

Understanding and responding to HIV/AIDS-related stigma and
stigma and
discrimination
in the health sector

Special recognition and appreciation goes to all people who generously contributed to the preparation of this publication.

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PREFACE

HIV/AIDS has become the biggest threat to human survival in the last 700 years. Important gains made in child health and life expectancy in the Americas are being threatened by this epidemic which is destroying many of the efforts and investments of past decades.

A generally silent but harmful added effect of the epidemic is discrimination against people who live with the virus. Discrimination derives from the understandable fear of a virus that is transmissible, incurable, and potentially deadly. But it also has other deeply rooted causes. Among them is prejudice against those groups that were hardest hit during the early stages of the epidemic, such as men who have sex with men, sex workers, and drug users.

Does such discrimination also occur within the health services? If so, how serious are the consequences? Prior to this publication, we did not have precise answers to these questions. To the best of our knowledge, this is the first comprehensive study of the origins, manifestations and impact of HIV-related discrimination in the health services. It also offers recommendations for identifying and eliminating discrimination on the basis of HIV status.

Health workers need all the support we can give them for the difficult task of caring for people with HIV and AIDS. Some need help to overcome their own prejudices. Others may need assistance in dealing with fear, coping with the stress of caring for the very ill, and preventing the emotional detachment that can occur among those who look after patients dying of AIDS. Caregivers also deserve the necessary training and resources to ensure that the risk of accidental transmission of the virus is kept to a minimum.

Conversely, we need to show special appreciation to the many doctors, nurses, laboratory workers, and other health personnel who joined the fight against the epidemic in its early stages. Their courage, altruism, and commitment to a public health mandate were larger than the danger of infection or risk of alienation from their own colleagues.

The example set by these pioneers is proof that health workers are destined to play a leading role in both the community and society in building a supportive, nondiscriminatory environment for people with HIV. We dedicate this publication to them.

MIRTA ROSES PERIAGO

Director

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SUMMARY

HIV/AIDS-related stigma and discrimination are as old as the epidemic itself. In every country and in every social setting since the disease was first identified, individuals who are or who are assumed to be HIV-positive have been subject to a variety of negative reactions, including physical and verbal abuse, loss of homes and employment, rejection by families, spouses and friends, and violations of basic human rights and fundamental freedoms.

Even in the health services, where people at risk of infection or living with HIV/AIDS seek and expect care and attention, stigma and discrimination have been common. Discriminatory acts vary from inappropriate comments to breaches of patient confidentiality, from treatment delayed to treatment and basic care and hygiene refused.

Some of these acts are not only a violation of basic human rights but they can also have a considerable negative impact on the health of both the individual and the broader community. Those who are discriminated against may suffer physically and psychologically, while those who fear discrimination may be reluctant to seek testing or treatment. Those living with HIV and those at risk of infection are less likely to protect themselves and their partners from infection.

This review aims to contribute to deeper understanding of HIV/AIDS-related stigma and discrimination in the health services. It does so firstly through an analysis of the components of the phenomenon, how they relate and where gaps in knowledge exist; secondly by comparing studies of stigma and discrimination and projects designed to reduce their incidence and impact; and thirdly by outlining strategies for a comprehensive response. The perspective is global, but this publication makes extensive references to Latin America and the Caribbean.

Two broad conclusions can be drawn. The first is that while there is general agreement as to the existence and form of HIV/AIDS-related stigma and discrimination, many aspects of the phenomenon are poorly understood. The issue is complex and the underlying components are often poorly distinguished, defined differently by different researchers and frequently studied without appropriate reference to the broader context. This makes it difficult to compare results of studies, provide a comprehensive analysis and discern prevailing trends.

Secondly, despite these constraints it is nonetheless clear that there has been a reduction in the extent of HIV/AIDS-related discrimination in the health services in some countries. Several factors are responsible, including increasing awareness of the issue and increasing availability of antiretroviral therapies, which weaken the disease's association with death. Other forms of stigma, however, such as homophobia, which preceded the epidemic and continues to fuel hostility towards people with HIV, remain strong.

Over the last twenty years many people, including people with HIV/AIDS have made significant advances in the fight against HIV/AIDS-related stigma, and discrimination. The authors of this document hope that it contributes to that ongoing struggle.

1. INTRODUCTION

Since the beginning of the epidemic, people living with HIV/AIDS¹ or believed to be vulnerable to infection have consistently reported being the target of stigma and discrimination. Experiences such as loss of family, friends, work and housing, verbal and physical abuse have been widely documented across social and political boundaries.

Not only are incidences of stigma and discrimination upsetting to the individual affected and may cause serious problems wherever they occur, but stigma and discrimination in health care settings² can have particularly severe consequences. Fear of being identified as vulnerable to infection or as HIV-positive prevents many people from coming forward for voluntary testing, with the result that they are less likely to adopt measures to protect themselves and others from the virus. Inappropriate behavior towards those who are ill can lead to depression, social isolation and a worsening of their condition, which in turn places a greater burden on those who care for them. Furthermore, international conventions agree that discrimination against people with HIV/AIDS is often also an abuse of their human rights.

As the first step in its goal towards contributing to the fight against HIV/AIDS-related stigma and discrimination, this review combines a survey of documentation with an analysis of the phenomenon derived from an overview of that documentation. Regrettably, a lack of consistency in approach and narrowness in interpretation have often led to a restricted perspective, to occasional lack of clarity and sometimes to assumptions which are not supported by the evidence. Therefore, to clarify the issue, Chapter 2 examines the different components of stigma and discrimination and the way in which they interact.

Chapters 3 (from a global perspective) and 4 (Latin America and the Caribbean) examine stigma and discrimination in health care settings. The primary foci are (a) health workers’³ knowledge, attitudes and practices, and (b) the experiences of people living with HIV/AIDS. These chapters confirm two major gaps in information – whether and how far health workers’ attitudes are reflected in their behavior, and the extent to which people with HIV have positive experiences in health care settings.

Despite incomplete information, there is enough evidence of good practice available for Chapter 5 to give a comprehensive overview of a range of actions that can combat stigma and discrimination in the health services. Chapter 6 synthesizes this into potential strategies. A comprehensive bibliography, with papers grouped according to their subject matter, is given in Chapter 7.

¹ In this document, “people (living) with HIV/AIDS” refers to all individuals who have contracted HIV whatever their situation. The phrase “patients with HIV/AIDS” only refers to individuals in situations where they are receiving health care.

² In this document, the phrase “health care settings” refers to any place where a health worker (see below) provides professional services, including hospitals, clinics (including dental, clinics, clinics for the treatment of sexually transmitted infections etc), nursing homes and any settings where such services are provided, including public places where health care is given, such as following accidents in the home or street.

³ In this document, the phrase “health workers” refers to all individuals who work in the health services and deal directly with patients, whether or not they provide health care: this includes doctors, psychologists, dentists, nurses and nursing assistants, occupational therapists, receptionists and other administrative staff.

2. DEFINING THE ISSUE

“HIV-related stigma may well be the greatest obstacle to action against the epidemic, for individuals and communities, as well as political business and religious leaders. An all-out effort against stigma will not only improve the quality of life of people living with HIV and those who are most vulnerable to infection, but meet one of the necessary conditions of a full-scale response to the epidemic.”

(UNAIDS: Piot & Seck, 2001)

2.1. Stigma and discrimination

2.1.1. Stigma

Stigma is as old as history. The concept is universal, although the origin of the word is Greek and refers to the physical mark made by fire or with knives on individuals considered outsiders or inferiors. Today the physical marks have gone, but stigma remains, based on one or more factors, such as age, caste, class, color, ethnicity, religious belief, sex and sexuality. Stigma, defined as a “deeply discrediting” attribute in the landmark study by Erving Goffman (1963) is applied by society and borne or possessed by groups and individuals. Stigma may be associated with specific acts, such as adultery or criminal behavior, with inherent qualities such as sex or skin color, or with quasi-inherent qualities, such as religion or nationality.

Some diseases and other health conditions often lead to stigma, affecting particularly people with mental illnesses and physical disabilities. In addition, stigma is sometimes associated with social stereotypes - the sometimes positive, sometimes negative, “short-hand” images that we all use to identify strangers and which determine our reactions to them.

Stigma is a means of social control, defining social norms and punishing those who deviate from the norm. At the heart of stigma lies the fear that those who are stigmatized threaten society. Underlying that fear is often ignorance, such as

ignorance of the way of life of HIV/AIDS stigmatized groups or ignorance of the realities of sexual behavior or the way in which diseases spread.

The word stigma is used by social scientists more than the general public. In English, in everyday speech, it has been replaced by such words as sexism and racism, which carry related but different meanings. And while in some societies some stigmas have weakened – it is, for example, much easier to be openly homosexual in an urban society in the West now than it was fifty years ago – in other societies stigma persists. Lower caste remains a marker of stigma in Indian culture, women are stigmatized in many societies and homosexual men are still the subject of ridicule and violence in many parts of the world. Stigma can be additive; to be a poor illiterate woman, for example, is worse than any of these conditions taken individually.

Although the concept is negative, stigma can have positive consequences. It can create a sense of community among stigmatized individuals, motivating them to support each other and make changes that will improve their lives. Stigma and persecution have been the cause of much migration, such as that of Jews to the United States in the late nineteenth and early twentieth centuries. In more recent years, dalits (“untouchables”) in India and homosexual men in many parts of the world have responded to stigma by demanding the right to live as full and equal citizens in their own societies.

Even though stigma may appear constant, it is more accurately described as a process. (Parker &

Aggleton 2001) New stigmas arise and others fade as changing knowledge and power structures lead to new hierarchies and social norms. Sex between older men and pubescent boys was once acceptable in many societies across the world but is now almost universally condemned. The stigma against Jews in many Western societies is considerably weaker than it was a hundred or a thousand years ago. And the form and intensity of HIV/AIDS-related stigma continues to fluctuate.

2.1.2. Discrimination

The original meaning of “discriminate” was to note differences. Over time, however, the word has come to mean to perpetrate an unjust action or inaction against individuals who belong, or are perceived to belong, to a particular group, in particular stigmatized groups.

Discrimination can be legislative – enshrined in law or policy – or community – actions or inaction in less formal contexts, such as the workplace or social settings such as a marketplace, sports center or bar.

International norms also provide definitions for discrimination. The “Inter-American Convention on the Elimination of All Forms of Discrimination

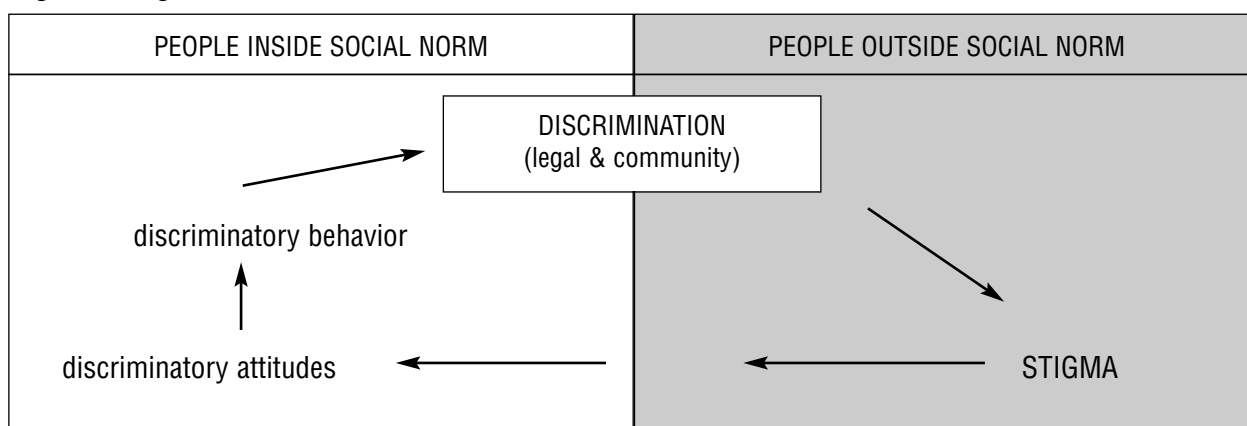
Against Persons With Disabilities” considers discrimination to be “any distinction, exclusion, or restriction” that violates the human rights and fundamental freedoms of the person.

Discrimination consists of three components: discriminatory attitudes (also known as prejudice), discriminatory behavior and discrimination. The first two (discriminatory attitudes and behavior) apply to individuals within the social norm, while the last (discrimination) applies to the relationship between those within the social norm and those who are stigmatized. (See Figure 1)

As Figure 1 suggests, stigma and discrimination exist in a vicious circle. Stigma allows or encourages discriminatory attitudes. These attitudes are often reflected in discriminatory behavior that results in acts of discrimination. Acts of discrimination draw attention to or increase stigma.

Sometimes, however, the pattern of stigma and discrimination is broken. It is possible for someone to suffer stigma but not discrimination, for example when legislation prevents stigmatized groups, such as an ethnic minority, being treated differently from other members of society. And attempts to reduce stigma may reinforce it, for example, when university quotas are reserved for members of underprivileged communities⁴.

Figure 1: Stigma and discrimination: an overview



⁴ This argument, that positive discrimination can increase stigma, is not universally accepted.

