Reducing HIV-Related Stigma: Lessons Learned from Horizons Research and Programs

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SYNOPSIS

Since the early years of the human immunodeficiency virus (HIV) epidemic, stigma has been understood to be a major barrier to successful HIV prevention, care, and treatment. This article highlights findings from more than 10 studies in Asia, Africa, and Latin America—conducted from 1997 through 2007 as part of the Horizons program—that have contributed to clarifying the relationship between stigma and HIV, determining how best to measure stigma among varied populations, and designing and evaluating the impact of stigma reduction-focused program strategies. Studies showed significant associations between HIV-related stigma and less use of voluntary counseling and testing, less willingness to disclose test results, and incorrect knowledge about transmission. Programmatic lessons learned included how to assist institutions with recognizing stigma, the importance of confronting both fears of contagion and negative social judgments, and how best to engage people living with HIV in programs. The portfolio of work reveals the potential and importance of directly addressing stigma reduction in HIV programs.

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Early in the history of the human immunodeficiency virus (HIV) epidemic, the late Jonathan Mann, former head of the World Health Organization's (WHO's) Global Program on Acquired Immunodeficiency Syndrome (AIDS), identified stigma as the "third epidemic," following the accelerating spread of HIV infection and the visible rise in AIDS cases. He recognized that stigma, discrimination, blame, and denial are potentially the most difficult aspects of HIV/AIDS to address, yet addressing them is key to preventing HIV transmission and mitigating the impacts of the disease on individuals, families, and communities.[1]

When the Horizons program began in 1997, stigma's insidious role in the spread of HIV was widely recognized, and a few programs attempted to address its impact. Yet despite this increased awareness, there was limited understanding of the underlying drivers of stigma or the specific ways in which stigma affects HIV outcomes, a lack of tools to reliably and effectively measure stigma and discrimination, and a dearth of information about which types of intervention strategies most successfully reduce stigma in different settings.

In response to this need, Horizons developed and implemented a wide range of activities in collaboration with numerous local and international partners in Africa, Asia, and Latin America. This article summarizes the key contributions of the Horizons stigma portfolio to describing the drivers of stigma, identifying effective interventions and approaches for reducing stigma in different settings, and improving methods for measuring stigma.

ARTICULATING THE ISSUES

To guide its operations research agenda, Horizons initially carried out three key activities to take stock of what was known about HIV-related stigma and ways to reduce it. In 1999, Horizons co-hosted a technical workshop with San Francisco State University that brought together stigma and HIV/AIDS experts. Horizons then published a literature review of stigma intervention strategies to date.[2] The third activity was an examination of existing conceptual frameworks and the development of new approaches for intervening on stigma and discrimination.[3] Findings from these activities showed the following:

- Stigma occurs at multiple levels, including the interpersonal, institutional (e.g., health facilities, schools, and workplaces), community, and legislative levels.

- Manifestations of stigma take many forms, including isolation, ridicule, physical and verbal abuse, and denial of services and employment.

- Experiences of stigma can differ by sex, reflecting broader gender inequalities. For example, women may be more likely to be blamed for bringing HIV into the household than men.

- HIV-related stigma reinforces existing stigmas against marginalized groups (e.g., men who have sex with men [MSM], sex workers, and injection drug users)—often called "compounded" stigma.

- Common stigma-reduction interventions have focused mainly on creating changes in individual knowledge, attitudes, and behaviors rather than broader social and environmental change.

- There have been very few rigorous evaluations of stigma-reduction interventions in the developing world.

The conceptualization of stigma as a deeply rooted social process with different manifestations at various levels of society had important implications for the development of the Horizons program's global operations research agenda. This article highlights findings from Horizons intervention studies that tested a range of innovative stigma-reduction strategies at the institutional and community levels to achieve individual, social, and environmental change (Figure 1).

INTERVENTION STRATEGIES

Help institutions recognize stigma

Horizons and partners recognized from the outset that to improve the environment for people with HIV in health-care settings, it was important for management and health providers to acknowledge that stigma exists in their facilities. They found that a participatory approach that included ongoing sharing of data about levels and types of stigma in institutions helped build staff and management support for stigma-reduction activities.

