

Comparative analysis: Research studies from India and Uganda

HIV and AIDS-related
Discrimination, Stigmatization
and Denial



Joint United Nations Programme on HIV/AIDS
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Foreword

From the moment scientists identified HIV/AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. Discrimination has spread rapidly, fuelling anxiety and prejudice against groups most affected as well as those living with HIV/AIDS.

Despite numerous conferences and expert consultations, and despite the passing of Resolution 49/1999 of the UN Commission on Human Rights prohibiting discrimination on the basis of HIV status, relatively little is known about the causes of these negative responses or how they can best be combated. For this reason, the Joint United Nations Programme on HIV/AIDS provided financial and technical support to the studies described here. Conducted by local investigators in India and Uganda, this research offers insight into the experiences of people living with HIV/AIDS, negative social responses encountered, and the roots of HIV/AIDS-related discrimination, stigma and denial.

While the work described in this report does not claim to offer the last word on these matters, it does highlight a series of practical steps that can be taken in policy, programming and research. These studies are part of a concerted effort to rid the world of the stigma and discrimination that hampers efforts to reduce levels of infection and impact, in addition to providing support for people living with HIV/AIDS.



Peter Piot, MD, PhD
Executive Director
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1

Introduction

It goes without saying that HIV/AIDS is as much about social phenomena as it is about biological and medical concerns. Across the world, the global pandemic of HIV/AIDS has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. But the disease is also associated with stigma, ostracism, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities. This rejection holds as true in the rich countries of the north as it does in the poorer and developing countries of the south.

All over the world, ignorance, lack of knowledge, fear and denial have engendered serious and often tragic consequences, denying people living with HIV/AIDS access to treatments, services and support, as well as making it hard for prevention work to take place. The epidemic of fear, stigmatization and discrimination first described by Jonathan Mann (1987) has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those infected (Merson, 1993).

The London Declaration on AIDS Prevention following the World Summit of Ministers of Health on Programmes for HIV Prevention in January 1988 was one of the first international statements to recognize that:

“Discrimination against, and stigmatization of, HIV-infected people and people with AIDS and population groups undermine public health and must be avoided.” (para. 6)

In 1988, Resolution WHA 41.24 of the 41st World Health Assembly subsequently urged Member States to foster a spirit of understanding and compassion for HIV-infected people and those suffering with AIDS. In addition, the resolution recommended Member States to protect the human rights and dignity of affected individuals and population groups so as to discourage discrimination and stigmatization in the provision of services, employment and travel.

In 1989, the United Nations Centre for Human Rights organized the first international consultation on HIV/AIDS and human rights. This forum reaffirmed the public health rationale for the prevention of HIV/AIDS-related discrimination and the promotion and protection of human rights in the context of HIV/AIDS – a view reaffirmed in United Nations General Assembly resolutions in 1990 and 1991.

In late 1996, the second international consultation on HIV/AIDS and human rights was convened jointly by UNAIDS and the Office of the High Commissioner for Human Rights. Twelve international guidelines on HIV/AIDS and human rights were

drafted at this meeting, the majority of which emphasized, once again, the need to avoid HIV/AIDS-related discrimination and to ensure the promotion and protection of the human rights of people living with, and affected by, HIV/AIDS.

International human rights law seeks to guarantee freedom from discrimination on many grounds including sex, race, language, religion, political opinion, birth or other status. In Resolutions 1995/44 and 1996/43, the UN Commission on Human Rights confirmed that the phrase “other status” is to be interpreted as incorporating health status, including HIV/AIDS. This means that discrimination against people living with HIV/AIDS – or those perceived to be at higher risk of infection – is legally prohibited.

Resolution 49/1999 of the UN Commission on Human Rights reaffirms that:

“Discrimination on the basis of HIV or AIDS status, actual or presumed, is prohibited by existing international human rights standards, and that the term, ‘or other status’ in non-discrimination provisions in international human rights texts should be interpreted to cover health status, including HIV/AIDS.”

Among its many provisions, the resolution encourages states, UN agencies, non-governmental organizations, UN treaty bodies and inter-governmental organizations to combat HIV/AIDS-related discrimination, prejudice and stigma and to monitor and enforce HIV/AIDS-related human rights.

Visibility and openness about HIV/AIDS are prerequisites for the successful mobilization of government and community resources to respond to the epidemic. Because they fear stigma and discrimination, people living with HIV/AIDS may be deterred from being open about their serostatus. This enables governments and others to deny that there is a problem. Consultations and meetings have already taken place designed specifically to review experiences and progress in combating the kinds of stigmatization and discrimination that are serious obstacles to prevention and care. Objectives also include sharing best practices with respect to existing codes and legislative frameworks, and to further contribute to international efforts ensuring that HIV/AIDS-related discrimination is reduced and its effects ameliorated (see, for example, HRI, 1996).

Given this intensity of activity, it may be surprising to learn that relatively little systematic research has taken place on the *forms* that HIV/AIDS-related stigmatization and discrimination take, the different *contexts* in which they occur and their varying *determinants*. Indeed, a review of the abstracts from recent regional and international conferences on HIV/AIDS shows that the majority of papers dealing with such concerns focus either on individual cases or experiences, or on the role of non-governmental organizations in exerting pressure on governments and national authorities to act to prevent further discrimination.

2 Background to the present studies

In 1994, under the auspices of the World Health Organization's former Global Programme on AIDS (WHO/GPA), the first steps were undertaken to develop a general research protocol to explore these issues systematically and in some depth (WHO, 1994). Given the relatively uncharted nature of the field, this protocol was developed in two parts: the first offered guidelines for a country-level extended rapid assessment of the determinants of HIV/AIDS-related discrimination, stigmatization and denial; the second provided guidelines for more in-depth study. Central to the issues highlighted were the following research questions:

- How are HIV/AIDS-related stigmatization and discrimination defined and perceived across different societies at the individual, institutional and policy levels?
- What forms do HIV/AIDS-related stigmatization and discrimination take at different stages of the epidemic and in what contexts do they occur?
- What are the main sources of HIV/AIDS-related stigmatization and discrimination?
- What are the responses to HIV/AIDS-related stigmatization and discrimination?
- What are the most appropriate research methods for analysing and understanding HIV/AIDS-related discrimination, stigmatization and denial?

After consultation with WHO's regional offices, three countries – India, Uganda and Venezuela – were identified as having the capacity and willingness to undertake extended rapid assessments along the lines outlined in the general research protocol. In all three countries the seriousness of the epidemic among all, or certain sections of, the population warranted the commissioning of such work. Potential principal investigators from each country were subsequently invited to prepare local research proposals based on the general research protocol and to submit these to WHO/GPA for scientific evaluation and approval. The approval of national authorities and national or local ethical review committees was sought in each case. Two studies undertaken by the Tata Institute of Social Sciences in India (Dr Shalini Bharat, Principal Investigator) and by TASO in Uganda (Ms Sophia Mukasa Moniko, Principal Investigator) were subsequently funded. With the support of UNAIDS, preparatory work commenced in 1997. Work was completed in late 1998.

This report brings together highlights from these investigations. It offers:

- a review of relevant literature;
- a statement of research questions and methods prioritized by each of the local investigations;
- a description of main findings from work conducted in India and Uganda;
- a thematic analysis of issues recurring in each study site; and
- recommendations for policy, programming, practice and further research.

3 Review of relevant literature

Prior to the development of the general research protocol, a literature review was carried out. Among other issues, the protocol examined the nature, sources and forms of HIV/AIDS-related discrimination, stigmatization and denial, key contexts in which it occurred (including the workplace, the health care system and in relation to travel and migration), and implications for intervention. An expanded and partially updated version of this review has subsequently been published (Malcolm et al., 1998). It is this version that forms the basis of discussion here.

Stigma and HIV/AIDS

In a now classic statement, the sociologist Erving Goffman (1963) defined stigma as a “significantly discrediting” attribute possessed by a person with an “undesired difference”. Stigma is a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits. It is a common response to perceived threat when escape from, or the destruction of, this threat is impossible.