2.1.3. “Felt” and “enacted” stigma

Attempts to analyze stigma and discrimination have led to narrower definitions that are not always universally understood, such as the distinction between “felt” and “enacted” stigma. (Scrambler & Hopkins 1986, Jacoby 1994, UNAIDS 2001) Felt stigma – which has also been referred to as self-stigmatization and as fear of stigma – refers to the expectations of stigmatized individuals as to how others will react to their condition. Felt stigma leads people to hide their stigmatizing condition, if possible, which limits the extent to which they experience discrimination. Meanwhile, enacted stigma is defined as actual experience of stigma and discrimination.

However, while “felt stigma” is a useful term that describes internal perceptions of stigma, “enacted stigma” is no more than an alternative term for discrimination. Furthermore, it can lead to confusion since it is the individual outside the social norm who “feels” stigma, but the individual or institution inside the social norm who “enacts” it - i.e. discriminates. “Experienced stigma” is a more appropriate term to describe discrimination from the affected individual’s point of view and it is used in place of “enacted stigma” in this document.

In other words, felt stigma is internal - how people outside the social norm perceive their status – while experienced stigma is external – how the same people experience discriminatory acts.

2.2. Stigma, discrimination and HIV/AIDS

The link between stigma, discrimination and HIV/AIDS has long been recognized. The London Declaration, issued in 1988 by the World Summit of Ministers of Health on Programmes for HIV Prevention, was one of the first international statements to recognize that “[d]iscrimination against, and stigmatization of, HIV-infected people and people with AIDS and population groups undermine public health and must be avoided.” (para 6) That principle has been reiterated by many international bodies

since then, including the World Health Assembly of the World Health Organization and the Commission on Human Rights and was confirmed by the United Nations General Assembly Special Session on HIV/AIDS held in 2001.

2.2.1. Causes

Stigma has long been associated with diseases that provoke strong emotional responses through their association with disfigurement, such as leprosy and polio, and death such as cholera. As the cause of both disfigurement (wasting syndrome, Kaposi’s sarcoma etc) and death, HIV/AIDS provides fertile ground for stigma to take root. That stigma increases where there is ignorance as to how HIV is transmitted, leading individuals and communities to fear casual contagion through such actions as shaking hands, coughs and sharing eating and toilet facilities.

Disease-related stigma⁵ can be reduced by education. A consistent finding in studies is that people who have little knowledge or are misinformed about HIV transmission are much more likely to hold discriminatory attitudes than those who are well informed. In other words, people who are aware that casual contagion is impossible are less likely to hold negative attitudes towards people with HIV/AIDS. (CDC 2000; Herek et al 2002)

A weakening of the association between HIV/AIDS and death also reduces stigma. Anecdotal evidence from several communities suggests that discrimination falls where people with the virus have access to the antiretroviral and other drugs that prolong life and make disfigurement less likely.

However, while some sources of prejudice fall away, others remain. HIV/AIDS is also linked to longstanding stigmas of sexual misconduct and, in some communities, illicit drug use. “People with HIV/AIDS are often believed to have deserved what has happened by doing something wrong. ... Men who become infected may be seen as homosexual, bisexual or as having had sex with prostitutes. Women with HIV/AIDS are viewed as having been ‘promiscuous’ or as having been sex workers.” (UNAIDS 2002a)

⁵ From this point onward, unless otherwise specified, stigma and discrimination refer to HIV/AIDS-related stigma and discrimination

Such stigmas persist, irrespective of the reality. In the United States, where sex between men accounted for less than 40% new cases of HIV transmission in 1997, up to 67% of one sample in a public survey admitted that they primarily associated the disease with homosexual men. Heterosexual men who contracted the virus were the subjects of less disapproval than homosexual men in the same position. (Herek & Capitanio 1999)

These two components of HIV/AIDS-related stigma – disease and pre-existing stigma – have led some commentators to distinguish between instrumental AIDS stigma and symbolic AIDS stigma. The former reflects fear of HIV/AIDS as a communicable and fatal disease; the latter results from the association the disease has with groups already stigmatized. (Herek 1999).

In rural Zambia, powerful imagery, metaphors and euphemisms for HIV/AIDS include terms associated with immorality, illness, death, denial, innocence and guilt. “Dominant in such discourse is the blame assigned to people with HIV/AIDS, and assumptions made about their past sexual history. Exceptions [are] grandmothers who assist women in labor and ‘deserve pity’ if they become infected.”

—(Panos / UNICEF, 2001)

2.2.2. Those affected

HIV/AIDS-related stigma affects men and women, young and old, rich and poor. It affects people known to have contracted the virus, people suspected of having contracted it or of being vulnerable to the virus, such as sex workers and homosexual men, and the families and caregivers of those who are ill. It occurs in every country, irrespective of the extent and impact of the epidemic itself. “One of the most surprising elements of AIDS stigma is its ubiquitous nature even where the epidemic is widespread and affecting so many people, such as in sub-Saharan Africa”. (Brown et al 2003)

As the examples given here show, stigma and discrimination affect different groups in different ways and at different stages of the disease.

Hemophiliacs

In theory, hemophiliacs and others who contract the virus through contaminated blood products are less stigmatized than those who contracted HIV through sex or injecting drugs. In practice, however, hemophiliacs with HIV/AIDS report incidents of discrimination no less hurtful than those experienced by others with the virus.

Children

Children infected with HIV in the womb are also theoretically less stigmatized than adults. The reality is, however, that children with HIV who are orphaned or abandoned are seldom adopted in some communities, and those who are known to be or are suspected of being HIV-positive have been turned away from school.

The poor

Poverty increases vulnerability to HIV. The lack of economic opportunities may lead to commercial or transactional sex, while poor education hinders prevention activities. In some cases, people want to buy condoms, but cannot afford them. As a result, poor people with HIV are often labeled as hopeless and irresponsible. In addition, poor are generally regarded as less “deserving”.

Women

Women who sell sex are stigmatized in most societies, whether or not they have contracted HIV. That stigma is often extended to the many women who contract HIV from their husband or long-term partner – HIV infection is so strongly associated with promiscuity that women with the virus are frequently assumed to be promiscuous, irrespective of their sexual history. When HIV is diagnosed, “men are more likely to be accepted by family and community. Women ... are more likely to be blamed, even when they have been accepted by their husbands in what for them have been monogamous relationships.” (UNAIDS 2001)

However, even though women face greater stigma, anecdotal evidence suggests that in communities where sex between men and women is the primary form of HIV transmission, women with the virus have stronger support networks and are likely to live longer after diagnosis than men. In communities where sex between men is the primary source of transmission, men tend to have stronger support networks. (Foreman 1999)

Homosexual men

Homophobia, which is generally defined as fear, hatred or disapproval of sex between homosexual men⁶, preceded HIV/AIDS-related stigma and discrimination and, as is noted several times in this report, continues to be strongly associated with the disease⁷.

The stigma and discrimination associated with sex between men affects such men in two different ways – lack of services and reluctance to access services. HIV/AIDS services for men are either absent in many communities, particularly in Africa and parts of Asia, or are insufficient, as in Latin America, where men who have sex with men comprise less than 10% of the population but 35% - 65% of reported cases of HIV. Where services are available, stigma and discrimination related to sex between men prevents many from accessing appropriate HIV/AIDS counseling, testing and care services. (Chakrapani 2002, Vivo Positivo 2002)

In some circumstances, homophobia even affects men who have only sex with women. There

are several reports of heterosexual men, particularly in Latin America, who are reluctant to work with people with HIV/AIDS or who are afraid of contracting the virus in a non-sexual setting (such as occupational exposure in a hospital) because they fear others will suspect they are homosexual.

Injecting drug users

There is considerable anecdotal evidence and some statistical evidence that underline the extent to which injecting drug users are the victims of stigma and discrimination, irrespective of HIV/AIDS. Drug users are often unable to access appropriate HIV/AIDS prevention and care services.

“One of the few reports which has examined discrimination against injecting drug users ... found that, of 300 injecting drug users interviewed in New South Wales, Australia, “ill treatment” had been experienced from police (80%), hospital staff (60%), doctors (57%), pharmacists (57%), employers (47%), dentists (33%), methadone providers (33%), drug treatment services (33%) and community health workers (7%). As the report noted: ‘Experiences of discrimination are so common and relentless many users fail to then recognize they are being discriminated against. It seems normal to be treated badly and vilified if you’re a user.’” (Burrows 2003b)

It has been suggested that the extent of stigma attributed to society and the extent to which the individual affected acknowledges or avoids stigma differs at different stages of HIV infection:

- *at risk: belonging to a group at high risk of infection but not taking an HIV test;*
- *diagnosis: confirmation of HIV infection;*
- *latent: HIV-positive but without symptoms of AIDS;*
- *manifest: with symptoms of AIDS and approaching death. (Alonzo & Reynolds 1995)*

Because antiretroviral drugs significantly reduce the association of HIV/AIDS and death, the latter stages of this model may be modified in societies where these drugs are available.

⁶ While the expression “men who have sex with men” is usually used in preference to “homosexuals” or “bisexuals” to make the point that not all men who have male sexual partners perceive themselves as homosexual (or gay) or bisexual, stigma and discrimination affect particularly those with homosexual identity.

⁷ While there are many strands to homophobia, a key factor is repressed homosexual tendencies – many men who are homophobic are afraid of recognizing that they themselves are to some extent attracted to men.

2.2.3. The impact of stigma and discrimination

Whether the result of specific legislation or policy, or the spontaneous act of individuals within the social norm, discrimination against people living with or associated with HIV is widespread and takes many forms. In addition to discrimination in health care settings described in Chapter 3, discriminatory acts include:

- Refusal of education
- Refusal of or removal from employment
- Denial of the right to marry
- Requirement to submit to an HIV test for work, travel or other purposes
- Lack of or reduced confidentiality
- Detention
- Deportation
- Demonization in the media
- Rejection by families, friends and communities
- Physical attack, including murder

Such acts have negative impact on the community and individual health. In some cases they may constitute an obstacle to the exercise or enjoyment of human rights and fundamental freedoms. In other instances they are per se a violation of such rights and freedoms.

Individual and public health

In an ideal world, prevention and care exist on a continuum whereby those at risk are encouraged to test for HIV infection, those who are found positive receive appropriate counseling services and those who are cared for are accepted by the community, creating an appropriate environment where those at risk are encouraged to test for infection and so on. (Figure 2a)

In reality, however, stigma interrupts this continuum by discouraging individuals from testing for the virus, reducing the options for care and support and limiting the input into prevention programs (Figure 2b). The result is that both individual and public health suffer.

To examine one component of the impact in stigma in greater detail: voluntary testing for HIV, the first essential step in protecting one's health. Whatever the result, people who take the test are more likely to practice safer sex and / or safer injecting practices. (Hays et al 1997, Janssen 2001) And people who know they are HIV-positive can access available treatment and maintain a better quality of life. In many countries, however, a large number of people living with HIV have not been tested and so are unaware of their status. In the United States it is

