CHAPTER FOUR

Communicating HIV/AIDS

By Colleen Lowe Morna and David Lush

Objectives

The objectives of this chapter are to:

- Analyse the shortcomings of HIV/AIDS campaigns from a gender perspective;
- Explore how reporting has helped to perpetuate prejudice, discrimination and blatant myths about HIV/AIDS and in particular to lay the blame and many of the burdens of the epidemic on women; and
- Develop new approaches to training media workers and communicators on integrating gender into advocacy and coverage on HIV/AIDS.

Participant in a GL workshop on gender violence in South Africa's Northwest province.

Introduction

Why is it that despite all the information now available on HIV/AIDS, behaviour has been so slow to change? The traditional theory of communication is that if sufficient information is provided, this will eventually be turned into knowledge; that if knowledge is applied, this will eventually affect attitudes and that if attitudes change, these will ultimately alter behaviour.

The aim of any social campaign is to change attitudes and behaviour. In the case of HIV/AIDS, where we have precise information on the way the virus is transmitted, and its devastating consequences, you would imagine that behaviour change would be quick to follow. The reality, as we know, has been different. In many countries in Southern Africa, one of the worst affected regions, the levels of unsafe sex and multiple partners continue to be extremely high. Why is this so?

There are several possible explanations. The kind of message being sent out from the highest political level about the pandemic is a critical factor. HIV/AIDS is, in the end, about the two things that in Africa we find most difficult to talk about: sex and death. It is no coincidence that the countries that are succeeding in rolling back the tide are those that have openly confronted these most sensitive of life's realities. That calls for unprecedented leadership.

Leadership in all our countries has strong gender dimensions. All the heads of state and the vast majority of decision-makers are men. The typical response of men to a disease that threatens their lifestyle and their notions of masculinity has been to deny its existence and gravity, and to try to shift blame elsewhere.

Many countries in the region have lost years and thousands of lives in the fight against the pandemic through long periods of denial or of sending out confusing messages.

South Africa is an example of a country that is relatively well endowed with human and financial resources that could be used to address the pandemic. The controversial stance taken by President Thabo Mbeki however, has caused incalculable damage. While his theorizing on the matter may be warranted in academic circles, his stance is a good example of how, in communication terms, simple, clear messages, rather than academic theorizing, are needed in a crisis.

This, indeed, is what President Yoweri Museveni of Uganda, and President Festus Mogae of Botswana have grasped. Museveni took the line in Uganda that when a snake is in your home, you do not wait to ask where it has come from. You get rid of it and then worry about its origins. Museveni has also taken a strong and consistent position on promoting gender equality. Uganda succeeded in lowering HIV prevalence from 21 percent in 1991 to six percent in 2001.

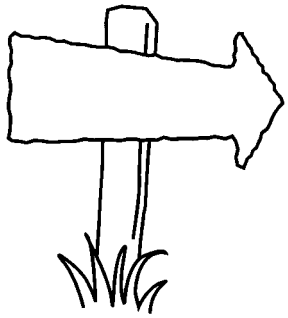
Researchers delving into the reasons for this success point out that in fact condoms have had very little to do with it, and that the success lay much more in real behaviour change. A recent Harvard study in Uganda revealed a drastic reduction in multiple sexual partnering, from a reported rate of 18 percent in 1989, to eight percent in 1995 and descending to two percent in 2002 (Mail and Guardian, 4-10 October 2002). It is fair to assume that most of this change has come from men.

Many campaigns in the region continue to give the impression that women are to blame for the spread of HIV/AIDS or that they need to take action, when in fact the reality is that many women are faithful but get infected by male partners having multiple relationships. These women often do not have the power to negotiate safer sex. Many women in poor countries do not have access to information about safer sex in the first place.

The media has often contributed to the hype and hysteria, as well as sexist stereotypes surrounding HIV/AIDS, rather than promoting a holistic, human rights-based approach. It has encouraged the view that HIV/AIDS is a disease of sinners and prostitutes; that women are to blame for contracting the virus, that they are responsible for the growing misery of AIDS orphans.

The media representation of men in relation to the epidemic has been similarly biased and prejudiced, but often the male gender issues have been subsumed under aspects of race, class, and cultural prejudice. For men, blatant gender discriminations around the AIDS epidemic are commonly seen as aspects of these other biases.

See Chapter Nine: The Role of Men.



Because of the gravity of HIV/AIDS in our region, many media training institutions are offering courses on the pandemic and/or seeking to "mainstream" it in their regular course offerings. Communicators more broadly – in government, NGOs and at community level – are also seeking to understand how best to structure and convey messages on HIV/AIDS that will lead to the desired behaviour change. The massive campaigns that are being conducted around HIV/AIDS across the region offer an opportunity not just to arrest the pandemic, but to talk about what underpins it. Gender equality needs to be at the heart of that discussion.

Opening the debate

Exercise one

A good way to start this session is through asking participants in pairs or in small groups to draw from their own experience of HIV/AIDS campaigns, and then to look at the Knowledge Attitude Practices Behaviour (KAPB) model in **Handout seven** and ask how effective the campaigns have been. **Handout eight** is a case study of the loveLife campaign that is rooted in South Africa, but has been influential in the region and can be used as source material for this session. Some questions might include:

- When you hear the words HIV/AIDS, what campaigns in your country or in the region come to mind? Why?
- How successful have these campaigns been? Why?
- Analyse these campaigns in terms of the KAPB model in the handout. How successful have they been? To what extent has knowledge about HIV/AIDS in your country translated into behaviour change?