While the societal rejection of certain social groups (e.g. “homosexuals”, injecting drug users, sex workers and migrants) may predate HIV/AIDS, the disease has, in many cases, reinforced this stigmatization. By attributing blame to specific individuals and groups, society can absolve itself from the responsibility of caring for and looking after such populations (McGrath, 1992). This is seen not only in the manner in which “outsider” groups are blamed for having brought HIV into a country or neighbourhood, but also in how such groups are subsequently denied access to the services and treatment they need.

Gilmore & Somerville (1994) have described what they see as the four main features of any stigmatizing response: the problem that initiates the reaction; the identification of the group or individual to be targeted; the assignment of stigma to this individual or group; and the development of the stigmatizing response. Other authors have found it helpful to distinguish between felt and enacted stigma. Felt stigma is more prevalent – feelings that individuals harbour about their condition and the likely reactions of others. Enacted stigma refers to actual experiences of stigmatization and discrimination (Scambler & Hopkins, 1986; Jacoby, 1994).

Felt stigma often precedes enacted stigma and may limit the extent to which the latter is experienced. For example, some people living with HIV, aware that many people with HIV/AIDS have been treated badly by others, may conceal their serostatus. To the extent that they are successful in “passing” as non-infected, such individuals may

limit the amount of enacted stigma prevalent in a society or community – at least in the short term.

Sources of HIV/AIDS-related stigmatization, discrimination and denial

An historical and sociocultural perspective may be helpful in understanding the negative reactions triggered by HIV/AIDS. In previous epidemics, the real or supposed contagiousness of disease has resulted in the isolation and exclusion of infected people (Volinn, 1989; Gilmore & Somerville, 1994). Sexually transmitted diseases in particular are notorious for triggering such socially divisive responses and reactions (Carrara, 1994; Goldin, 1994).

From early in the AIDS epidemic, a series of powerful metaphors were mobilized which serve to reinforce and legitimate stigmatization. These include HIV/AIDS as death (e.g. through imagery such as the Grim Reaper); HIV/AIDS as punishment (e.g. for immoral behaviour); HIV/AIDS as a crime (e.g. in relation to innocent and guilty victims); HIV/AIDS as war (e.g. in relation to a virus which needs to be fought); HIV/AIDS as horror (in which infected people are demonized and feared); and HIV/AIDS as “otherness” (in which the disease is an affliction of those set apart). Together with the widespread belief that HIV/AIDS is shameful (Omangi, 1997), these metaphors constitute a series of “ready-made” but highly inaccurate explanations that provide a powerful basis for both stigmatizing and discriminatory responses. These stereotypes also enable some people to deny that they personally are likely to be infected or affected.

People living with HIV/AIDS are seen as ignominious in many societies. Where the infection is associated with minority groups and behaviours (for example, homosexuality), HIV/AIDS may be linked to “perversion” and those infected punished (Mejia, 1988). In individualistic societies, HIV/AIDS may be seen as the result of personal irresponsibility (Kegeles et al., 1989). In yet other circumstances, HIV/AIDS is seen as bringing shame upon the family and community (Panos, 1990; Warwick et al., 1998). The manner in which people respond to HIV/AIDS therefore varies with the ideas and resources that society makes available to them. While negative responses to HIV/AIDS are by no means inevitable, they not infrequently feed upon and reinforce dominant ideologies of good and bad with respect to sex and illness, and proper and improper behaviours (Warwick et al., 1998).

De Bruyn (1999) has recently identified five factors as contributing to HIV/AIDS-related stigma:

- the fact that HIV/AIDS is a life-threatening disease;
- the fact that people are afraid of contracting HIV;
- the disease’s association with behaviours (such as sex between men and injecting drug use) that are already stigmatized in many societies;
- the fact that people living with HIV/AIDS are often thought of as being responsible for having contracted the disease;

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- religious or moral beliefs that lead some people to conclude that having HIV/AIDS is the result of a moral fault (such as promiscuity or “deviant” sex) that deserves punishment.

HIV/AIDS-related stigmatization causes resources essential to preventing infection to be displaced. People are victimized and blamed, social divisions are reinforced and reproduced, and new infections continue to emerge as long as people misread the nature of the epidemic and its causes. More importantly, while negative responses of stigmatization and discrimination seemingly give cohesion to societies and communities, they lead to greater instability in the long term. The social categories and barriers that have been constructed around it cannot contain HIV/AIDS. It requires a more effective means of prevention than this.

Forms of HIV/AIDS-related stigmatization, discrimination and denial

There are several levels at which HIV/AIDS-related discrimination, stigmatization and denial may be experienced and felt. These include societal and community levels, in addition to the experience of individuals.

Societal and community levels

Societally, laws, rules, policies and procedures may result in the stigmatization of people living with HIV/AIDS. A significant number of countries have enacted legislation with a view to controlling the actions of HIV/AIDS-affected individuals and groups (Tomasevski et al., 1992). These laws include legislation for:

- the compulsory screening and testing of groups and individuals;
- the prohibition of people living with HIV/AIDS from certain occupations and types of employment;
- the medical examination, isolation, detention and compulsory treatment of infected persons;
- limitations on international travel and migration;
- the restriction of certain behaviours such as injecting drug use and prostitution (Gostin & Lazzarini, 1997).

International experience now shows that such measures serve only to increase and reinforce the stigmatization of people living with HIV/AIDS and those at greatest risk of contracting the virus. In many countries, discriminatory practices such as the compulsory screening of certain populations or “risk groups” cause both the further stigmatization of such groups and a misplaced sense of security among those who do not see themselves as belonging to these sections of the population. A recent review has, moreover, pointed to the gaps between more liberal national policies and the application of these policies and principles in practice (Gruskin, Hendricks & Tomasevski, 1996). Even where supportive legislation exists, its application may be partial, uneven or ignored.

Restrictive and coercive measures – frequently enacted to “protect” society from infection – discriminate against, or exclude, those who are already infected. Laws that insist on the compulsory notification of HIV/AIDS cases and the restriction of a person’s right to anonymity and confidentiality, as well as the right to movement of those infected, have been justified on the grounds that the disease constitutes a public health emergency (Manuel et al., 1990). While with other infectious diseases such responses may be justifiable, in the case of an already highly stigmatized condition such as HIV/AIDS disease they result in punitive measures that further discriminate against people living with HIV/AIDS and may drive those infected, and those most vulnerable, further underground (Gostin & Lazzarini, 1997).

Perhaps in consequence, numerous countries have now enacted legislation to protect the rights and freedoms of people living with HIV/AIDS and to safeguard them from discrimination (Mann, Tarantola & Netter, 1992; Mann, Tarantola & Netter, 1996). Much of this legislation has sought to ensure the right to employment, education, privacy and confidentiality, as well as the right to information access, treatment and support. However, the failure of governments to protect people living with HIV/AIDS from discrimination, through legislation or through the active enforcement of such legislation, is a violation of their human rights. The apathy of some governments in providing effective systems of prevention, treatment and care may also arise from more deep-seated stigmatization at a societal level.

Governments and national authorities contribute to HIV/AIDS-related stigmatization in other ways. They may, for example, cover up and conceal cases or fail to maintain reliable and transparent reporting systems (Milner, 1991; Whiteside, 1993). Ignoring the existence of HIV/AIDS, neglecting to respond to the needs of those living with HIV infection, and failing to acknowledge burgeoning epidemics in the belief that HIV/AIDS “can never happen to us” are some of the most widely reported responses of denial (Daniel, 1991; Milner, 1991). This denial fuels stigmatization by making those few individuals acknowledged to have HIV/AIDS appear abnormal and exceptional. They do little to enable people to develop a more realistic appreciation of individual vulnerability, and contribute to a vulnerability to the epidemic (Mann, Tarantola & Netter, 1996; UNAIDS, 1997).

