campaign has noted that "special attention will be given to

South African AIDS activists lie down in front of parliament after hundreds marched through Cape Town 12 February 2001 to demand that the Government and pharmaceutical companies allow the importation of generic HIV/AIDS medicines.

protecting and serving vulnerable groups” and that “the Initiative will make special efforts to ensure access to antiretroviral therapy for people who risk exclusion because of economic, social, geographical or other barriers.” The Global Coalition on Women and AIDS has called for half the recipients of ART through the ‘3 by 5’ campaign to be women.¹⁰

Providing treatment for girls and women requires focusing on the constraints that make it difficult for them to adhere to drug regimens. They will often need counselling to help them stay on treatment in the face of opposition and stigma. Many families will also need social services to ensure that sheer destitution does not interfere with women taking the drugs, which require a certain amount of food in order to be effective. In situations where poverty limits the amount of food available and where women are the last to eat, it is nearly impossible for them to follow anti-retroviral therapy without support.¹¹

Projects such as the HEI in Haiti and a pilot programme in Khayelitsha, South Africa, run by the NGO Médecins Sans Frontières (MSF) have shown that it is possible to include gender concerns even in programmes and



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regions with extremely limited resources. In Khayelitsha, for example, concern over high rates of rape and gender-based violence led MSF to include follow-up services for rape survivors, including post-exposure prophylaxis (PEP),¹² a short-term antiretroviral treatment that—if taken within 72 hours—reduces the likelihood of HIV infection after potential exposure.¹³

Voluntary Counselling and Testing (VCT)

VCT is the entry point for treatment of HIV/AIDS as well as for prevention. The majority of people living with HIV/AIDS do not know their status, and most men and women who are at risk of infection have not been tested. In many cases, testing services are not available—only 12 per cent of people who want to be tested for HIV are able to do so.¹⁴ In other instances, people do not want to know their HIV status: They may feel that without treatment options there is no point; they may not be emotionally prepared to deal with the possibility of bad news; or they may fear the social stigma and risk of violence associated with being HIV-positive.

For women, the stigma is even greater than it is for men. Both in the

community at large and in their own homes, they are frequently blamed for infections and risk violence, abandonment or even being killed if they are found to be HIV-positive. The goal of VCT in terms of treatment is to ensure that those who test positive receive counselling about stigma and the impact of HIV as well as about ART. In order to achieve this, ART must be made more available and counselling services must also be improved and increased. Women should be able to discuss their fear of violence if they disclose a positive status, and receive referrals for help. Adolescent girls particularly need access to confidential counselling and care. Currently, many cannot be tested or receive treatment unless a family member gives permission. Counselling also helps clients adhere to treatment regimens. Studies in Brazil and South Africa show that intensive counselling, coupled with support from other HIV-positive patients, makes it more likely that AIDS patients will stay on drug therapy.¹⁵ For couples, having men and women in treatment together increases the chances for both of succeeding.

Evidence also shows that linking testing to treatment helps to reduce the stigma of HIV. In India, the Society for the Protection of Youth and the Masses reported a reduction in stigmatizing behaviour after a pilot project began

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training a core group of health professionals to provide care as well as education around HIV.¹⁶ Among Haitians participating in the HEI, the highly visible fact that they appeared healthy and were able to work after receiving ART has reduced stigma dramatically, according to Dr. Joia Mukherjee, a director of the Initiative (see Box, p. 24). The HEI found that in a 9-month period, 4,000 people were tested in HEI sites that offered testing and treatment, compared to only 43 people at a non-HEI site that only provided testing.

Ensuring Access

Projects such as the HEI and the Gheskio centres (see Chapter 2) show the importance of comprehensive programmes for reaching HIV-positive women. Because discrimination against women, gender stereotypes, women's domestic responsibilities and restrictions on their access to resources make it difficult for them to access health care unless they are pregnant, services need to be expanded to ensure that young women and women who are not pregnant are able to utilize a country's health-care system. Social stigma and the popular belief that infection is linked to promiscuity make it even more difficult for women than men to seek out treatment.

To counteract these problems, health services can use a variety of measures to reach women, such as providing mobile health centres, reducing or eliminating fees, providing child care at health centres and offering care to everyone in a family so no one member is being treated at the expense of others. Comprehensive care is essential to combating HIV/AIDS, but it means little if there is inadequate nutrition and food and no clean water, vaccinations or treatment for other major killers such as tuberculosis.

In some cases, reproductive health centres and family planning clinics are being expanded to offer this broader treatment to the community at large. Given appropriate training for health-care workers, these centres could provide vaccines and TB treatment, as well as integrated health services for HIV and STIs. Since women are often asymptomatic, STI testing is particularly important. To reach this goal, infrastructure must be improved, equipment and supplies must be provided and staff training must be intensified.¹⁷

The few programmes that exist for adolescents and youth living with HIV often have a judgmental attitude towards young people. One of the few exceptions is the Lovelife National Adolescent-Friendly Clinic Initiative (NAFCI) in South Africa, which is striving to provide comprehensive health services, including treatment for AIDS, to young people. In partnership with the South African Department of Health, Lovelife developed national standards for adolescent clinical services. It provides intensive technical assistance and training, as well as regular monitoring to ensure that quality care is maintained. A key part of the initiative is a peer outreach programme to make sure adolescents know about and take advantage of clinic services. The current goal is to pilot high-quality adolescent health services in 900 government clinics by 2006.¹⁸

Pregnancy and Treatment

Preventing mother-to-child-transmission (PMTCT) is an issue of prevention for infants, but it is an equally important potential entry point for treating pregnant women and mothers who are HIV-positive.

Antiretroviral drugs should be used within a framework of prevention, treatment and care both to prevent transmission to the child and to maintain the health of the mother and all other HIV-positive family members.

Unfortunately due to lack of resources, many PMTCT programmes focus only on the child. In much of the developing world, women's only access to ART is a single dose of antiretroviral medication at the onset of labour to protect the infant during delivery. Without ongoing treatment, HIV-positive women frequently give birth only to die a few years later. Stephen Lewis, the Secretary-General's Special Envoy for HIV/AIDS in Africa, described meeting three women in Rwanda who had taken nevirapine to protect their babies from HIV transmission. "They asked a poignant question that haunts me to this day," said Lewis. "They said, 'We'll do anything to save our babies, but what about us?'"¹⁹

Part of the answer to that question lies in the '3 by 5' campaign and increased access to AIDS drugs. Another important example of treating women in their own right is the MTCT-Plus initiative spearheaded by the Columbia University Mailman School of Public Health with other key partners. National AIDS plans are also increasingly recognizing that the growing number of AIDS orphans could be reduced if HIV-positive mothers and their partners were receiving ART. Many countries that are able to do so have already introduced ongoing access to ART for mothers, but these programmes are still limited.

Experience has shown that the best results come about when the larger community is involved in treatment. Treatment and perception are part of a reinforcing cycle, in which those who benefit from treatment become living testimony that AIDS need not destroy lives, and those who gain more knowledge about HIV/AIDS are able to support friends and family members who must learn to live with a chronic disease as well as prevent HIV from spreading further.