

HIV / AIDS and the Media

The Press Council of India under the mandate of Section 13(2)(b) of the Press Council Act, 1978 has built up a set of guidelines to facilitate the functioning of the Media. Of these, the guidelines on coverage of HIV/AIDS related matter was drawn up in the year 1993.

A writ petition no. CMP 52/2008 was filed by National Network of Positive People before Hon'ble Court of Juvenile, Thiruvananthapuram objecting to an incident relating to visual screened by the media of two children Betsy and Benson and the subsequent false reporting of the demise of Betsy, a child with HIV/AIDS. The Hon'ble Court observed that the Press Council of India should give appropriate direction to the Media while reporting HIV/AIDS by them. In pursuance of this matter the Council approached the representatives of UNAIDS and activists in the field to update the guidelines on HIV/AIDS reporting as the matter has undergone sea change since 1993. The core group held two workshops on September 18, 2008 and October 10, 2008 to discuss and debate on the guidelines formulated and proposed that these guidelines should be translated into as many languages as possible for the benefit of the journalists at various levels. These guidelines are equally relevant to print as well as electronic media.

❖ Be Objective, Factual and Sensitive

Journalists must ensure their story is objective, factual and sensitive, more so when they are reporting on HIV and AIDS. They should seek truth and report it in a balanced manner. Journalists should hold all decision makers accountable, from government to the pharmaceutical industry and advocacy groups. They should be engaged with, but not captive to, any interest group.

This means highlighting positive stories where appropriate, without underplaying the fact that HIV and AIDS is a serious issue. Omitting key information because it doesn't fit into the story is a breach of faith. The story must give both sides of the picture. Telling the whole story also means giving it a human face. The voices of people with HIV and AIDS must be heard more strongly and they must include the vulnerable and marginalised people.

The focus should be on facts. Distortion of facts in any manner to make the story salacious and therefore 'more saleable' is unacceptable. Censorship of relevant information too is unethical.

Accuracy is critical since important personal and policy decisions may be influenced by media reports. In the context of HIV and AIDS, this means that journalists need to be very careful about the scientific and medical details as well as statistics. With the combination of drugs and treatment regimens available known as antiretroviral therapy (ART), people infected with HIV can live for many years before showing any signs of illness. ART is a combination of drugs that reduces the amount of HIV in the body (viral load) by interfering with its replication. ART does not completely destroy the virus or cure the disease. With reduced virus in the body, the immune system can become stronger and fight infection more effectively, resulting in decreased morbidity for the patient. ART has been shown to benefit both adults and children living with HIV and AIDS.

Reporting on HIV and AIDS is complex and sorting through the epidemiological data can be challenging. Whether using data to support a story or reporting on the data itself, the specific data chosen and how they are used, will play a large role in determining what kind of story is told. In addition, the data is often so complex that there is a risk of misinterpretation. For example, some reporters may use 'incidence' and 'prevalence' interchangeably even though they

represent two different ways of measuring the epidemic. Experts/ epidemiologists should be consulted.

❖ **Ensure Accurate Language and Terminology**

When reporting on HIV and AIDS, language is extremely important. Journalists should be particularly careful to get scientific and statistical information right. They must integrate this with correct terminology. For instance, it is essential to know and make clear the difference between HIV and AIDS. Being a syndrome or a collection of symptoms, AIDS cannot itself be transmitted, nor is there an AIDS virus, nor an AIDS carrier. Similarly, a person either does or does not have AIDS. Since there are no degrees of AIDS, the expression 'full-blown AIDS' is meaningless.

With effective treatments now available, HIV infection does not necessarily lead to AIDS. It is important to reflect this in reportage. Since HIV is not synonymous with AIDS, 'HIV/AIDS' as a term is no longer considered accurate.

With AIDS not being a singular disease but a syndrome defined by a variety of diseases and cancers, a person does not 'die of AIDS'. It would instead be accurate to report that he or she died of an HIV-related illness.

Terminology used must be appropriate and non-stigmatising. The media must cross check changes in terminology and language. Terms like 'scourge' to describe the infection have been discarded. Other terms like AIDS carrier, prostitute, drug addict, AIDS patient/victim/sufferer also lead to stigma and should not be used.

