

HATiP

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HIV stigma, treatment and prevention

Definitions

The Microsoft Word Dictionary defines stigma as the shame or disgrace attached to something regarded as socially unacceptable. Sociologists have taken this a bit further. In a seminal study on stigma in 1963, stigma was defined as an attribute that is seen as deeply discrediting to a person or group (Goffmann). Those attributes could be an illness, physical deformity, aberrant behaviour or social group (based upon religion or ethnicity, etc...). Stigma lets people or groups see differences or "others" in a negative light while confirming their own sense of normalcy and decency.

Subsequent researchers have viewed this more as a social process that creates or perpetuates social inequities and which is used to legitimise discrimination. While this is generally true, stigma can also be a primal human response— particularly in the case of fearing a disease that is transmissible and potentially incurable.

Often, there is a moral component, nowhere more so than in the case of HIV. "There is a notion of blame and responsibility embedded in HIV-related stigma," said Virginia Bond, Ph.D., of the London School of Hygiene & Tropical Medicine at a presentation during the HIV/AIDS and Food and Nutrition Security Meeting held in Durban last April. Her findings were drawn from research on stigma in Zambia.

Dr. Bond noted that in adults, the cause of the condition is most often seen as the individual's fault, and HIV, in particular, is seen as being the consequence of immoral behaviour. Frequently, HIV-related stigma is compounded, because affected individuals often come from already stigmatised groups (such as drug users, sex workers, the poor and disenfranchised, etc...) (more on Dr. Bond's presentation below).

Additionally, the stigmatised often blame themselves. A recent USAID paper notes that: "the stigmatised often accept the norms and values that label them as having negative differences. As a result, stigmatised individuals or groups may accept that they "deserve" to be treated poorly and unequally, making resistance to stigma and resulting discrimination even more difficult." This is often called "internalised stigma" (see Impacts of Stigma below).

Some of the most complete and current data on the subject come from a four-country study, in which Dr. Bond participated, on HIV related stigma and resulting discrimination in Zambia Tanzania & Ethiopia (2001–2003), and, Vietnam (2002–2004). The study was led by International Center for Research on Women (ICRW), Washington (see Resources), which has recently published a report synthesizing the findings online (Ogden and Nyblade).

In the ICRW report, despite differences in the social, economic, political, historical, and geographic contexts and in the very different experience of the HIV/AIDS epidemic within each country, the fundamental similarities in relation to HIV and AIDS related stigma and discrimination across the four countries were striking.

"What we find looking across contexts," write Ogden and Nyblade, "are commonalities in what causes stigma, the forms in which stigma is expressed, and the consequences of stigma...Variations that stem from differences in language, culture, and epidemic history are largely of nuance and degree rather than substance."

While there are many excellent reports on stigma, we've chosen to focus on this one, because of its focus on the similarities of stigma across various contexts. Most of the following section is directly summarised from the ICRW report, augmented here and there with a few other materials.

The root causes of stigma

1) The role of knowledge about HIV and AIDS and fear surrounding it

Across all four countries, people were still afraid that HIV can be transmitted through ordinary, daily interactions with people living with HIV and AIDS. Even though the particulars varied in each setting, people are preoccupied with unlikely modes of transmission. Usually, the fear is that HIV could be transmitted by mosquitoes or through non-invasive contact with blood, sweat, diarrhea or other bodily fluids, but sometimes the "what if scenarios" were quite far-fetched. For example, in Ethiopia, there was a fear that raw chicken eggs could transmit the virus, if hens came upon and pecked at used condoms.

Fear of transmission leads directly to stigma such as the avoidance or isolation of persons living with HIV and AIDS. Sometimes even healthcare workers shared this fear of patients—even though they know how HIV is transmitted, they lacked confidence about how HIV is *not* transmitted.

Ogden and Nyblade believe that the fear of transmission from casual transmission, and the various "what if scenarios" are the result of 1) the lack of specific, in-depth information about HIV transmission, 2) fear-based public messaging, and 3) the evolving nature of knowledge about HIV and AIDS.

Even though people know that HIV is spread through bodily fluids, this is vague and leaves room for people to extend what they know about other infections to HIV. "Without a greater depth of knowledge about how HIV is, and is not, transmitted, and direct explanations from trustworthy sources as to why HIV cannot be transmitted in the same way as TB, diarrhoea, or malaria, doubt will remain that it can be," write Ogden and Nyblade. "Given the consequences of contracting HIV, as long as even the slightest doubt remains about the possibility of transmission through everyday contact, the choice will be made to, where possible, avoid contact with people with HIV."