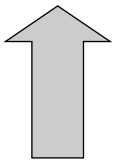
Tips for trainers – the KAPB model is often criticized for its linear approach and assumptions. This is particularly relevant when dealing with a complex subject like HIV/AIDS where experience has shown that the simple knowledge that AIDS is sexually transmitted and that it kills, does not necessarily lead to attitude or behaviour change. Models like this fail to take account of the socio-economic, cultural and social circumstances in which the pandemic is flourishing. Gender cuts across all of these factors. Most of our countries have adopted the Abstain-Be Faithful-Condomise (ABC) approach. Explore in the plenary session the gender dimensions of each of these. To what extent is abstaining an option and what are the different pressures on young men and women? Is the "be faithful" message being targeted at women or men and with what success? Who is the condom message being targeted at, and with what success? Is there any discussion in your country on the female condom?

The loveLife case study raises interesting issues about how best to target young men and women, and whether to emphasize safe sex, or mutual respect, and responsible sexual behaviour. loveLife would probably argue that it tries to do all these things. Critics are not so sure. The bottom line is that behaviour change in South Africa, where there have been huge multi-media campaigns on HIV/AIDS, has been dangerously slow in taking place.

handout seven

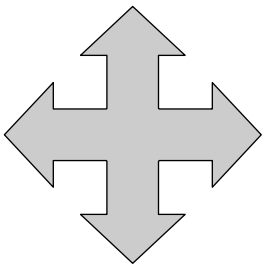
The KAPB model

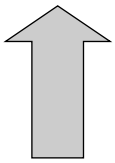
BEHAVIOUR CHANGE ---------- THE MOST DIFFICULT GOAL TO ACHIEVE!!!



ATTITUDES START TO LEAD TO CHANGES IN PRACTICES

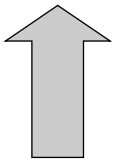
PRACTICES

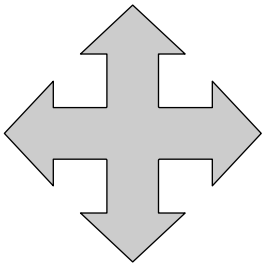




ATTITUDE

MORE ANALYTICAL INFORMATION INCREASES KNOWLEDGE; MAYBE SOME ATTITUDE CHANGE





KNOWLEDGE

CLEAR MESSAGES RAISE AWARENESS

handout eight

The loveLife campaign

loveLife claims to be, “one of the largest and most ambitious HIV prevention efforts in the world today”. Launched by a consortium of four South African non-government organizations in 1999, its primary aim is to positively influence adolescent sexual behaviour on a national scale. It targets youth between 12-17 years of age and draws upon a wealth of international and local experience. loveLife aims to reduce the rate of HIV infection amongst 15-20 year-olds by 50 percent over a five-year period. loveLife is both capturing and sustaining the attention of the youth through their simple message: “talk about it”. But critics say that the straight talk campaign, which they see as having a heavy bias towards urban and middle class youth, places too much emphasis on safer sex rather than on mutual respect and real behaviour change.

Research indicates that despite the 98 percent awareness rate of HIV/AIDS in South Africa, previous campaigns have had little effect in changing behaviour. The loveLife approach encourages open discussion and better, more direct communication about sex. In it’s initial year of operation, loveLife endeavored to create a lifestyle brand that capitalized on popular youth culture. A series of highly visual multi-media campaigns have been used to provoke discussion. loveLife has a billboard holding of approximately 2060 and each component of the images is carefully thought out and researched. The evocative, “Everyone he’s slept with is sleeping with you” or “One roll on all women want’” strike several viewers as being too bold and overt. However each image carries strong messages of mutual male and female empowerment, responsible decision-making, protected sex as well as delaying the first sexual experience.

loveLife Billboard Campaign: November 2002 – May 2003

Along with a number of outdoor, media, television and print campaigns, loveLife offers outreach and support programs as well as adolescent-friendly services in public clinics. Their toll free line, the thetha junction, receives over 30 thousand calls a month and is testament to the success of their campaign. loveLife continues to broaden its base though innovative projects such as 'loveLife games' where their involvement in school sport has provided exposure to four million students. Steps have also been taken to increase their impact at a local level. Several smaller organisations participate in the loveLife initiative and through them the loveLife campaign is being turned into community action. This, "franchise concept", has provided a base for peer educators to work and has allowed loveLife to accommodate the range of cultural diversity.

As a result of these initiatives, loveLife hopes their message will filter down into individual lives and be internalised. Behaviour change will be encouraged when the youth become a source of educators and when condom use is integrated into youth culture.

In November 2001 a national survey indicated that 62 percent of the South African youth were aware of loveLife and that of that group, 76 percent had become more aware of the risks of unprotected sex. Sixty-five percent of the group stated that the campaigns had delayed or caused them to abstain from sex and 64 percent felt it had created an opportunity for them to talk to their parents about HIV/AIDS. In general, the youth provide a positive assessment of the impact of loveLife and are receptive to their open communication strategy.

Others are more skeptical. A recent letter to the *Citizen* newspaper quoted a number of excerpts from the LoveFacts publication of loveLife including:

- "Why let others decide how we should behave and how far we will go?"
- "Friend, TEACHER, lover or partner? It makes no difference. When it comes to a relationship that involves sex – have safe sex!"
- "Bonking, jika-jika, screwing, have a ball but keep it safe"
- "Who with, how, where and when we want to do it. Its in our hands"

The letter points out that according to loveLife, 50 percent of South Africans have had full penetrative sex by age 16. They also point out that 55 percent of sexually experienced girls have been forced to have sex, mostly by their boyfriends. The letter points out that sexual intercourse with a minor under the age of 16 constitutes statutory rape, and forced sex is rape.

