

# REDUCING STIGMA AND DISCRIMINATION IN HOSPITALS: POSITIVE FINDINGS FROM INDIA

*Hospital managers who used a checklist to assess their facilities' policies and practices took action to improve staff safety and reduce AIDS-related stigma. Findings suggest that the actions taken, including education, training, policy formulation, and involvement of AIDS NGOs, contributed to improved knowledge, attitudes, and practices among health workers. UNAIDS has recognized the intervention as a best practice, and NACO has endorsed the intervention's tools and approaches.*



POPULATION COUNCIL

*To reduce AIDS-related stigma, health workers' concerns about exposure to HIV must be addressed.*

**A**IDS-related stigma and discrimination is a pervasive problem worldwide. People living with HIV in India, as elsewhere, face stigma and discrimination in a variety of contexts, including the household, community, workplace, and health care setting. Research in India has shown that stigma and discrimination against HIV-positive people and those perceived to be infected are common in hospitals and act as barriers to seeking and receiving critical treatment and care services (UNAIDS 2001).

Recognizing the need to move beyond documentation of the problem, three New Delhi hospitals; SHARAN, an Indian NGO; and the Horizons Program, with support from India's National AIDS Control Organisation (NACO),

collaborated on an operations research project to assess responses to hospital-based stigma and discrimination against people living with HIV. The collaboration aimed to develop and test tools and approaches to guide hospitals and other major medical institutions in upgrading their systems and services to provide timely, appropriate, and humane care for people living with HIV. A basic premise of the project was that establishing an environment free of stigma and discrimination required tailored interventions to protect the interests and well-being of both patients with HIV and staff. Therefore, individual and institutional factors needed to be addressed in order to improve care, including the knowledge and attitudes of hospital personnel, hospital policies and procedures, and services and supplies.

To read more about this study, go to the full report, [www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf](http://www.popcouncil.org/pdfs/horizons/inplhafriendly.pdf)

## Methods

Researchers used a pre-/post-test evaluation design to assess the outcomes of the pilot program conducted in three hospitals in New Delhi (one private and two government).

Prior to the implementation of the program, formative research was conducted in 2000 to understand the causes and manifestations of AIDS-related stigma and discrimination in health care settings. This involved conducting in-depth interviews with health workers and focus group discussions with people living with HIV and their caregivers. These findings informed the development of a checklist, a self-assessment tool for hospital managers to identify institutional strengths and weaknesses of services for people infected with HIV, and of hospital policies and procedures to prevent occupational exposure to HIV by staff. The checklist covers the following areas: access to care services, HIV testing and counseling, confidentiality, infection control, and quality of care.

To assess outcomes of the program, a baseline survey to measure HIV/AIDS-related attitudes, knowledge, and practices was conducted in 2000 with a random sample of 884 health workers from four departments: medicine, STD and skin, obstetrics and gynecology, and surgery. These health workers represented three cadres of hospital staff that have contact with people living with HIV: doctors, nurses, and ward staff (i.e., those responsible for the daily cleaning of patient areas). Findings from the formative research and baseline survey were discussed with hospital managers who then used the checklist to assess the extent to which their facilities followed gold standards to ensure AIDS-related staff safety and a non-stigmatizing and non-discriminatory hospital environment. Based on this assessment, hospital managers and senior representatives of doctors, nurses, and ward staff developed action plans to improve the situation. The project team and local AIDS service organizations helped each hospital carry out their action plan by assisting with training and the development and dissemination of policy guidelines

Horizons conducts global operations research to improve HIV/AIDS prevention, care, and support programs. Horizons is implemented by the Population Council in partnership with the International Center for Research on Women (ICRW), PATH, the International HIV/AIDS Alliance, Tulane University, Family Health International (FHI), and Johns Hopkins University.

and educational materials, such as posters on infection control.

To assess progress, the researchers administered a follow-up survey in 2003 to a random sample of 885 health workers and conducted qualitative interviews with hospital managers. As part of the baseline and endline surveys, a 21-item stigma index was included to examine health workers' attitudes toward

people living with HIV and discriminatory practices in the health care setting (see Box 1).

## Key Findings

### ***Manifestations of stigma and discrimination in hospitals range from condescending attitudes to denial of treatment.***

According to informants who were living with HIV, common manifestations of stigma and discrimination by hospital staff include condescending and judgemental remarks, unwarranted referrals to other facilities, segregation and labeling of patients, excessive use of barrier precautions, unconsented HIV testing, inadequate pre- and post-test counseling, withholding of HIV test results from the patient, unconsented disclosure of test results to family and non-treating staff, and denial of treatment.