Figure 2a: The Prevention to care continuum: ideal scenario

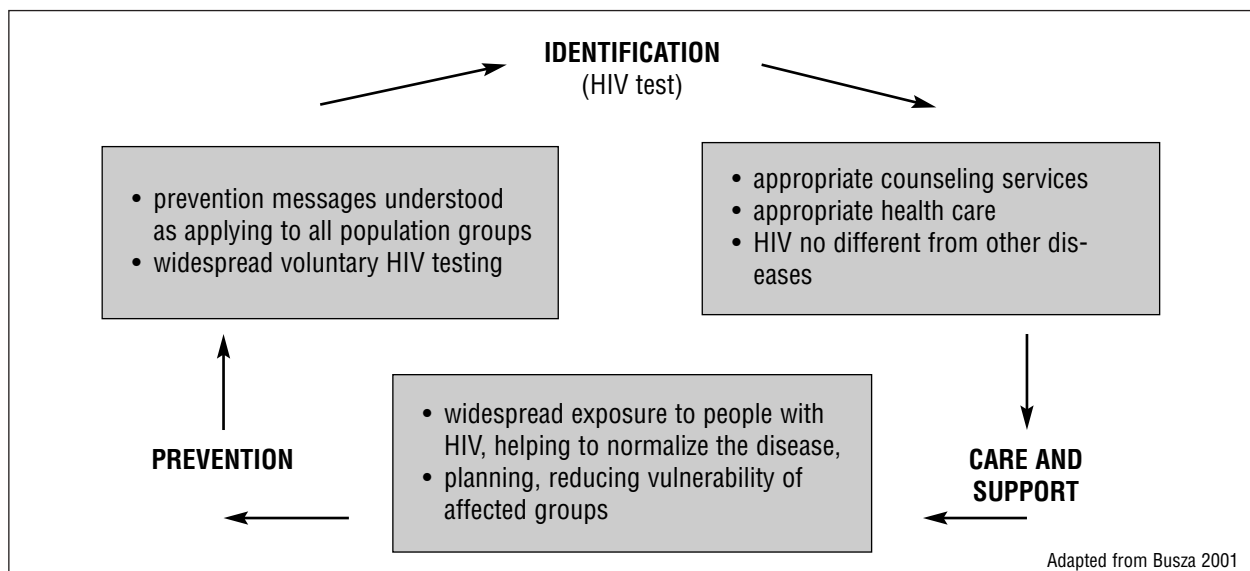
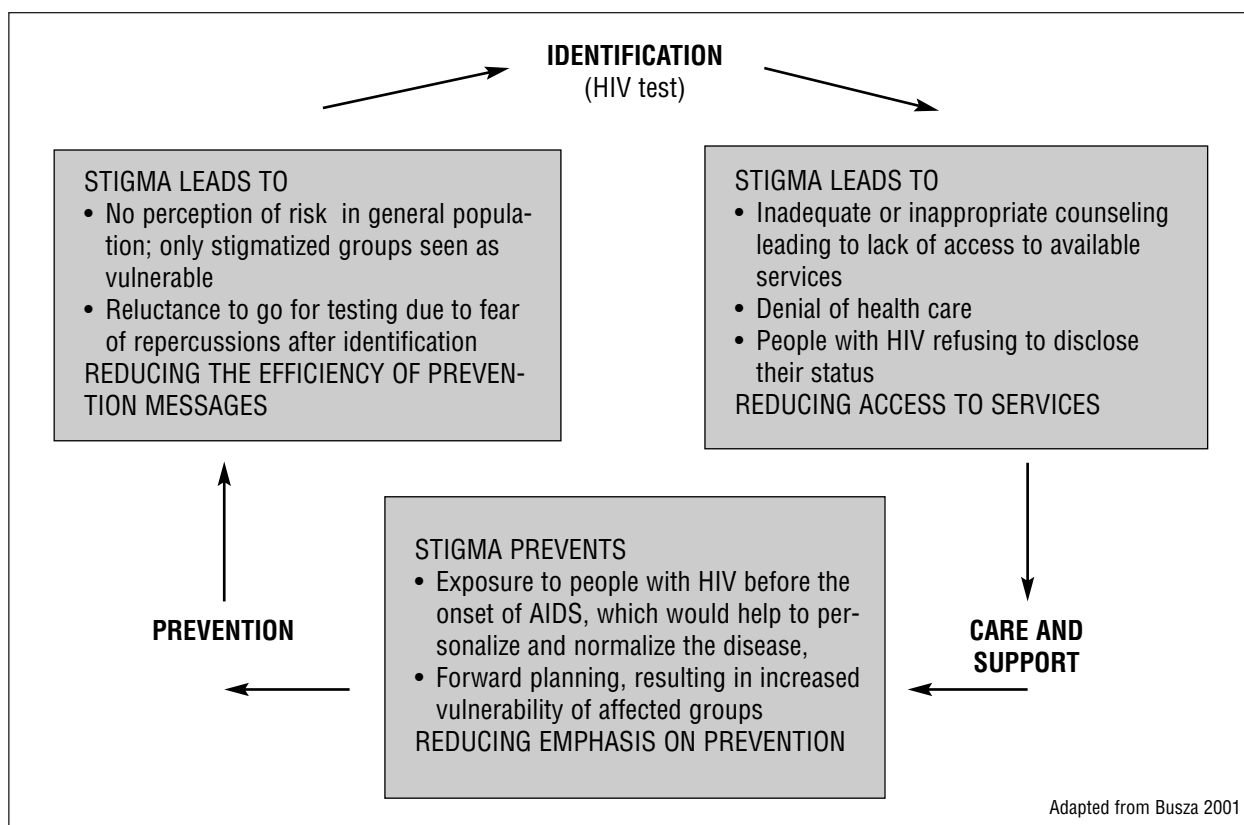


Figure 2b: The impact of stigma on the prevention to care continuum

estimated that at least one in three people living with the virus are unaware they are infected (CDC 1999) Similar or higher figures have been reported from Europe. (Castilla et al 2002, Hamers et al 1998)

While many people do not take the test because they are afraid of learning they are suffering from a fatal disease, particularly where antiretroviral therapies are not available, stigma and discrimination also play a role. Many of those who know they are at high risk are dissuaded by fear of being identified as HIV-positive or as a member a stigmatized group such as homosexual men. And the association between HIV/AIDS and stigma leads many people inside the social norm to consider themselves unaffected by the disease and to continue the practice of unsafe behaviors that place them at risk.

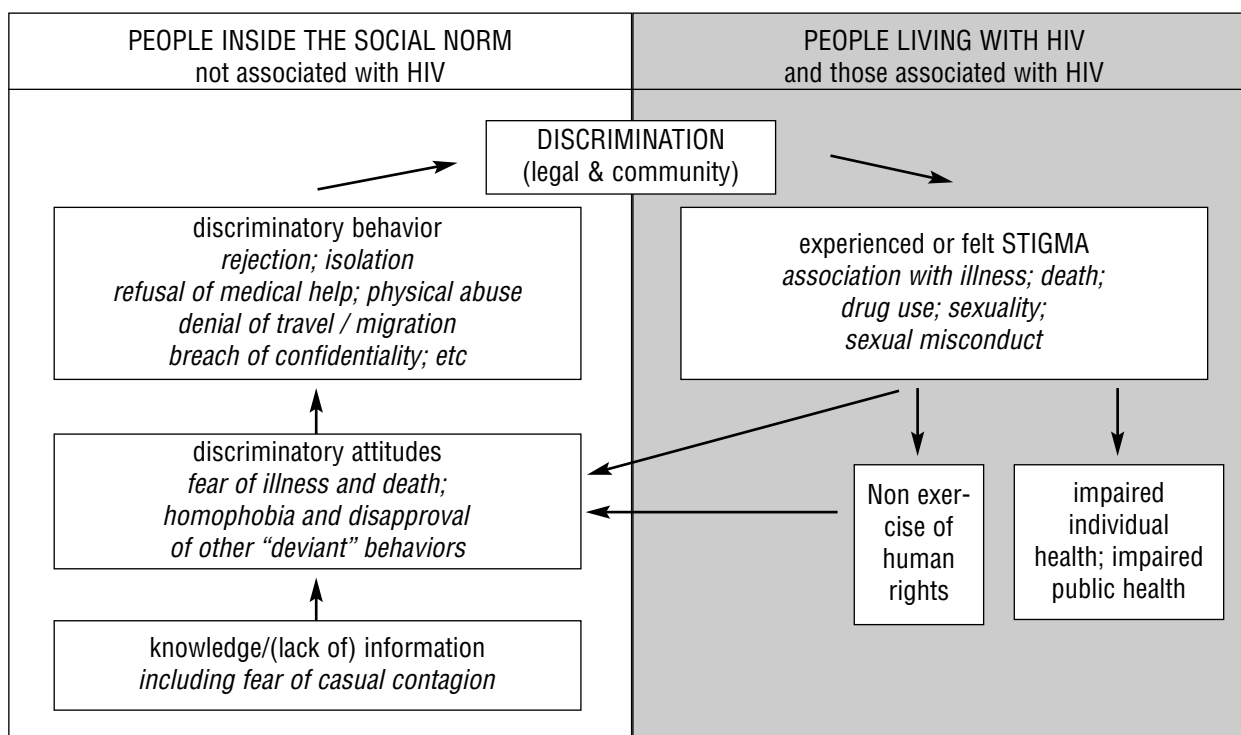
In other words, because it reduces the motivation to get tested and to look after one's own health, stigma and discrimination allow HIV to spread, with serious consequences for both the individual

and the community. Furthermore, stigma and discrimination may have strong psychological consequences on those who are HIV-positive, increasing social isolation and depression. (Lichtenstein et al 2002, UNAIDS 2002a)

Human rights

In general, there are many links between health and human rights. Violations or lack of attention to human rights can have serious health consequences, and health policies and programs can promote or violate human rights in the ways they are designed or implemented. Steps to respect, protect and fulfill human rights can reduce vulnerability to and the impact of ill health. (WHO 2002)

HIV/AIDS and human rights are intimately linked. On the one hand abuse of human rights can lead to vulnerability to HIV/AIDS, as when those at risk are denied the right to appropriate health information and care; on the other hand, being HIV-positive can lead to a non-exercise or non-enjoyment of

Figure 3: HIV/AIDS-related stigma and discrimination

human rights, as when those who are living with the virus suffer one or more of the acts of discrimination identified above.

Many international bodies, in particular the United Nations Commission on Human Rights in its resolutions 1999/49, 2001/51, 2002/31, have confirmed that the various international instruments on human rights cover health status, including HIV/AIDS. The vast majority of nations, which has ratified these instruments, have thereby committed themselves to upholding the human rights of people living with HIV/AIDS. Other international treaties in this area are the American Convention on Human Rights, the European Convention on Human Rights and Fundamental Freedoms and the African Charter on Human and People's Rights.

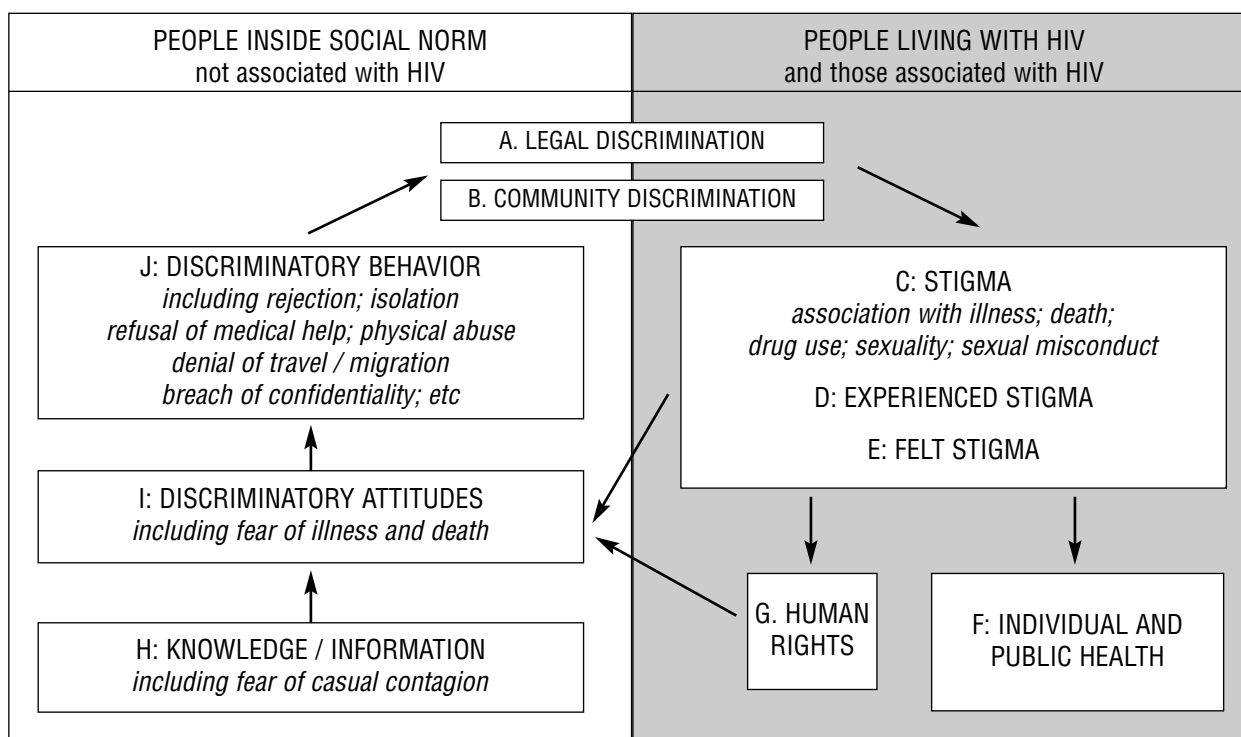
At domestic level, however, there often remains a considerable gap between this legal theory and the reality of individuals' lives. In particular, the weakest members of society are both more vulnerable to HIV and HIV-related discrimination and have least recourse to the law to protect them from discrimination.

A closer perspective

Figure 3 confirms that HIV/AIDS-related stigma and discrimination is more complex than it at first appears. Some of the issues identified have already been discussed; others are analyzed in greater detail below. The primary conclusion to be drawn from the diagram, however, is that an appropriate response to the phenomenon depends on a clear understanding of what stigma and discrimination are, how they arise and what forms they may take.

2.3. Measuring stigma and discrimination

Until recently, while many studies have surveyed the beliefs, attitudes, behaviors and experiences of small groups of people, surprisingly little research had been undertaken into the extent of stigma and discrimination in society as a whole. Furthermore, there has been no standard measurement that allows stigma and discrimination to be

Figure 4: Framework to measure HIV/AIDS-related stigma and discrimination

compared in different communities and at different periods in time.

Attempts are now being made to standardize analyses of stigma and discrimination. Indicators to measure legal and community discrimination (components A & B in Figure 4) across a wide range of social settings, including health care, employment and the legal process, have been proposed by UNAIDS. (UNAIDS 2002c) Attempts are also being made to update a standardized survey of attitudes (component I in Figure 4). (UNAIDS / Measure, 2001) In Africa in 2001 a three-day consultation identified issues for a research agenda on that continent. (UNAIDS / HDN / SIDA 2001)

However, such surveys do not measure all aspects of the phenomenon. Ideally, a comprehensive survey of stigma and discrimination in a community would measure each component according to a standardized analysis and note its relationship to other components, as described in Figure 4. Such a survey, however, has yet to take place.