❖ **Debunk Myths Related to Prevention of HIV and Miracle Cures**

The press should take care not to promote myths related to prevention and transmission of HIV or to claims that advertise protection from the infection. Nor should it give any credence to traditional cures that have no scientific verification. False hopes are raised by reporting claims around cures. Researchers have been working hard for decades yet there is no known cure for HIV or AIDS although the infection is treatable with a positive impact on the quality of life. The media should include telephone numbers of HIV and AIDS helplines/counselling services.

Advertisements related to HIV, STIs, skin diseases, tuberculosis and other opportunistic infections can be potentially misleading and should be carefully checked.

❖ **Make Photographs, Illustrations and Cartoons Positive**

Visuals have an immediate impact on audiences and are important to highlight stories. But the use of photographs in HIV and AIDS stories raises a lot of ethical issues. Care should be taken to ensure that photographs do not breach the confidentiality or privacy of infected people and their families.

Avoid photos that promote stereotypes related to HIV and AIDS and those that victimize the infected. Care should be taken to ensure that captions to photographs are factually correct and do not increase stigma.

Illustrations and cartoons also should avoid any negative implications

❖ For Visual Media

The visual media must deal sensitively and ethically with the identities of those who have HIV and AIDS as well as their families and associates. Care must be taken during interviews, off-the-record conversations, while taking photographs and recording their stories so that identity is kept confidential.

Some pointers:

- ❖ Keep the camera away from focussing directly on the face of person/case study. Instead, shoot hands, feet or back of the head
- ❖ Shoot in silhouette, keeping the camera behind the subject
- ❖ Since voice can also be an identifying factor, ask questions softly so that the replies are soft. In most cases, superimposition of subtitles should be used so that the audio does not need to be upped too much.
- ❖ Do not show pictures of the family. These too can lead to identification of the person
- ❖ Try to keep the location of the shoot ambiguous. For instance, avoid naming the village
- ❖ Establish the concerned person's journey through a third party's voice whenever possible
- ❖ An interview should be a one-to-one chat that allows the person to speak. Ensure questions are not deeply personal or accusatory. It should not put the person on the defensive
- ❖ Hidden cameras should never be used
- ❖ Try to show people living with HIV in a positive light by portraying them as individuals instead of 'victims'
- ❖ Wherever possible, obtain written consent

Even with permission, it may be best not to disclose the infected person's identity. The repercussions and pressures of being revealed on TV particularly can be terrible, especially for the family. The stigma gets heightened. In many cases permission to shoot openly is given without understanding the power of the visual media.

The person may feel safe appearing on TV in Delhi, away from their community, not realizing the possibility that their family is watching the story in a village/ town far away.

❖ For News Desk including Sub-Editors and Newsroom Staff

Special attention must be paid by the news desk and newsroom staff to ensure that the eye-catching headlines reflect the issue accurately and that the story is balanced and free of damaging stereotypes.

❖ Uphold Confidentiality and Obtain Informed Consent

Journalists should not disclose the identity of the person infected with HIV unless they have specific permission to do so. Whenever possible, they should get written consent.

If written consent is not possible, informed consent must be obtained. This means ensuring that people living with HIV and AIDS (PLHIVs) are aware of the implications of their identification.

The moral and professional responsibility of the story should be that of the journalist. Therefore, the journalist must exercise caution and use his/her judgment on how PLHIVs are to be portrayed. To minimize damaging repercussions it would be best to avoid identification even when written consent is obtained. This can be done by changing names and locations in the story.

❖ Avoid Discrimination

Journalists should avoid references to caste, gender or sexual orientation when reporting HIV and AIDS. Such references entrench existing prejudices against sexual minorities certain communities or groups already targetted, be they men who have sex with men (MSM), injecting drug users (IDUs), sex workers or migrants.

Sexual minorities includes people who are lesbian, gay, bisexual and transgender (LGBT)and covers men, women and all those who do not identify either as men or women (that is, transgender). Among the transgender are hijras. Hijras are essentially biological born males who do not identify as men and prefer to identify as women.

