

Dear all,

Internationally, there has been a recent resurgence of interest in HIV and AIDS-related stigma and discrimination, triggered at least in part by growing recognition that negative social responses to the epidemic remain pervasive even in seriously affected communities. Yet, rarely are existing notions of stigma and discrimination interrogated for their conceptual adequacy and their usefulness in leading to the design of effective programs and interventions. Taking as its starting point, the classic formulation of stigma as a 'significantly discrediting' attribute, but moving beyond this to conceptualize stigma and stigmatization as intimately linked to the reproduction of social difference, this paper offers a new framework by which to understand HIV and AIDS-related stigma and its effects. It so doing, it highlights the manner in which stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality. It highlights the limitations of individualistic modes of stigma alleviation and calls instead for new programmatic approaches in which the resistance of stigmatized individuals and communities is utilized as a resource for social change. Today we are sharing with you an article which highlights the stigma and discrimination regarding HIV&AIDS.

Stigma and Discrimination

From the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic. Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS. It goes without saying that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. Across the world the global epidemic 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, 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 countries of the south. Stigma is a powerful tool of social control. Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics. While the societal rejection of certain social groups (e.g. 'homosexuals, injecting drug users, sex workers') may predate HIV&AIDS, the disease has, in many cases, reinforced this stigma. By blaming certain individuals or groups, society can excuse itself from the responsibility of caring for and looking after such populations. This is seen not only in the manner in which 'outsider' groups are often blamed for bringing HIV into a country, but also in how such groups are denied access to the services and treatment they need.

Why is there stigma related to HIV and AIDS?

In many societies people living with HIV and AIDS are often seen as shameful. In some societies the infection is associated with minority groups or behaviors, for example, homosexuality, In some cases HIV&AIDS may be linked to 'perversion' and those infected will be punished. Also, in some societies HIV&AIDS is seen as the result of personal irresponsibility. Sometimes, HIV and AIDS are believed to bring shame upon the family or community. And whilst negative responses to HIV&AIDS unfortunately widely exist, they often feed upon and reinforce dominant ideas of good and bad with respect to sex and illness, and proper and improper behaviors.

Factors which contribute to HIV&AIDS-related stigma:

- HIV&AIDS is a life-threatening disease
- People are scared of contracting HIV
- The disease's is associated with behaviors (such as sex between men and injecting drug-use) that are already stigmatized in many societies
- People living with HIV&AIDS are often thought of as being responsible for becoming infected
- Religious or moral beliefs lead some people to believe that having HIV&AIDS is the result of moral fault (such as promiscuity or 'deviant sex') that deserves to be punished.

"My foster son, Michael, aged 8, was born HIV-positive and diagnosed with AIDS at the age of 8 months. I took him into our family home, in a small village in the south-west of England. At first relations with the local school were wonderful and Michael thrived there. Only the head teacher and Michael's personal class assistant knew of his illness."

"Then someone broke the confidentiality and told a parent that Michael had AIDS. That parent, of course, told all the others. This caused such panic and hostility that we were forced to move out of the area. The risk is to Michael and us, his family. Mob rule is dangerous. Ignorance about HIV means that people are frightened. And frightened people do not behave rationally. We could well be driven out of our home yet again."

- Debbie - speaking to the National AIDS Trust, UK,

Sexually transmitted diseases are well known for triggering strong responses and reactions. In the past, in some epidemics, for example TB, the real or supposed contagiousness of the disease has resulted in the isolation and exclusion of infected people. From early in the AIDS epidemic a series of powerful images were used that reinforced and legitimized stigmatization.

- 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 need to be fought)
- HIV&AIDS as horror (e.g. in which infected people are demonized and feared)
- 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, these images represent 'ready-made' but inaccurate explanations that provide a powerful basis for both stigma and discrimination. These stereotypes also enable some people to deny that they personally are likely to be infected or affected.

Forms of HIV&AIDS-related stigma and discrimination

In some societies, laws, rules and policies can increase the stigmatization of people living with HIV&AIDS. Such legislation may include compulsory screening and testing, as well as limitations on international travel and migration. In most cases, discriminatory practices such as the compulsory screening of 'risk groups', both further the stigmatization of such groups as well as creating a false sense of security among individuals who are not considered at high-risk. 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 forms a public health risk. Perhaps as a response, numerous countries have now enacted legislation to protect the rights and freedoms of people living with HIV and AIDS and to safeguard them from discrimination. Much of this legislation has sought to ensure their right to employment, education, privacy and confidentiality, as well as the right to access information, treatment and support.

Governments and national authorities sometimes cover up and hide cases, or fail to maintain reliable reporting systems. Ignoring the existence of HIV and AIDS, neglecting to respond to the needs of those living with HIV infection, and failing to recognize growing epidemics in the belief that HIV&AIDS 'can never happen to us' are some of the most common forms of denial. These denial fuels AIDS stigmas by making those individuals who are infected appear abnormal and exceptional.

Stigma and discrimination can arise from community-level responses to HIV and AIDS. The harassing of individuals suspected of being infected or of belonging to a particular group has been widely reported. It is often motivated by the need to blame and punish and in extreme circumstances can extend to acts of violence and murder. Attacks on men who are assumed gay have increased in many parts of the world, and HIV and AIDS related murders have been reported in countries as diverse as Brazil, Colombia, Ethiopia, India, South Africa and Thailand. In December 1998, Gugu Dhlamini was stoned and beaten to death by neighbors in her township near Durban, South Africa, after speaking out openly on World AIDS Day about her HIV status.

