5. ADDRESSING DISCRIMINATION IN THE HEALTH SECTOR: LESSONS LEARNED

Although its true extent remains unknown and the intensity undoubtedly differs from community to community, there is enough evidence available to confirm that stigma and discrimination are widespread and a significant barrier to HIV/AIDS care and prevention. Some aspects of the problem – in particular stigma, which is attributed by society as a whole rather than specific elements – cannot be isolated or abolished in the health services as long as they persist in other settings, such as the media, the workplace, the family, religious congregations, bars and other social spaces. However, some components of discrimination can be tackled in the health services, contributing to a reduction in stigma in society as a whole.

Proof that a reduction in discriminatory attitudes and behavior in the health services is possible comes from both anecdotal and statistical evidence. Anecdotes suggest that increased awareness of HIV/AIDS in society as a whole and increased familiarity with patients with the disease helps most health workers to feel more comfortable working with people with the virus. Statistical evidence demonstrates that training projects can increase health workers' understanding of HIV/AIDS and reduce negative attitudes towards people with the disease. Meanwhile, institutional changes can lead to a more welcoming environment for people with HIV/AIDS.

5.1. Health workers

As discussed in Section 3.1, several factors are crucial in ensuring a reduction in health workers' discriminatory attitudes: (a) accurate knowledge of the means of transmission and non-transmission of HIV, (b) skill in interacting appropriately with patients with HIV/AIDS, (c) regular contact with people with the virus, (d) techniques to avoid burnout and (e) awareness of human rights norms that protect patients with HIV/AIDS and of the consequences of violating those norms. Training workshops are the primary mechanism in imparting knowledge and skills, and these should be supported by institutional changes as discussed below.

However, training alone is not sufficient. Health services should also provide appropriate supplies to enable their staff to carry out their duties with minimum risk of occupational exposure; establish and support groups for health care workers; and provide prophylaxis, including post-exposure prophylaxis (PEP) for sharp injuries, and, as appropriate, ionized (INH) prophylaxis for tuberculosis and pneumonia (PCP) prophylaxis for bacterial infections.

Knowledge

Accurate knowledge depends on accurate information. Health workers primarily need precise information on how HIV is and is not transmitted, and once that information is acquired, fear of casual contagion falls. Secondary information, which is intended to reduce disapproval, includes such facts as the impact of stigma on people with HIV/AIDS, the realities of sexual and drug-injecting behavior and the different ways in which the lives of men and women are affected by the disease.

While it is clear that knowledge of the basic facts of HIV transmission reduces fear of casual contagion, there is less evidence that secondary information has had a significant impact on health workers' attitudes; this may be because fewer projects include such information, because the information was not accurate or was poorly conveyed or for other reasons that are as yet not understood. (Brown et al 2003)

Skills building

Interventions that only provide information are less effective in reducing stigma than interventions, which combine information with skills building. Skills building, which help health workers to interact with patients in a respectful and non-discriminatory manner, can take many forms. These include role-play, imagery and group desensitization. In imagery health workers are presented with hypothetical situations in which they have contact with people living with HIV/AIDS and are taught the appropriate skills to react. Group desensitization teaches relaxation training and then progressively exposes health workers to situations with people with HIV/AIDS, using the new techniques to defuse tension. (Brown et al 2003)

Contact

In the United States, studies that rely on health workers' responses to hypothetical patients (Brown et al 2003) and studies that analyze their reactions to actual patients (Dimick et al 1996, Grossman 1998) confirm that contact with HIV/AIDS patients and/or populations at risk, such as men who have sex with men, leads to health workers becoming more receptive to treating them and modify some of their negative attitudes[16].