It is important to understand that MSMs may never identify as homosexual. Therefore, the word MSM is used to denote behaviour only. So it is appropriate to say Oscar Wilde was a gay man and not Oscar was gay.

Sexual minorities are sometimes derisively referred to by terms which reinforce stereotypes about the community. Instead, it would be more appropriate to use terms like sexual minorities, gay man or lesbian. It is not necessary to call them that either as long as one does not stigmatise them.

While infomation about modes of transmission are important, instead of making value judgements the reports should try to focus on how the infection affects people, their work, their families and the gaps in policy and implementation of HIV programmes. Focussing needlessly on how a person was infected reinforces an attitude that seeks to blame those with HIV or AIDS for being infected.

Care should be taken to ensure that a particular region's language, cultural norms and traditional practices are understood and accurately reported.

❖ Ensure Gender Sensitive Reporting

The media must guard against gender stereotyping. It must not stigmatize HIV positive women. For instance, portraying sex workers and bar girls as being responsible for spreading the infection is common. Instead, stories should explore how the infection makes women particularly vulnerable to different forms of exploitation. Stories must focus on how it is possible to live a productive and reasonably normal life with HIV, about the inherent strength that enables women to shoulder challenges and about the ethical and legal rights of sex workers.

Stories should also focus on the new technology and medication available for prevention of infection from mother to child and the fact that infected women can have children who may be free of the infection.

An example of gender sensitive reportage is the use of PPTCT (Prevention of Parent to Child Transmission) instead of PMTCT (Prevention of Mother to Child Transmission). This way the report does not hold the mother solely responsible for passing the infection

❖ Ensure Sensitivity on Child-Related Stories

The identity of children infected and affected by HIV should not be revealed. Nor should their photographs be shown. This includes orphans and children living in orphanages, juvenile homes etc.

International and national laws specifically prohibit publication of any information or photograph that may lead to the identification of these children and violate their rights.

In India, the Juvenile Justice (Care and Protection of Children) Act, 2000 lays down that no report in any newspaper, magazine or visual media regarding a juvenile in need of care and protection shall disclose the name, address, school or any other particulars that lead to their identification. It also prohibits the publication of any photograph related to the child.

Journalists must also be sensitive to the fact that a child may or may not be aware of her/his HIV status. This fact must be ascertained before the journalist gets into the process of enquiry. This is of prime importance as some questions can be perceived as intrusive or insensitive and can leave a lasting impression on the child.

Keeping that in mind, it is nevertheless important for children to participate in matters that concern them. However, their identities must be protected while sharing their views/stories.

The fact that paediatric doses of ART medication are now available must be widely disseminated.

❖ **Ensure Balanced and Responsible Coverage**

News organisations should take the initiative to lessen the impact of a ‘negative’ story such as suicide due to HIV-related illness by carrying statements from positive people who have faced the challenge successfully or by giving helpline numbers.

Care should be taken that stories on infected individuals are not sensationalized. The stories should avoid falling into the trap of projecting infected persons as either ‘victims’ or ‘culprits’.

When reporting on specific professional groups such as uniformed services, health professionals etc, care should be taken to obtain data from authorised sources. Inaccurate reports will have an adverse impact on their morale and will also increase stigma. Such reports will also create an impression of lack of confidentiality that will hinder voluntary testing.

❖ **Ensure Regular Training on HIV & AIDS for Media**

Journalists must keep abreast of the changing realities of this fast-evolving infection. News organizations across the country must actively encourage training workshops and modules on the issue. Journalists should also keep themselves updated on court judgements related to the issue.

HIV is no longer just a health issue. Instead of concentrating on health reporters alone, people at all levels of the news organization should be trained and sensitised on the various dimensions, especially terminology of HIV and AIDS. The infection impacts on the country’s development, economics, business and politics. Surveys have shown that with training and sensitization, media reportage on HIV and AIDS, particularly in high-prevalence states, has been relatively more balanced and accurate.

❖ **Adopt Existing Stylebook or Guidelines on HIV & AIDS Reportage**

News organisations should adopt and widely disseminate existing standardised guidelines and terminology on reporting on HIV and AIDS. This will encourage responsible coverage of the issue.