In a study conducted in three public and private hospitals in New Delhi, India, hospital managers were initially unwilling to believe that stigma and discrimination were problems in their hospitals. Baseline data from interviews with health workers and HIV-positive patients as well as a survey of nearly 900 workers suggested otherwise.[4] After the research team shared key findings, the hospital managers and staff developed action plans to address hospital workers' misconceptions about HIV transmission, as well as their judgmental attitudes and differential practices

Figure 1. Summary of Horizons' intervention studies on stigma and discrimination, 1997–2007

Country	Years of study	Type of intervention	Target population	Sample size	Type of study (sampling technique)	Key findings
Brazil[a,b]	2002–2005	Holistic, nonstigmatizing health services	Male truck drivers	Baseline: 1,775 Endline: 2,415	Cross-sectional pre- and post-intervention evaluation with control group (systematic sampling)	The number of truckers who had ever had an HIV test increased significantly at the intervention site. The majority of participants reported that they found the services useful and nonstigmatizing.
India[c]	2000–2004	Staff training, data sharing, participatory policy development	Hospital workers	Baseline: 884 Endline: 885 (at three hospitals)	Cross-sectional pre- and post-intervention evaluation (stratified random sampling)	Health-care workers with the least stigmatizing attitudes increased from 12% to 27% and those demonstrating the highest level of stigma declined from 24% to 7% of the sample. Counseling and testing practices, protection of patient confidentiality, and use of universal precautions improved.
Kenya[d]	2003–2004	Adherence counseling	People on ART	Baseline: 183 Endline: 181	Longitudinal panel study with baseline and 12-month follow-up	Significant reductions in internalized stigma and significant increases in disclosure to a greater number of family members were observed. Disclosure in the community and workplace did not change.
Nicaragua[e]	2002–2005	Mass media: communication for social change	Young people (aged 13–24)	Participants completing surveys at all three intervals: 3,099	Longitudinal panel study with three data collection intervals, each spaced one year apart (cluster area random sampling)	Controlling for sociodemographic variables, individuals with the highest level of exposure to the intervention were significantly less likely to hold stigmatizing attitudes than individuals with less exposure.
Tanzania[f]	2001–2006	Community awareness and mobilization by NGO, community leaders	General population	Baseline: 978 Endline: 910	Cross-sectional pre- and post-intervention evaluation (cluster area random sampling)	The intervention did not reduce community-wide stigma, perhaps because the numbers of individuals who received training were not great enough to effect population-wide change. However, stigma reduction training had a profound effect on those trained, particularly the community leaders, leading to visible changes in their own behavior and leadership.
Senegal[g,h]	2003–2005	Peer education; sensitization training for STI providers and media representatives	Men who have sex with men	Baseline: 258 Endline: 290	Cross-sectional pre- and post-intervention evaluation (snowball sampling)	Qualitative findings at the end of the intervention period showed that men appreciated the availability of STI services, which they found to be of high quality and nonstigmatizing.
Vietnam[i]	2006–2007	Staff training, data sharing, participatory policy development, improvements in structural environment	Hospital workers	Baseline: 931 Endline: 889	Cross-sectional pre- and post-intervention evaluation (census)	Significant improvements were seen in quality of care (e.g., protection of patient confidentiality), reduction of discrimination (e.g., equitable use of universal precautions), and stigmatizing attitudes. Changes were most pronounced at the hospital receiving the extra half-day workshop on social stigma.

Figure 1 (continued). Summary of Horizons' intervention studies on stigma and discrimination, 1997–2007

Country	Years of study	Type of intervention	Target population	Sample size	Type of study (sampling technique)	Key findings
Zambia[j]	2001–2002	Training of youth members of "anti-AIDS clubs" in care and support	Young people (aged 13–25) and people living with HIV and their families	Youth: Baseline: 796 Endline: 983	Cross-sectional pre- and post-intervention evaluation with comparison group (random selection of clubs)	Qualitative evidence showed that, as a result of observing and interacting with the youth caregivers, family members became less stigmatizing and more involved in the care of HIV-positive relatives.
Zambia[k]	2004–2006	Community- and clinic-based education and mobilization on HIV, ART, and stigma	General population; people on ART	Community respondents: Baseline: 1,203 Endline: 1,191 People on ART: Baseline: 322 Endline: 501	Cross-sectional pre- and post-intervention evaluation with comparison group (community respondents: stratified random sampling; people on ART recruited sequentially as they came in for services)	Qualitative and quantitative data supported the association between ART access and reductions in stigma. Despite statistically significant reductions in stigma, existing levels of stigma remained high enough to be of concern.

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[g]Niang CI, Tapsoba P, Weiss E, Diagne M, Niang Y, Moreau A, et al. "It's raining stones": stigma, violence, and HIV vulnerability among men who have sex with men in Dakar, Senegal. Culture, Health & Sexuality 2003;5:499-512.