Contact may occur in training situations – for example, the presence of one or more people with HIV/AIDS in a workshop – or through work experience. However, contact without knowledge of HIV transmission is inappropriate. Ideally, contact should be supplemented with training that enables health workers, in particular nurses, to understand the issues underlying individual patient responses and to modify their own responses accordingly. (Kemppainen et al 1998)

Avoiding burnout

Burnout is sometimes the result of attempts to overcome stigma and discrimination. But it can also inadvertently become the cause of discrimination. The extent and intensity of burnout among staff working with patients with HIV/AIDS may be falling as a result of the introduction of antiretroviral therapies, although this has not been confirmed. Where burnout continues to be a problem, a number of techniques can be used to prevent or reduce it. These include "[a]utonomy, intellectual stimulation, opportunities for promotion and personal growth, and adequate communication with supervisors" (Brown et al 2002) as well as staff support groups to allow expression of feelings and emotions, and time away from the workplace. (Gueritault-Chauvin et al 2000, Tannenbaum & Butler 1992, Hayter 1999)

5.1.1. Training workshops

Since the beginning of the epidemic, educational programs for health workers have been shown to increase knowledge, reduce levels of fear and increase comfort in working with clients with HIV/AIDS (Riley and Greene 1993). In the last ten years, such programs have been carried out in a number of countries, including the United States in 1993 (Sadowsky & Kunzel 1992), China (Wu et al 2002), Nigeria (Uwakwe 2000, Ezedinachi et al 2002), and Thailand (Lueveswanji et al 2000).

The most common method of training are workshops, where a number of techniques from lectures to role-play are used to impart information and to encourage participants to analyze their own and others' attitudes towards HIV/AIDS. Such workshops usually provide basic information, including transmission, non-transmission and universal precautions; skill building; and principles of confidentiality and informed consent.

Each of the above-mentioned studies demonstrated improvements in reported knowledge and attitudes. In China, for example, where 55 staff from several health institutions in the rural province of Anhui attended training workshops and were given limited funds to conduct secondary workshops at local level, significant increases in knowledge were reported after 18 months compared to non-intervention. (88.5%-99.8% compared with 37.4%-53.7%) Condom use

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[16] In some cases, attitudes improve towards HIV/AIDS, in other cases towards men who have sex with men, and in some cases, towards both homosexuality and HIV/AIDS.

among health workers also increased (from 11% to 33% at last intercourse) and there were fewer incidences of extramarital sex (from 3.9 to 0.21 in previous six months).

Concerns

Although, in principle, training workshops are an excellent mechanism for improving health workers' understanding of the disease and of improving their attitudes towards HIV/AIDS, in practice, they often do not meet their full potential. Criticisms of workshops surveyed for this and other reports include[17]:

- Failure to observe directly the health workers'
- Small target populations
- Different measures used to assess discriminatory attitudes[18]
- Failure to assess the long-term impact of interventions
- Mixed results, including evidence of superficial changes in attitudes based on improved knowledge but little change in deep-seated fears
- Delays in reporting[19]
- Failure to acknowledge specific circumstances that may not apply to other communities – e.g. the availability or lack of antiretroviral therapies
- Failure to address specific elements of discrimination, such as attitudes towards women, homosexual men, and injecting drug users.

5.1.2. Guidelines and manuals

Some health institutions provide guidelines and/or manuals for staff working with patients with HIV/AIDS. One example is the San Camilo hospital in Lima, Peru, which includes the text of relevant legislation and codes, including a declaration of fundamental rights of people living with HIV/AIDS.

5.2. Institutional reform

Section 3.2 confirmed the many different ways in which patients' needs may not be met in health care settings. The majority of these can be addressed in two formats: staff training, as described above, and institutional reform.

As the examples given here demonstrate, institutional reform can take many forms. There are, however, some common general principles. In particular, services should be adapted to patients' needs, with different types of service for different patients, such as young people, women or men. This may mean identifying and responding to other aspects of stigma (not only HIV/AIDS) in people's lives. HIV/STI testing and counseling services in Chennai, India, for example, continually revised their services to respond to the different needs firstly of men, then of men who have sex with men and finally of both "masculine" and "feminine" men who have sex with men.[20] (Chakrapani 2002)

Also in India, in New Delhi, HIV-patient-friendly hospitals are being established to make services more attuned to the needs of people with HIV/AIDS. Among the measures being taken is policy development on matters such as pre- and post-test counseling, confidentiality and the importance of informed consent. Efforts are also being made to extend staff education and training, and to strengthen the application of universal precautions in patient care. (UNAIDS 2002a)

In a project providing mental health services for HIV-positive patients in Washington DC, the crucial elements were defined as (a) research into successful programs, (b) consultation with patients and their families, (c) removing the label of HIV from the process, (d) removing practical barriers, for example holding appointments at times convenient to the patients, providing childcare and travel assistance, (e)

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[17] Some of the following points draw on Brown et al 2003 and not all points apply to all studies.