This fear of HIV transmission is amplified when public health campaigns focus primarily on negative images of sick and dying people with HIV and AIDS, as well as by sensationalised media reports about risk-taking behaviour or infected persons purposefully exposing others.

Finally, since HIV disease is a relatively recent phenomenon and knowledge about it is continually evolving, people worry that the current information about transmission might be wrong. Media reports about rare routes of transmission invariably reinforce the view that "expert" information is wrong.

2) The role of values, norms, and moral judgment

The link between stigma and morality is an ancient one and is apparent in the original definition of the word, which meant a mark or physical sign of something bad. For example, in the Bible, stigma goes back as far as Genesis, when God "marked" Cain after he murdered his brother Abel. Most traditions have similar beliefs that illness is the result of some transgression or sin or social evil. This leads people to see the ill as deserving of their plight.

Departing somewhat from the ICRW stigma report, its easy to blame religion for stigma — but the tendency to stigmatise the ill is

so universal, it likely predates the development of faith and value systems. Several studies have postulated that stigma evolved as a mechanism to avoid disease — triggering specific emotions such as disgust or fear when encountering the ill, forming negative attitudes about them and behaviours such as avoidance or discrimination (Park, Faulkner and Schaller; Kurzban & Leary; Neuberg, Smith and Asher). Stigmatisation has been documented in non-human primates as well. For example, Jane Goodall observed that chimpanzees avoided other chimpanzees who had lost the use of some of their limbs as the result of polio.

“Whatever its roots, the tendency to associate illness with moral impropriety is a central contributing factor to HIV and AIDS-related stigma,” write Ogden and Nyblade. “This stigma is exacerbated by the seriousness of the illness, its mysterious nature, and its association with behaviours that are either illegal or socially sensitive (e.g., sex, prostitution, and drug use). Also relevant is the perception that HIV infection is the product of personal choice: that one *chooses* to engage in “bad” behaviours that put one at risk and so it is “one’s own fault” if HIV infection ensues.”

In addition, there was a tendency across contexts to create a continuum between guilt and innocence related to “how” someone got infected. On the innocent side of the continuum are children, followed by health workers infected by treating their patients; while on the guilty end are the drug users and sex workers. Given that sex work and drug use are already socially unacceptable, the “guilty” infected are doubly stigmatised.

An HIV-infected woman could be near either end of the continuum, depending upon whether she is believed to have become infected while faithful to her husband (innocent) or otherwise (guilty). The role of gender was another key similarity across all contexts. “Women generally bear the strongest brunt of this type of stigma,” write Ogden and Nyblade. “The reason underlying this seems to be that women in all of these settings are expected to uphold the moral traditions of their societies. HIV is regarded as evidence that they have failed to fulfil this important social function.”

Expressions and forms of stigma

Ogden and Nyblade divide stigma into four loosely defined groups: physical, social, verbal and institutional.

Social stigma Isolated from community Voyeurism: any interest may be morbid curiosity or mockery rather than genuine concern Loss of social role/identity: social “death”, loss of standing and respect	Physical stigma Isolated, shunned, abandoned Separate living space, eating utensils Violence
Verbal stigma Gossip, taunting, scolding Labelling: in Africa: “moving skeleton,” “walking corpse,” and “keys to the mortuary.” In Vietnam: “social evils,” and “scum of society.”	Institutionalised stigma Barred from jobs, scholarships, visas Denial of health services Police harassment (eg of sex workers, HIV-positive activists in China, outreach workers in India)

The consequences and impact of stigma

As mentioned earlier, people living with HIV and AIDS frequently lose their jobs/livelihoods as well as opportunities for marriage and childbearing. And where no HIV programmes exist, they may also receive poorer care from the health sector.

In the ICRW report, a nurse in Ethiopia explained:

“The wards don’t have gloves, so how would you expect a nurse to go and attend to a HIV/AIDS patient? That’s why you can find a patient lying in a pool of diarrhoea for many hours.” And a health worker in Vietnam admitted: *“We absolutely never inject [HIV] infected persons. We just give them medicines.... We also treat small children here, so we give [HIV] infected people no injections at all.”*

In most resource-constrained settings, people with HIV and AIDS frequently have to turn to their families for care. But even though most HIV-infected people receive loving treatment from their families, there are occasions when family members refuse to provide care, “whether out of fear of transmission, out of anger, judgment and moral condemnation, fear of experiencing the stigma of others, or a combination of these factors,” write Ogden and Nyblade.