[h]Moreau A, Tapsoba P, Ly A, Niang CI, Diop AK. Implementing STI/HIV prevention and care interventions for men who have sex with men in Senegal. Horizons Research Summary. Washington: Population Council; 2007.

[i]Oanh KTH, Ashburn K, Pulerwitz J, Ogden J, Nyblade L. Improving hospital-based quality of care in Vietnam by reducing HIV-related stigma and discrimination. Horizons Final Report. Washington: Population Council; 2008.

[j]Esu-Williams E, Schenk KD, Geibel S, Motsepe J, Zulu A, Bweupe P, et al. "We are no longer called club members but caregivers": involving youth in HIV and AIDS caregiving in rural Zambia. AIDS Care 2006;18:888-94.

[k]Samuels F, Simbaya J, Sarna A, Geibel S, Ndubani P, Kamwanga J. Engaging communities in supporting HIV prevention and adherence to antiretroviral thereapy in Zambia. Horizons Research Summary. Washington: Population Council; 2008.

HIV 5 human immunodeficiency virus

ART 5 antiretroviral therapy

NGO 5 nongovernmental organization

STI 5 sexually transmitted infection

AIDS 5 acquired immunodeficiency syndrome

toward HIV-positive individuals. These action plans ultimately addressed limited supplies for practicing universal precautions, providers' needs for information and sensitization, and the lack of management support before the intervention.

To help develop the action plans and set institutional goals, the project team developed a checklist allowing hospital managers to examine how well their facility provides a safe working environment for staff and a welcoming environment for HIV-positive patients. During the evaluation of the intervention, the hospital managers reported that data on stigma and discrimination and use of the checklist showed them how HIV-positive patients were treated differently in their hospitals, and helped catalyze reform.[4]

Similarly, after baseline findings on stigma and discrimination were discussed as part of a hospital-based intervention study in Vietnam, hospital management became enthusiastic participants in subsequent intervention activities to improve care for people with HIV and safeguard the health of hospital workers.[5] By proceeding gradually and involving staff in a non-confrontational manner, the intervention team was able to get institutional buy-in to make needed changes in policies and practices.

Address social stigma and the environment

The hospital-based intervention study in India focused on helping facilities establish an environment that provided timely, appropriate, and humane care for people with HIV. This required developing tailored interventions to protect the interests and well-being of both patients and staff. To catalyze social and environmental changes, the project team engaged hospital managers in a participatory process to develop action plans to address stigma. These action plans included establishing an HIV/AIDS care and management policy, enlisting people living with HIV to sensitize and train health-care workers, strengthening and mainstreaming HIV counseling, and developing and disseminating information on infection control procedures and the availability of post-exposure prophylaxis to staff.

After the intervention, health-care workers' attitudes about people with HIV and quality of care improved. For example, the proportion of health-care workers who, based on their scores on a stigma index, were categorized as having the least stigmatizing attitudes more than doubled (from 12% to 27%), and the proportion of respondents with the most stigmatizing attitudes declined considerably (from 24% to 7%). Counseling and testing practices and protection of patient confidentiality also improved, as did understanding and use of universal precautions with all patients.[4]

In Vietnam, Horizons and partners built on the results of the India study by conducting intervention research in four hospitals involving nearly 800 hospital workers. Activities included training for all cadres of hospital staff (e.g., nurses and janitors) on HIV and universal precautions, testimonials from people living with HIV as part of staff training workshops, participatory development of hospital policies, and key modifications of the structural environment (e.g., improved availability of hand-washing facilities and sturdy containers to dispose of needles and syringes). Two hospitals received these activities alone, while the other two received the same package of activities plus a half-day workshop focused on the causes and manifestations of social stigma, co-facilitated by people living with HIV.

Following the intervention, hospital practices improved, including significant declines in the labeling of patients' files and beds with their HIV status, a reduction in the overuse of barrier protections (e.g., using gloves during casual contact with HIV-positive patients), and better hospital-wide implementation of universal precautions. Health workers in all four participating hospitals significantly improved their mean scores on both fear-based and socially based stigma indices ($p < 0.05$). While both interventions successfully reduced stigma, results from hospitals with the extra half-day staff workshop on social stigma showed more impact. For example, workers in these hospitals were 4.7 times less likely to report marking the files of HIV-positive patients ($p < 0.001$) and 2.3 times less likely to report placing signs on beds indicating HIV status ($p < 0.001$), compared with workers at the other two hospitals.[5] To further illuminate the impacts of these promising intervention packages, it would be useful in future studies to separate and compare different components of these interventions.