[18] "The measurement of stigma was rudimentary in a number of studies, often based on a single question in a survey. Although some studies developed and tested scales to measure the concept of tolerance toward an HIV-positive person, others reported tolerance levels such as willingness to sit beside / eat with / share utensils with a [person living with HIV/AIDS]." (Brown et al 2003)

[19] For example, the Nigerian study (Ezedinachi 2002) was carried out in 1996-1997 but not published until 2002.

[20] Although this study describes a response to patients' needs – and therefore a positive act - it should be noted that adapting facilities to meet the demands of "masculine" men who were reluctant to share services with "feminine" men can also be seen as reinforcing stigma and discrimination against the second group of men.

making interventions relevant to the patients' lives, (f) creating culturally sensitive interventions and (g) focusing on healthy living rather than HIV/AIDS. (Lyon & Woodward 2003)

In Kenya seven program components were identified for improving access to high-quality HIV/AIDS prevention and care services in maternal and child health care settings. These were (a) training and motivation to improve the performance of health care workers, (b) supervision of HIV services and quality assurance of HIV testing, (c) caring for mothers, (d) voluntary counseling and testing services, (e) counseling on infant feeding, (f) provision of antiretroviral drugs to reduce mother-to-child transmission, and (g) involving male partners. (Rutenberg et al 2002)

In Buenos Aires, Argentina, weekly meetings between a group of transvestites and staff in a large public hospital resulted in changes to routine that responds to the transvestites' needs. Issues covered include convenient consulting hours and use of appropriate names. These efforts to reduce stigma have led to increased protection of public health, as the transvestite group now promotes voluntary counseling and testing at the hospital and has helped identify places for condom distribution. (Barreda & Isnardi 2003)

> *In the long term, full integration of HIV/AIDS into other health services may be a desirable goal. In the short term, however, separate HIV/AIDS services are generally seen as an appropriate means of both providing special care and, assuming sensitive issues such as the name of clinics and customary practice are properly observed, reducing stigmatization and discrimination. (Surlis & Hyde 2001)*

5.3. Legislation

According to UNAIDS, efforts to tackle HIV/AIDS-related stigma and discrimination "seem doomed to fail in the absence of a supportive legal framework … Interventions targeting discrimination need to take place concurrent with the establishment of a supportive legal framework that includes generic anti-discrimination laws covering health care [and other social settings]" (UNAIDS 2001a)

New legislation that outlaws HIV/AIDS-related discrimination has been passed in several countries, sometimes specifying the link between HIV/AIDS and human rights, as in Costa Rica. Insofar as the health services are concerned, such laws usually confirm that people with HIV/AIDS must not be denied appropriate care and treatment and often regulate other responsibilities, such as confidentiality and screening blood products. However, as noted above (Section 4.3), legislation may also mandate health services to notify the partners of patients with HIV/AIDS, which overrides the confidentiality clause. This review was unable to identify studies that evaluated the implementation of HIV/AIDS legislation and its impact on stigma and discrimination in the health services.

At the same time, other laws may indirectly have an impact. Lack of access to antiretroviral therapies has been noted both as a cause and as a consequence of stigma and discrimination. Existing legislation has been used in several countries in the Americas to force governments to recognize the right of people living with HIV/AIDS to free antiretroviral therapy, which they cannot afford. In Brazil, the government undertook to do so after strong protest from non-governmental organizations; in Costa Rica, Venezuela and elsewhere, non-governmental organizations took the government to court to ensure that these rights were recognized and the drugs made available. (UNAIDS 2002b).

Since discrimination surrounding HIV/AIDS is not limited to the disease itself and often focuses on stigmatized groups, other areas of concern remain. Legislation preventing discrimination against men who have sex with men exists in very few countries, but would have a significant impact on HIV/AIDS-related discrimination throughout Latin America and the

Caribbean and other parts of the world. Legislation protecting injecting drug users from discrimination is more difficult, given that in most cases the drugs they inject are illegal; nevertheless, there is scope to investigate this possibility further.