Stigma and discrimination, both real and perceived, may also arise from a variety of community-level responses to HIV/AIDS. The harassing and scapegoating of individuals suspected of being infected or of belonging to a particular group has been widely reported. It is often stimulated by the need to blame and punish and can, in extreme circumstances, extend to acts of violence and murder (Nardi & Bolton, 1991). Attacks on men who are presumed gay have increased in many parts of the world, and have been associated with the growing HIV/AIDS epidemic. Sex workers and street children in Brazil have likewise been singled out for violence and abuse (Peterson, 1990; Byrne, 1992). HIV/AIDS-related murders have been reported in countries as diverse as Brazil, Colombia, Ethiopia, India, South Africa and Thailand (Panos 1990; AFAO, 1997). In December 1998, Gugu Dhlamini was stoned and beaten to death by neighbours in

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her township near Durban, South Africa, after speaking out openly on World AIDS Day about her HIV status.

Individual experience

People's experience of HIV/AIDS-related stigmatization and discrimination is affected by commonly held beliefs, forms of societal stigmatization, and factors such as the extent to which individuals are able to access supportive networks of peers, family and kin. It may also be influenced by the stage of the epidemic and whether individuals feel they can be open about their serostatus, age, gender, sexuality and social status – among a host of other variables.

Overall, the negative depiction of people living with HIV/AIDS – reinforced by the language and metaphors used to talk and think about the disease – has reconfirmed fear, avoidance and the isolation of affected individuals and, in some cases, friends and families. In a highly stigmatizing environment, people may withdraw from society as a means of self-preservation. This isolation can extend to exclusion from social and sexual relationships and – in extreme circumstances – has led to premature death through suicide or euthanasia (Gilmore & Somerville, 1994; Hasan et al., 1994). More often, however, stigmatization causes a kind of *social death* in which individuals no longer feel part of civil society, and are no longer able to access the services and support they need (Daniel & Parker, 1990).

Who to tell, how and when, can be a potential source of fear and anxiety among many people living with HIV/AIDS and may prevent individuals from accessing treatment and care (Moynihan et al., 1995; Omangi, 1997). Even where laws have been enacted to protect the rights and confidentiality of people living with HIV/AIDS, few people are prepared to litigate in case their identity will become widely known. Those who are identified as belonging to marginalized and/or minority groups may also worry about the reactions of others, regardless of their serostatus. Fear of telling family members about their homosexuality has recently been cited by some Mexican men as equal to the fear of revealing their serostatus (Castro et al., 1998a; 1998b).

The impact of HIV/AIDS on women is particularly acute. In many developing countries, women are already economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. Being outside the structures of power and decision-making, they may be denied the opportunity to participate equally within the community and may be subject to punitive laws, norms and practices exercising control over their bodies and sexual relations. In a number of societies, women are erroneously perceived as the main transmitters of sexually transmitted infections (STIs), which may be referred to as “women’s diseases” (de Bruyn, 1992). Together with traditional beliefs about sex, blood and other kinds of disease transmission, these perceptions provide a fertile basis for the further stigmatization of women within the context of HIV/AIDS (Ingstad, 1990; Peterson, 1990; Mushingeh, Chana & Mulikelela, 1991; Thant, 1993).

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There is clear evidence from recent UNAIDS-supported studies of household and community responses to HIV/AIDS in developing countries (Warwick et al., 1998; Aggleton & Warwick, 1999) that seropositive women are likely to be treated very differently from men. Whereas men are likely to be “excused” for the behaviour that resulted in their infection, women are not. In India, for example, the husbands who infected them may abandon women living with HIV/AIDS. Rejection by wider family members has also been reported as common (Bharat & Aggleton, 1999). In some African countries, women whose husbands have died from AIDS-related infections have been blamed for the death. Remaining relatives may also evict the surviving spouse from her home (Henry, 1990). Fearful of such situations, some women may prefer to remain ignorant of their serostatus or may keep it a secret.

Perhaps in consequence, individual denial of risk and vulnerability is not an uncommon response to the epidemic. Such denial may manifest itself in self-distancing from the problem and, in extreme cases, can result in people misperceiving their vulnerability. Denial can also discourage voluntary testing among many people, particularly among members of especially vulnerable groups. This, in turn, may increase the potential risk of HIV transmission within the community (Lie & Biswalo, 1996). Such action undermines prevention, care and support.

Contexts of HIV/AIDS-related stigmatization, discrimination and denial

HIV-related discrimination, stigmatization and denial may appear in a variety of contexts. Central among those are the family and local community, employment and the workplace, and the health care system.

The family and community

In the majority of developing countries, families are the primary care-givers to sick members. There is clear evidence of the important role that the family can play in providing support and care for people living with HIV/AIDS (World Bank, 1997; Warwick et al., 1998; Aggleton & Warwick, 1999). However, not all family response is positive. Infected and affected family members may still be stigmatized and discriminated against within the home. There is also mounting evidence that women (Bharat & Aggleton, 1999) and non-heterosexual family members (Castro et al., 1998a; 1998b) are more likely to be badly treated than children and men.

The family's efforts to “manage” stigmatization within the wider community also have consequences for quality of care. Families may shield affected members from the wider community by keeping them within the house or by protecting them from questioning (Lwihula et al., 1993). The extent to which such strategies are successful may depend upon the wealth of the household concerned and its capacity to provide care without calling upon other community members for support.

Fear of rejection and stigmatization within the home and local community

may prevent people living with HIV/AIDS revealing their serostatus to family members (McGrath et al., 1993). Families may reject seropositive members not only because of the stigma associated with HIV/AIDS, but also because of the connotations of homosexuality, drug use and promiscuity that HIV/AIDS carries (Panos, 1990; Misra, 1999; Mujeeb, 1999).

Employment and the workplace

While HIV is not readily transmitted in the majority of workplace settings, the supposed risk of transmission has been used by numerous employers to terminate or refuse employment (see, for example, Barragán, 1992; Gostin, 1992; Panos, 1992; Shisam, 1993; Hasan et al., 1994; Omangi, 1997). There is also evidence that where people living with HIV/AIDS are open about their serostatus at work they are likely to experience stigmatization and ostracism by others (Panos, 1990; Gostin, 1992; Gostin & Lazzarini, 1997).

Pre-employment screening takes place in many industries – particularly in countries where the resources for testing are readily available and affordable. In poorer countries screening has also been reported as taking place, especially in industries where health benefits are available to employees (Parker, 1991; Jackson & Pitts, 1991). Employer-sponsored insurance schemes providing medical assistance and pensions for employees have come under increasing pressure in countries that have been seriously affected by HIV/AIDS. Some employers have used this pressure to deny employment to people living with HIV/AIDS (Whiteside, 1993; Williams & Ray, 1993).

Only a very few companies in developing countries appear to have developed strategies to combat fear, stigma and discrimination in the workplace (see Hughes, 1988, for example), and an equally small number have begun to define the responsibilities of employers towards employees with HIV/AIDS (Jackson & Pitts, 1991; Bezmalinovic, 1996).

The health care system

Many reports reveal the extent to which individuals are stigmatized and discriminated against by the health care system. Numerous accounts also proliferate of withheld treatment (see, for example, AIDS Bhedbhan Virdhi Andolan, 1993; Carvalho et al., 1993; Panebianco et al., 1994); non-attendance of hospital staff to patients left lying in their beds (see, for example, Daniel & Parker, 1990; Ogola, 1990; Masini & Mwampeta, 1993); HIV testing without consent, breaches of confidentiality, and denial of hospital facilities and medications (see, for example, Panebianco et al., 1994).

Contributing to such responses are ignorance and lack of knowledge about HIV/AIDS transmission (Kegeles et al., 1989; Herek & Capitano, 1993; Herek et al., 1998); fear (Blendon & Donelan, 1988; Tesch, Simpson & Kirby, 1990; Rosasco Dulato, 1992); moralistic assumptions of guilt (Cole, Zhang & Chen, 1993; Masini & Mwampeta, 1993); and the perceived incurability of HIV/AIDS. All of these conspire to make it appear pointless to offer good-quality care.

