2
2008
Exchange
on HIV/AIDS, sexuality and gender

Facing HIV-related stigma in Ukraine p. 10

Community Conversations in Ethiopia p. 13

Challenging stigma

Last June, Anand Grover from India, lawyer and director of the HIV/AIDS Unit of the Lawyer's Collective, was appointed UN Special Rapporteur on the Right to Health, an important position. One of his most famous cases was the lawsuit against the imprisonment of Dominic D'Souza, who had been detained for over two months in 1989 for the sole reason of being HIV positive. "I live in the hope of a world that will be, if not free of disease, free of fear and discrimination", D'Souza said after his release. He became a fervent HIV activist but unfortunately died from AIDS three years later.

This issue of *Exchange* magazine is on HIV-related stigma, how it affects the health and well-being of people living with HIV and what can be done to reduce it. This issue highlights the role that people living with HIV, and the networks and organizations lead by them, can play in diminishing stigmatizing attitudes, discriminatory actions and harmful policies. After an overview article summarizing the main elements of an anti-stigma approach, examples follow of strategies taken by networks of PLWH in Ukraine, South Africa and India, as well as an HIV/AIDS programme in Ethiopia.

This special issue on stigma reduction is the last one I have published as an editor. My successor, Eliezer Wangulu from Kenya, will take over from now on. I wish him good luck and express my hope that he will enjoy this assignment as much as I did!

Nel van Beelen
Managing editor

Reducing HIV-related stigma – components of an effective approach

In ancient times, a 'stigma' was the mark made in the flesh (burning/cutting) of a slave or criminal. Since the Canadian sociologist Goffman in 1963 defined stigma as "an attribute that is deeply discrediting within a particular social interaction" and "a deviation from the attributes considered normal and acceptable by society," many other definitions have been proposed, bringing attention to different aspects and causes of stigma. This illustrates the complex interactions and factors leading to stigmatization. Stigma is not something especially new, in the field of HIV. People have always been stigmatized: psychiatric patients, leprosy patients, people with alternative sexual behaviours, people with cancer, people with tuberculosis, people with physical or mental disabilities, etc. The negative impact of HIV-related stigma has been described many times. People living with HIV (PLWH) have been forced from their homes, dismissed by their employers, rejected by their families and friends, and refused access to some basic services.

Stigma not only affects the quality of life of PLWH and their access to quality treatment and care, but also fuels an invisible internal fire, causing further spread of the virus. When people know that they will encounter stigma and discrimination, they will be less motivated to go for testing and disclose their HIV status. A study in South Africa showed the association between fear of stigma and non-disclosure to sexual partners. It also showed that non-disclosure is closely related to behaviours that support the transmission of HIV.[1] Often, due to stigma, the delay in time between knowing one's HIV-positive status and the time of disclosure (to sexual partners) can be months up to years, while during this time episode unprotected sex is not unusual.

To give an impression of the complexity of HIV-related stigma, some issues will be mentioned in this article, not pretending to present an overall overview or framework.

- HIV stigma is related to fear in communities, fear of infection with the virus, fear of death, and in some cases, fear of being punished by God. Religious or cultural norms can fuel HIV-related stigma. Also cultural issues related to gender might blame women for bringing HIV in the family, even when it is more likely that they were infected by their husbands.