The letter argues: "to say that we know young people are doing things that are wrong, and then encourage them to continue, makes us accessories before the fact…tell children what they need to know, but also instill in them a sense of pride, self respect and respect for others."

Professor Suzanne Leclerk-Madlala, head of anthropology at the University of Natal comments (Mail and Guardian 4-10 October 2002): "the youth are portrayed as middle class, sophisticated and seem likely to spend their weekends enjoying multiracial camaraderie in sub-urban rave clubs. Wittingly or unwittingly, the thrust of our national HIV/AIDS prevention efforts speaks primarily to a narrow band of privileged youth."

Using the Uganda experience, where studies have shown that promotion of abstinence before marriage and faithfulness in relationships – rather than promotion of safe sex – may be key to halting the spread of HIV/AIDS, she notes that when it comes to reducing HIV infection, South Africa has "nothing at all to teach the rest of Africa."

But she adds that promoting abstinence and mutual faithfulness in South Africa is highly unpopular: "who would be willing to produce glossy media materials to convey such killjoy messages?" On the other hand, she argues, "in the raging epidemic such as we have here, messages that promote real sexual behaviour change are far more than moral choices. They are about sensible health choices and basic survival tactics."

(The organizations involved are the Advocacy Initiative, Health Systems Trust, Planned Parenthood Association of South Africa and the Reproductive Health Research Unit. Case study compiled by Janine Morna).

What gender messages are sent out in HIV/AIDS campaigns?

Exercise two

Ask participants to bring with them examples of posters from HIV/AIDS campaigns and to analyse them in groups. What messages do these posters convey? Here is one example from Zambia that you could write up on a flip chart:

KARA COUNSELLING TRUST POSTER

"Respect yourself to decide for yourself
HIV/AIDS is a threat and the end of the world if you do not know the facts

Abstinence is better than AIDS

Stay away from pre-marital sex and extra-marital sex

Women make a difference in deciding on matters concerning your health".

Tips for trainers: The loveLife campaign poster- "Everyone he's slept with is sleeping with you" – see loveLife campaign – can also be used to spark off a lively discussion. The campaign has been quite controversial in South Africa.

The one thing that these two posters have in common is that they target women ("women make a difference" and "everyone he's slept with") and give the impression that a) it is women's sole responsibility ("respect yourself to decide for yourself") and b) that women have the power to change things ""women make a difference". They also use scare tactics ("HIV/AIDS is the end of the world"; "Everyone he's slept with, is sleeping with you"). The loveLife poster conveys the message that men have free license to sleep around and that other women are passive victims of this fact. You may wish to pose the question why the messages in these two posters – what they convey to women and to men, and what impact they are likely to have on behaviour. Critique as many different posters as possible and draw some conclusions on the way in which gender issues are conveyed in HIV/AIDS campaigns.

Role of the media in HIV/AIDS campaigns

Exercise three

Invite a panel of editors to come and speak on what they see as the role of the media in HIV/AIDS campaigns and whether they have ever thought of the gender dynamics of the pandemic. Use this panel to draw out a discussion on the role of the media: is it just to provide the facts, or to help change behaviour?

Tips for trainers: The following are some comments from the media quoted in a study by the Centre for AIDS Development, Research and Evaluation (CADRE) in South Africa called "What's News: Perspectives on HIV/AIDS in the South African Media" that provide some hints of the different perspectives on this issue:

- "If its news, it will end up in the paper...
- If my work were partisan, I would not have the good relationship that I have with all role players".
- "I think its hypocritical to say – and I'm thinking here of the AIDS dissident argument – that we have to give both sides of the story when one side is being presented by a lunatic."
- "The idea that it is the moral responsibility for a newspaper in the public domain to play an advocacy role is such a dangerous territory. A paper's moral imperative is to make money. That's the reason it exists.... The media are riding the consensus, not creating it, because that is how they make money."
- " My personal view is that newspapers ought to reflect society in general, but ought to lead society in particular in those areas such as AIDS.... Don't ask me to set the limits because I don't know where they are."

The research also raised a number of constraints to coverage including:

- The imperatives of news values;
- HIV/AIDS is not amusing and engaging;
- HIV/AIDS is not new;
- HIV/AIDS is not dramatic enough;
- Attempts to influence journalistic coverage towards an educational agenda are based on a misunderstanding of the journalist's role and news values;
- Lack of commitment to the story;
- Economic and resource constraints; and
- Inadequate in-house journalistic expertise.

Media coverage of gender and HIV/AIDS

Exercise four

Look through a sample of media coverage on HIV/AIDS. What messages are conveyed on gender and HIV/AIDS? You may also want to refer to the attached case study by a South African researcher on gender and HIV/AIDS in the South African media or to relevant research from your country. What do the articles and research reveal? Give participants a copy of the article, "Have you had sex with this woman?" in **Handout nine.** They should answer the following questions:

- What are the gender, HIV/AIDS and violence issues raised in the article?
- What messages does the article convey?
- Identify the gender stereotypes that emerge from the article.
- What impact is the article likely to have on the public?

Follow this through with the excerpts of research on the portrayal of women in **Handout ten.**

Tips for trainers: Encourage the participants to discuss the difference between the messages sent out by the headline and the contents of the article itself. The article in many respects is a thoughtful piece, while the headline is sensational and stereotypes women, blaming them for the spread of the infection. Qakisa's research adds useful information on gender biases in coverage of HIV/AIDS.