Framework components

A LEGAL DISCRIMINATION

A review of existing and proposed legislation and policy and the extent to which it has been implemented

B COMMUNITY DISCRIMINATION

A review of discriminatory behavior and actions, as practiced by those within the social norm (J) and perceived by people living or associated with HIV (D), compared with the incidence of non-discriminatory behavior and actions

C STIGMA

A review of the negative (and positive) attributes associated with HIV/AIDS in the eyes of both the majority and those living with HIV

D EXPERIENCED STIGMA

A review of experiences of discrimination, compared with the incidence of non-discriminatory behavior and actions.

E FELT STIGMA

A survey of actions and inaction taken by people with HIV to prevent facing potential discrimination

F INDIVIDUAL AND PUBLIC HEALTH

An analysis of the impact of discrimination and stigma on individual and public health

G HUMAN RIGHTS

A survey of actions and inaction leading to violations of basic human rights and fundamental freedoms, protection of the human rights of people living with HIV/AIDS, and promotion and dissemination of the human rights norms that protect people living with HIV/AIDS

H KNOWLEDGE / (lack of) INFORMATION

A survey of people's knowledge regarding HIV transmission and the behaviors of stigmatized groups

I DISCRIMINATORY ATTITUDES

A survey of people's attitudes towards HIV/AIDS and people living with the virus

J DISCRIMINATORY BEHAVIOR

A survey of people's behavior towards HIV/AIDS and people living with the virus - noting the potential anomalies between self-reported behavior, observed behavior and behavior perceived by people living with HIV/AIDS.

- Confusion between components
- Focus on self-reported knowledge, attitudes and experiences to the exclusion of other techniques, in particular observation
- Analysis of one component without linking that component to the overall picture
- Small samples (often under 100 people and / or restricted to one institution)
- Differing methodologies
- Similar methodologies but with details (such as questions on questionnaires) which vary considerably from author to author
- Surveys that emphasize negative experiences and give no indication of the extent of neutral or positive experiences
- Surveys published two or more years after they were undertaken
- Failure to take into account changing circumstances, such as increased access to antiretroviral drugs.

In practical terms, the most glaring deficiencies are:

- Discrimination or discriminatory attitudes or behaviors described as stigma
- Little or no analysis of the correlation between attitudes and behaviors
- Reliance on self-reporting rather than observation
- Little or no link between reported attitudes from those within the social norm and reported experiences from people living with HIV/AIDS
- Emphasis on the negative.

2.3.1. Existing surveys

In an attempt to provide a comprehensive analysis of the different components of stigma and discrimination, this review identified, through health libraries and similar resources online and through non-specialist resources such as Google, a range of studies from different countries between both the general population and health workers. (See Bibliography)

A pattern was identified whereby some components of stigma and discrimination were studied far more than others. Those that were most studied include components H and I (knowledge and attitudes in the general community) and component D (experiences of stigma and discrimination among people with HIV/AIDS). Even in those areas, however, inconsistencies and defects prevented development of an accurate standard with which to compare different communities or different periods. These inconsistencies and defects include:

Therefore, the conclusion that this review draws is that while HIV/AIDS-related stigma and discrimination are clearly widespread, it is difficult to accurately measure the extent of the problem. Because there is not space in this report to examine each of the components described above, the rest of this section focuses on the knowledge and attitudes of those inside the social norm (components H and I) and the experience of stigma of those outside it (component D).

2.3.2. Public knowledge and attitudes

The United States, where the disease was first identified over twenty years ago, has seen both some of the most intensive HIV/AIDS-related prevention and information campaigns and the most comprehensive surveys of stigma and discrimination. Despite the efforts of the former, the latter reveal that misinformation about the disease and discriminatory attitudes persist in a significant proportion of the population.

While recent surveys confirm that education campaigns have increased the public's awareness of how HIV is transmitted, a significant percentage of the population still does not have a clear idea as to how the virus is not transmitted. In a 1999 survey of 669 people, 50% of respondents believed that HIV could be contracted through sharing a glass with, or from a sneeze or cough from someone with HIV/AIDS, while 40% believed the virus could be contracted from public bathrooms. (Herek et al 2002) In 2000, a survey of 5,641 people showed 40% or respondents believing that HIV could be transmitted through sharing a glass and 41% believing that transmission could result from a cough or sneeze. (CDC 2000)

Surveys of attitudes confirm that in the United States at least, the majority of the population does not stigmatize people with HIV/AIDS. However, approximately one in six of those interviewed in 1999 believed that the names of people with HIV should be published; one in five experienced fear when interacting with an individual with the virus; one in four believed that people who inject drugs or have sexually risky behavior "deserve to have been infected"; 29% would avoid buying from a local store if they learned that its owner had HIV; and 30% would be uncomfortable with the idea of a child with HIV/AIDS attending the same school as their son or daughter. (Herek et al 2002) The 2000 survey found that almost 19% stated that persons who acquired the disease through sex or drug use had "gotten what they deserve" and that men, white people, older people, the poor, the ill and those with less education were more likely to attribute stigma. (CDC 2000) High though these

figures are, overt expressions of discrimination declined in the USA throughout the 1990s, with support for the most coercive responses to the disease, such as quarantine, at very low levels by 1999. (Herek et al 2002)

Studies from other countries reveal a similar picture in that knowledge and awareness appears highest where there has been most publicity. A survey of 6,777 people in China in 2002 revealed that only 7% of city residents and 17% of town residents were unaware of HIV/AIDS. A higher number were uncertain how the virus is transmitted (26.6% city residents; 37.5% town residents) or did not know that condoms offered protection (68.5% city; 76.5% town). Discriminatory attitudes were high: only 41% of city residents and 31% of town residents believed people with HIV should be allowed to return to work, although that percentage diminished with education and among the 26-35 year old age group. (Futures Group 2002) In Singapore a survey of 413 young people confirmed widespread knowledge about how HIV can be transmitted but uncertainties over possible transmission through casual contact. (Lim et al 1999)

2.3.3. Experiences of people living with HIV/AIDS

What is the exact link between misinformation and discriminatory attitudes in the general population and experiences of people living with HIV/AIDS? Does everyone with a discriminatory attitude consistently behave in a discriminatory manner towards people with HIV/AIDS? If 25% of a given population hold negative attitudes and behave accordingly, does that mean that only 25% of people living with HIV/AIDS experience discrimination, or that all people with HIV/AIDS experience discrimination, but only 25% of the time? Or, as is most likely, is the reality more complex than can be conveyed in percentages?

Unfortunately, that information is difficult to ascertain. Ideally, a direct comparison could be made between attitudes and behavior by surveying not only a population group but also the people living with HIV/AIDS that they come into contact with. In a sample taken from the general popula-

tion, however, this is almost impossible. And even if that obstacle were overcome, behavior remains the most difficult component of stigma and discrimination to measure, because it either takes place in private or is modified in the presence of observers.

In place of observing behavior, therefore, most analyses survey the extent to which people living with HIV/AIDS report being subject to discrimination. Surveys developed in Chile (Vivo Positivo 2002), India (UNAIDS 2002a) and Uganda (UNAIDS 2002a) report widespread and severe discrimination against people living with HIV/AIDS. This occurs in a variety of settings, including the family, workplace, the community and health care settings.

The primary defect of such surveys is that they are almost all anecdotal and focus on negative experiences. An accurate picture of experienced discrimination depends on a statistical analysis that would include information such as: (a) the percentage of people living with HIV/AIDS who have ever experienced discrimination, (b) the number of times they have experienced discrimination, (c) the sources and (d) impact of that discrimination (for example, an offensive comment from a passing stranger may have less impact than repeated discrimination at work or in a hospital), and – most importantly, for an accurate picture – (e) comparison with incidences of neutral or positive behavior.

Furthermore, surveys would take into account the availability of antiretroviral drugs. These reduce the incidence of opportunistic infections and significantly prolong active life for people living with HIV/AIDS. Anecdotal evidence suggests that the

resulting disassociation of the disease and death has begun to reduce the extent of discrimination and, potentially, the depth of stigma in communities where medication is widely available. And irrespective of the availability of antiretroviral therapies, there is evidence that improved health leads to fewer incidents of stigma and discrimination. (Heckman et al 1997)

2.3.4. Information missing

There is no doubt that HIV/AIDS-related stigma and discrimination is real, extensive and frequently causes considerable distress to those affected by it. In its extreme form it can lead to physical violence and murder. It harms individual and public health by discouraging those who are at risk, including those who do not know they are at risk, from seeking counseling, information and treatment.

But we do not know the extent of stigma and discrimination. We do not know whether it is the norm for every individual living with HIV/AIDS or whether or how much some groups or individuals are more affected than others. Nor do we know how much the situation is changing.

Such information may not be essential – responses to stigma and discrimination should not depend on whether a minority or majority are affected or whether it is less prevalent than before – but without understanding of the true extent of the phenomenon, we cannot accurately measure the effectiveness of programs that seek to reduce it.

3. HEALTH CARE SETTINGS: A GLOBAL PERSPECTIVE

Because they define health and illness and grant or deny access to life-saving treatments, the health professionals have a tremendous influence on the physical and emotional welfare of people with HIV or who are vulnerable to infection. It is not surprising, therefore, that people with HIV/AIDS are highly sensitive to the attitudes and behavior of health workers. In a study developed in 1990s in the United Kingdom, 96% of HIV/AIDS patients interviewed reported that the attitudes of health personnel were more important to them than their competency or the effectiveness of the treatment. (Beedham & Wilson-Barnett 1995)

Unfortunately, individuals living with HIV/AIDS have frequently described feelings of stigmatization, social rejection and discriminatory behavior from health personnel. This reality crosses frontiers and continents. In Zambia, “the most extreme forms of stigmatization towards people known or suspected to have HIV were reported in health care settings. This included denial of drugs and treatment, being left in the corridor waiting, being dealt with last, being labeled or called names; being subjected to degrading treatment and breaches of confidentiality.” Similar attitudes were reported from Burkina Faso, India and Ukraine. (Panos / UNICEF 2001)

This chapter focuses on those areas which have been most studied – health workers’ knowledge and attitudes and experiences of people living with HIV/AIDS in health care settings. It discusses findings and conclusions and areas that have yet to be resolved. The perspective is global; Chapter 4 reviews the issue in Latin America and the Caribbean.

3.1. Health workers

Many surveys of health workers’ knowledge and/or attitudes towards HIV/AIDS have been carried out since the disease was identified. These have been in isolation or as baseline or follow-up studies to training programs designed to improve knowledge and reduce discriminatory attitudes. Recent surveys include studies undertaken in China (Wu et al 2002), India (Tibdewel & Wadhva 2001), Israel (Ben-Ari 1996), Ivory Coast (Diarra et al 1996), Morocco (Laraqui Hossini et al 2000), Nigeria (Ezedinachi et al 2002), Pakistan (Najmi 1998), Singapore (Bishop et al 2000), South Africa (Chamane & Kortenboud 1997), Spain (González López 1996) and the United States (e.g. studies referred to in Bennett 1995, 1998 and Brown et al 2003).⁸

Among the different health professions, nurses have been the personnel most studied, followed by doctors, laboratory technicians and dentists. There appears to have been little research into the knowledge and attitudes of other professionals linked to the health services, such as psychologists, counselors, social workers, occupational therapists and administrative staff.

The problems that arise in comparing studies were identified in the previous chapter, in particular lack of consistency between papers in terms of methodology and content. Not only do studies use different mechanisms to elicit responses, but also interpretation of those responses may be open to question. Studies may emphasize the negative or draw conclusions that others might not share, for example confusing homophobia with fear of contagion. (Bennett 1995)

⁸ Dates refer to year of publication, not the study. For example, the research for Bishop et al was carried out in 1996-1997, although the results were only published in 2000. In some cases the year of research is not given.

However, enough information is available to provide a general overview. This is followed in Chapter 5 by examples of programs which have been shown to improve health workers' understanding of HIV/AIDS and which have led to some reduction in discrimination.

3.1.1. HIV transmission and fear of contagion/infection

Surveys of health workers' knowledge of HIV/AIDS are generally restricted to awareness of how the virus is and is not transmitted. Such surveys generally reveal moderately high (over 10%) or high (over 20%) ignorance of this topic⁹. Thus, among recent studies, 46% - 62% of health workers in China who had not received HIV/AIDS training were misinformed on transmission and non-transmission, compared to 0% - 11% who had received training (Wu et al 2002); 11% of Moroccan health workers were uncertain of means of transmission (Laraqui Hossini et al 2000) and 10% to 25% of health workers in Singapore believed that the virus could be transmitted by mosquitoes (Bishop et al 2000). Among older studies, 15.5% of Israeli health workers could not confirm that HIV cannot be transmitted through sharing food or eating utensils and 22.9% did know that sterilization was required to ensure needles and syringes were HIV-free (Ben-Ari-1996).