Poverty compounds the impact of such stigma because it limits the amount of care a given family is able to provide, especially when someone is seen as “a hopeless case” (see Poverty below).

Internalised stigma

It should only be expected that people with HIV and AIDS would also start to stigmatise themselves, since they share the same belief systems as the rest of the community and are constantly subjected to the cruel, thoughtless, and hurtful actions of others.

The ICRW report notes “the near universality of [internalised stigma] is indicated in our research findings across these diverse settings, but also by the myriad contributions worldwide to a recent listserve discussion on the issue (see <http://archives.hst.org.za/stigma-aids>).”

Some of the commonly observed forms of internalised stigma in the ICRW research included loss of hope, feelings of worthlessness (even suicidal feelings) and inferiority, and belief that they no longer had a future. Many people with HIV drop out of school or give up on long term plans. People internalising stigma also isolate themselves from society, friends and family.

Secondary stigma

Friends, families, children and caregivers of people living with HIV and AIDS are also stigmatised “by association.” For example, parents are blamed for their child’s “bad” behaviour, which led to his or her becoming HIV infected. Consequently, loss of reputation and livelihood occur due to secondary stigma as well.

Consequences of stigma for HIV and AIDS treatment and prevention efforts

Impact on treatment

According to Ogden and Nyblade “it is clear in all sites that the presence of stigma and the fear of experiencing its effects has a profound impact on the ability and willingness of people to access and utilize the services that are available for controlling the further development of the epidemic. In all sites, for example, we found that HIV and AIDS-related stigma inhibits people from seeking treatment for infections that are closely associated with HIV, such as TB, skin

rashes, and certain types of diarrhoea, whether or not they have tested positive for HIV.” Another report by Dr. Bond describes this latter phenomenon in more detail (see link).

Impact on prevention

Stigma affects prevention in a variety of ways. For example, it allows the uninfected to deny their own risk of infection (and perhaps not take adequate precautions to protect themselves). “Even where there is a fairly high sense of vulnerability to HIV,” write Ogden and Nyblade “stigma seems to interfere with the ability of individuals or couples to discuss condom use and use condoms regularly and correctly. Condoms themselves have acquired a strong stigma through their close association with HIV in the press and health promotion campaigns. Thus, the mere suggestion of using a condom in any given sexual encounter can be interpreted as tantamount to admitting one’s own infidelity, or that one suspects one’s partner has not been faithful.”

Impact on testing and disclosure

HIV and AIDS-related stigma also discourages people to get tested or when they do get tested, from returning for their test results. People especially avoid clinics known to be HIV testing sites. People also commonly reported that they believed that the fact that they had been tested would eventually reach the rest of the community.

A related consequence of stigma is that it discourages people from disclosing a positive test result to others. According to the ICRW report, “people live with the knowledge that they have HIV for years without telling even their most intimate partners for fear of stigma and its consequences, which can include physical violence and/or abandonment. As was the case for one woman, who continued to have sexual relations with her husband without condoms, and who had another child without availing herself of mother-to-child transmission prevention services, this can mean that the necessary measures are not taken to prevent the further transmission of the virus.”

Similar to this ICRW finding, operational research conducted on the PMTCT programme in South Africa, as described in a recent HATIP suggests that fear of disclosure also affects the decisions that mothers with HIV make about infant feeding. While both exclusive formula feeding and exclusive breastfeeding are considered valid options for mothers with HIV, many find it difficult to use formula or avoid mixed feeding – the cultural norm – because of the risk that this might reveal their status to others. As a result, infants are put at a higher risk of exposure to the virus.

Conclusions of the ICRW report

Ogden and Nyblade conclude that HIV and AIDS-related stigma operates “as a key driver of the epidemic” and that “combating stigma is a matter of utmost urgency for all HIV programs to address. However, “to date, efforts to reduce HIV and AIDS-related stigma and discrimination have not adequately matched the magnitude and apparent universality of the problem.” One explanation is that the expression and experience of HIV and AIDS related stigma was seen as too diverse to tackle in a “programmatically useful way.” The four-country study findings suggest that the “differences are largely superficial and need not stand in the way of developing programs and interventions.”

