

STIGMA OF HIV/AIDS IN SUB-SAHARAN AFRICA

HIV/AIDS Stigma Kills

According to United Nations data, the number of humans living with HIV/AIDS in sub-Saharan Africa is 24.7 million, which is nearly 2/3 of all those afflicted worldwide. During 2006, more humans acquired HIV/AIDS in sub-Saharan Africa than in all other regions of the world combined, and the 2.1 million humans who died from HIV/AIDS in the region were almost 75% of all deaths from HIV/AIDS.

HIV/AIDS is not mentioned in obituaries in sub-Saharan Africa. Social and legal pressure has kept healthcare professionals from recording HIV/AIDS on death certificates and, in the past, from recording HIV infection in patients' medical files. As has been the practice in the United States, a disease such as pneumonia or tuberculosis is cited as the cause of death, without mentioning HIV/AIDS as a contributing factor. In 2005, a South African family filed a complaint against state pathologist Leon Wagner for reporting HIV/AIDS as the cause of death on a medical certificate. He awaits further investigation and possible disciplinary action by the national Health Professions Council, according to several African and European news sources.

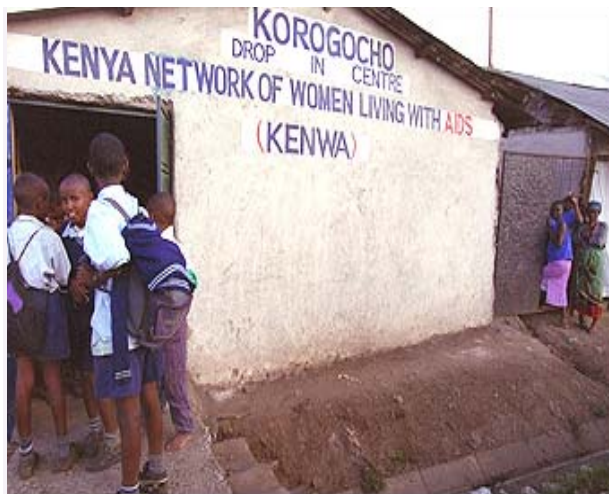
A South African study published in the journal *AIDS Care* in 2006 reported interviews with 144 patients at 2 HIV/AIDS clinics in Johannesburg about disclosing their HIV infection; 1/5 did not tell their sexual partners they were infected and over 1/3 did not tell their family members.

Because many in Africa are threatened by more immediate dangers, such as famine, poverty, and armed conflict, they might be less concerned about the delayed risk of HIV infection. Another reason humans do not talk openly about HIV/AIDS in Africa is the shame and discrimination that accompany the disease.

HIV/AIDS STIGMA DEFINED

According to the American dictionary Merriam-Webster, the word *stigma* comes from a Latin word meaning *mark* which is similar to a Greek term meaning *to tattoo*. The original term referred to a mark that was put on the body of a slave, traitor, or criminal. It signified the supposed low moral status of the bearer and warned others to stay away.

AIDS-related stigma is an identifying characteristic that can come from the bodily deformities that occur with symptomatic HIV infection or from being seen receiving HIV testing or treatment. Stigma related to HIV/AIDS results in prejudice toward those who either are - or are thought to be - living with HIV/AIDS. This prejudice also spreads to the individuals and groups with whom humans with HIV are



Clinic of Kenya Network of Women Living with AIDS in Kenya from the Bill and Melinda Gates Foundation, <http://www.gatesfoundation.org>.

associated.

"Stigma often involves a conscious or unconscious exercise of power over the vulnerable and marginalized," reports the Joint United Nations Programme on HIV/AIDS. HIV/AIDS stigma is used to separate the infected from the rest of society and create social hierarchy. This process is reflected in prejudicial behaviors by individuals and by institutions. It is seen even in language. In parts of Tanzania, according to the International Center for Research on Women (ICRW), a human with HIV/AIDS may be called *maiti inayotembea* (*walking corpse*) or *marehemu mtarajiwa* (*expected to die*). ICRW also reports that in Ethiopia, Tanzania, and Zambia, as in the United States, HIV/AIDS is perceived as an avoidable situation resulting from immoral behavior.

This perception, coupled with the fact that HIV/AIDS is a life-threatening, incurable disease when access to treatment is denied, as is the case for many Africans, makes the stigma attached to HIV/AIDS worse than the stigma of other diseases. HIV/AIDS can be seen as a hopeless, self-inflicted condition.

THE HUMAN COST OF STIGMA

The reluctance of those with HIV/AIDS to tell anyone or to seek treatment has several causes. These include the risks of losing a livelihood, rejection by family and friends, and physical violence. Consequently, humans with HIV/AIDS may attempt to "pass" as unaffected to avoid being harmed, thus delaying treatment and increasing the likelihood that they will infect their sexual partners and children. These are problems reported globally; however because HIV/AIDS is more prevalent in sub-Saharan

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Africa, the impact on the region is great.