Respond to the needs of stigmatized populations

In Brazil, formative research showed that truck drivers, a population often at increased risk of HIV infection, were wary of HIV services because of the stigma attached to accessing them.[6,7] In response, Horizons and partners tested a model combining HIV-related services with other health services and targeted them to truckers. A health unit was established inside a border customs station in southern Brazil that provided a variety of services, including voluntary counseling and testing (VCT) for HIV and sexually transmitted infections (STIs), syndromic management of STIs, and HIV/STI information, as well as basic health services not related to sexual health (such as blood pressure and glucose testing).

At baseline, less than half of the respondents had ever had an HIV test. By follow-up, the number of truckers who had ever had an HIV test increased by 49% in the intervention site, but only by 15% in the comparison site ($p < 0.01$). The majority of participants reported that they found the services useful and nonstigmatizing.[6]

MSM are another highly stigmatized population in need of HIV services. In Senegal, Horizons and partners found that the stigma and discrimination suffered by many MSM results in the concealment of sexual behaviors from health-care providers, making it difficult for this population to receive appropriate STI services.[8] The project team worked to create and train a network of health providers, sensitized to the special needs of MSM, who were available to provide confidential, nonjudgmental medical and psychosocial care. Qualitative findings at the end of the intervention period showed that men appreciated the availability of STI services, which they found to be of high quality and nonstigmatizing. According to a 23-year-old informant, "They are doing a wonderful job because they are available when we need them, and they are not judgmental."[9] Additional research is needed to determine whether these improvements in the health-care environment have led to an increased uptake of STI services.

Use the media to show that AIDS has a human face
In Nicaragua, Horizons helped evaluate a communication-for-social-change strategy that sought to empower young men and women to prevent HIV infection through critical discussion of social and cultural issues (e.g., stigma, gender inequality, and violence). To address these issues in an accessible and entertaining way, the project team created a national television soap opera series called "Sexto Sentido," a youth-directed radio show, and various community-based activities (e.g., training of youth leaders and networking with other nongovernmental organizations [NGOs] to reinforce intervention messages and create advocacy networks).[10]

After following a representative cohort of more than 3,000 young people from three large cities over two years, researchers found that individuals with the highest level of exposure to the intervention were significantly less likely to hold stigmatizing attitudes than individuals with less exposure. After controlling for sociodemographic variables, the high-exposure group demonstrated a 20% greater reduction in stigmatizing attitudes ($p < 0.001$) compared with the lower exposure group. Further, survey results indicated that the intervention resulted in a significant increase in knowledge and use of HIV-related services, as well as interpersonal communication about HIV prevention and sexual behavior. Qualitative data suggested that the soap opera reduced stigmatizing attitudes by helping viewers relate to affected individuals as human beings who have rights and need compassion and support.

The study also found that some aspects of stigma and discrimination are easier to change than others. For example, stigma against MSM and sex workers as vectors of HIV was resistant to change, even though other forms of stigma were significantly reduced among those exposed to the intervention. These results demonstrate the complexity of stigma as an intervention outcome and that one intervention strategy may not address all aspects of stigma and discrimination.[10]

A Horizons intervention study in Senegal found that the media contribute to the stigmatization of MSM by communicating negative and sensational stories about them. As part of its intervention activities, the project team held a workshop for media representatives in Dakar that included the participation of MSM, who brought a human face to the issues and helped journalists better understand the hidden realities of the men's lives, which are often punctuated by stigma, discrimination, and violence. Over the next 18 months, the project team reviewed local newspapers and found that no offensive or stigmatizing articles had been written about MSM.[9]

Involve people living with HIV in service delivery
Horizons has found that efforts to involve people with HIV in providing HIV services and in sensitizing other service providers about the realities of their lives empowers HIV-positive individuals, improves service delivery, and contributes to stigma reduction among health workers and community members. Studies in Burkina Faso, Ecuador, India, and Zambia revealed that when programs provide adequate support and training to HIV-positive team members, involvement in NGO activities can reduce their isolation, enhance their self-esteem, and improve community perceptions about their productivity. Further, involvement of people living with HIV can improve care and support services by making them more relevant and personalized. As one HIV-positive peer counselor in India noted, service recipients derive hope from seeing other HIV-positive individuals actively involved in delivering NGO services.[11]

The hospital-based stigma-reduction programs in Vietnam and India are other examples of successful collaborations with people living with HIV. In these interventions, health-care workers heard—often for the first time—from HIV-positive trainers about living

with HIV, and began to relate to them as people, not just as patients.[4,5]