Media under the spotlight: Training workshop in the Western Cape.

HAVE YOU HAD SEX WITH THIS LADY?

- Caught the disease through sexual contact
- Became too sick to look after her daughter
- Every breath came with a pain in her lungs
- Brave Sally was finally consumed by AIDS
- No need for whispered grave-side gossip

HEY DAYS: Sally pictured in '94 when she was sexually active

Sally Modise wanted everyone to know that she had AIDS. Her life was her message. She died last week aged 32.

BY STAFF REPORTER

Sally's death came exactly a year after she gave an interview to *The Voice* following her decision to publicly reveal her condition. She was the first fully blown AIDS patient in Botswana to take this brave step.

She wanted people to know that the disease was real. She was the living proof of its existence, its human face. She was not afraid to tell people of her condition and how she became infected.

Sally wanted people to see how the disease was destroying her.

Her aim was to educate and warn.

Sally did not get AIDS by accident. She was sexually active. She caught the disease from sexual contact with an infected person. She in turn infected others before she became aware of her condition. You may not have slept with Sally but the chain of infection is long. She was only one tiny link in a network of mass destruction.

Brave Sally was finally consumed by the fatal disease at her home in Mahalapye. Her death was as much a relief to her as it was to family and friends who had watched helplessly as Sally suffered through the long and painful end to her life.

Announced

At the grave-side her sister announced that Sally had died of AIDS. Probably this was the first AIDS funeral where the cause of death did not remain an unspoken secret.

Sally had spent the last year of her life repeating her message. "AIDS is real. I am its human face." There was no need for whispered grave-side gossip or speculation.

For the last month she had had to be nursed by her mother and two sisters as she was too weak to leave her bed. Every breath she took was accompanied by a sharp pain that pierced her lungs and reminded her that death was near.

She confided to a friend a few days before the end," I'm beginning to be afraid of death. I don't have enough time left to live. The pain is too much for my lungs to work."

Pedzisani Motlhabani, the AIDS project coordinator at the University of Botswana, who Sally worked with and had come to regard as a mother figure, paid tribute to her courage.

"Sally was an outstanding woman whose bravery as the first fully

■ TURN TO PG 2

handout ten

The portrayal of HIV-positive women in the South African media

Excerpt from research by Mpine Qakisa

The media's message about AIDS has been skewed right from the beginning. AIDS was looked at as a disease of "sinners " such as prostitutes, homosexuals and people with multiple partners. Popular media continued to carry reports of people who may be infected knowingly by sufferers who are seeking revenge.

Media scare stories, negative images, the nature of AIDS stories, and the reporting of AIDS related stories have all helped frame how people understand and react to the epidemic. In South Africa, this is even more pronounced because of the political and economical history of racism and sexism.

In an effort to identify the way women are portrayed with regards to HIV/AIDS as people who are infected and affected, I visited the newsroom library of the Independent Newspapers. I first looked at all AIDS articles published between 29 June 2000, a week before the World AIDS Conference in South Africa, and 9 February 2001 in The Star, the Saturday Star, The Sunday Independent, The Weekly Mail & Guardian and The Sowetan.

To identify relevant articles, a keyword search was conducted using The Independent Newspapers library database. The search yielded 805 articles on AIDS between 29 June 2000 and 9 February 2001. This means that there was an average of 3.6 articles on the subject of HIV/AIDS in these selected newspapers. There is no doubt that AIDS as a subject is covered extensively in the South African media. After looking at AIDS articles, I then screened out articles that did not focus on women.

Of the 805 articles on AIDS, 107 of them focused on women. About 13.2 percent of all AIDS articles dealt with women and HIV/AIDS. I then divided the articles into three categories. The first category looked at women in their reproductive role, that is, HIV positive pregnant women, infected infants and drugs to stop the transmission of HIV to unborn children. The second category of articles focused on violence/abuse on HIV positive women. The third category of articles dealt with general issues.

Of the 107 articles, 56 articles focused on the issue surrounding the availability of drugs to stop the transmission of HIV from mother to child. In these articles, it was clear that pregnant women with HIV are perceived as transmitters of HIV to innocent unborn babies, not as individuals with a life threatening illness.

What the media messages are not saying is that although HIV can be transmitted from mother to child, transmission does not occur to a majority of babies born to HIV positive mothers. According to the World Health Organisation, two-thirds of babies born to HIV positive mothers are not infected at all. Of the remaining one third that is infected, two thirds are infected in the womb or during childbirth and the remaining one-third is infected through breastfeeding (loveLife, 2000). If this type of information is available in the news media, then HIV positive mothers will be in a better position to make informed choices about their lives.

The underlying factor is that "women with HIV are perceived as incubators of sick babies who are destined to become a burden to society, not as individuals with a life-threatening illness, nor as a mother in struggle and in pain" (Cline and Mackenzie 1996:388) hence the headlines "Saving the Innocents" (*Sowetan,* 31 January 2001), "SA AIDS babies tragedy grows" (*Citizen,* 10 January 2001), "Drugs could save babies" (*Citizen,* 12 July 2000), "Study promises life to babies" (*Business Day,* 12 July 2000).

In almost all the articles that focused on babies there is no mention of women's health except the fact that they are carrying the babies and may infect their babies with the deadly virus. These babies, according to the articles, should be saved from their "irresponsible mothers" who basically got what they wanted. In fact, the largest single issue of the mother to child transmission relates directly to the government's policy of not providing anti-retroviral drugs to HIV-pregnant mothers. Even the screaming "Free treatment for HIV positive mums" headline failed to address the issue of HIV positive women.