- Stigma can be divided into internal stigma, as perceived by PLWH, or as external or enacted stigma. This last type is linked to the cascade of different possible appearances of stigma: stigmatization in itself (leading to isolation, etc.) which can proceed in discrimination (for instance less access of PLWH to health facilities) and subsequently to violence against PLWH.
- A specific issue is the stigmatization and discrimination of PLWH by health-care workers. This might be partly due to secondary stigmatization, which means that people who are often in close contact with PLWH because of their profession or because of being a family member are also stigmatized by society, although they are not HIV positive. As a reaction, health-care workers stigmatize their patients. Also the fear of contamination will play a role.
- Another important aspect to be mentioned is the spread out of HIV-related stigma to one of the most frequent opportunistic infections, which is tuberculosis. Many people are already confronted with the first signs of HIV-related stigmatization after coughing for some time.
- Also, HIV is linked to groups encountering pre-existing stigma such as female sex workers or intravenous drug users. These groups might be seen in societies as being responsible for the occurrence of HIV. Subsequently, all PLWH are seen as members of one of these groups.
- Finally, it should be mentioned that positive discrimination of PLWH in poor communities, e.g., by reserving all antibiotics available in a health centre exclusively for use by PLWH, excluding other community members, might be a sensitive trigger for stigmatization of PLWH. This links stigmatization to the issue of strengthening health systems for the community as a whole in instead of setting up good but isolated vertical programmes.

This issue

Ineffective stigma-reduction approaches

Given the deeply rooted aspects of stigma described above, it will be clear that a 'one-liner-approach-project' will not be of much use in the fight against HIV-related stigma. Unfortunately, well designed studies to evaluate the long-term effect of different approaches in stigma reduction are hardly available. Available evidence (usually based on an analysis of best practice case studies) indicates that broad-based strategies taking into account the different aspects and different levels of the fight against the HIV pandemic, seem to be crucial in creating real impact in the reduction of stigma. This also becomes clear from best practice studies collected by UNAIDS.[2] The employment of broad-based strategies is closely linked to the 'Towards Universal Access by 2010' initiative of UNAIDS and WHO, which is aimed at strengthening the main pillars of the fight against HIV and AIDS: prevention, treatment, care and support. It is inefficient to address one aspect (e.g., stigma and discrimination) without paying attention to the other relevant aspects.

> Stigma not only affects the quality of life of PLWH and their access to quality treatment and care, but also fuels an invisible internal fire, causing further spread of the virus

The following examples illustrate the weakness of isolated approaches. Collecting cases of discrimination against PLWH and bringing them to court without bringing the community in contact with PLWH might give justice to the victims of discrimination, but will not lead to the desired effect. The community might isolate these persons even more than before going to court. A mass anti-stigma campaign without community leaders involved and backing-up such an event will hardly contribute to stigma reduction. Encouraging HIV-positive people to disclose their status without having access to ARV's will appear to be not very efficient, although there is also evidence that in societies where people disclose their status more frequently, PLWH have better access to essential resources and can even take positive leadership roles in communities.[3]

Mainstreaming stigma reduction

The central approach in fighting HIV-related stigma seems to be 'mainstreaming' of stigma-reduction strategies in projects, programmes and policies. Translated to daily practice this means that it is important to collaborate with all stakeholders involved at different levels, from national (e.g., CCM) to grassroot level. The idea is to ensure that the entire spectrum – from prevention to support – is covered.

It is paramount to involve PLWH, the main stakeholders in this process. If essential

aspects of the spectrum are not covered by the available stakeholders in the project area, a specific lobby and advocacy strategy can be put in place. Examples can be how to guarantee access to treatment, or how to include education about stigma in the curriculum at secondary schools. Contact with specific actors outside the project region can be made for assistance where there are gaps in the prevention to care continuum.

After collaboration has been ensured, a stigma reduction strategy could be formulated as part of an integrated work plan for the specific project area. In each existing project or programme, stigma reduction should be mainstreamed. For example, a home-based care project can have a component of family counselling; PLWH and community leaders can be actively involved in a mass education campaign, or health staff can be offered a skills-building course in order for them to be more confident in contacts with patients with HIV.