The ICRW report then makes several recommendations about how to tackle stigma (discussed later in this article).

“The wider context? – Other things are happening” – Virginia Bond

But before discussing interventions intended to reduce stigma and/or mitigate its impact, it’s important to note other factors which can exacerbate stigma, or rather, make it more difficult for the stigmatised to cope with the impact of stigma and discrimination.

“Stigma should not be isolated from other social, political, economic processes and phenomena; stigma occurs within these,” Dr. Bond noted at her presentation at the Food Security Conference in Durban. In particular, she focused on the intersection of stigma and poverty – which is the context for stigma in Zambia. Her complete presentation can be seen online at <http://www.ifpri.org/events/conferences/2005/durban/ppt/bondP.P.ppt>.

“Zambian society is staggering under weight of economic hardship, the impact of HIV, poor education and health services, disillusionment with government, and inequality” said Dr. Bond.

Seeing people with HIV and AIDS as an economic burden to the family may be considered stigma, but in this context, it can be a very real problem.

“When someone is sick and the family is poor, there are talks over what to eat, small things which need money. This brings problems in the family. Where will the family get the money?” [a man living with HIV, in rural Zambia]

People with HIV and AIDS are not always able to contribute to household living when sick, and may soak up the family’s limited money, energy, time, space. As a result, families sell assets, sex, borrow money, even steal – to meet the basic needs of patient (i.e. to pay for treatment, food, soap and water). Such activities – especially sex work – increase the vulnerability of other family members to HIV.

Poverty reduces the ability of families affected by HIV/AIDS to cope, increasing the stigma that the person with HIV experiences within the context of the family – sometimes even leading to neglect.

“Some household members say it is a burden and some of them are the people killing their own children very fast. They leave them to die slowly, painfully because they insult them and say bad names. They stop buying medicine, saying “we can’t manage”. If you [the patient] want a type of food, they say “you have to eat what we have because we have no money. We never costed you but you costed all these, all the problems you have brought into this house”. Others are shunned very much” [nutritionist, urban Zambia]

In part, the stigmatisation of people with HIV may be a collective result of the desire of families to avoid being stigmatised for taking the uncomfortable decision that the sick are too much of a financial, practical and social burden.

“There are some people even when they were OK, they were so useless to the family, and when such people are found in this situation [with HIV & AIDS] they are considered a burden.” [headmaster, urban Zambia]

According to Bond, “one strategy to reduce stigma and discrimination related to HIV and AIDS in the context of poverty is to alleviate household stress by provide services, better services, special services and support.”

Approaches to mitigate or combat HIV and AIDS related stigma

A number of strategies have been proposed to combat stigma. Some researchers have proposed tackling stigma directly with an educational approach targeted at the root causes of stigma. Bond's presentation illustrates the importance of addressing the social context in which stigma occurs.

The ICRW report authors agree that structural issues, such as poverty, which contribute to stigma and discrimination and that perpetuate social inequalities need to be addressed, but they also believe that it is possible to affect change by targeting individuals. "We... call for an approach to intervention that starts with the conviction that individual attitudes can and do make a difference, and that long-term and far-reaching stigma reduction can start with individuals," write Ogden and Nyblade.

Information and educational programmes addressing stigma in the individual have had only limited success in the past, so the ICRW report recommends a more in depth and interactive approach, "moderated by a knowledgeable and trusted facilitator... [and] ensuring that people have a deep enough understanding of what HIV is and how it is transmitted so that they are equipped to make correct assessments of actual HIV risk in any given life situation they encounter."

They also call for tackling values, norms, and moral judgments that contribute to stigma. Here they call for the use of non-value laden language in describing behaviours with a high risk of transmission. Even so, it is questionable how much difference such a measure will make, without engaging faith-based organisations, key institutions and opinion leaders that help shape and reinforce societies' values.

Finally, they call for involving people with HIV and AIDS as integral members of all programmes.

Palliative care

Another approach that incorporates many of these principles is palliative care. Although often associated with end-of-life care or home-based, palliative care is actually a "continuum of care" that begins from the time a person is diagnosed as HIV positive. Palliative care includes psychosocial and spiritual support to help people with HIV/AIDS and their families cope with stigma and illness. It also includes more emphasis on comfort for people living with HIV/AIDS, relieving or lessening symptoms for people suffering from AIDS.