Of the remaining 56 articles, 28 of them focused on women abuse and violence. These articles dealt with destitute HIV positive women who were abandoned by their families when they heard that they are HIV positive or dying of AIDS. Most of these women lived on the streets with their children until some "Good Samaritan" picked them up and that's how they end up in the media.

What these articles are saying is that if you reveal your HIV status you may end up like a 29-year-old HIV positive woman who have been kicked out of her home by her husband after she told him that she had AIDS. Her husband told her that she is useless because she could no longer cook, wash his clothes or clean the house. He also did not want her to die in his house. He threw her out at night and she just managed to sleep under a nearby tree soiled and dirty. A neighbour picked her up and a week later she died in her shack (Sowetan, 8 February 2001). Although this article is trying to bring the human face and suffering of this woman to the public, it also discourages disclosure. People may interpret this story as warning not to tell or talk about your HIV status with your partner. If you reveal that you are HIV positive, you may end up like this abandoned woman.

Media messages are failing to tell people that people who are living with HIV can live a full and productive life for many years. Almost all the articles analysed used expert opinion or government official as the source of information and in the process sidelined the people with first hand information. Right from the beginning of the epidemic, the AIDS story was never told by a sufferer.

The personal can be professional

The first step journalists can take towards understanding HIV/AIDS is to look at how the topic affects their own lives. Many journalists fall into the millions throughout Southern Africa who have never taken an HIV test. Yet this one step could help journalists develop not only empathy, but help them to cover the issue from an informed perspective.

Exercise five

Find out during the training how many people have had an HIV/AIDS test. Ask if there are any volunteers willing to undergo a test and write about their experience. An example of how this might work is given in **Handout eleven** – the story written by a student at the Polytechnic of Namibia during the workshop there to test this training manual.

Tips for trainers: Although this may be a sensitive exercise, when handled with care it can be educational. As the story in the handout illustrates, a visit to a testing centre can be most revealing. It helps those in the communications business to challenge their own fears and prejudices before they presume to communicate on this subject to others. Note that in the Namibia exercise the outcome of the test remained confidential.

Counselling in session at the New Start Centre in Windhoek, Namibia.

handout eleven

Time for a "new start"?

By Immanuel Kooper

Windhoek: Just the idea of being tested sent shivers down my spine. But what else could I do, because I had already decided to go through the process to get a first hand feel for voluntary testing and counselling before presuming to write about it. I calmed myself down and decided to go ahead.

On arrival I went for registration with a friendly receptionist who opened a file. A secret code was attached to the file. She asked me to give a fictitious name, which would be used with the code.

I asked myself what difference this code and names would make, because it would not change the outcome of my results. People might find out at any stage anyway, I reasoned, and the test is really not that confidential since the centre would be the first to know.

If the result is positive, I mused, might they stare at me when I came to collect it? Will I be able to handle all this? What if I test positive? What will happen to my family and how will I break the news to them? These were the questions that went through my mind.

Then came the next stage in which the counsellor called me in after a few minutes in the waiting room. Again, I asked myself, what type of questions is she going to ask? Will she not dig too deep into my sexual life and find out my deepest secrets, and how will my life change after all this?

But every thing went well. I came out with a bright smile on my face. I felt like staying a bit longer, but did not have time.

As I write, the result is still to come, but this does not bother me at all because I am ready to accept any outcome, thanks to the professional counselling session I had at "New Start" – a brand name under which centres such as Catholic AIDS Action, Council of Churches in Namibia (CCN), Red Cross and Life Line Child Line are providing voluntary testing and counselling.

"HIV spreads very fast because of people not knowing their status", notes Mike Haidula at the Council of Churches in Namibia (CCN) in Katutura says. The centre, he adds, "is easily accessible, cheap, fast and confidential."

Counselling is important, he noted, since people often do not know how to handle the situation after being diagnosed HIV positive.

"When the centre started officially in February this year, around eight hundred people visited the centre," Haidula says. Of the 239 people who visited the centre in March this year, 94 (39.3 percent) were male and 145 (60.7 percent) female, with 57 percent between the ages of 20 – 29. He attributes the high level of young female clients to the fact that this is the segment of the population most affected by the pandemic.

Counsellor Esmelda Peterson adds: "There should be a way for people to overcome the stigma and discrimination by sharing their status and being counselled to accept their conditions and to live positively with the disease."

First person accounts

Once someone is willing to speak openly about living with HIV/AIDS, there is a tendency for the media and AIDS organisations alike to latch onto them and to set them up as some kind of representative of people with HIV/AIDS. This too can be counter productive, as different people respond to HIV/AIDS in different ways, and no one person can possibly represent the views of all people.

There is no single representative "face of AIDS". (as an additional resource on this point, the trainer can refer to an interview that David Lush had with Sue Valentine of Health-e News (www.health-e.org.za/view.php3-id=20011022.)

To enable people to tell their own stories, the way they want to, requires journalists to drop the professional instinct to control the media production process and to tell the stories the way they see them.

Rather, journalists should put their professional communication skills at the disposal of others. In doing so, journalists and other media workers will be facilitators rather than mediators. This too requires, time, effort and the need to address ethical issues.

Self-expression and self-representation through the media can be incredibly empowering for anyone who has been stigmatised and denied a voice in the way that people with HIV/AIDS have been.

But it is important to emphasize that the media on its own does not change behaviour. People alone change their behaviour. What the media can do is to provide the public with the kind of information needed to make informed decisions.