The manifestations of HIV/AIDS stigma at the institutional level in sub-Saharan Africa include loss of employment, denial of admission to schools, termination of membership in religious groups, segregation by health workers, and selective application of medical treatment, among others. Some progress has been made in terms of legislative measures to deal with institutional AIDS-related discrimination (criminalizing arbitrary termination of employment, for example), but humans avoid litigation if it will reveal their HIV/AIDS diagnosis.

Humans who reveal they have HIV/AIDS also risk marriage problems, including divorce or domestic violence, and chastisement or abandonment by friends and relatives. Even those who receive some support among family members have reported being banished to a separate room or given separate eating utensils.

Yet another category of stigma is the self-stigmatization of guilt and voluntary isolation. In the study of disclosure rates among patients with HIV/AIDS at 2 Johannesburg clinics, 9% said they had suicidal thoughts after their diagnosis. These data suggest that stigma leads patients to devalue themselves and to agree with their exclusion from society.

Humans afflicted with HIV/AIDS have been murdered because of their disease. Gugu Dhlamini was a South African woman who was stoned and beaten to death by neighbors after speaking openly on World AIDS Day 1998 about her HIV infection, according to a WHO publication.

Women with HIV/AIDS in sub-Saharan Africa are more stigmatized than men, according to United Nations data. For every 2 men with HIV in sub-Saharan Africa, 3 women are infected. In Malawi, a sexually transmitted disease is known as a "woman's disease."

At the same time, in most African cultures, multiple partnerships are accepted for men, but women are expected to be monogamous, reported the president of the Global AIDS Interfaith Alliance, William Rankin, and his colleagues in *PLoS Medicine*. "In addition to women's subordinate status in many [African] societies, they are also frequently stigmatized as the vectors of HIV transmission, despite overwhelming evidence to the contrary. Husbands have beaten or abandoned wives living with HIV/AIDS. Wives are frequently infected by their husbands."

So, in sub-Saharan Africa, where antiretroviral therapy is available to fewer than 10% who need it, humans suspecting they have HIV/AIDS have little

incentive to seek help. The strong disincentive is that seeking help risks stigmatization, which spreads to their families and others who are close to them.

STIGMA BLOCKS ACCESS TO PROGRAMS

Stigma limits the effectiveness of HIV testing, treatment, and prevention programs across sub-Saharan Africa in many ways.

Having an HIV/AIDS diagnosis is an important aspect of efforts to halt the further spread of infection, but in African villages, patients visiting HIV/AIDS test sites are shamed, which undermines willingness to seek out testing. A study of more than 1,200 adults from 5 districts in Botswana measured attitudes toward a routine HIV/AIDS testing policy implemented by the Botswana government in 2004. Although the majority of the study participants believed this policy would decrease HIV/AIDS-related stigma, 43% of the participants believed that it would cause humans to avoid going to university-trained healthcare professionals for fear of testing, and 14% believed it would increase testing-related violence toward women. Consistent with other studies in Africa, HIV/AIDS stigma was associated with decreased odds of having been tested for HIV/AIDS, of undergoing routine testing, and of planning to undergo testing by humans not previously tested.

The World Health Organization reports that condom use for HIV prevention is inhibited in many parts of Africa because it may result in suspicions of infidelity and the risk of abuse from one's partner. A further disincentive against the use of condoms is that a married woman who does not bear a child may be scorned by her husband and community.

Where treatment is available to prevent mother-to-child transmission of HIV/AIDS, women do not always feel free to accept it. In 2003, the Botswana-Harvard AIDS Institute Partnership reported the results of a randomized trial in Botswana to prevent mother-to-child transmission from breast milk. Mothers with HIV/AIDS had suboptimal adherence to infant feeding recommendations, in part because they did not want to alert others that they had HIV/AIDS by using formula. The results of this trial extended concerns raised in other studies that women with HIV/AIDS who are informed of the risk to their infants tend to continue traditional infant feeding methods to avoid stigmatization.

Finally, when humans do not talk openly about the disease, its danger is less apparent to those at risk, and less understood.

THE IMPERATIVE TO RESPOND

Characterizing the response to HIV/AIDS across sub-Saharan Africa as silence and denial is incorrect. Africans' social responses to the disease are diverse,

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and attitudes are changing. In South Africa, activists don "HIV Positive" T-shirts to increase awareness and decrease stigma, and recent surveys indicate that stigmatizing attitudes toward HIV/AIDS are decreasing. According to UNAIDS at least 1/3 who need antiretroviral therapy in Botswana and Uganda do receive it.

But despite these positive advances in many regions of Africa, HIV/AIDS continues to spread throughout the continent. Prevention efforts remain inadequate overall. Education and awareness of the disease do not equate with removal of stigma in all contexts, which may explain in part why education programs have not yet been effective enough to control the spread of disease.

STRATEGIES TO REDUCE STIGMA

Important considerations in designing aid programs and reducing stigma are the diversity of cultures in sub-Saharan Africa and the cultural differences between Africa and foreign aid organizations. One solution will not fit all regions or countries. Failure to recognize socio-cultural differences impedes efforts to improve healthcare and can increase stigma. For example, the low compliance rates with infant feeding recommendations in the randomized trial in Botswana led the research team to conclude that alternative strategies that work with, rather than

against, local traditions should be pursued.