APPENDIX 1
UNAIDS TERMINOLOGY GUIDELINES
www.unaids.org

APPENDIX 2
CODE FOR SELF-REGULATION IN ADVERTISING BY THE ADVERTISEMENT STANDARDS COUNCIL OF INDIA (ASCI)
www.asci.co.in

APPENDIX 3
HIV/AIDS AND THE LAW - A JUDICIAL COLLOQUIUM BY HUMAN RIGHTS LAW NETWORK (HRLN)
www.hrln.org

❖ **Do'S**

- ✓ Media must inform and educate the people, not alarm or scare them
- ✓ Be objective, factual and sensitive
- ✓ Keep abreast with changing realities of fast-evolving infection
- ✓ Use appropriate language and terminology that is non-stigmatising
- ✓ Ensure headlines are accurate and balanced
- ✓ Be responsible; give all sides of the picture, using voices of people living with HIV and AIDS (PLHIVs)
- ✓ Dispel misconceptions about prevention and transmission
- ✓ Debunk myths about miracle cures and unscientific claims of protection from infection
- ✓ Highlight positive stories without underplaying seriousness of the issue
- ✓ Uphold confidentiality of infected people, their families and associates
- ✓ Ensure photographs do not breach their confidentiality
- ✓ Ensure photo captions are accurate
- ✓ Ensure gender sensitive reporting and avoid stereotyping
- ✓ Obtain data from authorised sources as inaccurate reports have adverse impact on morale and increase stigma
- ✓ Journalists are responsible for ensuring interviewees understand repercussions of revelations/identification
- ✓ Ensure informed consent, in written form wherever possible
- ✓ Balance coverage of a negative story like HIV-related suicide or incidence of discrimination by including contacts of helplines/counselling centres
- ✓ Broaden reportage to examine impact of infection on economic, business, political and development issues
- ✓ When in doubt contact the local network of positive people or state aids control society or existing terminology guidelines for clarification
- ✓ Ensure questions are not deeply personal or accusatory
- ✓ Show PLHIVs in a positive light by portraying them as individuals instead of 'victims'

❖ **Don'ts**

- ✓ Don't sensationalise the story
- ✓ Don't make value judgements that seek to blame PLHIVs

- ✓ Don't use terms like 'scourge' to describe the infection or describe PLHIVs as AIDS carrier, prostitute, drug addict, AIDS patient/victim/sufferer
- ✓ Don't focus needlessly on how a PLHIV was infected
- ✓ Don't identify children infected and affected by HIV and AIDS by name or through a photograph even with consent
- ✓ Don't use hidden cameras
- ✓ Avoid alarmist reports and images of the sick and dying that convey a sense of gloom, helplessness and isolation
- ✓ Don't use skull, crossbones, snakes or such visuals as graphics
- ✓ Avoid references to caste, gender or sexual orientation
- ✓ Don't reinforce stereotypes about sexual minorities including those who are lesbian, gay, bisexual or transgender (LGBT)
- ✓ Don't portray infected persons as victims, culprits or objects of pity
- ✓ Don't promote misleading advertisements related to HIV, STIs, skin diseases, tuberculosis and other opportunistic infections
- ✓ Don't breach the confidentiality of those opting for voluntary testing

Consent Form

I, _____ Son/ Daughter of _____, am a responsible adult / Parent/legal guardian of ----- Aged ----- years, agree that you.....(name of interviewer/photographer) and your photographer/cameraman have my permission to record my statement/interview and take my photograph for print/audio visual media, on HIV and AIDS related issues.

I understand that my statement/interview will not be distorted or misused in any way wherever it is used. The photographer will also ensure that photographs do not breach my confidentiality or that of my family.

You will also ensure that statement/interview taken of ----- (name of interviewee), who is a minor, does not reveal his/her identity in any way.

It has also been explained to me in my language (-----) that there could be potential fallout of my statement that could include stigma and discrimination directed towards me, my family members, relatives and friends.

ADDRESS: _____

Phone: _____

DATE: _____

SIGNATURE: _____