Exercise six

Share with participants the first person story written by one of the participants at the Gauteng workshop to test this manual in **Handout twelve.** Why do such stories make for powerful media? What relationships need to be built between People Living with AIDS and the media for such stories to be told?

Tips for trainers: The story illustrates the "who feels it knows it" principle. It is always best for people to be able to speak in their own words. See also the personal accounts of men in Chapter Nine, The Role of Men.

handout twelve

From despair to hope: my personal story

By Hazel Tau Mlangeni*

I was diagnosed as HIV positive in November 1991, seven years after being married. I told my husband. On 2 November 1993 I found a divorce decree between the base and mattress of my bed.

I had never received a summons. My male counsellor advised me to go and see the Aids Law Project. As the case was being investigated, I came home from counseling one day to find my house empty. My husband had taken every thing in the house and the house had been sold, even though we were married in community of property.

My friend took me to her house to rest, cry and express my anger. The next day I found out that my husband, a prison warder, had been transferred to Durban Westville.

My life started to change. I hated men. I did not have any income. Staying in the back room of the home of my friend, who has a caring husband and two sons, I felt so alone.

In 1994/95, I decided to lodge a case against my husband. Although I had support from the AIDS Law Project, in court, I found myself pitted against powerful male lawyers hired by my husband. I felt powerless before the legal system. I could not live with the stress. I decided to withdraw the case.

Through the help of my male counselor and my friend, I slowly regained my confidence. I decided to speak out and become involved in the campaign against HIV/AIDS. I got a job as a counselor at ACCT. I went on to work at the AIDS Help Line, where I am now a senior counselor.

Last year, I fell very ill. After appearing on a TV show, an anonymous donor offered to pay for anti-retroviral drugs for me. My health has improved considerably.

It has not been easy to deal with the pain I have felt over the past years. But now I have learned as a woman that I was robbed of my legal rights.

As a counsellor, I tell my story to other women to give them courage and strength. My message to them is: Keep fighting. Be positive. There is hope, even in the depths of despair.

**Hazel Tau Mlangeni wrote this story during the Gauteng workshop to test the manual.*

Practical tips for media practitioners

The media needs to work closely with everyone involved in the HIV/AIDS struggle to make sure that the information it disseminates compliments efforts to help people to cope with the disease.

The media should not be unquestioning conduits for AIDS propaganda. On the contrary, the failure of HIV/AIDS communication to date has been partly a result of media workers' failure to criticize and question experts and officials, who often propagate a very narrow and sterile perspective of the epidemic.

Journalists should always abide by one of the basic rules of journalism: there are two sides to every story. This is as true about the coverage of men and HIV/AIDS as it is about any other story.

Exercise seven

Ask the group to brainstorm on some of the practical measures that media practitioners can take to be more professional in their reporting of HIV/AIDS. Then share with them some of the pointers in **Handout thirteen** on "What the Media Can Do."

Tips for trainers: It is important for media practitioners to recognise that there is no conflict between a human rights approach to reporting and the principles of good journalism. They are not being asked to practice advocacy journalism. They are merely being asked to be fair and balanced reporters.

Language

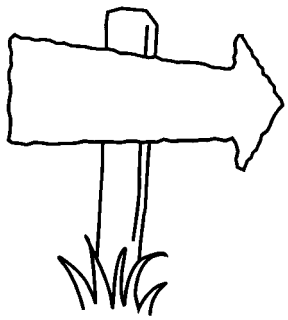
Our thoughts, ideas and prejudices are transmitted through language. Thus language is often unwittingly the transmitter of biases. As in any sensitive area of reporting, it is important for reporters to think carefully about the words they use in communicating about HIV/AIDS.

Exercise eight

Brainstorm with participants on some of the language that is commonly associated with HIV/AIDS, especially by the media. What does this language convey? What alternatives might be used? The handout contains some examples that can be built on.

Tips for trainers: Because language is a powerful conveyor of stereotypes, this discussion is a good way of drawing out deeply ingrained prejudices. Thinking of alternatives is also a good way of challenging these stereotypes. Examples are given in **Handout fourteen.**

See also "English as Medium of Discrimination" page 116 and 117,
"Gender in Media Training, A Southern African Tool Kit: GL and IAJ, 2002"



handout thirteen

What the media can do

The following pointers, although targeted at journalists, are guidelines for anyone working in the area of information, education and communications on HIV/AIDS.

- **Good contacts:** Journalists must invest the time and effort to build good contacts among people living positively with HIV and with people working for HIV/AIDS organisations. Taking the time to get to know people living positively with HIV/AIDS, helps to increase the journalist's understanding of the issues that are important to them, and builds their confidence and trust in the journalist.

- **Confidentiality:** Journalists should always respect confidentiality. This is fundamental to professional and ethical reporting (see also ethics section later in this chapter).

- **Empathy is not sympathy:** Journalists should approach those being interviewed, and write their stories, with understanding, compassion and empathy. Journalists should beware of expressing sympathy, and of viewing people living with HIV/AIDS as powerless, without hope, and unable to make choices.

- **The personal can be professional:** To write from an "informed" position journalists need to take stock of how HIV/AIDS affects their own lives. Journalists must remove the layer of aloofness and check their own biases and prejudices that often lead to one-dimensional, stereotypical and misleading reporting on HIV/AIDS.

- **Look within one's own house:** Media institutions must begin to address the impact of HIV/AIDS within their own organisations.

- **Do not create "tokens":** There is no single representative "face of HIV/AIDS". The media should tell as many stories as possible about how men, women, boys and girls are responding to HIV/AIDS.