There is a high correlation between ignorance of the means of HIV transmission and the fear of contagion / infection; in some cases the proportion of health workers expressing fear is much greater than the number who have misconceptions about transmission.¹⁰ For example, 56% of doctors and 62% of paramedics in Morocco admitted anxiety in taking care of a patient with HIV. (Laraqui Hossini et al 2000)

In fact there are two kinds of fear: the unfounded fear of casual contagion, which can be dispelled through accurate information in appropriate training, and fear of the real but low risk of infection from occupational exposure – needle stick injury or body fluids when treating an open wound. (Brown et al 2003)

Unlike the first, this second fear is rational. "When the possible consequence is immense or inevitable, even negligible risk is not so acceptable. Thus, it is not so unreasonable to find that despite the greater transmissibility of hepatitis, nurses appraise HIV risk as more serious, given the greater morbidity and mortality (virtually 100% risk) associated with its (albeit unlikely) transmission". (Bennett 1998) While it may be reduced through adherence to appropriate control procedures, it may not be appropriate to seek to totally eliminate fear of this form of infection; a better approach may be to seek a clearer understanding of the different fears related to HIV/AIDS and to develop appropriate responses.

Fear of HIV may be exhibited in different ways. A study in the mid-1990s identified several different reactions among nurses that could be the result of fear, including support for policies intended to protect health workers from infection, fear of contact with blood and body fluids, rejection of people with HIV/ AIDS, restricting care to those who "deserve" to be helped and fear of being abandoned if the health worker him-/herself contracted HIV/AIDS. (Wang & Paterson 1996) Fear can lead to extreme reactions, such as support for measures to isolate all patients with HIV/AIDS and to ban children with HIV/AIDS from attending school. (Ben-Ari 1996)

3.1.2. Vulnerable groups

Surveys of health workers generally show that about 10% - 20% hold negative attitudes towards people living with HIV/AIDS. Such attitudes are associated with both fear of transmission and fear or disapproval of the actual or presumed lifestyles of people living with HIV/AIDS.

In 1992 16.6%-19.1% of nurses in Georgia, USA, expressed resentment at "having to risk [their] health

⁹ Ideally, comprehensive research into the HIV/AIDS-related stigma and discrimination would undertake comparative studies with other diseases. These were not identified, so it is not certain whether health workers are more, equally or less knowledgeable about HIV/AIDS than, for example, hepatitis, influenza or other viral or bacterial infections.

¹⁰ This fear was identified above (Section 2.2.1) as instrumental to AIDS stigma.

Fear of contagion may also represent a symbolic response to threats associated with the unknown, sexuality, punishment and mortality; in this analysis, fear is rooted less in the reality of risk than in the deep social and cultural values which mold people's perceptions of the disease. (Meisenhelder and LaCharite 1989) As an example of this phenomenon, anecdotal reports from Latin America suggest that in that region, and possibly elsewhere, fear of occupational exposure and homophobia may combine. Some heterosexual male health workers report being afraid of contracting HIV at work, not so much because the disease is fatal, but because when HIV-positive, they may be identified as homosexual.

to treat persons who became infected with HIV from multiple sex partners / intravenous drug use". (Dimick et al 1996) Similar attitudes were expressed in an Israeli survey of health workers, when 46.3% of health workers agreed with the statement that "The high cost of treating AIDS is unfair to other people in the hospital", and 71.3% agreed with the statement "There is more talk than actual discrimination against people with AIDS". (Ben-Ari 1996)

Homophobia is a significant element in health workers' negative attitudes. In the United States, where HIV transmission between men has fallen from over 75% of all cases in the early years of the epidemic to 40% of all cases in recent years, homophobia continues to be a significant element in health workers' negative attitudes. In 1993, one study reported that student nurses were more "afraid" of homosexuality than of HIV/AIDS (Eliason 1993) and several other studies in the early 1990s found antipathy towards homosexual men (Glad et al 1995).

Such a response may not be universal; a later study of student nurses in the United Kingdom found more prejudice towards HIV/AIDS than towards homosexual men (Stewart 1999) while it has been suggested that in some studies where health workers' reactions were interpreted as homophobia, the

response could actually reflect fear of casual contagion. (Bennett 1995) Nevertheless, in Latin America and elsewhere, there is sufficient anecdotal evidence to suggest that homophobia is an important, or even over-riding, element in HIV/AIDS related stigma, but there is little statistical information to confirm this.

Meanwhile, little research has been undertaken into the extent to which negative attitudes towards injecting drug users and women sex workers are a component in HIV/AIDS-related stigma and discrimination.

3.1.3. Personal contact

It is generally agreed that personal contact, combined with accurate knowledge of the disease, is a significant element in improving health workers' attitudes and behavior towards people with HIV/AIDS. (Brown et al 2003) As noted above, personal contact varies, with nurses spending more of their work time in contact with patients than any other health profession. However, little research has been undertaken into the substance or impact of the interactions between HIV-positive patients and health staff. One exception is a US study which noted that "the behavior of nurses greatly affect the nature of the behavioral response returned by the patients"¹¹, but the implicit correlation – nurses' reactions to patients – was not studied. (Kempainen et al 1998)

Greater contact time means that nurses are both more able to develop personal relationships with patients, but also that they are more vulnerable to occupational exposure to HIV, particularly through syringes. It has been suggested that despite the higher risk of infection, nurses tend to stigmatize and discriminate less against people with the virus than physicians. This is attributed partly to greater familiarity, and therefore ease, with patients and partly to the fact that nurses, who are mostly women, are less hostile to men than men who have sex with men. While that may be true in some communities, other studies have indicated, a large percentage of nurses feel threatened by or are antipathetic towards homosexual patients. (see Sections 3.1.4 and 4.4)

¹¹ A positive approach from nurses led to a positive response from patients, while a negative approach, such as anger or lack of respect, similarly led to a negative response from patients.

Furthermore, personal contact does not always lead to positive attitudes. While some nurses in resource-rich communities welcome the opportunity to develop close relations with such patients (Hayter 1999), others are anxious because patients often have greater knowledge of the disease and they (the nurses) fear to appear incompetent or ignorant (Taylor 2001). Meanwhile, health workers in communities with few resources may respond negatively, particularly if they feel overburdened. For example, some Zambian care providers claim that patients with HIV/AIDS are “more difficult because of their multiple infections, their ‘hysteria’, their ‘attention seeking’ and their ‘many thoughts’ (i.e. the need for psychological as well as medical support).” (Panos / UNICEF 2001)

It is widely agreed that interventions such as management of pain, malaise and fever, nutritional assessment and counseling, STI management, management of TB and other HIV related diseases should ideally be the responsibility of primary care (PAHO 2000). However, care is mostly provided in specialized centers, such as reference clinics and hospitals. This means that health workers in primary care have little experience with people with HIV and the result may be greater discrimination in the primary care services than in the secondary and tertiary levels.

3.1.4. Systemic failures

Both patients and health workers point out that failures in health systems may lead to discrimination even where no discrimination is intended. Such failures include:

- Limited human & financial resources, resulting in:
 - Inadequate HIV/AIDS-related training and skills
 - Overwork
- Lack of cure and/or lack of available treatment for HIV/AIDS
- Lack of protective equipment and/or other health supplies
- Lack of support for health workers with HIV/AIDS or at risk of infection
- Lack of an environment and infrastructure that

supports both patients’ and health workers’ needs

Any combination of these factors may result in inappropriate treatment as health workers adopt the attitude, “if the system does not care for me, why should I care?” (ICN 2003). And the lack of antiretroviral therapies can lead even the health staff that cares to be overcome by a sense of helplessness and/or to the opinion that the patient is less important than others who can be treated. Zambian health workers “admitted that HIV/AIDS patients were often not given the same services because doctors know they are going to die and, therefore, spent less time on them.” (Panos / UNICEF 2001)

3.1.5. Burnout

Health workers working with patients with chronic fatal conditions such as cancer and HIV/AIDS frequently suffer from burnout, also known as fatigue or compassion fatigue. Burnout may be defined as end-stage discouragement with one’s work that is comprised of three components: emotional exhaustion, depersonalization and a reduced sense of personal accomplishment. Health workers suffering from burnout develop more negative or cynical attitudes about their patients and burnout can affect organizational functioning by contributing to employees’ physical symptoms and reduced job performance. (Brown et al 2002)

Many different factors underlie burnout, including anxiety over safety practices and close identification with dying patients. “[M]ost individuals who have AIDS belong to the same age group as service providers; more than 60% of people with AIDS are under the age of 40. ... In addition, gay physicians are more likely than heterosexual physicians to report increased fear of death and higher levels of anxiety with AIDS patients [who are mostly gay]”. (Gueritault-Chalvin et al 2000) Paradoxically, burnout is sometimes the result of attempts to overcome stigma and discrimination. But it can also inadvertently become the cause of discrimination.

Research in the early 1990s in the United States suggested that burnout with HIV/AIDS occurred more intensely than with cancer. (Bennett et al 1991) The rate of change of health personnel in care centers

for hemophiliacs with HIV/AIDS may reach 35% (Brown et al 2002), and burnout may affect up to 66% of nurses caring for people with HIV/AIDS (Hayter, 1999). However, given that burnout is strongly associated with high rates of death among patients, rates of burnout may have begun to fall in settings where anti-retroviral drugs are widely available.

In Burkina Faso, India, Ukraine, Zambia, “[t]here was evidence in all sites of health workers feeling overwhelmed and powerless. Some service providers were forced to deal with situations beyond their means. In Zambia, for example, when women are denied treatment within clinics, the traditional birth attendants are left to provide the care to women in the villages. ... One nurse / midwife [in a rural health centre] recalls: ‘We are also at risk of HIV and are negligent, not using gloves... If a woman comes [to the health centre] in the second stage of labor and the baby has the cord around its neck, what can you do? You have to assist.’” (Panos / UNICEF 2001)

3.1.6. Stigma and discrimination experienced by health workers

It is not only patients who are subject to HIV/AIDS-related stigma. In the early years of the epidemic, infectologists – the physicians who worked mostly with people with AIDS – were themselves stigmatized and suffer discrimination and even threats from other physicians. Today, there is anecdotal evidence that physicians who specialize in HIV are applauded by colleagues who are grateful and relieved that they take this responsibility.

An increasingly important issue is the stigma and discrimination against HIV positive health workers, who may have contracted the virus sexually or, in rare instances, through occupational exposure. Health workers with HIV often are transferred to administra-

tive services, restrained to perform certain activities or to take safety measures that are not supported by the universal precaution guidelines.

3.2. Patients’ experiences

Although the majority of health workers report neutral or positive attitudes, the experiences of people with HIV/AIDS in health care settings suggest that discrimination is widespread. Discriminatory behavior is not only directed at people known to be HIV-positive, but also, in many cases, applies to individuals known or perceived to belong to vulnerable groups. Reported discriminatory actions and inaction in health care settings include:

- Treatment delayed
- Treatment withheld
- Inappropriate treatment provided
- Other forms of care (e.g. presentation of food, hygiene) delayed or withheld
- Premature discharge
- Refusal to admit patients to health care facility
- Non-attendance to patients in beds
- Non-attendance to individuals in outpatient clinics
- Testing without consent
- Breach of confidentiality within the health care system
- Breach of confidentiality outside the health care system
- Inability to diagnose the clinical manifestations of AIDS¹²
- Inability to give news of HIV-positive result
- Inappropriate comments
- Inappropriate behavior (e.g. shouting, rudeness, etc)
- Selective use of theoretically universal
- Use of excessive precautions

Any of these acts may have a significant physiological or psychological impact on the individual concerned and it is certain that the lives of at least thousands of people have been affected or even shortened by the actions or inaction of health work-

¹² For example, failure to diagnose AIDS in married women.

ers. Unfortunately, however, as noted earlier, studies of patients' experiences almost always failed to measure the extent of discrimination by including reports of positive or neutral experiences; nor do they attempt to measure the impact of discriminatory acts.

The only document studied for this report, which undertook a statistical analysis of HIV/AIDS patients' experiences identified more positive (participation, appreciation, respect, proximity: 42%) than negative experiences (anger, distance, disrespect: 26%). The authors concluded "Patient responses in this study

contrast with current literature which continues to place emphasis on the overall negative prevalence of nurses' attitudes and behaviors." (Kemppainen et al 1998) Another study of patients' experience, although focusing on the negative, also recognized that health workers occasionally displayed neutral and positive behavior. (Surlis & Hyde 2001) These studies were undertaken in the United States and Ireland; anecdotal reports suggest that positive experiences are not unusual in other Western countries and they may be more common than is reported elsewhere.