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Lack of confidentiality has been repeatedly cited as a particular problem in health care settings. Wide variations in practice exist between countries, and between health care facilities within countries. In some settings signs have been placed near people living with HIV/AIDS with words such as "HIV-positive" and "AIDS" written on them. Elsewhere, registers of HIV-positive people have been compiled and their names released to media and police without permission (Panos, 1990; Singh, 1991).

Principles of confidentiality also vary between countries and cultures. In some places, for example, confidentiality may be less an individual issue than a community and collective concern. The term "shared confidentiality" describes a situation where family and community members feel they have the right to know the serostatus of family members, neighbours and friends (Campbell et al., 1997).

Implications for enquiry

The above are not the only settings in which HIV/AIDS-related stigmatization and discrimination take place. It should be clear that responses in one setting (e.g. the hospital and health care setting) may have consequences for the way in which people react in others (e.g. at work or at home). We need to examine more closely the fields in which stigmatization occurs, the forms that HIV/AIDS-related discrimination takes, individual, social and institutional determinants, and the responses to which stigmatization gives rise. Only by understanding more about such processes will it be possible to develop the kinds of programmes and interventions that will be successful in preventing HIV/AIDS-related stigma and the negative consequences to which it gives rise.

4

Research questions

As stated earlier, a common core of research questions underpinned the investigation. To ensure that research remained sensitive to local priorities and needs, these were modified according to issues of particular local relevance.

The study in **India** therefore examined:

- What are the various direct and indirect forms of expression of HIV/AIDS-related discrimination, stigmatization and denial in India, and how do these forms vary across different city locations?
- What are the different contexts, namely kinship relations, work settings or caring settings, in which discrimination and stigmatization occur, and how do such expressions vary according to the contexts and level at which they occur?
- What are the dominant individual, socioeconomic or cultural factors that influence or contribute to HIV/AIDS-linked discrimination, stigmatization and denial?
- What is the overall status of HIV/AIDS-related stigmatization and discrimination on the national agenda regarding human rights debate, public health issues and existing social tensions and conflicts?
- What is the role played by policies, media and advertising to support or contain HIV/AIDS-related stigmatization and discrimination? What has been the role of non-governmental organizations?
- What are the outcomes of HIV/AIDS-related discrimination, stigmatization and denial, and can some of these experiences be used in interventions?

(Source: Tata Institute of Social Sciences application for funding, dated 25/10/95)

The study in **Uganda** aimed to give special attention to:

- Analysing the different forms of HIV/AIDS-related discrimination, stigmatization and denial in contrasting sites within Uganda:

What are the different forms of HIV/AIDS-related discrimination, stigmatization and denial in specified study areas? How are these forms defined in various cultural, economic and social contexts? Do the different stages of the epidemic influence the forms of HIV/AIDS-related discrimination, stigmatization and denial? How are these different forms manifested at the individual, family, institutional and policy levels?

- Establishing the factors that influence different forms of HIV/AIDS-related discrimination, stigmatization and denial:

What are the origins of HIV/AIDS-related discrimination, stigmatization and denial? What are the specific factors responsible for enhancing these forms? What is the relative impact of factors influencing HIV/AIDS-related discrimination, stigmatization and denial? How does the impact vary across different cultural, social and economic settings?

- Assessing the various responses to which HIV/AIDS-related discrimination, stigmatization and denial give rise:

What has been the response of people living with HIV/AIDS to discrimination, stigmatization and denial? What has been the response of affected families and communities; and of institutions such as education, health care and employment systems? How has the legal and judicial system addressed issues related to discrimination, stigmatization and denial?

(Source: TASO application for funding, dated 29/7/96)

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Methodology

Sites

India

Given that the forms and determinants of HIV/AIDS-related discrimination, stigmatization and denial vary according to context, principal investigators in India and Uganda were encouraged to identify two or more sites from which data might be collected.

In India, investigators intended to collect data in three contrasting locations: Mumbai, where the impact of HIV/AIDS is particularly severe; and New Delhi in the north of the country and Bangalore in the south – both cities in which numbers of cases of HIV infection are rising rapidly. Given the tight time-frame for the preliminary work, it was possible to conduct in-depth work in only two of these locations: Brihan Mumbai or Greater Mumbai in the state of Maharashtra and Bangalore in the state of Karnataka. These cities differ dramatically from one another: Mumbai, well established as the financial capital of India, and Bangalore, rapidly developing following the introduction of new technology. In the words of the Principal Investigator:

“ Referred to as the ‘metaphor for modern India’, Mumbai (makes) one of the most significant contributions to the Indian economy and (is) a major partner in the global process of development. With its ever growing population, the ‘Dream City’ is a breeding ground for drug peddlers, traders of flesh and people indulging in high risk behaviour...”

“ (Bangalore) once a quaint cantonment town is today a vibrant metropolis with a cosmopolitan population... Well known for the electronic and computer software industries, Bangalore is recognized as the Silicon Valley of India and today has the distinction of being the fastest growing city in South Asia. But its expansion has brought in its wake unplanned development, disparities in living standards and large scale migration... Unlike Mumbai, Bangalore has no well-demarcated red-light area. The sex trade is spread all over the city and is mainly street based.”

Because of prior reporting of significant levels of HIV/AIDS-related discrimination, stigmatization and denial in the workplace, in the health care system and within the home and community, it was decided to restrict the focus of the investigation to these three settings. Much valuable contextual data relevant to the latter two settings existed from an earlier study of household and community responses to HIV/AIDS supported by WHO/GPA (Bharat, 1995).

Uganda

In Uganda, the study took place in two contrasting locations: Kampala District and Mbarara District. Kampala District is the largest urban area in Uganda and houses the capital city of the country. It is a major centre endowed with social, professional, welfare and legal organizations and services active in the struggle against HIV/AIDS. The district contains a heterogeneous population of different cultures, ethnic groups and ways of life. In contrast, Mbarara District is a rural area that is relatively homogeneous with respect to culture, behaviour and perceptions. There are far fewer organizations providing HIV/AIDS-related services in this part of the country. It is generally assumed that knowledge of, and awareness about, HIV/AIDS is lower in Mbarara than in Kampala.

In Uganda, TASO's prior experience providing care and support to people living with HIV/AIDS and their families had suggested that it would be profitable to focus on three contrasting settings within which HIV/AIDS-related discrimination, stigmatization and denial might be expected to manifest itself. These are the individual and family level, the institutional and community level (including the workplace, health care system and places of worship), and the policy level. It should be recognized, however, that these three settings to some extent overlapped, and that responses within one of these environments might be expected to influence those in others.

Methods

The general research protocol for the UNAIDS studies of the determinants of HIV/AIDS-related discrimination, stigmatization and denial had identified the appropriateness of several different methods in the investigation of relevant issues. These included both primary and secondary approaches to data collection and analysis.

Primary approaches included key informant and in-depth interviews with individuals living with and affected by HIV/AIDS-related discrimination, stigmatization and denial; focus groups in communities and settings affected by HIV/AIDS-related discrimination, stigmatization and denial; and observation in workplace, health care and community settings where HIV/AIDS-related discrimination, stigmatization and denial might manifest itself.

Secondary approaches included the analysis of existing sources of information such as newspaper, radio and television reports describing instances of HIV/AIDS-related discrimination, stigmatization and denial; legal records and case notes relating to relevant court cases; and national and local policies relating to HIV/AIDS-related discrimination, stigmatization and denial. Principal investigators were, however, given the option of choosing one method over the other (or emphasizing the use of particular approaches) depending upon local expertise and issues examined.

India

In India, key informant interviews, in-depth interviews and focus group discussions were the main methods used to collect data. These were complemented by case studies of individuals who reported having been subjected to HIV/AIDS-related discrimination, stigmatization and denial; by observation of HIV/AIDS patients in health care and other settings; and by “dummy” patient interviews. Respondents were selected specifically so as to illuminate key issues and concerns. Given the nature of the enquiry (an extended rapid assessment) and the absence of relevant sampling frames, no attempt was made to utilize more representative forms of sampling.