*The doctor did a very wrong thing, he told everyone [my HIV status]. I am very troubled because of this.*

Person living with HIV

*We are often refused treatment in...hospitals. They tell us 'we have no bed, we have no empty bed.' Another thing that they say is 'we don't have facilities for treating HIV.' They then refer us to other hospitals.*

Person living with HIV

Interviews with health workers corroborated reports about stigmatizing and discriminatory practices by hospital personnel.

## Box 1 Selected items from the stigma index

### I. Attitudes toward PLHA

- People living with HIV/AIDS have a right to decide who should know about it.
- HIV/AIDS spreads due to immoral behavior.
- Men who get HIV/AIDS get what they deserve.
- Sex workers are the only women who have to worry about getting HIV/AIDS.
- Would you be willing to share a meal with an HIV-positive person?
- If you found out that a co-worker has HIV/AIDS would you be willing to work with him/her?

### II. Attitudes toward health care-related practices

- Patients' blood should never be tested for HIV without their consent.
- Patients who test positive have the right to decide whether or not their relatives should be informed.
- When a person tests positive, the doctor should inform the patient's partner.
- The need for consent is exaggerated. HIV tests should be handled like any other blood test.
- Patients with HIV/AIDS should be kept at a distance from other patients.
- Clothes and linen used by HIV patients should be disposed of or burned.

*There is a separate bed which is earmarked for an HIV-positive patient and I see to it that it is not occupied by any other patients.*

Doctor

*We put bed signs for HIV-positive patients. We write 'High Risk Patient.'*

Nurse

Stigmatizing attitudes of health workers at baseline were assessed using the 21-item stigma index. A total score could range from a minimum of 21 to a maximum of 63 (indicating greater stigma). The mean score for the entire group of health workers (n = 884) was 42.79, with individual scores ranging from a minimum of 23 to a maximum of 61. There was a significant difference between the mean scores of the three groups of health workers ( $p < .0001$ ); ward staff had the highest mean score (47.80), followed by nurses (39.99) and doctors (36.60).

#### ***Both individual and institutional factors contribute to AIDS-related stigma.***

Staff misconceptions about HIV transmission contribute to differential treatment of HIV-infected clients in the study hospitals.

*We burn the linen of the patient. Even utensils of AIDS patients are thrown away.*

Ward staff

Data from the baseline survey demonstrate a relationship between stigmatizing attitudes and misconceptions about HIV transmission. Health workers who believe that HIV can be transmitted through casual contact (e.g., touching, serving food, or coming close to an HIV-positive patient) had significantly higher scores on the stigma index, indicating greater support for stigmatizing attitudes.

Staff prejudice against HIV-positive patients and patients considered to be at risk for HIV also fuel AIDS-related stigma and discrimination.

*High-risk population means lower class people—they live in slums in unhygienic conditions. One sleeps with anybody and everybody...*

Doctor

In addition, institutional factors such as a lack of hospital policies protecting people living with HIV and ensuring staff safety, and inadequate training of staff on infection control foster stigmatizing attitudes and behaviors among staff.

***When presented with data from their institutions, managers instituted hospital-wide initiatives.***

After reviewing the baseline data and using the checklist to assess their institution, the managers, many of whom were previously reluctant to acknowledge problems, set and achieved action plan goals. These included establishing an HIV/AIDS care and management policy, enlisting NGOs to sensitize and train health workers, strengthening and mainstreaming HIV counseling, and developing and disseminating information to staff on infection control procedures and availability of post-exposure prophylaxis.

***Understanding of HIV transmission increased among health workers.***

Overall, there were large increases in knowledge, especially among ward staff. For example, there was a significant increase ( $p < .05$ ) in the number of ward staff who reported that HIV cannot be transmitted by touching someone with HIV/AIDS (81 percent vs. 96 percent), by sharing utensils (67 percent vs. 83 percent), by sharing clothes (63 percent vs. 86 percent), and by coming close to someone with HIV/AIDS (81 percent vs. 98 percent).

These changes were supported by comments from hospital managers at endline.

