



Research Update

June 2002

Understanding HIV-Related Stigma and Resulting Discrimination in Sub-Saharan Africa

Emerging themes from early data collection in Ethiopia, Tanzania and Zambia

The International Center for Research on Women (ICRW) is leading a USAID-funded research initiative in three African countries and in Vietnam 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 stigma and how they create barriers to HIV prevention, care, and support efforts. The CHANGE Project/Academy for Educational Development (AED) will use the research findings to develop pilot interventions in Africa that minimize the influence of HIV-related stigma on the use and provision of prevention, care, and support programs.

This research update is based on preliminary analysis of data collected from the African sites since the data collection began in August 2001. Researchers have collected data from three community sites in three countries (see box on page two), as well as from several supplementary studies. Although analysis of the data is ongoing and even more data is yet to be gathered, several clear themes are already emerging. We share these themes early in the study because of the urgency presented by the epidemic and because we are committed to on-going dissemination of findings as the research progresses rather than only at the end of this three-year project.

The data confirms what we already know: that HIV-related stigma is highly complex, dynamic, and deeply ingrained. More importantly, this data allows us to distill the complexities of stigma into separate, manageable aspects and therefore to better focus on areas of intervention to reduce HIV-related stigma and discrimination. The data shows how the causes of stigma, its

intensity, forms, and consequences differ by stage of the disease, the setting (household, health services, neighborhood, places of worship, or workplace), individuals' identities in a particular setting, and over time.

Six key themes are emerging from data analyzed to date:

- ▶ People are largely unaware that their attitudes and actions are stigmatizing
- ▶ Language is central to how stigma is expressed
- ▶ Knowledge and fear interact in unexpected ways that allow stigma and discrimination to persist
- ▶ Sex, morality, shame, and blame are closely related to HIV-related stigma
- ▶ Disclosure of positive HIV status is advocated, but acknowledged as difficult and unusual
- ▶ Widespread care and support for people living with HIV/AIDS (PLHA) co-exists with stigma and discrimination

People are largely unaware that their attitudes and actions are stigmatizing

Data suggests that people often do not recognize that a word, action, or belief is stigmatizing or discriminatory towards PLHA and are unaware of the consequences for the individual, as well as the larger community.

Respondents talk on one hand about how important it is to not stigmatize or discriminate and that they would never behave this way, yet at the same time describe how people who get HIV are promiscuous or indulge in other “immoral” behaviors, deserve what they get, or are being punished by god for their sins. Respondents also say that they know that HIV is not transmitted casually, but that they would not buy food from a

vendor with HIV (as with almost two-thirds—61 percent—of those surveyed in Ethiopia) or would separate utensils, linens, and other household items used by the PLHA from those used by other household members. For example, one respondent in Ethiopia who intended not to stigmatize PLHA talked about caring for PLHA: “*I will not discriminate [against] him because he has the disease. I will console and be close to him...I would put his things, clothing and those utensils he uses separate. I will ask him what help he needs and buy him things he needs, but make sure that members of the family, including children, do not use things he uses.*”

Sources and Methods for Data Collected as of June 2002

Ethiopia

Rural Community Study—Melka Oda, Shashemene Wareda, Oromia region

- ▶ 5 key informant interviews (community leaders)
- ▶ 18 in-depth interviews (various people familiar with different aspects of community life)
- ▶ 6 focus group discussions with 51 participants (one each with young men age 15-24, young women age 15-24, older men age 25-49, and two with older women age 25-49)

Quantitative Survey—Addis Ababa and Melka Oda

- ▶ 402 randomly selected respondents (200 urban, 202 rural)

Tanzania

Urban Community Study—Kimara ward, Dar es Salaam

- ▶ PRA activities (community mapping, transect walks, listing of health problems, HIV/AIDS timelines)
- ▶ 26 key informant interviews (youth, religious leaders, health professionals, teachers, NGO members)
- ▶ 18 in-depth interviews (PLHA, religious congregants, female and male elders, employers, home-based care providers, family care givers, community members)