A total of 31 key informant interviews took place in Mumbai and a further 54 in Bangalore. They included voluntary sector workers active in HIV/AIDS prevention and care, deans and heads of hospitals, medical professionals from a range of specialities, the heads of personnel and social welfare departments in selected industries and companies, and experts from the fields of insurance, law and consumer rights.

In-depth individual interviews took place with 31 HIV-positive people in Mumbai and nine of their household care-givers. In Bangalore, 13 interviews were conducted with people living with HIV/AIDS, and five with household care-givers. Additionally, six in-depth interviews were conducted with HIV-positive members of socially marginalized groups in Mumbai and three in Bangalore. These groups included *hijra*, gay men and women sex workers.

Twenty focus group discussions took place with hospital staff in Mumbai and 13 in Bangalore. Four focus group discussions took place with women sex workers in Mumbai and one in Bangalore. One focus group discussion took place with *hijra* in Mumbai and one in Bangalore.

Twenty-seven private clinics were selected for dummy patient interviews in Mumbai and 13 in Bangalore. In both sites, additional contextual data were collected from community support group members, community members, truck drivers (Bangalore) and other groups. For a full breakdown of the sampling, see Bharat (1999).

Uganda

In Uganda, researchers conducted an initial reconnaissance exercise in each of the districts in which they intended to conduct the study. They sought to identify particular areas within each district in which the study might be conducted, establish the household concentration of people living with, and affected by, HIV/AIDS, and identify community leaders and obtain their consent for the study. Additionally, researchers aimed to identify local organizations working with, and providing services for, people living with HIV/AIDS.

Eight potential categories of respondents were identified: people living with HIV/AIDS, families affected by HIV/AIDS, counsellors, legal professionals, medical personnel, community leaders, religious leaders, and NGO and community-based

organization (CBO) workers. This approach allowed the study to focus on the different factors determining HIV/AIDS-related discrimination, stigmatization and denial.

Data were collected by means of individual interviews, focus group discussions and observation. In-depth individual interviews were held with 22 people living with HIV/AIDS in Kampala, 20 in Mbarara, and 10 representatives of families affected by HIV/AIDS in each of these locations. Additionally three counsellors, three medical personnel and two community leaders were interviewed in each site. Three religious leaders in Kampala and two in Mbarara, two legal professionals in Kampala and one in Mbarara, and three NGO/CBO representatives in Kampala and one in Mbarara were also interviewed.

Focus group discussions took place with two groups of people living with HIV/AIDS (one male and one female) in Kampala and Mbarara, respectively. One mixed focus group discussion involving people living with HIV/AIDS was held in Kampala and two were held in Mbarara. Focus group discussions with counsellors also took place in Kampala (1) and Mbarara (2), and with community workers in Mbarara (1).

Observations took place in hospital environments where people living with HIV/AIDS received care. Attention focused not only on the way in which such individuals were received in reception areas, but also the manner in which staff responded to their needs. Additionally, it was possible to observe how relatives and care-givers within the home responded to people living with HIV/AIDS.

As was the case in India, sampling was carried out on the basis of awareness of the contexts and settings in which HIV/AIDS-related discrimination, stigmatization and denial has been documented to exist. Further details of the sampling and data collection and analysis can be found in Mukasa Moniko, Otolok Tanga & Nuwagaba (1998).

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Key findingsIndiaForms

A wide range of different forms of HIV/AIDS-related discrimination, stigmatization and denial were identified in the study conducted within Mumbai and Bangalore. While the focus of the fieldwork was on stigmatization and its consequences within the health care and employment settings, discrimination, stigmatization and denial in intimate relationships at home, in the community and even after death (in relation to the disposal of bodies and funeral arrangements) were also discussed. In each of these settings, felt and enacted stigma were discerned, as well as HIV/AIDS-related discrimination, stigmatization and denial in both overt and covert forms.

The majority of people living with HIV/AIDS who were interviewed had learned about their serostatus either during an illness, surgery or pregnancy. Differential treatment was reported as occurring immediately after (and sometimes even before) disclosure was made. As Saroja, the 38-year-old HIV-positive wife of a man diagnosed in hospital in Bangalore, recounted:

“The staff were looking after my husband well, but after they tested his blood for HIV their behaviour changed and they separated our vessels, pushed him to a corner of the room and talked about us in hushed tones. I couldn’t understand why their behaviour had become so cold.”

The experience of the following HIV-positive person receiving treatment for tuberculosis was typical of many others in the same hospital in Bangalore:

“My blood was tested and from that day they stopped giving me injections. They didn’t tell me why.”

In Bangalore, individuals diagnosed with HIV/AIDS in private hospitals were frequently transferred to government hospitals where conditions and the quality of care are often far worse. As a surgeon in a government hospital explained:

“In private hospitals the news of HIV-positive patients once detected is closely guarded and the patient is conveniently transferred to a government hospital.”

Likewise in Mumbai, a nephrologist attached to a private hospital said:

“ We are not bound by any rule to give treatment to positive patients. Let the government hospitals take that responsibility. There is a great risk of infection to my staff in the nephrology department, and I’m responsible for my staff’s welfare and health.”

Elsewhere in Mumbai, a few private hospitals were reported as accepting people living with HIV/AIDS as patients – although this acceptance came with a price. The costs of fumigating operating theatres and labour rooms, or liberally providing double and even triple hand gloves to staff, and an HIV/AIDS kit to all staff assisting in surgery, amounted in some medical professionals’ eyes to an indirect form of discrimination against people living with HIV/AIDS.

During the course of the study, it was possible to identify some of the ways in which the identity of HIV-positive patients was marked. Medical files in the majority of hospitals in Mumbai are theoretically kept in the safe custody of the ward nurse, but in at least one private hospital the identity of HIV-positive patients on the general ward for economically poorer patients was plain for all to see. A ward boy explained:

“ When the patient comes to our ward, it’s written on the file ‘HIV’ in big letters. Anybody can see it. It’s kept next to the patient. Anybody can see it.”

Less obvious, but nevertheless stigmatizing, practices were noted in some Mumbai hospitals. In a private hospital, staff reported keeping tubs of disinfectant under the beds of HIV-positive patients in which eating vessels, clothes and linen were soaked prior to being washed separately. As one care-giver explained:

“ The tub is the symbol for the staff. We don’t use any board, etc., to declare AIDS but the tub lets us understand.”

Other ways of letting staff know who is HIV-positive and who is not include shouting to ward boys “take this HIV-positive patient for X-ray”. In a public hospital in Mumbai and in Bangalore beds are earmarked for HIV-positive patients to allow the staff to easily identify them. As a senior doctor put it:

“ We never keep them in the middle of other patients because they may also contract the infection. But we do not tell other patients about positive patients.”

In the course of the study, numerous accounts were elicited of medical and nursing staff breaking the confidentiality of an HIV-positive diagnosis and telling family members and relatives before the patient him/herself. A couple interviewed in Bangalore revealed the following:

Husband: *“ The doctor didn’t inform me. He informed my wife and asked her to inform me.”*

Wife: *“ I took my husband to the lab and got his blood tested. After two days they called me and informed me that my husband's blood test result was positive. My husband informed them he had illegal relationships with a woman three years back. The doctor told me the news. ”*

In the case of less-educated or economically poor patients, other family members might be informed first so they could help explain the situation to their relatives.