A well-designed and implemented palliative care programme can include a complete package of services adapted to deal with each social context of stigma, and lessen the burden of caring for a person with HIV in the community.

Other forms of support for people living with HIV and AIDS

Similarly, disability grants, food support and income generation may not directly deal with stigma, but they can help people with HIV cope and reduce vulnerability to discrimination.

Finally, effective antiretroviral therapy may reduce stigma by restoring people living with HIV to health — returning the "keys to the mortuary."

Resources, toolkits and tools to measure the effectiveness of interventions

Understanding and challenging HIV stigma: toolkit for action

Growing out of ICRWs four-country study, this Toolkit provides "evidence-based guidance for launching stigma-reduction activities with key groups, including religious and political leaders, people living with HIV and AIDS, and community members."

The toolkit contains more than 125 exercises and was developed through interactive, participatory workshops in all three African countries, with a total of 75 participants from 50 NGOs. The toolkit since has also been adapted for use in Vietnam. The first edition was developed in Africa and is available in English and Kiswahili. An adaptation of the first edition for the Asian context is available in both English and Vietnamese.

<http://www.changeproject.org/technical/hivaids/stigma.html>

The International Center for Research on Women (ICRW)

is a private, nonprofit organization that focuses primarily on women in developing and transition countries. In addition to the Four-Country Report, many of the individual country reports on stigma, and related papers can be found on their website, see

http://www.icrw.org/html/projects/projects_hivaids.htm

Reducing stigma and discrimination related to HIV and AIDS: training for health care workers

The training course guides health workers through an investigation of the root causes of stigma and discrimination while helping them to understand their own attitudes about HIV, AIDS, and individuals affected by these conditions and how these attitudes might affect the care they offer. The training also provides a review of clients' rights in receiving health care services, information about the use of standard precautions and proper infection prevention techniques to help minimize the risk of occupational exposure to HIV, and guidance in developing action plans to help the participants put what they have learned into practice at their service settings. The training employs participatory education techniques—such as role-plays, small- and large-group discussions, and brainstorming.

<http://www.engenderhealth.org/res/offc/hiv/stigma/>

The Siyam'kela Project: measuring HIV/AIDS related stigma

Siyam'kela (SI-YUH-MU-GE-LAR) is an African word from the Nguni language. Translated it means "We Are Accepting" expressing a collective embracing, understanding and acceptance of a challenge at a particular time. The word has thus been interpreted as "Together We Stand" for this project.

Siyam'kela has been designed to explore HIV-related stigma and is a joint project of the POLICY Project, South Africa; The Centre for the Study of AIDS, University of Pretoria; The United States Agency for International Development (USAID); and The Chief Directorate: HIV/AIDS & TB, Department of Health.

The project is an excellent resource with research papers, stigma mitigation guidelines for faith-based organisations and the workplace, best practices, as well as a tool programmes can use to measure the progress of HIV/AIDS stigma mitigation.

<http://www.csa.za.org/article/articleview/228/1/6/>

Voices for Equality and Dignity

Qualitative research on stigma and discrimination issues as they affect PLWHA in Malawi

See

http://hivaidsclearinghouse.unesco.org/ev_en.php?ID=2700_201&ID2=DO_TOPIC

Measuring HIV stigma: results of a field test in Tanzania

According to the USAID abstract: The demand for stigma indicators has continued to increase, particularly from USAID global missions and their partner agencies. In response to this need, USAID funded this first step of field-testing and validation of an initial set of stigma indicators at one site in Tanzania, based on selected stigma indicators from the Blue Book (USAID Expanded Response Guide to Core Indicators for Monitoring and Reporting on HIV/AIDS Programs), and the 2004 S&DIWG workshop. The results of this effort are found in this working report.

http://www.synergyaids.com/documents/StigmaIndicatorsReportFinal_JuneEdited.pdf

Faith-based resources and articles

<http://news.adventist.org/data/2005/09/1128950532/index.html.en>

<http://medicine.plosjournals.org/perlserv/?request=get-document&doi=10.1371/journal.pmed.0020247>

once again see <http://www.csa.za.org/filemanager/fileview/73/>

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(see online

http://www.icrw.org/docs/2005_report_stigma_synthesis.pdf)

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about HATiP

A regular electronic newsletter for health care workers and community-based organisations on HIV treatment in resource-limited settings.

The newsletter is edited by Theo Smart (Cape Town) and Keith Alcorn, NAM's Senior Editor (London).

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