Longitudinal VCT Study—stand-alone VCT center in Dar es Salaam

- ▶ 40 in-depth interviews with clients seeking VCT services
- ▶ 179 quantitative enrollment interviews with VCT clients (101 men, 78 women)
- ▶ 20 in-depth interviews with HIV+ clients (9 men, 11 women) one month after VCT (December 2001-January 2002)
- ▶ 9 in-depth interviews with HIV+ clients (5 men, 4 women) three months after VCT (March-April 2002)

Zambia

Urban Community Study—Kamwala and Misisi compounds, Lusaka

- ▶ PRA activities (community mapping, transect walks, freelistings, picture discussions, (TB and HIV/AIDS timelines)
- ▶ 22 key informant interviews (politicians, caregivers, traditional healers, religious leaders, educationists)
- ▶ 14 in-depth interviews (community members)
- ▶ 9 focus groups that met for 3 sessions, and 2 focus groups that met for 1 session, with 111 participants (traditional healers, elders, young men age 19-24, young women age 15-22, students, business persons, pregnant women, gatekeepers, tuberculosis patients, and school children)

Household Study on TB and HIV—Kamwala and Misisi compounds, Lusaka

- ▶ 6 rounds of interviews in 13 households, with 15 respondents (8 men, 7 women) who have had TB, mixed HIV status

Language is central to how stigma is expressed

The use of words is a powerful means to stigmatize. Often, however, speakers are not aware that they are stigmatizing with their words or of the damaging impact of what they are saying. This is the case whether these are words used by individuals, the media, or educational materials. This might be due in part to the fact that some countries, such as Tanzania and Zambia, have no word for stigma (although there is a commonly understood word for discrimination). Researchers here learned about stigma by asking how PLHA are talked about and treated, or by using pictures to begin discussions, rather than by asking “does stigma exist?”

One way that language can be stigmatizing is in the use of derogatory references to those with HIV/AIDS. Discussing or naming HIV/AIDS openly, even in the abstract, is uncommon; in interviews, for example, HIV/AIDS is often referred to as “that disease we learned about.” Words with negative connotations to describe PLHA are part of daily conversation and are used in rumors, gossip, and even in the media. For example, PLHA in Tanzania are referred to as “maiti inayotembea” (walking corpse) and “marehemu mtarajiwa” (expected to die).

An analysis of terms for HIV in Tanzania and Zambia reveals that they vary depending on the history of the disease in the community and by the group (youth, men, women) using them, and that they are influenced by popular culture and HIV education messages. The Zambian terms to describe PLHA reflect the stigma associated with HIV/AIDS and can be grouped into seven main categories: individual deviant behavior; death euphemisms; physical appearance (especially frailty – metaphors of light or slight); public disclosure (no longer able to hide disease); acceptance of the existence of the disease; other diseases (related to HIV, e.g. TB, diarrhea); and the burden of having a PLHA in the household. In Tanzania, terms changed with visible progression of the disease. For example, healthy-looking PLHA are called “nyambizi” (submarine), but PLHA exhibiting signs of AIDS are called “utakufa kilo mbili” (you will die weighing two kilos).

Knowledge and fear interact in unexpected ways that allow stigma and discrimination to persist

Ignorance or lack of knowledge of HIV is considered in the literature to be a contributing factor to stigma and

resulting discrimination. Thus, knowledge is one of the key issues the research focuses on. The data suggests that people maintain both correct and incorrect knowledge. However, even when people know how HIV is transmitted or prevented, fear of casual transmission persists, in part because people feel compelled to adopt extraordinary risk-averse behavior due to their fear of certain death if infected with HIV; and also because casual transmission would help explain the high prevalence of the disease. Moral judgments about sexual behavior often associated with HIV further compound the problem of stigma and discrimination.

There is a high level of correct knowledge about HIV transmission and prevention that is mixed with incorrect knowledge. In the Ethiopian survey, 46 percent of respondents listed a combination of both correct and incorrect means of transmission of HIV, and 37 percent did the same for prevention.