“ 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. ” (Gynaecologist, private hospital, Mumbai)

Sometimes doctors and nurses argued that this was done so as to protect the patient from shock and possible self-destructive behaviour. As a nurse in Mumbai explained:

“ The patient, as it is, is half-dead. If he is told of the test results, he might commit suicide. ”

That said, there was considerable evidence that once the news had reached relatives the outcomes were far from supportive. Young women in particular reported being blamed and rejected by in-laws and other family members. Men were dealt with far more supportively and positively. As Mary, a 25-year-old HIV-positive woman in Mumbai, explained:

“ My in-laws blame me for their son's death. They have severed all relationships with me. They never discriminated with their son but to me they say, 'You also have AIDS. Stay happily wherever you are.' I took great care of their son – never felt dirty cleaning him up. But they always say 'You married him and our son got bedridden'. I have lost faith in everybody. ”

And as Nigamma, a 40-year-old HIV-positive widow in Bangalore, recounted:

“ My in-laws do not have a good opinion about me. They say that my husband got this disease from me. I sometimes feel why should I live with the insult. It is better to die. But I am living for the sake of my children. ”

HIV-positive interviewees reported experiencing strong pressures to keep their serostatus secret within the workplace. The shame of admitting to colleagues and friends that you have HIV, coupled with the perceived likelihood of being dismissed on discovery, combined to silence the majority of respondents. As one HIV-positive 23-year-old man put it:

“ You know how the society is. They want your reputation to be sullied. I know if my HIV status comes to be known to them, they will call me names, laugh at me, jeer at me, and I’ll have no other option than to commit suicide. I shudder at the very thought.”

And as another HIV-positive respondent explained:

“ And who will give me a job? My health will not be good. I will not be able to work so they will think. What will I do for my living? So it is better not to tell anybody.”

The experience of those few respondents who had revealed their serostatus at work was far from reassuring:

“ Those staff members who know about me talk about it. They point at me and say, ‘Look, he is the HIV fellow.’ They... keep their distance from me and remain aloof. I don’t share my tiffin box with them any more. I don’t feel like coming to work. I remain absent for 10-15 days and then lose wages.” (Tatya, 38-year-old hospital ward boy)

“ My colleagues didn’t openly say anything to me, but the environment was no longer the same. They avoided me. If I entered the room they would leave abruptly. Then they asked me to keep a separate glass for water. I decided to quit the job.” (Daljit, 25-year-old factory worker)

If there was a margin of security for hospital and some factory workers who were open about their serostatus, the same was certainly not true for those employed in more marginal occupations. Ram Niwas, for example, used to sell *bhel puri* in an upper-middle-class residential neighbourhood in Mumbai. He used to consult his local doctor about his medical condition and when he came down with an STD was advised to take an HIV-antibody test as well. He showed the positive result to his doctor who explained it to him but also alerted the local police inspector. The next day the police asked him to move out from the locality of the rich and influential people since he was said to pose a risk to their health.

In the majority of businesses with whom contact was made, denial was the order of the day. Personnel managers and welfare officers refused to acknowledge either that HIV infection was a problem or that it might be so in the future. A local transport company in Mumbai was reported as not having a written policy on HIV/AIDS because “there is not a single case of HIV reported in the company so far”. The human resource development officer in a software company in Bangalore said in interview that:

“ Our staff is very highly paid. They are drawn from the most reputed institutes and we are quite sure they do not have behaviour which makes them suspect for HIV. They are very well educated and have easy access to sources of information, so cannot easily fall for such things.”

ideologies of
gender result in
women
being blamed
for the
transmission of
sexually
transmitted
infections

In a small-scale private box manufacturing company in Mumbai, the managing director, who reported believing that HIV was spread by infected water and blood, said there were no medical facilities available for staff. If workers did not pack the required number of boxes each day they were simply not taken on for work the next day. If they were sick, they were sent home immediately.

Determinants

Clearly, many factors underpin the forms of stigmatization and discrimination described above. Many of these relate to the very real fear of HIV/AIDS that exists among both the general public and professionally qualified health care workers. The sources of these fears are complex and include lack of knowledge and understanding, as well as the manner in which AIDS has been reported in the national and local media (e.g. as being highly “contagious” when in fact it is not).

Other causes of stigma and discrimination have their origins deep within Indian culture and the manner in which “sexual wrongdoing” is popularly understood. Others – particularly those within the health care setting – appear to relate both to lack of knowledge about HIV/AIDS, its routes of transmission and means of protection, as well as to local beliefs about infection through closeness and proximity.

Long-standing ideologies of gender that result in women being blamed for the transmission of sexually transmitted infections – either directly as the supposed “vectors” of transmission or indirectly through failing to “satisfy” their husbands – influence the ways in which families and communities react to the seropositivity of their members. While seropositive men may be offered support and care, the same is unlikely to be true for women – many of whom are blamed for the illnesses from which they and their husbands may suffer.

Processes of stigmatization, whereby people living with HIV/AIDS are rendered outsiders and “others”, are also reinforced by the tendency for people living with HIV/AIDS to make themselves invisible and to disavow their condition. This enables employers and others to deny that there is a problem.

Responses

Clearly, HIV/AIDS has evoked a variety of responses in the Indian context, some of them positive, others considerably less so. At the positive end of the spectrum are the reactions of households and families who agreed to provide care and support for affected members. These responses, it has to be said, were relatively infrequent, but were more likely to occur when male household members rather than women were affected.

Much more common were responses of ostracism and rejection. The predominant effects at the individual level were fear and withdrawal leading to secrecy about HIV status and self-imposed social isolation. In a few cases, suicidal tendencies were noted, and in a few other instances people living with HIV/AIDS sought to avoid stigmatization by denying their serostatus, thereby risking transmission of infection to others.

negative responses in the health care setting can lead people to conceal their HIV status

Negative responses in the health care setting (or the belief that there will be negative responses) lead people to conceal their HIV status in treatment facilities for fear of being denied care. Individuals who are sick may also delay seeking treatment until the last moment, harming their own health in the process.

Within the workplace, widespread denial that HIV/AIDS is a problem means the majority of companies and employers have no policies and procedures with which to respond to seropositive employees. The belief that HIV only affects promiscuous people, and that “such types” are unlikely to work in a given location further contributes to institutional denial. Because of the social stigma associated with HIV/AIDS and in the absence of legislation and procedures stipulating how people living with HIV/AIDS should be treated at work, many prefer to keep their serostatus secret. This contributes to the invisibility of the epidemic and makes life more difficult for those individuals affected.

Occasionally, however, HIV/AIDS-related stigma may trigger more positive responses such as the altruistic actions of those who carve roles for themselves as educators, counsellors and HIV/AIDS activists. Through their work, such individuals may develop a collective identity and mobilize group support that results in a greater awareness of the epidemic and more positive responses towards those affected.

Uganda

Forms

While the Ugandan Government has enacted a national multisectoral policy on HIV/AIDS which stipulates that:

“All Ugandans have individual and collective responsibility to be actively involved in AIDS control activities in a coordinated way. The fight against AIDS is not only directed at the prevention of the spread of HIV, but also addresses the active response to, and management of, all perceived consequences of the epidemic.”

While capacity-building and non-discrimination have been highlighted as central features of Uganda’s response, there was clear evidence from data collected in both sites that the rejection of people living with HIV/AIDS by family and community continues. Approximately the same number of people living with AIDS in each site reported having been rejected by their families as reported having been accepted – a finding which initially surprised the principal investigators of the Uganda study.

Women in particular were often blamed for the death of a husband. As a member of an all-woman focus group of people living with AIDS in Mbarara explained:

“The majority of old men think that it is women who spread AIDS in families. Others think that to get AIDS one must have been promiscuous to others. It is (seen as) a curse on the family.”

In another focus group discussion conducted in this same site, respondents suggested that:

“People would wish that a widow living with AIDS died sooner rather than later so that she does not spread AIDS after she has got treatment and looks healthy.”

Legal professionals interviewed as part of the study reported that:

“Widows have told us many times that, after the death of their husbands, among the consequences faced is ostracism, the children are taken away from them, property is grabbed by the in-laws, and people mock them that much...”

Members of a women's focus group conducted in Mbarara described how:

“One father-in-law sold land that belonged to his deceased son, including the plot where the widowed daughter-in-law lived. She was told to go where she got AIDS from!”

Perhaps in fear of punitive actions, some women in Kampala were reported as deserting their sick husbands before the death as a means of avoiding reprisal afterwards. Men participating in a focus group conducted with people living with HIV/AIDS said:

“Kinship/relatives always blame their widowed in-law for having ‘killed’ their son in case he dies of AIDS. Other reasons (for running away) are that the widow fears the likely reprisal but also running away is a demonstration of a kind of denial, not wanting to face the truth there and then.”