In an editorial in *The Lancet*, Rachel Jewkes, a director of the South African Medical Research Council, explores another facet of stigma. She remarks that focus on removing stigma is itself negative and that traditional interventions to decrease HIV/AIDS stigma may have failed because of this focus. She advocates a fresh approach to reduction of HIV/AIDS stigma, "If the focus shifts, we could provide positive role-modelling in care and support, and, in so doing, shift discourse from the negative (this is what we do, and it is wrong) to the empowering (this is what we do, we care for humans with HIV/AIDS). Such approaches fit much better with established theories of behaviour change, as well as with contemporary political imperatives to end the propagation of negative stereotypes of black Africans."

In an article published in *AIDS & Public Policy Journal* in 2005, John Ehiri and coworkers in the United States and Nigeria outline a plan that echoes Dr Jewkes' views on shifting the focus away from the negative impact of stigma and toward positive action. They believe that action should be targeted, at the institutional level, toward members of society whose attitudes and behaviors have the most direct impact on humans with HIV/AIDS. Dr Ehiri's group recommends that programs against HIV/AIDS stig-



Healthcare in an HIV/AIDS clinic in South Africa. Photo courtesy of Wilson Lee.

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ma be targeted at the following groups:

1) Health workers: Data show that health workers can be a source of stigma. Interactive training programs could help them to acquire the right skills to promote access to care and testing services.

2) Religious leaders: Ehiri and colleagues report that when encouragement comes from spiritual leaders, "the impact can be significantly greater, since it carries the additional authority of an accepted ethical system." Workshops could provide comprehensive information about HIV/AIDS and training in giving anti-stigma sermons.

3) Members of the judicial system: The rights of humans with HIV/AIDS and their families must be protected. Understanding epidemiology and modes of transmission is the first step.

4) Mass media executives and journalists: "Fear-inducing messages" make stigma worse, but if key staff are properly informed and trained, the media can produce positive information and acceptance of humans with HIV/AIDS.

5) Humans with HIV/AIDS and their families: Those directly affected by stigma should be offered counseling or other cognitive behavioral therapy, training in home management of HIV/AIDS, information that encourages self-esteem, and education about their rights.

Dr Ehiri and his coworkers emphasize that because of the diversity of cultures in sub-Saharan Africa, interventions to reduce HIV/AIDS stigma should be tailored to social, economic, geographic, and historic characteristics of each region. Finally, they stress that all intervention programs must be monitored, documented, and evaluated, and the results of evaluations should be widely disseminated.

Oni Blackstock, a physician who studied the experi-

ences of patients taking antiretroviral medications at an HIV/AIDS clinic in Ghana, described her findings in the *New England Journal of Medicine*:

"Although they might regain strength and vigor when given antiretroviral medication, the facets of life that many patients valued most remained elusive; unable to participate in the social and cultural rituals of their community, they felt disappointed and disillusioned. Antiretroviral drugs were not, after all, the remedy to all their troubles."

As antiretroviral therapy becomes more accessible throughout Africa, the benefits for humans with HIV/AIDS will be limited unless stigma is adequately understood and effectively removed.

By Jennifer Withers MS

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BILL & MELINDA GATES FOUNDATION GRANTMAKING PRIORITIES FOR HIV/AIDS

Preventing HIV infection through research to discover, develop, and clinically test HIV vaccines, microbicides, preventive therapies, barrier methods such as diaphragms, and other prevention tools and strategies.

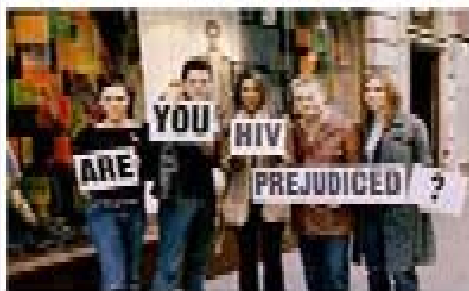
Demonstrating the effectiveness and feasibility of HIV prevention strategies by supporting large-scale prevention initiatives, both in countries with emerging epidemics such as India, and in countries with high HIV prevalence such as Botswana.

Accelerating access to new tools and technologies through efforts to secure adequate financing for product introduction, and develop product distribution plans well in advance of product approval.

Advocating to increase financial support and build commitment and awareness among decision makers and opinion leaders for a comprehensive, science-based approach to addressing the HIV/AIDS epidemic. **The foundation also supports advocacy initiatives to reduce the stigma of HIV in developing countries;** to integrate HIV prevention and antiretroviral therapy efforts; and to adapt HIV prevention strategies ...in the context of greater access to anti-retroviral therapy.

From <http://www.gatesfoundation.org>

Stigma & discrimination



National AIDS Trust page on the illegality of HIV/AIDS discrimination in Great Britain. Screen shot of <http://www.nat.co.uk>.