



Information Bulletin

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Addressing HIV-Related Stigma and Resulting Discrimination in Africa: A Three-Country Study in Ethiopia, Tanzania, and Zambia

The International Center for Research on Women (ICRW) is leading a research initiative in three African countries to investigate the causes, manifestations, and consequences of HIV/AIDS-related stigma and subsequent discriminatory acts. The basis for analysis is the community and its institutions—health facilities, the workplace, schools, and religious groups. ICRW and its in-country partners hope to gain an understanding of those factors that perpetuate or mitigate stigma and how they affect access to HIV prevention, care, and support efforts. Preliminary results are expected mid-2002. The CHANGE Project/Academy for Educational Development (AED) will use the research findings to develop pilot interventions that will minimize the influence of HIV-related stigma on the use and provision of prevention, care, and support programs.

Stigma Accompanies and Fuels HIV/AIDS

From the beginning, the HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance, and denial, leading to stigmatization of and discrimination against people with HIV/AIDS and their family members (Herek and Glunt 1988; Mann 1987). In addition, many more who do not know their serostatus live in fear of facing stigma and discrimination should they contract the disease. HIV-related stigma is increasingly recognized as the single greatest challenge to slowing the spread of the disease (Rao Gupta 2001). In spite of increasing awareness that the impact of stigma must be addressed in policies and programs aimed at reducing HIV/AIDS, efforts are impeded by the dearth of information on stigma and HIV/AIDS.

HIV/AIDS-related stigma and resulting discriminatory acts create circumstances that fuel the spread of HIV (UNAIDS 1998). Fear of being identified with HIV prevents people from learning their serostatus,

changing unsafe behavior, and caring for people living with HIV/AIDS. An ICRW study in Botswana and Zambia found that stigma against HIV-positive people and fear of mistreatment prevented people from participating in voluntary counseling and testing (VCT) and programs to prevent mother-to-child transmission (MTCT) (Nyblade and Field 2000). Whether it is these programs, home-based care, or other support services, stigma prevents individuals and communities from using HIV/AIDS services. Stigma and its resulting discrimination also intensify the pain and suffering of both the people living with HIV/AIDS and their families.

Understanding Stigma

Stigma is generally accepted to be an “attribute that is deeply discrediting” that reduces the bearer “from a whole and usual person to a tainted, discounted one” (Goffman 1963). Link and Phelan (2001) describe stigma as occurring when four interrelated components—distinguishing and labeling differences;

associating human differences with negative attributes; separating ‘us’ from ‘them’; and status loss and discrimination—converge in the context of social, economic, and political power.

Stigmatization often leads to discrimination, which refers to any form of distinction, exclusion, or restriction affecting a person by virtue of a personal characteristic (Gilmore and Somerville 1994).

Stigma is not unique to HIV/AIDS. It has been documented with other infectious diseases like tuberculosis, syphilis, and leprosy (Herek et al. 1998; Goldin 1994). Stigma is most frequently associated with diseases that have severe, disfiguring, incurable, and progressive outcomes, especially when modes of transmission are perceived to be under the control of individual behavior. It is also common in diseases that are perceived to result from the transgression of social norms, such as socially unsanctioned sexual activity (Crandall and Moriarty 1995). These criteria fit HIV/AIDS.

Ignorance and fear underlie HIV-related stigma. An inadequate understanding of the modes of HIV transmission leads to fear of transmission from casual contact. This fear, combined with a better understanding of the deadliness of the disease, can lead to physical and social ostracization of people living with HIV/AIDS and other forms of discrimination.

For many of those with the disease, the impact of HIV-related stigma is compounded, as people who experience it are often members of already disempowered or stigmatized groups such as women, sex workers, the poor, or homosexuals (Herek and Glunt 1988). Through stigma, society often blames infected people for being ill and justifies discriminatory acts against them while asserting the innocence and health of those who stigmatize.

The Research Initiative

Although there is widespread recognition that stigma impedes efforts to reduce the impact of HIV/AIDS, there is insufficient data to inform the design of interventions to reduce stigma and subsequent discriminatory acts. In response, USAID has funded a collaboration between ICRW and the CHANGE Project to address HIV/AIDS-related stigma.