Occasionally, more extreme responses were noted, as in the following story, told by other women in a focus group conducted with women infected with HIV in Mbarara:

“A 20-year-old woman had got results that she was HIV positive. She had to be put aside for crisis counselling. She had vowed to kill her children as she had never gone with anybody else apart from her husband.”

Despite the fact that legal measures have been taken against companies that have attempted to discriminate against people living with HIV/AIDS within their workforce, seropositive workers reported being fearful of revealing their serostatus in the workplace. “Finger-pointing” was a frequently cited workplace response to people living with HIV/AIDS who were open about their condition at work.

“Even if your boss has not shown any sign of dismissing you, the fellow workmates talk behind your back. In this case, the boss may sack you and

your job (is) given to a healthier person, judging from what was always talked about you.”

There was also evidence in the Uganda study of the mediating effects of relative affluence on the manner in which individuals with HIV/AIDS might expect to be treated by family and community. In rural areas in particular, families were reported as providing support and care only as long as their livelihood and standard of living could be maintained. As a group of women living with HIV/AIDS interviewed in Mbarara explained:

“PWAs [people living with HIV or AIDS] live freely in families in which they belong and experience love and care. But this is only as long as the family has enough resources. If the resources are depleted, then the PWA takes the blame because after all he has to die.”

Beyond the enacted stigma and discrimination evident in the instances described above was the felt or perceived stigma that led individuals to police their own behaviour to prevent their serostatus becoming known to others. As one interviewee stated:

“It is not good to reveal one’s serostatus because once one’s friends know, they start spreading rumours which may even reach schools where one’s children study, and obviously such children get affected.”

In some cases, this self-stigmatization resulted in an individual’s avoidance of particular social settings and/or places of work. These included bars and clubs as well as other environments in which individuals felt they might be subjected to stigmatization and discrimination. With respect to employment, counsellors in a focus group discussion in Kampala emphasized how they had:

“... encountered clients who have not been dismissed from their work but who have sort of dismissed themselves due to self-stigma.”

Others also saw felt stigma as triggering an uncooperative attitude as individuals refused to accept the help and support offered to them.

“Some people are not very supportive because the PWA him/herself may not be cooperative to other members (of the family). He/she may stigmatize him/herself, hence repelling the would-be help from other people.” (Focus group discussion, Mbarara)

Determinants

The writers of the report on the Uganda study identified a range of determinants of HIV/AIDS-related discrimination, stigmatization and denial. Among the key individual and family determinants identified were lack of knowledge coupled with the persistence of lay or popular beliefs about HIV/AIDS. Despite years of government publicity and work by non-governmental and community organizations, and regardless

of efforts to encourage non-discrimination and social solidarity, at family and community level, HIV/AIDS is still perceived as a condition linked to promiscuity and sexual wrongdoing.

Among some rural people, HIV/AIDS continues to be associated with witchcraft and curses, making ostracism and stigmatization seem legitimate, in addition to causing individuals to be singled out for condemnation within their own communities. As a man with HIV/AIDS participating in a focus group discussion in Mbarara explained:

“In my family I was the first to get AIDS. At one time during funeral rites (for another person), an announcement was made that I had got AIDS and that I had brought a curse to the family.”

As highlighted above, the consequences of becoming infected are not the same for women and men. Long-held ideologies and beliefs make it seem logical that, while men may seek many partners (and receive social status for doing so), women should limit themselves to only one. To some extent, such practices are legitimized by the traditional marriage bond that denies women the opportunity to object when their husbands put them at risk. The authors of the Uganda report quote from Ngugi's (1996) work:

“I knew my husband was having sex outside our marriage with several partners but I have no power to refuse sex with him according to our tradition. He is my husband and had paid bride wealth. I tested HIV positive and I am bitter. And because of my socioeconomic status I cannot just walk away.”

The similarities between the above situation and respondents' accounts in the present study are striking. The origins of these behavioural discrepancies can be found in traditional values and beliefs.

“African cultural values and value systems increase the spread of HIV even within wedlock... Most women have continued to acquire HIV through such biased cultural norms and values that allow extra marital sexual relations for men.”

There was clear evidence throughout the Uganda study that both socioeconomic status and contact with community-based organizations (CBOs) could mitigate the stigma associated with HIV and AIDS. Wealthier people were seen, for example, as having the capacity to better manage both the flow of information relating to affected family members and the care of affected persons – at least until AIDS-related sickness begins to impose hard financial burdens upon individuals and the household.

In relation to contact with CBOs, respondents in both Mbarara and Kampala reported some ambivalence to the support provided by CBO workers who arrived in vehicles with “TASO” (or an equivalent name) emblazoned on the side.

“We are happy with the services provided to us... But I feel a bit uncomfortable when TASO staff come in their vehicles to visit me. I prefer to come to TASO but not TASO come to my home.” (PWA focus group discussion, Kampala)

Finger-pointing was not unknown in the self-help meetings organized by some CBOs.

“Although you could not visibly see them, whenever I went to CBO meetings people would point fingers at me saying my husband died of AIDS. I had to stop going to their meetings.” (PWA focus group discussion, Mbarara)

Clearly CBOs need to consider carefully the way in which they make their services available and the manner in which they work with clients if their efforts are to have maximum benefit.

Responses

Reported responses to the stigma, discrimination and denial of HIV/AIDS in the Uganda study were of three main types. First, there were responses of an individual nature. These included “coming out” to the family and community as having HIV/AIDS. Interestingly, revealing HIV/AIDS status was found in some cases to diminish the stigma associated with the condition. As reported in a counsellors’ focus group discussion in Mbarara,

“One lady who had AIDS had earlier been rejected by the relatives and the community, but after she went public and declared her serostatus, those who had deserted her now come for assistance and guidance on how to cope with AIDS.”

In this case, we can see how acknowledging one’s serostatus may lessen both the felt and enacted components of HIV/AIDS-related stigma. An additional perceived benefit for some women was that acknowledging their seropositivity lessened the likelihood that other men would approach them for unwanted sexual relationships.

The power of counselling to support people in confronting HIV/AIDS-related stigma and discrimination is a recurrent theme throughout the Uganda study. In a focus group discussion of people living with HIV and AIDS in Mbarara, it was reported that:

“Once you have been counselled, you don’t mind about people’s comments and reactions against you.”

However, there were others who did not gain the strength to be fully open about their condition. For them, a more secluded and often isolated life was the only option. The psychological rejection that derives from HIV/AIDS-related stigma can seriously undermine the individual’s feeling of self-worth and self-esteem, and in extreme

circumstances it can lead to individuals dying alone from treatable conditions such as tuberculosis.

At the family and community levels, HIV/AIDS-related stigmatization and discrimination were reported as having lessened as more and more families were affected, and as responses of support had been forthcoming. In a focus group discussion involving men living with HIV/AIDS in Kampala, it was said that:

“Many people (families) have lost their dear ones. It is due to this reason that they come to help with the situation and not to stigmatize and discriminate against PWAs.”

And in a similar group discussion in Mbarara, a man reported:

“My family and relatives from the time I revealed my serostatus have been supportive, sympathetic and caring. I was delighted that my family accepted me. They advised me to go to TASO for long life, care and support. One of them organized a TASO counsellor for me.”

However, as reported earlier, the responses women received were likely to be very different from those accorded to men.

“Self-stigmatization” could also be a problem for some:

“Some people are not supportive because the person with AIDS him/herself may not be cooperative with other (family) members. He/she may stigmatize him/herself hence repelling help from other people.”
(Mixed focus group discussion, Mbarara)

Within the institution, HIV/AIDS-related stigmatization and discrimination have influenced the responses of many health care staff, some of whom are now reported as taking active steps to challenge the kinds of stigma that existed early on in the epidemic. As a key informant interviewed in Kampala put it:

“The attitude of health workers towards people living with AIDS and HIV is positive (now) because almost everybody has been affected. Nearly everyone has lost a relative, a friend or neighbour.”