"They don't want to look after you because they say it's a waste of money, you are going to die after all." (Botswana: ICN 2003)

"The staff were looking after my husband well, but after they tested his blood for HIV their behavior changed." "My blood was tested and from that day they stopped giving me injections. They didn't tell me why." (India: UNAIDS, 2001)

"I used to say 'I'm in pain.' [The nurse] used to say 'Well, that's what you get for using drugs.'" (Ireland, Surlis & Hyde 2001)

"Some of [the nurses] used to [say]: 'We haven't got time for you, there's more sicker people than you.' ... It was because I was a criminal and drug user." (Ireland, Surlis & Hyde 2001)

"[Junsuda] learnt about her HIV-positive status, when her test results were publicly announced in front of other patients and their relatives. "I did not feel human anymore," she states, "My papers were taken from me by the nurses who passed them around the room to other nurses." ... She believes her HIV status became known around town due to lack of confidentiality by the hospital. The HIV-associated stigma was more than her family could bear. Her mother feared ... that the local community's prejudice would have a negative impact on the family's food-selling business. At 18, Junsuda was evicted from the family home." (Thailand: Sexual Health Exchange 2002)

"I went to the health centre with gastritis. I am not supposed to pay because I am HIV-positive. When I told the clerk this he was amazed and went to see the sister-in-charge. She came to me and told me 'There is no need for you to have medicine because you are going to die.'" (Zambia: Panos / UNICEF 2001)

"The nurses went over to the sick man and said 'if you want to go to the toilet get out of that wheelchair and help yourself on the ground outside. When your relatives come they are going to clean up the place and make sure you dress up before you climb back on the wheelchair.' The sick man pleaded with the two nurses that he didn't have the strength to get off the wheelchair and that made the nurses go mad and they started shouting at him. 'Were we there when you were enjoying yourself? And is that why your relatives are not taking care of you?' [... on the following day] I found the man outside on the same wheelchair asking for food from well wishers. One man attempted to give him some food. The nurses refused them and said whoever is going to give him food will be responsible for any mess that he was going to make on the bed, and that person is going to wash up the linen."¹³ (Zambia: Panos / UNICEF 2001)

3.2.1. Institutional issues

Some of the above acts and quotes are the result of discrimination by individuals and not the policy of the institutions where they work. Others, such as inability to diagnose the clinical manifestations of AIDS or some inappropriate comments may be the result of poor training. Where HIV/AIDS is rare and health workers are unfamiliar with appropriate management techniques, incidences of unintentional discrimination are likely to be high.

However, there are also instances of institutional discrimination. This may be active policy; for example private health services in several countries have been reported as refusing admittance of patients with the disease. It may also be the result of failure to respond to patients' specific needs. For example, "[m]ost services established to provide medical and other forms of assistance to people living with HIV/AIDS have been designed to meet the needs of people who acquired HIV infection sexually. They have generally not been specifically designed to meet the needs of HIV-positive injecting drug users." (Burrows 2003)

3.3. Unresolved issues

In this chapter several areas of uncertainty have been noted and they need to be resolved. Firstly, studies of health workers' knowledge are often restricted to uncontroversial facts such as the means of HIV transmission. No studies were identified which surveyed their knowledge of the background, context and lives of vulnerable groups. Such knowledge is likely to be influential in reducing discriminatory attitudes, but yet that relationship has to be proved.

Secondly, the term "health workers" covers a wide range of professions, each having different relationships with people living with HIV/AIDS. These range from those working in clinics who see individual clients only once or sporadically in such circumstances as testing for HIV or other infections,

to doctors who see patients more frequently, particularly when the patient is ill, and nurses in wards who have daily contact with patients. While most surveys of health workers specify the branch of the profession they work in, not all of them take account of these variations in their discussion.

Thirdly, surveys of the experiences of people living with HIV/AIDS often fail to take into consideration the different contexts in which discrimination occurs or the impact of discriminatory acts. For example, an offensive remark from a receptionist may be remembered (and therefore have psychological impact), while poor treatment from a doctor is forgotten, despite the fact it may have lasting physiological impact.

Finally, there is the apparent anomaly, while surveys of health workers consistently indicate that the majority has accurate knowledge and neutral or positive attitudes towards people with HIV, surveys of patients indicate high levels of discriminatory behavior. Future studies should, wherever possible, compare attitudes and perceived behaviors within the same health care settings.

There are three possible explanations for this. First, discriminatory behavior may be widespread. What people say and what they do may be very different and neutral and positive attitudes may not translate into neutral or positive behavior (see box below). Yet the opposite may also be true – discriminatory attitudes may not become discriminatory behavior: health workers who claim they have the right to refuse treatment may not in fact do so. (Bennett 1995) At least one study has found that nurses who held negative attitudes regarding patients who had contracted HIV sexually or through injecting drugs were, nevertheless, willing to offer those patients the same care as patients who had contracted the virus through blood transfusions. (Cole & Slocumb 1993, 1994)

Second, discriminatory behavior may not be widespread, and reports of experiences described by people living with HIV/AIDS give a misleading

¹³ It is arguable that this case reflects both discrimination and institutional failing. In a society where much hospital care is provided by relatives, part of the nurses' reluctance to clean up after the patient may be based on concern that other patients would expect the same treatment.

impression by focusing on the negative and omitting positive or neutral experiences. Reports of positive experience may be rare because they are not seen to illuminate a problem that needs to be resolved. (An alternative explanation, not researched, is that negative experiences are the norm, but health workers do not discriminate because they are equally abusive to people suffering from diseases other than HIV/AIDS.)

Third, experience may vary considerably within a society, even within a locality. Studies that demonstrate that most health workers have neutral or positive knowledge and attitudes may be undertaken in different health care settings from surveys that emphasize patients' negative experiences. Both may be equally valid for the circumstances they describe.

3.4. Grounds for optimism

However, despite many negative reports of discrimination in the health services, there are grounds for optimism. From the perspective of health workers, consistently high levels of knowledge (75% and over) and low levels of discriminatory attitudes (under 25%) are reported. And while surveys of the experiences of people living with HIV/AIDS highlight the negative, the little statistical data available suggests that in at least some communities neutral or positive experiences are the norm.

The true extent of discrimination remains unknown, but there is some evidence that the situation is improving. Statistical surveys are rare, but a 1994 survey in Oklahoma, US, showed significant improvement in health workers' attitudes compared with 1986 (Latman et al 1996). Meanwhile anecdotal reports suggest that in a number of countries people living with HIV/AIDS have, in recent years, perceived a reduction in discrimination in the health services.

Better training and greater access to accurate information have undoubtedly helped. Furthermore, stigma and discrimination may diminish once "saturation point" has been reached. In Zambia, "although stigma is prevalent ...", there is also evidence of changing values, together with increased pragmatism, care and compassion. Media images of the epidemic are now more positive and informative, and a gradual shift in the attitudes of health workers was noted. (Panos / UNICEF 2001) In Uganda many health workers are reported as taking active steps to challenge stigma and in one community health workers have a socio-medical committee specifically aimed at addressing the social aspects of people living with HIV/AIDS. (UNAIDS 2001).

Nevertheless, if left unchallenged, stigma and discrimination in the health services are likely to persist for many years to come. It is therefore essential to identify mechanisms for reducing stigma and discrimination in the health services and to promote these mechanisms widely. Such mechanisms are discussed in Chapters 5 and 6.

Behavior that may be perceived as discriminatory by people living with HIV/AIDS or observers may be motivated by good intentions. Two examples come from India: "When a young woman who is first-time pregnant is found to be HIV positive, we call her mother-in-law. We explain the report to the mother-in-law and ask her to get the son also tested. These patients who come in here are from low-income groups, and if the girls are newly married they are really dumb and don't understand anything, so mother-in-law is called." "The patient, as it is, is half-dead. If he were told of the test results, he might commit suicide." (UNAIDS 2001)

Furthermore, health professionals may unwittingly encourage patients with the virus to feel stigma by emphasizing potential negative reactions from others or by giving unwanted or over-cautionary advice. (Taylor 2001) Training can help health professionals carry on their duties in a more appropriate manner.

4. HEALTH CARE SETTINGS: LATIN AMERICA AND THE CARIBBEAN

Studies and reports of HIV/AIDS-related stigma and discrimination in the health services in Latin America and the Caribbean that use similar methodologies suffer from the same defects and portray a similar situation as in the rest of the world. Extreme forms of discrimination, such as calls for isolation, are rare, but discriminatory attitudes and behavior continue in many communities, with a negative impact on the psychological and physical wellbeing of people living with HIV/AIDS.

Because most of the surveys reviewed below took place at a time when antiretroviral therapies were not widely available and the disease still had strong associations with death, they do not necessarily reflect the current situation. Furthermore, anecdotal evidence suggests that while the stigma of HIV/AIDS is indeed diminishing in some communities, sex between men remains highly stigmatized, with the result that some individuals are more concerned to hide their sexuality than their HIV-positive status (see below). While homophobia is recognized by some organizations as an issue, stigmas

associated with injecting drug use and women sex workers are almost certainly widespread but have not been the subject of investigation.

Regrettably, this review identified only a handful of studies in the region. It is certain that many other surveys of stigma and discrimination in the health services in Latin America and the Caribbean have been undertaken and so conclusions here must be taken as preliminary.

Homophobia

Despite the emergence of gay rights organizations and some acceptance of openly gay men in liberal social circles, homophobia remains widespread throughout Latin America and the Caribbean and is a major factor in HIV/AIDS-related discrimination.

In many sectors of Latin American society, homosexual activity is acceptable if the man only penetrates his partner. Men who are penetrated or perceived as being penetrated are considered “less-than-men” and therefore “legitimate” subjects of stigma.

Violence against men known or suspected of having sex with other men is common in the region and includes rape and murder. Cases have been most documented in Brazil but are reported from almost every country. HIV/AIDS is often a rationale for attacks, with the victim being accused of spreading the virus, whether or not he is HIV-positive. Violence often occurs in sexual situations and is fueled by the attacker’s fear and anger that he is being accused of being a man who is penetrated. (Mott et al 2002)

Although sexual activity between two men is legal in most countries in the region¹⁴, the police use laws referring to public morality to prevent men from congregating or to restrict their behavior in public or

Transvestites are particularly vulnerable to homophobia. One Argentinean study points out that transvestites consider hospitals and other health centers as extremely discriminatory and a place only to visit in extreme need: “I prefer to die in a hotel surrounded by gay men than alone in a hospital bed.” Gender identity is often a source of experienced stigma: “Once I was in a waiting room and they called me by my masculine name and surname. ... I almost died of shame. ... I didn’t get up, I waited until they called someone else and then I left.” (Barreda & Isnardi 2003)

¹⁴ Unusually, Nicaragua criminalized sex between men in 1992.

semi-public places such as bars. Police violence against homosexual men is also widely reported.

Homophobia in the health services in the region is widely reported (see Chile, Guatemala and the Caribbean) but the extent to which it is a factor in HIV/AIDS-related discrimination has not been statistically researched. Such research is essential in the construction of an appropriate response to stigma and discrimination.

Legislation

The American Convention on Human Rights (Additional Protocol) contains an article on “Right to Health”, which compels countries to ensure “satisfaction of the health needs of the highest risk groups and of those whose poverty makes them the most vulnerable”.

A 1991 survey of HIV/AIDS-related legislation in Latin America noted the wide range of factors influencing the drafting of legislation, including the attitudes of health workers, the effectiveness of government bureaucracy in addressing the issue, the role of the Catholic Church and the mass media. Three approaches were identified: restrictive, “based on the perception that the AIDS epidemic can and should be controlled by restrictive laws and regulations” and humanistic, stressing “the need to respect the human rights of AIDS patients and persons who are HIV positive, as well as those of their families and friends”, and pragmatic, based on the rationale that “only regulations which address specific, concrete situations can accomplish the goal of preventing and controlling spread of the disease”. The survey pointed out that several countries adopted more than one approach, such as a Costa Rican decree that prevents discrimination against prison inmates on grounds of sexual orientation or HIV/AIDS status, and a law in the same country requiring HIV tests for foreigners seeking permanent or temporary residence. (Linares 1991)

More recent reviews of legislation have been less comprehensive. The Pan American Health Organization published a brief report on legislation and access to treatment in 2003 (PAHO 2003), and a review of Central American legislation is discussed in Section 4.3.

4.1. Spanish-speaking South America

4.1.1. Argentina

Health workers’ attitudes

A 1996 survey of health professionals working in HIV/AIDS confirmed high rates of fear in treating injecting drug users (57%), homo/bisexual men (26%), the children of HIV-positive mothers (12%), hemophiliacs or blood product recipients (12%) and heterosexual patients (5%). (Frieder 2003)

A 2000 study in five hospitals in Buenos Aires showed reduced rejection of people with HIV/AIDS; however, a strong link between stigmatized behaviors – focusing on sex and injecting drugs – continues to produce difficulties in the relationship between doctor and patient. (Biagini 2000)

Experiences of people with HIV/AIDS

Patricia Pérez of the Latina branch of the International Community of Women living with HIV/AIDS comments that discrimination has fallen as health workers have more information about the disease and have more contact with people who are HIV-positive as an increasing number of people are diagnosed. She points out that a minority of VIH positive people have been helped by greater knowledge of their rights. ICW Latina is working with the Anti-discrimination Office to reduce stigma and discrimination in hospitals, self-help groups and schools. (Personal communication)

4.1.2. Bolivia

Health workers’ knowledge

An undated (believed to be 1998) study revealed very high rates of ignorance among 305 health workers in Cochabamba regarding HIV/AIDS diagnosis and treatment (79.4% were unaware of the need to confirm a positive ELISA test; 72.1% were unfamiliar with drugs used to combat HIV/AIDS) and low rates of confidence regarding working with patients with the disease (30.3% considered they had the skills to

work with HIV/AIDS patients; 33.8% were afraid of the patients and believed they should be isolated). These figures crossed all aspects of the profession, including doctors, nurses, nursing assistants and laboratory assistants. (Valdez Carrizo & Saudan nd)

4.1.3. Chile

General population

According to a speech made by a Chilean government delegate to the United Nations in November 2000, 75% of the population “is willing to share social spaces, such as places at work and at school with persons living with HIV/AIDS” while the “number of those surveyed who declared that we are all vulnerable increased from 6.9 per cent in 1991 to 28.2 per cent in 1994. It is believed that this figure has increased significantly since then.” Since then anti-discrimination legislation has been passed that promotes prevention and non-discrimination against persons living with HIV/AIDS had been approved by the Chamber of Deputies was being considered in the Senate.