*There has been a big change. Earlier ward staff were not willing to touch these patients: now they know it does not spread by ordinary touch, they are not scared.*

Nursing supervisor

*The scare that used to be earlier is gone. About three or four years back, we had an HIV-positive patient who had come for treatment to our department. The ward staff sprayed DDT [a pesticide] all around the patient's bed so that the virus would not spread. Now these things do not happen. Now if you go and tell my staff that you are HIV-positive, then they will not even lift their eyes and look at you.*

Doctor, Head of department

Despite improvements, some misinformation persists, particularly among ward staff. For example, at endline, only 35 percent of ward staff believed that HIV is not transmitted by mosquitoes and 51 percent that it is not transmitted through sputum.

***Health workers' attitudes toward people living with HIV improved.***

Over time, the mean score on the stigma index for all health workers declined significantly from 42.79 to 38.07 ( $p < 0.05$ ), indicating an improvement in their attitudes toward people living with HIV and reduced support for discriminatory hospital practices. As part of the analysis, the total scores were trichotomized into three categories—low stigma (mean score 21–34), medium stigma (34–48), and high stigma (49–63). As shown in Figure 1, after the intervention the proportion of health workers who were categorized as being the least stigmatizing more than doubled (from 12 percent to 27 percent) and the proportion of respondents in the most stigmatizing category declined considerably (from 24 percent to 7 percent).

In general, the data show that a large proportion of doctors and nurses improved their attitudes by moving into the low stigma category from the moderate stigma category. There was also a considerable shift among ward staff: a large proportion moved from the high stigma category to the moderate stigma category.

At endline, the majority of all health workers fell into the moderate stigma range, thus indicating that work is still needed to address their attitudes, particularly relating to fear of contagion in the health care setting.

***Doctors reported improvements in their HIV testing and counseling attitudes and practices.***

After the intervention, doctors were more likely to agree that patients should not be tested for HIV without their consent (37 percent vs. 67 percent;  $p < .05$ ). Similarly, among the doctors who had referred

patients for an HIV test, there was a significant increase in the number who had sought informed consent the last time they ordered an HIV test (40 percent vs. 59 percent;  $p < .05$ ). There was also a significant increase in the number who always sought informed consent from the patient prior to testing (33 percent vs. 53 percent;  $p < .05$ ).

Reported communication of test results by doctors improved following the intervention. At endline, there was a slight increase in the proportion of doctors who informed a patient of an HIV-negative test result the last time they referred a patient for an HIV test. A similar change was also detected the last time a patient they referred for an HIV test tested positive. In addition, there was a significant ( $p < 0.05$ ) increase in the number of doctors who reported they always informed their patients of an HIV-negative result (35 percent vs. 54 percent) and an HIV-positive test result (54 percent vs. 85 percent).

***Understanding and practice of universal precautions and infection control improved among health workers.***

At endline, more doctors reported wearing gloves for at-risk procedures (65 percent vs. 91 percent;  $p < .05$ ) and fewer ward staff reported a lack of supplies for universal precautions and infection control (21

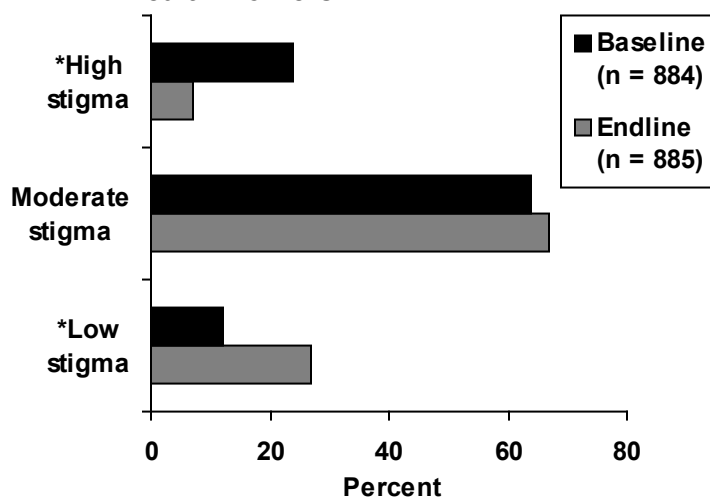
percent vs. 13 percent;  $p < .05$ ). Also, health workers were more likely to report that they can access post-exposure prophylaxis if they have been occupationally exposed to HIV (29 percent vs. 39 percent;  $p < .05$ ) and less likely to report that clothes and linen used by HIV-positive patients should be disposed or burned (69 percent vs. 54 percent;  $p < .05$ ).