In Mbarara, some health workers were even planning to have money deducted from their salaries every month to provide support for people living with HIV/AIDS. As the administrator of the local hospital explained:

“Health workers in this area have a socio-medical committee specifically aimed at addressing the social aspects of persons living with AIDS. They are proposing to fund it by deducting some money from their own monthly salaries.”

As mentioned earlier, efforts have been made at government level to enact legislation to protect people living with HIV/AIDS from discrimination and to promote a more compassionate and caring response. While an evaluation of the impact and effectiveness of this legislation was well beyond the scope of the Uganda study, the authors conclude that the existence of a clear legislative framework to promote the human and civil rights of people living with HIV/AIDS is a crucial component of any programme to lessen HIV/AIDS-related stigma and discrimination.

7

Thematic analysis

A number of themes recur throughout both of the studies.

FIRST, it is important to recognize that HIV/AIDS-related discrimination, stigmatization and denial can appear in a variety of forms, at a variety of levels and in a variety of contexts. Mapping these forms is the first step towards being able to identify their determinants. It may be important theoretically as well as practically to differentiate between individual, family-level, community and institutional determinants.

SECOND, pre-existing local cultural practices and beliefs are both determinants and legitimators for HIV/AIDS-related discrimination, stigmatization and denial. These beliefs frequently establish categories of person or types of behaviour that are likely to be stigmatized (e.g. sexually “promiscuous” individuals, sex workers, drug users and homosexuals). The advent of HIV/AIDS frequently reinforces these already existing types of stigma, imbuing them with new and potent legitimacy.

THIRD, there is an important distinction to be made between “felt” and “enacted” stigma. Felt stigma arises from the real or imagined stigmatizing responses of others. It has an important role to play in “policing” the behaviour of people living with HIV/AIDS, causing some to deny their serostatus, others to conceal it, and all to experience anxiety about telling others and seeking care. The consequences of both felt and enacted stigma undermine efforts to challenge HIV/AIDS-related discrimination, stigmatization and denial. Both prevent people living with HIV/AIDS publicly acknowledging their serostatus and playing their full and proper role in prevention and care.

FOURTH, socioeconomic status and relative financial (and productive) security can influence the stigmatizing process. By enabling some families to “conceal” HIV/AIDS-affected members either within the home or in private medical facilities, some individuals are able to avoid being overtly stigmatized. At the same time, however, it may be especially shameful for wealthy individuals and their families to acknowledge being affected. More generally, socioeconomic status and wealth allow people to better manage the flow of information relating to HIV/AIDS and its impact upon family and household members.

FINALLY, it is clear that there is a strong gender bias in HIV/AIDS-related discrimination, stigmatization and denial. Women and men are not dealt with in the same way when they are infected – or believed to be affected – by HIV/AIDS. There is evidence that men are more likely to be accepted by family and community. Women, on the other hand, are more likely to be blamed, even when they have been infected by their husbands in what for them have been monogamous relationships. This double standard exacts a terrible toll on women as mothers, as daughters, as care-givers and as people living with HIV/AIDS. HIV/AIDS-related stigma, and the discrimination to which it leads, therefore plays a key role in intensifying gender inequalities.

8 Implications for policy, programming and future research

what is urgently needed is government anti-discrimination policy supported by a law that will ensure the protection of (HIV) positive people's rights

The local studies of the determinants of HIV/AIDS-related discrimination, stigmatization and denial described here took the form of extended rapid assessments of six months' duration. When originally planned, they were seen as the precursors to subsequent enquiries involving larger numbers of respondents and a more in-depth approach. Given the scope and nature of the enquiry, therefore, it would be unreasonable to expect detailed policy and programming implications to be derived from the data. This was not the aim of the local investigations carried out.

However, with respect to **policy development** the following general points can be made:

- Efforts to tackle HIV/AIDS-related discrimination, stigmatization and denial seem doomed to fail in the absence of a supportive legal framework. In the words of the India report, "It is not enough to spread awareness about HIV/AIDS, its transmission matters or even about legal rights. What is urgently needed is government anti-discrimination policy supported by a law that will ensure the protection of (HIV) positive people's rights."
- Even where such laws exist, or where governments make active efforts to combat HIV/AIDS-related discrimination, it is vital to challenge popular myths, stereotypes and judgements that provide the ground upon which HIV/AIDS-related stigma can grow. At the policy level, prevention programmes should foster tolerance and social solidarity using, wherever possible, an approach which is non-judgemental and not based on fear.
- In both employment and health care, discriminatory policy needs to be developed to protect and safeguard the employment and health care rights of people living with HIV/AIDS. Central to this must be principles of confidentiality and respect for human rights.
- 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, employment, education, housing and social security, as well as effective enforcement mechanisms. Other important and complementary activities must include efforts to change attitudes through communication campaigns in the media, education and training.

In future prevention, care and impact-mitigation **programming**:

- Interventions and activities should aim to move from providing only information to providing services and social support aimed at countering the prejudices and popular beliefs about HIV/AIDS that seemingly justify stigmatization and discrimination.
- Greater attention needs to be given to the gender-biased nature of HIV/AIDS-related stigma. Efforts should be made to address not only women's risks of HIV/AIDS infection but their heightened vulnerability to the social stigma associated with HIV/AIDS. In the majority of societies, a double standard exists whereby men are permitted (and even encouraged) to have more than one partner, while women are blamed for the consequences of this behaviour. The effects of this double standard on women's health and well-being, property rights and rights of access to children are serious, and need to be addressed urgently.
- Efforts must be made to tackle the forms of felt and enacted stigma that make it difficult for people living with HIV/AIDS to be open about their serostatus. This secrecy causes them to withdraw from social life, and makes it difficult for them to play a full part in prevention and to benefit from care.

With respect to future **research**, more needs to be learned about:

- The overt and the more hidden and institutionalized forms of HIV/AIDS-related discrimination, stigmatization and denial that exist in different settings and at different stages of the epidemic.
- The determinants of these different kinds of HIV/AIDS-related discrimination, stigmatization and denial, and the circumstances and factors that lead to a reduction in stigmatization and its negative consequences.
- The pervasive discursive, cultural and structural frameworks that act as sources of HIV/AIDS-related discrimination, stigmatization and denial, the manner in which these are utilized and resisted, and their consequences for the social exclusion of certain categories of individual.
- The processes and dynamics of exclusion that accompany HIV/AIDS-related discrimination, stigmatization and denial, including the self-exclusion associated with felt stigma and the collective exclusion associated with institutionalized forms of discrimination.
- The positive responses to which HIV/AIDS-related discrimination, stigmatization and denial can give rise, the circumstances in which these occur, precipitating and supporting factors, and the key parties involved.
- The price that societies and communities pay for HIV/AIDS-related discrimination, stigmatization and denial, its impact upon family and community, health care systems, labour and productivity.

greater attention needs to be given to the gender-biased nature of HIV/AIDS-related stigma

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UNAIDS both mobilizes the responses to the epidemic of its seven cosponsoring organizations and supplements these efforts with special initiatives. Its purpose is to lead and assist an expansion of the international response to HIV on all fronts: medical, public health, social, economic, cultural, political and human rights. UNAIDS works with a broad range of partners – governmental and NGO, business, scientific and lay – to share knowledge, skills and best practice across boundaries.

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Discrimination, stigmatization and denial have been recognized as important issues to be addressed in the context of HIV/AIDS. Discrimination against those living with HIV/AIDS, or presumed to be infected, is a violation of human rights. All individuals deserve equal respect and dignity, whatever their situation and whatever their health status.

This *Key Material* succinctly describes and compares findings from studies, conducted in India and Uganda, of the nature, determinants and effects of HIV/AIDS-related discrimination, stigmatization and denial. The comparative analysis demonstrates the profound consequences of these negative processes for the individuals, families and communities involved. Policy, programmatic and research issues are also highlighted.



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