Health workers’ attitudes

A 1997 study showed that 48.5% of nurses in the health services in Concepción were favorable to working with patients with HIV/AIDS, 41.6% were indecisive and 10.1% had negative attitudes. (Ortíz & Del Carmen 1997)

Experiences of people with HIV/AIDS

A 70-page report on “Situations of discrimination affecting people living with HIV/AIDS in Chile”, including health care settings, collected data and interviews from 13 cities was made in 2002. The document describes in detail “the situations of discrimination which people living with HIV experience in health settings, particularly in the lack of access to antiretroviral treatments, discrimination in health services as well as the infringements of medical ethics which occurs in these clinics. (Vivo Positivo 2002)

“Informants reported the fewest positive experiences in health settings. Even when, in general, people recognize that they have noticed a change in [health] professionals’ attitudes towards patients, particularly within HIV programs, this change does not match the requirements and needs of people living with HIV/AIDS.” (Vivo Positivo 2002)

The report notes underlying causes of discriminatory behavior, including lack of staff, training and information and carries extensive criticism as well as recommendations.

Patient: “Doctor, what’s the result of my exam, what’s wrong with me?”

Doctor: shouting in a crowded waiting-room “What you’ve got is AIDS, now you’re going to die.” (Bolivia: Fundación Mas Vida, nd)

Nurse: “The young man who had the biopsy is bleeding, the wound needs stitching and dressing.”

Doctor: “I’ll see them all except the *sidoso*¹⁵.” (Bolivia: Fundación Mas Vida, nd)

“When I entered the program I did it as a heterosexual; my wife and children came. But two years passed and my homosexuality emerged. Then the treatment changed immediately. Here they discriminate against you, the treatment they give heterosexuals is different from the treatment they give homosexuals. ... I’m on rescue therapy. The doctor told me that the only way to get on it was to enter my family group, since I had a wife and children.” (Chile: Vivo Positivo 2002)

“It’s very important to be informed, to acquire the terminology, to know what a protease inhibitor is, what a transcriptase inhibitor is. When you go to the doctor and use the terminology, the treatment changes.” (Chile: Vivo Positivo 2002)

¹⁵ *sidoso*: insulting Spanish term for someone with AIDS.

4.1.4. Uruguay

Doctors' knowledge and attitudes

A nationwide study in 1995 surveyed physicians' knowledge and attitudes on such questions as when an HIV test should be recommended, whether the doctor should give the patient a positive result, whether others (family, spouse, medical staff, work colleagues) should be informed of a positive result (i.e. breach of confidentiality), what recommendations should be given to an HIV-positive patient. It concluded that discriminatory practices were rare but existed, and that confidentiality remained a controversial subject. (CEIPV 1998)

4.1.5. Venezuela

Health workers' attitudes

A 1996 study of 322 health workers revealed higher consistent negative attitudes among dentists (36% rejection; 45% discrimination) and nurses (26% rejection; 46% discrimination) than among doctors (27% rejection; 42% discrimination) and students (23% rejection; 42% discrimination). This was "[p]robably due to the higher risk of contagion present in the clinical activities of these professionals". (Prieto Belisario 1996)

4.2. Brazil

Health workers' attitudes

A 1995 study of 21 nursing professionals in Campinas, State of São Paulo, confirmed that the primary issues for respondents were fear of contracting the virus, emotional involvement, aspects of sexuality and drug addiction, continuous contact with death and burnout. (Figueiredo & Turato 1995) A 1997 study of 17 São Paulo health workers (including doctors, a psychiatrist, nurses, assistants and sociologists), 14 of whom had worked with HIV/AIDS patients for at least 5 years, revealed very high levels (more than 50%) of frustration, depression, anger and anguish. (Malbergier & Stempliuk 1997) Both these studies, however, have been superseded by the availability of antiretroviral

drugs, which, anecdotal evidence suggests, has significantly reduced the stigma of HIV/AIDS.

Experiences of people living with HIV/AIDS

Two studies of women living with HIV/AIDS revealed relatively little experience of discrimination. In 1997, 7% respondents reported incidences of discrimination, of 1,068 women surveyed. (Gaspar Tunala 2002) In 1999-2000, 14.4% reported indifference, 5.1% discrimination and 2.0% criticism from the health worker who gave them the positive test result. Women who were tested at maternities or private health services were more likely to have felt discriminated, criticized or been treated with indifference. Only 42.1% of the women reported receiving pre-test counseling, and 62.5% post-test counseling. Other areas where respondents considered that insufficient services were provided included psychological support, nutrition care and oral health. (Cotrim Segurado et al 2003)

In 2002, the government launched a national campaign intended to promote diversity and to reduce discrimination against homosexual men.

4.3. Mexico, Central America and Spanish-speaking Caribbean

According to a 2001 study of HIV/AIDS-related laws in Central America, post-1990 legislation in the region has moved significantly towards protecting the rights of people living with the virus or associated with it. This includes laws prohibiting discrimination and confirming that the human rights of people with HIV/AIDS should be respected. However, some discrepancies between the law and human rights remain, such as compulsory testing of sex workers in some countries.

Health services in the region are obliged to provide treatment and maintain confidentiality, although this may be subject to exception; in Guatemala and Panama, people living with HIV/AIDS must inform any contacts that might be at risk of infection; if they do not do so, the health authorities are instructed to do so. (PASCA 2001)

4.3.1. Dominican Republic

Health workers' attitudes

A 1994 study of surgeons revealed that 30.3% of respondents experienced anxiety over treating HIV-positive patients; other responses included insomnia (6.6%), tachycardia (7.6%) and migraine (7.9%). 82.9% said they treated HIV+ patients, but with extra precautions; 10.5% said they did not treat HIV-positive patients and 6.6% said they treated them in the same manner as HIV-negative patients. (Nuñez et al 1995)

4.3.2. El Salvador

Health workers' attitudes

A 1999 paper reports that counseling for HIV-positive patients improved after the Ministry of Health recognized that “most [health workers] did not know how to counsel or even recognize the need for counseling”. (Calderón 1999)

4.3.3. Guatemala

Experiences of people living with HIV/AIDS

In 1997, parliamentarian Zury Ríos Montt notified the National Assembly that discrimination against people with HIV/AIDS was widespread, including lack of confidentiality in health centers and laboratories and medical professionals refusing to treat patients with the virus. (PASCA 2001)

.Anecdotal evidence suggest that while HIV/AIDS-related discrimination in the health services has fallen, stigma related to men who have sex with men remains high. According to Rubén Mayorga, executive director of the non-governmental organization Oasis, it is relatively common for men to admit they are HIV-positive but to remain silent on the fact that probably contracted the virus through sex with men.

4.3.4. Mexico

Experiences of people living with HIV/AIDS

In the early 1990s, it was reported that most of accusations regarding violations of human rights of people living with HIV were attributed to health workers. (Panebianco et al 1993)

Health workers' knowledge and attitudes

A survey of 204 health workers in Ciudad Juárez showed that on average respondents gave correct answers to 82% questions on knowledge of HIV/AIDS. 81% were willing to provide AIDS care; 87% were worried about contracting HIV; 72% had positive or neutral attitudes towards homosexual men; and 44% had negative attitudes towards injecting drug users. (Fusilier et al 1998)

A 1999 study of 124 family physicians in Mérida showed that specialized doctors and those who had recently graduated were more willing to care for HIV-positive patients. Thirteen percent would prefer not to have HIV/AIDS patients if possible, and 33% agreed with the statement that “taking care of a patient with HIV/AIDS is dangerous”; 10% recommended isolation and 4% preferred not to have homosexual patients, whether or not they were HIV-positive. (Barrón Rivera et al 2000)

4.3.5. Nicaragua

Health workers' knowledge

A 2003 survey of health workers in Managua about knowledge, attitude and practices found that 41% of the nurses had important knowledge gaps about HIV/AIDS. (Sequeira Peña et al, 2003)

4.4. English-speaking Caribbean

Health workers' attitudes

Interviews carried out in 1996 with nurses working with HIV/AIDS patients in Jamaica (before the advent of antiretroviral therapies) revealed some sympathy,

but more discomfort and rejection. This behavior appeared partly as the result of many patients being brought in at terminal stage of the illness, disorientated and unable or unwilling to control their body functions. “Some patients with AIDS are very problematic. I don’t know why some of them, even when they are oriented and able to walk to the bathroom, like to go around the ward dropping feces on the floor.” The attitudes of many nurses were influenced by the presumed source of infection.” To me, being sympathetic with a patient [with AIDS] depends on the way he contracted the disease.” “We can be more sympathetic with children [with AIDS], or with somebody who got infected through a transfusion.” Very strong antipathy towards homosexual men was recorded. Misconceptions about means of HIV transmission were common and some nurses were aware that they lacked sufficient knowl-

edge and training. Scarcity of protective materials sometimes led to patients being given insufficient care and attention. (Ramirez 1996)

Experiences of people living with HIV/AIDS

Workshops in 2002 on stigma and discrimination organized by the Caribbean Epidemiology Center (CAREC) confirmed that the phenomenon was widespread and identified poverty, attitudes towards sex between men and substance abuse as major underlying factors. Health workers were reported as overworked, scared and ill prepared to deal with the disease, while people with HIV/AIDS in health facilities felt dirty, ashamed and fatalistic. The workshop also laid out priorities for action to tackle stigma and discrimination in a number of social settings, including the health services.

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 attitudes¹⁶.

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. (Kempainen 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 (Sadovsky & 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

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 include¹⁷:

- Failure to observe directly the health workers'
- Small target populations
- Different measures used to assess discriminatory attitudes¹⁸
- 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 reporting¹⁹
- 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)

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, multisectorial 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 accepted, 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.

6. STRATEGIES

Stigma may seem irreversible. Once assigned, it is difficult to erase. And some of the underlying “causes” of stigma – such as being HIV-positive, a woman, and a homosexual – cannot be changed. Nevertheless, there have been many instances where stigma associated with ethnicity, religious belief and even health condition has diminished or disappeared – many people in the United States are now proud of their Irish origins, while their ancestors were ashamed; many forms of Christianity in Europe that were once stigmatized are now part of the mainstream; and in many parts of the world people who suffer from Hansen’s Disease (once known as leprosy) are no longer ostracized.

Because of the pivotal role they play in every society, health workers can make a major contribution to “reversing” stigma and discrimination to the point where being HIV-positive is no greater an impediment to an individual’s well-being than the intrinsic health condition.

An effective response to HIV/AIDS-related stigma and discrimination in the health services requires a well-conceived strategy with the cooperation of all concerned, including health service staff and administrators, local and national authorities, people living with HIV/AIDS and concerned non-governmental organizations.

6.1. Needs analysis

Any response to stigma and discrimination in the health services, whether in a single hospital, a group of hospitals or nationwide, should be based on the understanding of the nature and extent of the problem. Ideally, a needs analysis would cover all the components of discrimination described in Section 2.3. However, such a comprehensive study is both time-consuming and beyond the resources of most health services. In such circumstances needs analysis can be limited to research that identifies the following issues. Such research is likely to comprise a combination of questionnaires, interviews and literature research:

The Declaration of Commitment adopted by the United Nations General Assembly Special Session on HIV/AIDS in June 2001 highlights global consensus on the importance of tackling the stigma and discrimination triggered by the disease.

“By 2003, [nations should] ensure the development and implementation of multisectorial national strategies and financing plans for combating HIV/AIDS that address the epidemic in forthright terms; confront stigma, silence and denial; address gender- and aged-based dimensions of the epidemic; [and] eliminated discrimination and marginalization” (paragraph 37)

“By 2003, [nations should] enact, strengthen or enforce, as appropriate, legislation, regulations and other measures to eliminate all forms of discrimination against, and to ensure the full enjoyment of all human rights and fundamental freedoms by, people living with HIV/AIDS and members of vulnerable groups, in particular to ensure their access to, inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information and legal protection, while respecting their privacy and confidentiality; and develop strategies to combat stigma and social exclusion connected with the epidemic” (paragraph 58)

- Patients' experiences (distinguishing the experience itself, context and impact)
- Patients' perceptions
- Patients' recommendations, distinguishing the needs of specific groups, such as:
 - o Women
 - o Homosexual men (and other men who have sex with men)
 - o Injecting drug users
 - o Young people
- Health workers' knowledge, attitudes, and practices and understanding of human rights norms and standards in connection with HIV/AIDS, distinguishing between:
 - o Doctors
 - o Nurses
 - o Counselors
 - o Etc.
- Health workers' experiences with:
 - o Patients
 - o Colleagues
 - o Hierarchy of the organization where they work
- Health workers' recommendations, addressing the needs of:
 - o Doctors
 - o Nurses
 - o Counselors
 - o Etc.
- Recognition of the needs of HIV-positive health workers
- Existing projects designed to reduce stigma and discrimination in similar establishments
- Existence of relevant legislation, policy and guidelines

Some of these issues are covered by indicators drafted by UNAIDS to measure the existing stigma and discrimination in society as a whole (UNAIDS/Measure, 2001) and in the health services (UNAIDS 2002c). Depending on the setting (e.g. in one small hospital or in a city-wide review) such research can normally be carried out within one to three months. The results should identify the areas requiring urgent intervention. The results would also serve as baseline data while the research techniques can and should be modified as part of ongoing monitoring and evaluation of the projects that are developed.