***Although there have been some improvements in patient confidentiality, more work is needed.***

The findings were mixed regarding the importance and protection of patient confidentiality by health workers. After the intervention, a greater proportion of doctors (74 percent vs. 85 percent;  $p < .05$ ) and nurses (89 percent vs. 92 percent) said that HIV-positive individuals have the right to decide who should know their status, but this was not the case among ward staff (73 percent vs. 66 percent). At baseline, health workers often took it upon themselves to inform peers and other staff in the hospital about a patient's HIV-positive status. At follow-up there was some improvement among doctors, as a smaller proportion reported informing nurses (87 percent vs. 71 percent;  $p < .05$ ) and ward staff (51 percent vs. 30 percent;  $p < .05$ ) about a patient's serostatus. Nurses corroborated this trend; compared to baseline, a smaller proportion at follow-up reported being informed by doctors of a patient's positive HIV status (31 percent vs. 17 percent;  $p < .05$ ). But there was essentially no change among nurses telling ward staff (97 percent vs. 99 percent), therefore they do not appear to have become more discreet at follow-up.

Baseline findings indicated that a patient's confidentiality was often breached by the use of labels or bed signs proclaiming his/her HIV status. Although doctors did not report any significant change in this practice, nurses reported a decrease in the labeling of files (91 percent vs. 82 percent;  $p < 0.05$ ). Ward staff corroborated this decrease in marking files; at endline fewer reported acquiring information about a patient's positive status from file markings (15 percent vs. 3 percent;  $p < 0.05$ ). At one of the study hospitals, the head nurse reported that the practice of labeling files and widely sharing patients' HIV status had stopped or reduced considerably even

**Figure 1 Changes in stigma levels of all health workers**



\* $p < .05$

though some of the doctors were not supportive of this change.

*Earlier there was a practice to put stickers on the outside of files of the HIV-positive patients but now we have stopped.... We also used to tell positive status of the patient to all staff—there was no confidentiality at all. But, now we are very careful about this—we have stopped labeling and telling other staff. However, some doctors still feel that there should not be any confidentiality, and object to the whole idea.*

Nursing superintendent

### ***Hospital managers appreciated the research process and the tools developed to improve the hospital environment.***

All 24 respondents interviewed, which included medical superintendents, hospital directors, department heads, and nursing and ward staff supervisors, gave positive feedback about the study process, and the intervention and its impact.

*The research helped us to get on our toes and acted as a quality control tool. This study has brought into light our flaws and also shown us the direction to take to rectify these flaws and help us in this process of rectification too.*

Doctor, Head of department

*The training that was given to our ward staff through this project was really useful. There should be mass training programs at regular intervals for our department—for OT staff, bearers, and lab technicians.*

Sanitary staff supervisor

Overall, the respondents were very appreciative of the intervention tools developed for the study, such as the policy guidelines and the posters on universal precautions. Even the sensitization training of health workers was seen as very useful for improving staff attitudes.

*We have implemented the guidelines and they are used during the in-house training sessions of*

*the nurses, ward staff, and paramedic staff. These have been put all over the hospital in all the nursing stations, wards, operation theaters, and out-patient departments.*

Hospital medical superintendent

Most respondents felt they could now describe their hospital as being friendly to people living with HIV. But others felt that they needed to work harder to reduce stigma and discrimination before they could categorize their hospital in this way.

*We are only 50 percent friendly. We are not optimally friendly with the positive patients. We are trying to fight with this stigma.... There needs to be more teamwork, we need more social workers and better counseling facilities in our hospital.*

Senior doctor, Head of department

## **Conclusions and Recommendations**

The formative research findings clearly indicated the need to address stigma and discrimination in the hospital setting and corroborated many of the findings of earlier research in India in this context (UNAIDS 2001). Common manifestations of differential treatment of people living with HIV in the participating hospitals included delay in treatment, unwarranted referrals to other facilities, segregation, labeling, excessive use of barrier precautions, breaches of confidentiality, unconsented HIV testing, inadequate pre- and post-test counseling, and withholding HIV test results from patients. The study also found that many health workers lacked adequate knowledge and training in the basics of HIV transmission, infection control, and clinical management of HIV/AIDS. Also, a lack of hospital policies protecting people living with HIV and ensuring staff safety contributed to differential treatment.

These findings highlight that stigma and discrimination in health settings is fueled by both individual and institutional factors. Therefore, reducing AIDS-related stigma and discrimination in clinical settings requires addressing not just the attitudes and practices of health workers but also their needs for information, training, and supplies.