- **Do not silence people's voices:** Journalists should drop the professional instinct to control the media production process and to tell the stories as they see them. Journalists should put their professional communication skills at others' disposal enabling them to tell their own stories in the way they want.

- **Know the limits:** The media on its own does not change behaviour. People alone change their behaviour. The media should strive to provide the public with the kind of information it needs to make informed decisions.

- **Multi-sector approach:** It is not only institutions and governments that should take a multi-sector approach to cope with HIV/AIDS. The media too needs to work closely with everyone involved in the HIV/AIDS struggle to ensure that the information disseminated through the media compliments efforts to help people cope with the disease.

- **Balanced reporting:** The media should not be an unquestioning conduit for AIDS propaganda. Reporters must remember the basic rule of the profession: There is more than one side, one perspective, to every story.

handout fourteen

The language of HIV/AIDS

LANGUAGE TO AVOID	WHY	RECOMMENDED LANGUAGE
AIDS scourge/ plague	Suggests HIV cannot be controlled. Sensational.	HIV epidemic, HIV pandemic.
AIDS test	Does not exist. Only tests to determine if HIV exists.	HIV test.
To catch AIDS	Cannot be caught or transmitted People become infected with HIV Transmission of HIV is correct.	To become infected with HIV To contract HIV.
AIDS sufferer	Many people with HIV/AIDS can have relatively good health for years.	Person living with HIV/AIDS.
AIDS victim	Gives the impression the person is powerless.	Person living with HIV/AIDS.
Safe sex	No sex is completely risk free.	Safer sex
Promiscuous	This is accusatory and derogatory.	Having multiple partners.
Prostitute	A derogatory, insulting, value laden word.	Sex worker.
Drug abuser, drug addict.	It is the act of injecting with a contaminated needle, not drug use itself, that can transmit HIV.	Intravenous drug user.
To die of AIDS	AIDS is not a disease but a syndrome, a group of illnesses. HIV causes the weaknesses that lead to opportunistic infections.	To die of an AIDS-related illness.

("Reporting on HIV/AIDS in Africa: A Manual", The African Women's Media Centre).

Ethical issues in covering gender and HIV/AIDS

Communicating and writing on HIV/AIDS for media articles and public awareness campaigns presents both ethical and legal challenges to journalists and communicators.

The prejudice and stigma attached to being identified as an individual living with HIV/AIDS is often in conflict with the need to end the silence around the epidemic.

Ethical reporting of the HIV epidemic requires that journalists and communicators understand and acknowledge the unequal power relations between women and men, and the link between these unequal relations, human rights and women's vulnerability to HIV infection.

Reporting on HIV/AIDS requires that journalists and communicators also are mindful of the individual's human rights. This requires care in the treatment of information gathered and places a responsibility on the journalist and communicator to be accurate, fair, and to use language that reduces stigma and discrimination.

Exercise nine

Give participants a copy of the case study, "Sensitive Reporting on Gender and HIV/AIDS" **(Handout fifteen).** Break participants into two groups and ask the groups to read the case study provided and then answer the following questions:

- What are the gender, HIV/AIDS and rights issues raised within the case study?
- What issues on ethical and sensitive reporting emerge?
- What messages on stigma and discrimination are conveyed by the case study?
- What steps should journalists and communicators working on HIV/AIDS information take to ensure ethical reporting on gender and HIV/AIDS?

Tips for trainers: Other media articles or information case studies on gender and HIV/AIDS can be selected from material available within your country to illustrate the issues of gender, HIV/AIDS and ethical reporting. Some key issues to consider are:

- Privacy and confidentiality;
- Avoiding blame and harmful stereotypes;
- Empowering versus victimizing;
- Compassion and support; and
- Handling the bereaved.

Using the case study, you can also ask participants to draw up a set of guidelines on reporting HIV/AIDS. An example of this is given in Handout sixteen.

handout fifteen

Sensitive reporting on HIV/AIDS and gender

By Ruth Ansah Ayisi*

Arranging for journalists to cover a story as part of the training is the best way to sensitise them to the difficulties and ethics of good reporting on HIV/AIDS and gender. It was as part of the fieldwork during the Gender Links (GL) gender violence workshop in Maputo that I personally learnt important lessons about this sensitive area of work.

I accompanied a group of six journalists to Kindlimuka, a centre for people living with HIV/AIDS. Already, we encountered our first challenge: finding women who were prepared to talk to journalists about their HIV status and their experience of domestic violence; two subjects which are taboo in most countries. But after some convincing, we managed this, especially when we assured them that if they wished, their anonymity would be guaranteed.

The journalists had been briefed about the ethics of confidentiality. They were told to brief the interviewee fully about the purpose of the interview and why it was important that her story be told. They were also to make it clear that the article would be published, so if she wished, a pseudonym could be used. The photographer discussed different techniques, such as shooting from behind or a silhouette shot to make sure the interviewee could not be recognised.

But even these precautions proved insufficient.

The journalist and I interviewed a 32-year-old mother of two children who told of how her husband beat her and raped her when she requested he used a condom. This was despite the fact that he was having a relationship outside the marriage and had a syphilis sore on his penis. The husband, who has since left her, is now also sick with what she suspects are AIDS-related illnesses. The woman said she fears she is HIV positive, but has not yet had a test.

The first problem was over the confidentiality issue. The woman had indicated that she was happy to have her real name used. But on hearing her story, it became clear that neither her children nor her family admit that her husband is living with HIV/AIDS. We realised it was our duty to explain again the implications of the women's story coming out in the newspaper, at which point she decided to give a pseudonym.