6.2. Interventions

The following principles²¹ should underpin all projects that seek to reduce stigma and discrimination in the health services:

Central concepts:

- Respect for the dignity and human rights of all individuals;
- Recognition of the complexity of stigma and discrimination;
- Awareness of the origins, components and impact of stigma and discrimination in society, including links between HIV/AIDS and other inequalities and injustices;
- Understanding of the origins, components and impact of stigma and discrimination in the health services;
- Recognition of health workers and of people with HIV/AIDS concerns; and
- Understanding gender issue – the way in which women and men may be discriminated in different ways or at different stages of the health care process;

Planning requisites:

- Needs analysis (see above)
- Clear identification of objectives
- Involvement at all stages of:
 - o Staff, including administration and HIV-positive staff
 - o People living with HIV/AIDS
 - o As appropriate, stigmatized or affected groups such as:
 - Men who have sex with men
 - Injecting drug users
 - Women
 - Young people
 - Etc.

²¹ This section draws on a number of documents, including ICN 2003, UNAIDS 2002a and UNAIDS / HDN / SIDA 2001.

Possible goals:

- Staff receiving appropriate knowledge and skills
- Conspiracy of silence and secrecy broken
- Supportive and safer workplaces created
- Adequate supplies and protective equipment provided
- Increased access to post-exposure care and treatment
- Resources improved/streamlined:
 - o Human
 - o Financial
 - o Institutional
- Appropriate policy and guidelines²² to govern interaction between health workers and patients, including:
 - o Codes of ethics
 - o Confidentiality guidelines
 - o Counseling guidelines
- Appropriate policy and guidelines to sustain staff welfare
- Mechanisms for monitoring and evaluating the implementation of policy and guidelines
- Recognition of and response to working conditions that make it difficult to maintain a code of ethics
- Means of enforcing the code of ethics that focuses on the transgression rather than the individual who transgresses²³
- Reinforcement of the implementation of universal precautions²⁴
- Recognition of and response to institutional issues which enable or encourage discrimination or which prevent or make difficult an effective strategy for reducing discrimination

New systems must be carefully tested before they are put into practice. For example, in one hospital in Ukraine a new system of codes on patient records designed to promote confidentiality confused many health workers. Some reverted to writing 'HIV+' on reports which were then left open to public view at the registration desk. (Panos / UNICEF 2001)

- Inclusion of the above principles in health professional training as well as health care settings

Target audiences:

- Identify different categories of clients and their respective needs
- Identify different categories of health workers and their respective needs

Partnerships:

- Establish partnerships with concerned organizations in and out of the health care system, including those representing:
 - o People living with HIV/AIDS
 - o Non-governmental organizations working in HIV care and prevention
 - o Affected groups, such as sex workers, mothers, and men who have sex with men
 - o Different branches of the health professions
 - o Local and/or national authorities, including the Ministry of Health
 - o International (multilateral and bilateral) organizations

Methodologies and activities:

- Training for all health workers, including information and building of practical and attitudinal skills²⁵
- Development of guidelines and policies
- Establishment of non-stigmatizing HIV/AIDS clinics and wards
- Promotion of voluntary counseling, testing and care (including post-exposure prophylaxis) for all health workers
- Development of administrative systems, including referral and discharge, which do not stigmatize patients.
- Establishment of patient support groups
- Establishment of staff support groups
- Support for general and specialist professional associations in AIDS care

²² HIV/AIDS can be included in existing codes / guidelines, or codes / guidelines can be developed that apply to all health care contexts while explicitly including HIV/AIDS.

²³ This approach takes into account the fact that some transgressions are the result of institutional failure (eg lack of appropriate training) rather than the fault of the individual(s) concerned.

²⁴ It should be noted that limiting discussion of universal precautions to HIV/AIDS may reinforce rather than reduce stigma. (Bennett 1995)

²⁵ All health workers should receive some training on HIV/AIDS; specialized training may be required for health workers who work primarily or exclusively with patients with HIV/AIDS.

- Providing mentors for personnel
- Development of simple, effective systems that maintain confidentiality at all levels
- Publication and widespread dissemination of policy, guidelines, training resources and other materials, in an appealing format

Where projects are scaled up, successes and failures must be clearly identified and appropriate changes made to the model. Meanwhile, all activities should comply with human rights norms, which should be supported by legislation addressing discrimination in the health services and elsewhere, as discussed in Section 6.3.

6.2.1. Early diagnosis

As indicated in Chapter 2, stigma has a strong negative impact on the prevention and care continuum. Stigma prevents individuals of coming forward for testing, and thus limits the number of people aware of their status, which implicitly adds fuel to stigma.

In a cycle of cause and effect, a reduction in stigma will encourage more people to come forward for testing, therefore, there will be an increased number of HIV+ receiving appropriate treatment at an early stage of the infection. Eventually if more people are detected and are open about their status, it is likely that stigma will decrease. Thus sensitive and appropriate campaigns that encourage widespread testing are not only beneficial in terms of individual and public health, but can be an important tool in stigma reduction. (Valdiserri 2002)

6.3. A multisectorial approach

While some reduction in stigma and discrimination in health care settings can be achieved in individual cases, interventions are much more likely to be successful when they are part of broader action taken in the community. If possible, these should include local and/or national government structures, the commercial sector, religious organizations, the media, etc. The initiative for such interventions may come from any of the mentioned institutions or the health services. Interventions should be wide-ranging and include activities as a public information

campaign through billboards and the media, sensitization of leaders from different sectors in the community, development of legislation and / or policy etc. (see Section 4.2 above)

Ideally, a multisectorial approach includes strategies as advocacy, legislation, involvement and empowerment of people living with HIV/AIDS, community mobilization, responses to other factors that limit access to HIV prevention and health care (such as racism, sexism, poverty, etc), legal protection for people with HIV/AIDS, workplace education and involvement of religious leaders. (UNAIDS 2002a). Legislation should protect basic human rights, establish national monitoring mechanisms and include:

- Formulation of policies and legislation to protect people living with HIV/AIDS, incorporating the international standards and human rights norms;
- Formulation and establishment of national monitoring mechanisms of human rights and discrimination through the Ombudsman offices or other domestic human rights bodies;
- Dissemination of international human rights norms and standards that protect persons with HIV/AIDS against discrimination and other forms of human rights violations; and
- Dissemination among persons with HIV/AIDS, family members, non governmental organizations of information regarding the international mechanisms and remedies available before human rights commissions and courts.

6.3.1. Specific populations

A multisectorial approach is not only desirable but also essential, given that stigma regarding homosexual men, injecting drug users and women sex workers, pervade society as a whole. Interventions must therefore be developed which address the whole of society, similar to the Brazilian campaign to reduce homophobia (Section 4.2).

Vulnerable populations, including those that are less stigmatized, (e.g. youth), must be the target and co-developers of appropriate strategies. On the one hand, inclusion of such groups sends a message to those communities that their concerns are acknowledged and will be responded to; on the other hand, inclusion increases understanding among program designers of the

group's concerns. In many countries, support groups of people with HIV/AIDS have formed the backbone of a community response to the disease and have had significant influence on the response from district and national governments.

Furthermore vulnerable groups have often devised sophisticated analyses of and appropriate responses to the way in which their lives are affected by HIV/AIDS, which includes stigma and discrimination and the health services. These responses may be local, national or international. In Latin America, for example, such organizations as SIDALAC (AIDS Initiative for Latin America and the Caribbean), ASICAL (Association for Integral Health and Citizenry in Latin America), FUN-SALUD (Mexican Fund for Health) and the Ecuador Equity Foundation have made significant contributions to the development of strategies that involve men who have sex with men at different levels of the response to HIV/AIDS.

6.4. Concerns

Given the complexity of HIV/AIDS-related stigma and discrimination – its many origins, its many manifestations and its wide-ranging impact – interventions designed to reduce the extent of the phenomenon may not always achieve their goals. Planned interventions should therefore take the following and among other issues into consideration:

- Confusion caused by apparently mixed messages, for example, saying that risk is negligible but suggesting the need to be hyper vigilant. Training and hospital policies may promote excessive use of precautions rather than rational practice.
- Focus on the phenomenon rather than the cause: for example: reassuring patients that confidentiality will not be breached, but not implementing appropriate systems of confidentiality; or providing support groups for staff faced with burnout but not addressing questions of long hours or insufficient resources
- Over-emphasizing the differences between HIV/AIDS and other diseases (many other diseases are fatal, transmitted through sex or drug

injection and are stigmatized). “Emphasizing how AIDS is different from other diseases ... may be counter-productive. AIDS must be threaded through curricula, and all aspects of nursing science and skill must be applied to AIDS care. Practicing nurses need help to make links between knowledge they already possess and its applicability to HIV disease.” (Bennett 1995)

- Provision of services for one group rather than everyone affected by HIV/AIDS may not be helpful. In Zambia, anger was created by a project that provided HIV/AIDS-related services for sex workers but not for the community as a whole. (Panos/UNICEF 2001) In Cuba, people with HIV are reportedly concerned that stigma may be fuelled by the extra food rations they receive.

6.5. A changing profile

Early in this report it was noted that stigma and discrimination are not a static phenomenon but a process. Similarly, the profile of the HIV/AIDS epidemic has changed since it was first identified and it is likely to continue to change. This section examines some possible developments and the potential positive and negative impacts on stigma and discrimination in the health services.

• *Increasing access to antiretroviral drugs* *Positive*

- May cause a reduction in stigma by changing the image of HIV as a fatal disease and enabling people with HIV to live a normal and productive life.
- Health workers may feel more motivated as their efforts will have strong and long-term benefits for the health of the patients.

Negative

- In some countries increased or universal access may generate demand beyond the capacity of the health system, particularly ambulatory services, and result in increased burnout for health workers.

- *Increasing role of primary care services*

- Positive*

- Patients may no longer need to attend services identified as HIV/AIDS care, and may, therefore, feel less stigmatized.

- Negative*

- Without training, discrimination may increase, as primary care workers have less experience and less contact with patients with HIV/AIDS; some patients may fear disclosure of their status to the community, particularly when the service is close to their residence.

- *Increasing use of rapid HIV test*

- Positive*

- May motivate the health workers to improve care of people with HIV, as it represents an uncomplicated and quick way to determine serological status and allows prompt intervention.

- Negative*

- The test would be simple and quick which may make health workers careless about the confidentiality guidelines.
 - The test may be used outside traditional health care settings (for instance, by employers), which may make it difficult for health workers in such situations to keep high standards of confidentiality etc.
 - Surgeons, nurses and other health workers may be more likely to require unnecessary tests and to refuse or provide inappropriate treatment to those who test negative.

Changes in the profile of the epidemic, such as increased numbers of cases among the poor, women and youth may increase the stigma that these groups suffer (which is less virulent than against homosexual men, for example but still present). Poor people tend to be less involved in social organizations and are more likely to have their rights abused. Young people tend to be outspoken and demanding, which can trigger a contrary reaction from health workers; and women, as discussed above, tend to suffer preconceptions regarding their sexual behavior.

6.6. Resources

Many organizations have resources for tackling stigma and discrimination, although relatively few have focused on the health services. Such organizations include:

- ASICAL (Association for Integral Health and Citizenry in Latin America)
<http://www.sigla.org.ar/asical.htm>
- Horizons Project
<https://www.popcouncil.org/hiv aids/stigma.html>
- International Council of Nurses
Nurses: Fighting AIDS Stigma, Caring for All, (ICN 2003)
- UNAIDS
 - o *Regional Consultation Report: Stigma and HIV/AIDS in Africa: Setting the Operational Research Agenda* (UNAIDS/HDN/ SIDA 2001)
 - o *A conceptual framework and basis for action: HIV/AIDS stigma and discrimination* (World AIDS Campaign 2002-2003) (UNAIDS 2002a)
 - o *Protocol for the identification of discrimination against people living with HIV* (UNAIDS 2002c)

Section 7.4 also includes a number of potential resources.

6.7. Conclusion

There is no doubt that HIV/AIDS-related stigma and discrimination persist in the health services of many countries. It is a complex phenomenon where the true extent of discrimination and its impact on individuals and communities remains unknown. While there is some evidence of increasing acceptance of people with HIV/AIDS in the health services, some groups still face high levels of discrimination. But whoever is affected, as long as the phenomenon persists, it will bring psychological and physical distress to the individuals affected and severely hamper HIV/AIDS prevention and care efforts in the community as a whole.

Furthermore, interventions that tackle stigma and discrimination in the health services not only affect people living with HIV. Well designed and implemented programs also support health workers, reducing stress levels from fear, ignorance and prejudice and enabling them to achieve a greater sense of satisfaction from caring for the men, women and children in their care. It is hoped that this review has contributed to that process.

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