The data indicates that while people may “know” about HIV and about some means of transmission and prevention, they generally lack a greater depth of knowledge about HIV and AIDS. For example, it is not well understood that there is a difference between HIV and AIDS, how the disease progresses, what the longevity of a person with HIV/AIDS is, and that opportunistic infections in PLHA (such as tuberculosis) are treatable and curable. An HIV-positive test result is often equated with imminent death. In the absence of greater depth of knowledge about HIV, this coexistence of some correct knowledge about HIV transmission and prevention and little knowledge about other aspects of HIV means that concerns about casual modes of transmission endure.

In all three countries, there is a genuine fear that HIV is transmitted casually despite “knowing” it is not. People fear getting HIV through food, linens, hand shaking, contact with dead bodies, and caring for someone with HIV/AIDS. Even highly knowledgeable people have genuine fears and concerns about casual transmission and a belief that death is imminent once infected with HIV. Thus, even those who have a relatively accurate knowledge about HIV transmission might be prone to avoiding PLHA, isolating their belongings, or stigmatizing them in other ways.

In Tanzania and Ethiopia, the persistence of concerns about casual transmission despite knowledge is linked to strong fears of death and the severity of suffering that

accompanies HIV/AIDS. “When you hear the word HIV you immediately think of death,” an urban respondent explains. The fear of death is so strong that people keep distance from those suspected to have HIV, even when they know that HIV is not transmitted through casual contact.

In Zambia, fear about casual transmission emanates less from a lack of information and more from people seeking explanations for how prevalent HIV/AIDS is and etiology around other diseases. There appears to be some disbelief that a disease that is so prevalent can have so few means of transmission.

A third explanation for persistent stigma and discrimination when knowledge of transmission and prevention is moderately high might be that people hold strong attitudes and moral judgments about sexuality. People who know that HIV is transmitted predominately through sexual contact might still distance themselves from those whom they believe engaged in behaviors they disapprove of.

Sex, morality, shame, and blame are closely related to HIV-related stigma

In all three countries, much of the stigmatizing language and description of stigmatizing and discriminatory behavior centers on the sexual transmission of HIV. “Those” with HIV get it through their own bad behavior, namely sexual activity that is not socially sanctioned or goes against religious teachings. Respondents describe behaviors like pre-marital sex, extra-marital sex, and multiple partners as immoral and leading to HIV. Those who get HIV are “promiscuous,” “careless,” or “unable to control themselves” and have brought HIV upon themselves, and they are blamed for bringing it into the community. In Ethiopia the belief that HIV is a punishment from god for sins committed is particularly strong.

Several groups are singled out as spreading HIV. In Tanzania and Ethiopia, respondents believe that the young are getting HIV because their sexual behavior is irresponsible, they do not listen to their elders, and they do not uphold traditions. In Tanzania, there is special concern about young girls who are seen as increasingly sexually active and vulnerable to infection from older partners. In Zambia and Ethiopia, merchants, truck drivers, and other people whose work includes traveling are seen as high-risk groups that are promiscuous and

spread the disease from place to place. Sex workers and bar ladies are seen in Ethiopia to be at high risk, but are regarded sympathetically as people believe they are involved in this work because of poverty and lack of other available work. In Zambia, however, sex workers are more likely to be stigmatized.

The concept of shame is another integral component of HIV-related stigma. An urban respondent in Tanzania explains: “Someone who is very sick cannot look you in the eye because of shame.” This shaming extends to close family members, other relatives, and children of PLHA. Fear of secondary stigma (stigma attached to those associated with PLHA) is frequently expressed in Tanzania, while stigma experienced by children of PLHA is discussed in Zambia.