> Available evidence indicates that broad-based strategies taking into account the different aspects and different levels of the fight against HIV, seem to be crucial in creating real impact in the reduction of stigma

Components of an effective approach

Some general aspects that seem to be of value in stigma-reduction activities are:

- *Information* – Giving information about how HIV is transmitted, but also how it is not transmitted is a basic requirement for all types of interventions. Giving the right information will diminish anxiety and fear. However, isolated mass education campaigns seem to be of little use in interventions against stigma, although they have a place in creating a more open environment to discuss stigma in the community.
- *Skills* – Teaching people skills on how to make and remain in contact with PLWH is a second step which has been proven (at least in the short term) to be more effective compared to giving information alone. Also teaching skills to PLWH on how to cope with stigma and discrimination seems to be important.
- *Empowerment* – Surprisingly, a study in Uganda showed that in an area where nearly every household had one HIV-infected member, stigmatization was very high. Therefore, empowering PLWH and their families that are suffering because of internal or external stigma, and rebuilding their self-esteem, can be of use.
- *Participative interaction* – Also bringing non-infected people in contact with PLWH has proven to be of additional value. E.g. a visit of a person with HIV to a meeting could have an impact on the attitude of the people in the meeting towards PLWH.
- *Home-based care* – HBC might be a good setting to bring PLWH and non-infected people for a longer time together. HBC is giving non-infected people the experience (and shows this to the community) that working in close contact with PLWH is not contaminating them. It can also give a feeling of a common responsibility for the problem of HIV in the community.
- *Medical care* – Good medical treatment and care of people with AIDS, leading to an improved clinical condition demonstrates to lead to greater acceptance or even re-acceptance of PLWH in their communities compared to non-treated PLWH. Also low-threshold access to VCT centres equipped with well trained counsellors is important.
- *Disconnection* – General anti-stigma messages should be disconnected from already pre-existing stigma. E.g. do not link your general message to specific groups as female sex workers. When you make this linkage you have an extra battle to fight: pre-existing stigma. That task will appear to be too heavy and your project might easily fail. However, this does not mean excluding any group suffering from pre-existing stigma from any support given to HIV-positive people. These groups might need a more specific targeted approach.
- *Leadership* – Involvement of (religious) leaders in prevention activities might be very helpful in getting the community involved in the conversation about HIV and AIDS. Disclosure of an HIV-positive status by a prominent church leader in Uganda had a tremendous spin-off.
- *Anti-discrimination policy* – Having anti-discrimination-policies in place (and functional) might be helpful, at least, in having a framework to refer to. It might probably not stop stigmatization itself. Also, such a policy should be embedded in a broader context: giving information, involving PLWH, building relationships, etc.

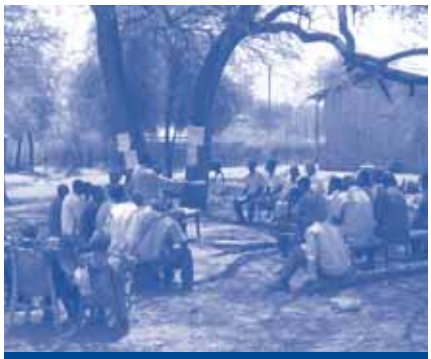

Photo: Rijk van Ginkel

Community Conversation organized by the Ethiopian Red Cross on how to reduce stigma, Arba Minch, Southwest Ethiopia

Measuring stigma and its decline

Many indicators have been developed to investigate different levels and aspects of HIV-related stigma. A lot of them have been summarized in a publication of the International Federation of the Red Cross and Red Crescent Societies (IFRC), GNP+ and UNAIDS.[4] They can be used in epidemiological surveys (e.g. the percent of respondents expressing accepting attitudes towards PLWH), but can also be used to measure the existence and decrease of stigma as the result of concerted actions or a single project or programme.[5]

Examples of indicators

Measuring	Indicator
Acceptance	The percent of respondents expressing accepting attitudes towards PLWH
Avoidance	Number of PLWH who report cases of others who distance themselves from them physically
Rejection	Number of people who feel that PLWH would not be welcomed in their homes
Moral judgment	Number of people who use the concept of blame to inform their response to PLWH
Abuse	Number of PLWH who have been physically abused as a result of their HIV status
Pre-existing stigma	Number of cases of discrimination against MSM in the public/private health systems.
Internal stigma: self-exclusion	Number of PLWH who choose not to apply for a job because of their fear of being exposed as HIV positive.
Stigmatization in health care	Mechanisms in place to identify PLWH in the health system / Number of health centres with anti-discrimination workplace policies
Stigmatization by media	Number of media reports discussing the rights of PLWH