Countries that ratify international human rights conventions incorporate the provisions of such instruments as part of their domestic legal framework. Compliance in those countries is monitored by mechanisms created by the conventions, which generally are comprised of human rights commissions and courts. In addition, new laws on HIV/AIDS in every country should incorporate those international human rights norms and standards such as the guidelines developed by the United Nations and other international bodies.

5.4. Working with the broader community

Interventions in the health services are most successful when they are part of a broader campaign to reduce stigma and discrimination in the community as a whole. The initiative for such a campaign may come from the health services approaching other institutions, such as ministries, Ombudsman offices, judiciary, religious organizations, non-governmental organizations, journalists and the private sector, or from these institutions approaching the health services. Community and national campaigns have taken place in many countries, both before and after UNAIDS' decision to make stigma the focus of its World AIDS Campaigns; these have often included health workers and health services. However, studies have not been identified that confirm the impact of these interventions.

Surveys of responses to stigma in south-east Asia confirm that "[w]hat unifies these interventions is their emphasis on process, meaning that they can be integrated into numerous approaches to HIV/AIDS, and indeed mainstreamed into basic community development projects." (Busza 2001)

In the province of Phayao in northeast Thailand, multisectoral work bringing together a range of governmental and nongovernmental organizations was essential reducing new infections in this badly affected area in the late 1990s and promoting good-quality home- and community-based care. A people-oriented approach facilitated greater openness about the epidemic, and the promotion of a "care not scare" approach reportedly stimulated greater social cohesion and support. (UNAIDS 2002a)

Because individuals are members of different 'communities', projects can and should look beyond any one context of discrimination. The Hope Foundation in the Philippines not only introduced seminars and training sessions for health workers in private and public hospitals, but also worked with religious organizations, academic institutions and labor groups. The Foundation's "networking and capacity building efforts serve as an excellent example of such a comprehensive community-based approach. Even activities that focus on one context of discrimination can strength their impact by acknowledging links to other contexts." (Busza 2001)

In parts of Uganda, cooperation between a TASO, a national non-governmental organization, and hospitals has helped to provide comprehensive health care and support for people living with HIV/AIDS, particularly new mothers. Measures to reduce discrimination are an integral aspect of the scheme.

The open involvement of people with HIV/AIDS is critical to the success of such projects. "The increased visibility of people with the disease [HIV] in the community can result in greater community acceptance and support." (Malcolm et al 1998)

5.5. Unresolved issues

The lessons learned in addressing discrimination in the health services include several issues that have yet to be resolved. These include:

• *Mixed results*: As indicated above, not all training programs have a significant impact on knowledge and attitudes. A three-day program for Thai dentists, for example, increased willingness to treat patients with HIV from 49% to 64% of the group, but fear of infection and negative attitudes remained high. (Lueveswanji et al 2000) This and similar results indicate that while the principle of

training workshops is widely accept, the content and format of many workshops does not respond to the specific needs of their audiences.

Similarly, institutional changes may not be successful in every field. The Kenya study reported above concluded that "success in integrating elements of HIV-related care into the [maternal and child health care] setting has been mixed, and many challenges remain before such care becomes routine." (Rutenberg et al 2002)

- *Gender*: Few interventions appear to have distinguished clearly or responded to the different ways in which stigma and discrimination affect (a) women, (b) men who only have sex with women and (c) men who have sex with men.

- *Size*: While there have been some large-scale interventions aimed at the general public, most in the health services have been targeted at small audiences. There is anecdotal evidence, but no statistical evidence that large-scale interventions are possible or have had an impact.

- *Evaluation and sustainability*: Few interventions have been studied more than a year after they came to an end. There is anecdotal evidence, but no statistical evidence that interventions have a long-term impact. Furthermore, it is difficult to distinguish the impact of one project in a context where many other factors, such as media coverage, can also influence attitudes.

- *Antiretroviral therapies*: Apparently the impact of antiretroviral drugs availability has not been studied or taken into consideration.