Disclosure of positive HIV status is advocated, but acknowledged as difficult and unusual

People generally report that disclosing one’s positive HIV status is a good thing to do and should be encouraged. In Ethiopia in particular, and to a lesser degree in Tanzania, there is a call for PLHA to go public and “teach” and be an “example” to others. At the same time, respondents note that most people would fear disclosing an HIV-positive status because of how they would be treated and viewed by others. They feel that family and community need to be more open and supportive to make disclosure easier. More than 80 percent of those surveyed in Ethiopia think that PLHA should disclose their status to the community, but very few apparently do: Respondents state that people rarely find out about someone’s HIV-positive status through a PLHA’s own disclosure and usually infer status through change in behavior, symptoms, or loss of weight. In the Tanzanian VCT study, before knowing their status, about 50 percent of respondents said they would disclose to their partner, about 35-45 percent to a family member and about 20 percent to a close friend. Follow-up data from a sub-sample of positive respondents shows that disclosure occurs, but to a very limited number of trusted persons.

Widespread care and support for PLHA co-exists with stigma and discrimination

Across the three studies it is clear that families care compassionately for their own family members living with HIV/AIDS. Care from those outside of families—friends, neighbors, or the community at large—is not

expected. Although loving care and support is given, it can be accompanied by stigmatizing and discriminatory attitudes and behavior from caregivers (like blaming and scolding), even though they may not recognize it as such. In the Ethiopian survey, over 70 percent of respondents say that PLHA are at fault, deserve what they got, or should feel guilty; yet at the same time, they feel that PLHA deserve sympathy or support. In Zambia, stigma is reported as being most intense in the home and the clinic, where the most intensive care takes place. Neighbors and the community stigmatize through voyeurism, where visitors come to “see” how the patient is progressing (or the body of the deceased), and then feed this information into gossip and rumors.

Some of this stigmatizing behavior is caused by limited resources and fatigue. Although caregivers in the family and community provide care, they often regard PLHA as a burden. The feeling of burden is fueled by the knowledge that there is no cure and the belief that those with HIV/AIDS will soon die. Communities do not acknowledge the capabilities of PLHA. In some cases in Tanzania and Ethiopia, PLHA are described as “useless” and “worthless.” In Ethiopia, the perception of PLHA being “worthless” is attributed to the commonly held belief that PLHA could not or should not work hard because of the detrimental impact on their health. In the Tanzanian VCT study, several PLHA with no symptoms of AIDS who disclosed their status were sent back to their villages by their urban-resident family, a practice usually reserved for only the very sick.

Summary

An overarching theme emerging in all three countries and in the different facets of stigma discussed above is the co-existence within an individual or a community of apparent contradictions. We saw that people who believe it is important not to stigmatize PLHA in fact do. Individuals maintain correct and incorrect knowledge about transmission of HIV simultaneously, but even those who know that HIV is not transmitted through casual contact continue to have doubts and behave as if it is. People express both sympathetic and stigmatizing attitudes about PLHA. Families provide

genuine care and compassion for PLHA and concurrently stigmatize and discriminate against them. People are also ambivalent about disclosure, which is described as positive and necessary but also as uncommon and difficult. These contradictions are an indication of the elusive and pervasive nature of stigma and how it will be difficult to diminish.

Challenges emerging for programs targeting stigma

Though it is early in the research process, certain challenges are emerging from this preliminary data for programs that aim to reduce HIV-related stigma and resulting discrimination.

- ▶ The lack of recognition of stigmatizing attitudes, language and discriminatory behaviors and their consequences is a major and basic challenge.
- ▶ Combined with this challenge is the lack of a common word to discuss stigma in many languages and the need to unravel the concept of stigma to begin discussion.
- ▶ The co-existence of seemingly contradictory HIV-related knowledge, stigmatizing and sympathetic attitudes, and discriminatory and caring behaviors, while a challenge, also offers a space within which to work to reduce stigma.
- ▶ The lack of depth in HIV/AIDS knowledge allows “correct knowledge” about transmission to co-exist with genuine fears of casual transmission.
- ▶ HIV-related stigma is closely related to attitudes about sexual behavior and what is moral or immoral. A central challenge to reducing stigma will be to talk openly and frankly about sex and what communities sanction as socially acceptable behavior.

This research update is the first in a series. As we continue to collect data and conduct analysis in all three countries, we will deepen our analysis of these themes and explore new ones. Future updates will present findings and analysis from these continuing efforts and will focus on implications for interventions.

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