In class we discussed how due to lack of education and exposure, women often need more advice about anonymity. It is, we agreed, the journalists' responsibility to make sure the interviewee fully understands what is at stake.

Besides changing the name, we made sure that the information included in the article would not give away her identity. We also checked the photo to make sure it had been shot from behind with only my face and that of the journalist showing.

However, the following week, the local Savanna newspaper, which carried the workshop' supplement, had confused me with the interviewee. Fortunately the interviewee had her back to the camera, but my face had an ineffective, small white strip across my eyes. Two mistakes had been made. In the production, not only had they portrayed me as the interviewee, but also even more serious they had not even hidden my face properly.

For the first time in my life I realized how it must feel, not only to be misrepresented in the press, but also to fear reactions of people who would mistakenly think I am HIV positive, and had been raped and beaten up by my partner. The following afternoon after the paper had come out, I had to attend a school function for my eight-year-old son. Every time somebody looked at me, I was convinced that it was because they had recognised my picture in the newspaper and I had become the centre of gossip amongst our friends.
I wondered whether I was just being paranoid, but then my heart sunk when close friends actually came up to me for an explanation.

I can only hope that fellow trainers don't have to go through the same experience to realize how important it is not just to be ethical, but follow through on all the technical processes of production, in making sure we access the voices we need, without adding to their suffering.

**Ruth Ansah Ayisi is a communication consultant, specialising in the effect of conflict and HIV/AIDS on women and children in Africa. She has written brochures and articles on these issues in Mozambique, Sierra Leone, Uganda, Botswana, Lesotho and Angola, regularly undertakes assignments for UNICEF, and served as the Africa editor of the New Delhi-based Women's Feature Service.*

handout sixteen

Useful guidelines for reporting on gender and HIV/AIDS

Confidentiality

The rule is clear – do not publish the name of anyone living with HIV/AIDS without their permission. Human rights law recognises the rights of individuals to maintain their privacy, and there are few exceptions to this rule in the context of the HIV/AIDS pandemic.

Reducing stigma

Stigma can be reduced by avoiding words that compare the pandemic to the plague, and by identifying people living with the virus as carriers of the infection. Words such as promiscuous and evil also should not be used.

Reporting on treatment and cures

Reports should be accurate and journalists and communicators must be familiar with the scientific and medical issues. Journalists and communicators should not give credibility to false cures and/or to individuals who claim to have found cures that often have a negative influence on those who are ill or marginalised. However, it is equally important that journalists and communicators report on new scientific and medical developments in a way that is accessible and informative.

Misconceptions

A number of factors can lead to inaccurate and misleading reports on HIV/AIDS. Martin Foreman, the former global director of the HIV/AIDS programme for the London-based PANOS Institute has identified the following:

- Carelessly used, misunderstood or misused language;
- Scientific or pseudo-scientific information that is reported indiscriminately;
- Sensationalised information;
- Reports that are influenced by the personal attitudes of writers or editors;
- Sub-editors' headlines;
- Repetition of information that is out of date or distorted; and
- Inappropriately used quotes.

Journalists and communicators should be aware of the consequences of repeating and reinforcing commonly held myths about the epidemic.

Sources of information

There are many different sources available and journalists and communicators should be aware of as many of them as possible. Information obtained should be independently verified as far as possible, and it should be accurate and relevant. Ethical reporting requires that journalists and communicators take the time to distinguish the facts from the source presenting them.

Minorities and vulnerable groups

These include sex workers and prisoners, among others who are often subjected to prejudice and discrimination. These groups often are blamed for spreading the virus. Journalists and communicators should be careful not to perpetuate stereotypes about vulnerable groups and to ensure that in their reporting, the rights of these groups are respected.

Story ideas from this chapter

- What communication campaigns are being run in your country on HIV/AIDS? What impact have they had? Why is behaviour slow to change?
- Has there been any research into/ analysis of media coverage of HIV/AIDS? What does this point to?
- How do editors and media practitioners feel about their role with regard to the HIV/AIDS pandemic?

Key learning points

- Despite the huge amount of information now available on HIV/AIDS, this has often not been accompanied by behaviour change.
- Traditional KAPB models used for designing campaigns have often failed to take sufficient account of the socio-economic conditions, and underlying gender dynamics that fuel the spread of HIV/AIDS.
- The mass media has found itself caught in a dilemma over whether its role is simply to "convey the facts" or play an advocacy role over HIV/AIDS. This links to a broader debate over the role of the media in development and indeed in society. Is it the role of the media just to convey what is, or what could be?
- Media practitioners are often ill equipped to cover the pandemic, and especially the gender dynamics that underpin it. Media coverage is often event, rather than issue driven. HIV/AIDS is a complex issue, deeply rooted in social, cultural, political and economic realities. It is not just, as many media houses often treat it, a health issue.
- The natural propensity in the media to focus on the bizarre, the unusual and the sensational, and the deeply entrenched gender biases that permeate most newsrooms, have often led the media to be part of the problem, rather than of the solution, where HIV/AIDS is concerned.
- The media has often contributed to stigmatisation and discrimination around HIV/AIDS. It has revived old prejudices and stereotypes, giving these renewed life in an HIV context.
- Specifically, the media has ignored, downplayed, misrepresented and distorted the gender dimensions of the epidemic.
- The media could play a potentially critical role in providing accurate information and education on HIV/AIDS, including of the role of gender. Accurate media on HIV/AIDS could allow us to deal with the pandemic not only as a threat, but also an opportunity to bring about a more just and equal society.