Women and stigma

The impact of HIV&AIDS on **women** is particularly acute. In many developing countries, women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. In a number of societies, women are mistakenly perceived as the main transmitters of sexually transmitted diseases (STDs). Together with traditional beliefs about sex, blood and the transmission of other diseases, these beliefs provide a basis for the further stigmatization of women within the context of HIV and AIDS

HIV-positive women are treated very differently from men in many developing countries. Men are likely to be 'excused' for their behavior that resulted in their infection, whereas women are not.

" My mother-in-law tells everybody, 'Because of her, my son got this disease. My son is as good as gold-but she brought him this disease. "

- HIV-positive woman, aged 26, India -

In **India**, for example, the husbands who infected them may abandon women living with HIV or AIDS. Rejection by wider family members is also common. In some African countries, women, whose husbands have died from AIDS-related infections, have been blamed for their deaths.

Families

In the majority of developing countries, families are the primary caregivers to sick members. There is clear evidence of the importance of the role that the family plays in providing support and care for people living with HIV&AIDS. However, not all family response is positive. Infected members of the family can find themselves stigmatized and discriminated against within the home. There is also mounting evidence that women and non-heterosexual family members are more likely to be badly treated than children and men.

"My mother-in-law has kept everything separate for me-my glass, my plate, they never discriminated like this with their son. They used to eat together with him. For me, it's don't do this or don't touch that and even if I use a bucket to bathe, they yell - 'wash it, wash it'. They really harass me. I wish nobody comes to be in my situation and I wish nobody does this to anybody. But what can I do? My parents and brother also do not want me back. "

- HIV-positive woman, aged 23, India -

Employment

While HIV is not transmitted in the majority of workplace settings, the supposed risk of transmission has been used by numerous employers to terminate or refuse employment. There is also evidence that if people living with HIV&AIDS are open about their infection status at work, they may well experience stigmatization and discrimination by others.

"Nobody will come near me, eat with me in the canteen, nobody will want to work with me, I am an outcast here."

- HIV positive man aged 27, India -

Pre-employment screening takes place in many industries, particularly in countries where the means for

testing are easily available and affordable.

In poorer countries screening has also been reported as taking place, especially in industries where health benefits are available to employees. Employer-sponsored insurance schemes providing medical care and pensions for their workers have come under increasing pressure in countries that have been seriously affected by HIV and AIDS. Some employers have used this pressure to deny employment to people with HIV or AIDS.

"Though we do not have a policy so far, I can say that if at the time of recruitment there is a person with HIV, I will not take him. I'll certainly not buy a problem for the company. I see recruitment as a buying-selling relationship. If I don't find the product attractive, I'll not buy it."

- A Head of Human Resource Development, India -

Health care

Many reports reveal the extent to which people are stigmatized and discriminated against by health care systems. Many studies reveal the reality of withheld treatment, non-attendance of hospital staff to patients, HIV testing without consent, lack of confidentiality and denial of hospital facilities and medicines. Also fuelling such responses are ignorance and lack of knowledge about HIV transmission.

"There is an almost hysterical kind of fear...at all levels, starting from the humblest, the sweeper or the ward boy, up to the heads of departments, which makes them pathologically scared of having to deal with an HIV-positive patient. Wherever they have an HIV patient, the responses are shameful."

- A retired senior doctor from a public hospital, currently working in a private hospital, India -

A survey conducted , among some 1,000 physicians, nurses and midwives in four Nigerian states, returned disturbing findings. One in 10 doctors and nurses admitted having refused to care for an HIV&AIDS patient or had denied HIV/AIDS patients admission to a hospital. Almost 40% thought a person's appearance betrayed his or her HIV-positive status, and 20% felt that people living with HIV&AIDS had behaved immorally and deserved their fate. One factor fuelling stigma among doctors and nurses is the fear of exposure to HIV as a result of lack of protective equipment. Also at play, it appears was the frustration at not having medicines for treating HIV/AIDS patients, who therefore were seen as 'doomed' to die.

Lack of confidentiality has been repeatedly mentioned as a particular problem in health care settings. Many people living with HIV&AIDS do not get to choose how, when and to whom to disclose their HIV status. When surveyed recently, 29% of persons living with HIV&AIDS in India, 38% in Indonesia, and over 40% in Thailand said their HIV-positive status had been revealed to someone else without their consent. Huge differences in practice exist between countries and between health care facilities within countries. In some hospitals, signs have been placed near people living with HIV&AIDS with words such as 'HIV-positive' and 'AIDS' written on them.

The way forward

HIV-related stigma and discrimination remains an enormous barrier to effectively fighting the HIV and AIDS epidemic. Fear of discrimination often prevents people from seeking treatment for AIDS or from admitting their HIV status publicly. People with (or suspected of having) HIV may be turned away from healthcare services, employment, refused entry to foreign country. In some cases, they may be evicted from home by their families and rejected by their friends and colleagues. The stigma attached to HIV&AIDS can extend into the next generation, placing an emotional burden on those left behind.

Combating the stigma and discrimination against people who are affected by HIV&AIDS is as important as developing the medical cures in the process of preventing and controlling the global epidemic.

So how can progress be made in overcoming this stigma and discrimination? How can we change people attitudes to AIDS? A certain amount can be achieved through the legal process. In some countries people who are living with HIV or AIDS lack knowledge of their rights in society. They need to be educated, so they are able to challenge the discrimination, stigma and denial that they meet in society. Institutional and other monitoring mechanisms can enforce the rights of people living with HIV or AIDS and provide powerful means of mitigating the worst effects of discrimination and stigma.

However, no policy or law can alone combat HIV/AIDS related discrimination. The fear and prejudice that

lies at the core of the HIV&AIDS discrimination needs to be tackled at the community and national levels. A more enabling environment needs to be created to increase the visibility of people with HIV&AIDS as a 'normal' part of any society. In the future, the task is to confront the fear based messages and biased social attitudes, in order to reduce the discrimination and stigma of people who are living with HIV or AIDS.

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