There are indicators specifically for health-care settings and for measuring stigmatizing behaviour in the media. There are also indicators taking into account pre-existing stigma concerning specific groups such as men having sex with men (MSM) and indicators measuring internal stigma (see the side-box for some examples). It is always important to be sure that observed or felt stigmatization is due to HIV-positive status, as every human being encounters negative reactions from other people for whatever reason once in a while.

> The central approach in fighting HIV-related stigma seems to be 'mainstreaming' of stigma-reduction strategies in projects, programmes and policies

Being confronted with many possible indicators linked to stigma, it is crucial in the selection and use of these indicators to be totally clear what is the main purpose of measuring these indicators and which ones are most useful in a specific context. The most suitable indicators should be defined before starting any stigma-related activity and these indicators should be evaluated after the end of the project. Also within general HIV/AIDS-related activities (e.g. HBC or peer education) one or two indicators linked to the impact of the project on stigma can be formulated in order to monitor the 'mainstreamed' component of stigma reduction within the project. Without these well performed evaluations, we will never succeed in developing a real evidence-based strategy to tackle HIV-related stigma.

HIV-related stigma is often deeply embedded in societies. The impact on PLWH is often dramatic, but also the effect on the further spread of the virus. Due to the multiple and interlinked interactions concerning stigma, a multi-sectoral approach seems to be the most effective in the long term (linked to the Towards Universal Access by 2010 framework). This means: working together within a specific (project) area, with as much as possible stakeholders involved in any aspect of the fight against HIV in an effort to mainstream stigma reduction in all policies, strategies, projects and programmes. As stated before, the most important stakeholders in this regard are the people that are most affected by stigma and discrimination: men and women living with HIV and AIDS.

Increasingly, networks and organizations of PLWH have taken up the issue and started lobbying governments, educating the public, and training and empowering other PLWH on how to deal with stigma. Strategies they have come up with are organizing awareness-raising events; sharing personal stories in the media; monitoring of stigmatizing language in newspapers; involving religious and community leaders as well as famous persons; exposing government officials and the public to PLWH and their stories, etc. Three examples of the work of networks of PLWH in this regard, in India, South Africa and Ukraine, can be found in this issue. ■

Rijk van Ginkel
HIV/AIDS advisor, the Netherlands Red Cross Society

Correspondence:
Leeghwaterplein 27
PO Box 28120
2502 KC The Hague, The Netherlands
Tel: +31 70 4455 791
E-mail: RvanGinkel@redcross.nl
Web: http://www.redcross.nl

1. L. Simbavi, S. Kalichman, A. Strebel et al, Disclosure of HIV status to sex partners and sexual risk behaviors among HIV positive men and women, Cape Town, South Africa. *Sexually Transmitted Infections*, 2007; 83: 29-34
2. *HIV-related stigma, discrimination and human rights violations: Case studies of successful programmes*. UNAIDS Best Practice Collection, 2005: http://data.unaids.org/publications/irc-pub06/JC999-HumRightsViol_en.pdf
3. A. Norman, M. Chopra & S. Kadiyala, Factors related to HIV disclosure in 2 South African communities. *American Journal of Public Health*, 2007; 97 (10): 1775-1781
4. *Developing indicators for measuring stigma and discrimination and the impact of programmes to reduce it: Summary of projects and research to date*. IFRC, GNP+ & UNAIDS, 2004: http://www.aids.md/files/library/2004/562/developing-indicators-measure-stigma-discrimination-program-impact.pdf
5. *Understanding and Challenging HIV Stigma: Toolkit for Action* (Revised Edition). International HIV/AIDS Alliance, ICRW & AED, 2007: http://www.aidsalliance.org/custom_asp/publications/view.asp?publication_id=255&language=en