The study also showed that all cadres of health workers, including doctors, nurses, and ward staff, carry out discriminatory practices. This supports the intervention's basic premise of involving all levels of health workers, from ward staff to hospital superintendents, in improving the hospital environment rather than simply trying to effect change from the top down by only working with management.

The participatory methods used by the project team proved to be crucial in mobilizing hospital managers to take action to reduce stigma and discrimination. Facility-specific survey data, the checklist, and other tools sparked action among managers to make the hospitals more friendly to people living with HIV and facilitated ownership of the process. The hospital managers were engaged in designing and implementing the multi-level intervention that included training, materials development, and policy reform.

Although the study design does not allow the researchers to prove the efficacy of the approach, pre- and post-survey data show significant improvements in health workers' reported knowledge, attitudes, and practices related to the care and management of people living with HIV. Interviews with hospital managers corroborated many of the changes detected by the quantitative data. But, despite these positive findings, there is room for improvements. The study demonstrated that some attitudes and practices may be more difficult to change than others and may require more focused activities. The meanings and values placed upon seemingly universal principles like confidentiality may, in fact, differ in different settings. For example, in this setting, while there was improved respect for patient privacy in general, many health workers continued to feel that they were entitled to know the HIV status of their patients and continued to share such information with one another. Therefore, more work is needed to change attitudes, beliefs, and practices.

Even in large public hospitals confronting a wide range of institutional challenges, it is possible to create positive change. This study demonstrates that government, private/non-profit, and research groups each have a role to play in reducing stigma and discrimination in the health sector. However, a respectful and open attitude on the part of each sector is

required for such a partnership to succeed. When the intervention began, hospital managers feared that data about discrimination would be used for lawsuits and negative publicity, and AIDS NGOs tended to blame health workers for stigmatizing or discriminatory practices. In response, the study team reassured the hospitals that the data would be confidential and not be reported by hospital, and sensitized NGO staff about the concerns and difficulties of health workers who practice in overburdened, resource-constrained settings.

The following recommendations emerged from the study:

***Assess and improve HIV-related knowledge and attitudes of all health workers.***

Misinformation and judgmental attitudes among all cadres of health workers can foster stigma, fear, and differential treatment of people living with HIV. This study showed that even the most senior health workers do not have a complete understanding of HIV transmission and prevention. Therefore, it is important for programs to target all levels of health workers with initial and ongoing refresher training. Such training should go beyond providing information to include sensitizing staff to the needs, concerns, and rights of people living with HIV.

***Create a safe working environment for health workers.***

This study has shown that health workers perceive themselves to be at high risk of infection because of their exposure to the virus during service delivery. Thus, training alone may not have the desired impact on their attitudes and practices if they do not perceive the environment within which they work to be safe to implement their newly acquired knowledge and skills. Thus it is essential to assess and acknowledge health workers' fears and risks, and then develop and implement workplace policies that ensure staff safety and respect for health workers' rights. These policies need to ensure the availability of essential supplies (e.g., gloves) for maintaining op-

timum infection control practices to not only protect health workers but also to protect their patients from exposure to infection.

***Use a participatory and partnership approach to reduce stigma and discrimination in health settings.***


The reported improvements in health workers' attitudes and practices and in hospital policies support an approach characterized by participatory problem identification and problem solving, and the involvement of all levels of staff in intervention activities, from ward staff to hospital superintendents. Groups and organizations wishing to work in health care settings should also consider positioning themselves as true partners rather than as critics or watchdogs/whistle blowers if their goal is to improve the health care environment for people living with HIV.

***Conduct further research to determine the impact of the intervention.***

Conducting this research in Indian hospitals that now are seeing greater numbers of people living with HIV or in regions with a higher HIV prevalence would enable researchers to gain valuable feedback about the intervention from HIV-positive patients. Also, any further research should examine the role of increased availability of antiretrovirals on stigma and discrimination in health care settings.

**For more information about the study and the intervention, contact Vaishali Sharma Mahendra (vmahendra@popcouncil.org)**

## Utilization of the Findings

The results of the study galvanized the collaborating New Delhi hospitals to expand the program hospital-wide to all departments. In addition, NACO endorsed the use of the checklist for use in all public hospitals and has disseminated it to the State AIDS Control Societies in the country. The checklist, policy guidelines, and other materials have been widely distributed to NGOs and health care organizations, including the Employees State Insurance Corporation, one of the country's largest insurance-based health delivery systems. In addition, UNAIDS has recognized the intervention as a best practice (UNAIDS 2005). 

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