In the first phase of this collaboration, ICRW is leading a research project with local research partners in Ethiopia, Tanzania, and Zambia to better understand the causes, manifestations, and consequences of stigma and how these translate into discriminatory behaviors. The initiative is searching in particular for implications from the research that can be applied to programs and policy.

The research uses an iterative process, applying various qualitative methods. Primarily, the project is using a variety of research tools to do the following:

- ▶ Understand the underlying factors that cause and allow stigma and discrimination to occur
- ▶ Analyze how stigma and discrimination are experienced by different gender and socioeconomic groups
- ▶ Document how stigma and discrimination are manifested in various communities and institutional settings
- ▶ Identify community and institutional responses, such as how hospitals, schools, churches, the media, and workplaces either diminish or contribute to stigma and discrimination
- ▶ Map the consequences of stigma and discrimination for individuals and communities, including the impact on their use of HIV/AIDS services
- ▶ Describe the strategies that both people living with HIV/AIDS and their households use to deal with stigma and discrimination
- ▶ Make recommendations for future interventions to reduce HIV/AIDS stigma and discrimination

The study design and research focus reflect local circumstances and priorities in each country, while maintaining comparability across countries.

Leadership advisory councils, composed of a cross-section of local influential leaders, were formed in each of the participating countries to both inform the researchers on the communities they represent, and also to develop a sustainable core of advocates on the issue of HIV/AIDS-related stigma and discrimination for these communities. In addition, these advisory councils will assist the researchers in their use and dissemination of research findings. Research results, as well as program and policy recommendations, will

be disseminated, starting in May 2002, on an ongoing basis as fieldwork is conducted. Results are first expected from the Tanzania study.

In the second phase of the project, CHANGE will draw upon the research findings and recommendations to launch pilot interventions that address stigma and discrimination in one or more of the countries. Due to the urgency of the AIDS crisis in these countries, pilot interventions are expected to begin as the research is being conducted.

As the core component of each country study, ICRW and its partners are investigating the dynamics of stigma and discriminatory behavior in one urban and one rural community. The studies are examining the community in its entirety—individuals, couples and families, community groups and social institutions—to elucidate the various responses to the HIV epidemic. Representatives from the health services and schools, religious leaders, and employers will help researchers create a history of the epidemic in their communities. Researchers will use a series of qualitative research activities—key informant and in-depth interviews, focus group discussions, listing exercises, local narratives, and stop-start drama—to understand the motivations of those who perpetuate or reinforce stigma and to document the effects of stigma on the spread of HIV/AIDS. The studies will examine how selected characteristics such as gender, age, education, ethnicity, and socioeconomic status influence experiences with stigma and discrimination.

Ethiopia

The Miz-Hasab Research Center is the collaborating partner in Ethiopia. In addition to the community-level study, a longitudinal sub-study will explore experiences with and coping mechanisms to stigma. People living with HIV/AIDS will keep diaries and will be interviewed to record their experience with HIV/AIDS; positive and negative reactions towards them; occurrences of stigma and discriminatory

behavior; and their coping mechanisms. The community study and the sub-study will explore the extent to which poor understanding of HIV/AIDS and responses such as fear, prejudice, or concern act as sources of stigma and discrimination.

Tanzania

The Department of Psychiatry, Muhimbili University College of Health Sciences, is the collaborating partner in the Tanzania country study. A longitudinal sub-study with HIV-positive men and women who sought test results through VCT is underway to document issues related to disclosure and experiences with stigma and discrimination over the course of one year. A similar sub-study is being conducted among a cohort of women offered testing through an MTCT prevention program. Interviews with students and/or instructors at a medical training facility will focus on stigma in the health care system and providers' role in reducing it.

Zambia

ZAMBART (a collaborative project between University of Zambia's School of Medicine and the London School of Hygiene and Tropical Medicine), the principal collaborating partner, is working with Kara Counseling and Training Trust (KCTT) to conduct the research in Zambia. The emphasis of the Zambia study is on the association between tuberculosis (TB) and HIV/AIDS and combating the dual stigmas of each illness.

ZAMBART and KCTT are also pursuing a sub-study of two existing urban household cohorts. Households are selected if a member has had TB or knows his or her HIV status. Researchers will interview a small number of households twice monthly over four months to investigate why HIV is considered a "disease of promiscuity"; notions of infectiousness; the relationship between TB and HIV in popular discourse; and the impact of secondary stigma on children in the household.

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