

Setting Standards for Ethical Reporting on HIV/AIDS

By Mohuya Chaudhuri

It's now been over two decades since HIV/AIDS first surfaced in India. From being a completely unknown disease shrouded in mystery and dread, today a large proportion of the Indian population is well aware of the virus that causes AIDS. The media has played a crucial role in this dissemination of information. Newspapers-national and vernacular, the government-run television channel, Doordarshan, and the private networks have taken the message to the people through public service announcements (PSAs), news reports, investigative journalism and even through soap operas or serials.

While all agree that the message has been delivered, some believe, reporting on HIV/AIDS has had its own pitfalls. Lack of proper guidelines within the media has caused several setbacks in the communication of HIV/AIDS. Several tragic incidents reveal instances where the media ended up increasing discrimination and perpetuating stereotypes instead of busting them. These cases have now forced many health journalists and even editorial teams in news organisations in India to review the need for universal reporting guidelines for HIV/AIDS.

Like any other emerging disease, HIV too was followed relentlessly by the media in the initial years. There was a novelty attached to writing or reporting on an issue that was so intimately linked with death and tragedy. In this pursuit, ethics were often given the short-shrift since the story had to be sensational. The first reports on the disease revolved around certain high-risk groups-sex workers, the gay community and truck drivers. The data released by agencies did point to them as most vulnerable to the disease. But since they were "fringe" groups, such reporting ended up branding them-"them" vs. "us". It was insinuated that somehow, these groups were responsible for getting infected because of their "immoral" lifestyle. This kind of reporting created panic around the disease and "victimised" these groups, who were shunned even more by civil society. It also led to a certain degree of complacency-that all those who didn't belong to these groups, were safe from HIV/AIDS. It was only later that we would learn that this confidence was highly misplaced.

Defining ethics

To be fair, many individual newspapers and newly set up TV channels did follow a general set of rules, especially related to identities. But many groups felt targeted-sex workers, truckers and the gay community. At NDTV, a story being offered by a cub reporter on the risks faced by the gay community was abruptly turned down at the news meeting. It was only later that we learnt it was a carefully considered decision, as the story would only reinforce stereotypes. NDTV finally did stories on the discrimination faced by PLWHAs in the workforce. This expanded the scope of HIV/AIDS reporting. It was a small but valuable lesson.

But HIV reporting is a continuous challenge. For instance, how does a channel deal with the identities of those who have HIV/AIDS or their families and associates in interviews (especially on television), off -the record conversations, photographs, and stories? Guarding the privacy of these people and refraining from reporting confidential information, and above all, refraining from treating them as victims-are issues that confront us daily. And answers to these form the very basis for ethical, just, and constructive coverage of HIV/AIDS.

Like any kind of journalism, reporting on HIV/AIDS must follow the same fundamental principles. It must be

fair, accurate and objective. But, like all health communication, there is an added tenet-sensitivity-since the lives of many people are involved. One stray comment or remark can jeopardise the safety of an entire family or even a community.

"My first tryst with HIV/AIDS was in early 2002. I received a phone call and the caller told me about the ordeal of a 50-year-old man, Ram Bahadur, who, after being diagnosed with the virus was unable to get himself treated for a urinary tract problem," says a young reporter while recounting some of her earlier experiences while covering HIV. He had been refused treatment by six major hospitals, including the All India Institute of Medical Sciences. It was only after the court intervened that he was admitted.

"Ram Bahadur had been through such acute discrimination and the agony of being abandoned that he decided to come out with his status and requested me to publish his story with a picture and his name. The story, widely followed by other news organizations, taught me many lessons. Though media has a very important role in preventing HIV/AIDS and in protecting the rights of people living with this virus, insensitive, incorrect or sensational reporting could lead to tragic consequences for a family. In this case, some newspapers published wrong versions of Ram Bahadur's story which infuriated the doctors," she says.

Even now, there are no formal guidelines of reporting in most Indian media and young reporters learn from their mistakes, often after witnessing tragic consequences of their stories. This is one area where stigma is bigger than the story. HIV/AIDS reporting is not only about getting a good story to highlight the issue but it is about highlighting the issue sensitively to protect the people involved.

Fundamental principles

Looking at various sources in Africa, where the disease is so widespread, and the United States, where it was first discovered and reported extensively, and comparing it with the Indian experience, here are some basic tenets that journalists must follow:

- 1) Tell the truth. It is imperative that the public gets to the truth because that is the media's primary mandate. This right should not be compromised.
- 2) Keep the public updated. Informing the public about the latest relevant and interesting developments helps to arm people
- 3) Keep the facts straight. Distortion of facts for the sake of sensation is unacceptable. This includes presenting all sides of the story. Omitting key information because it doesn't fit into your story is a breach of faith. Censorship of relevant information is unethical because it deprives the public of information needed to make well-informed decisions. For instance, the ongoing clinical trials for the AIDS vaccine have thrown open new debates-whether or not to highlight the role of volunteers or hide their identities? Whether or not, the trial is going to be successful? Journalists must strive to explain as best they can and not speculate or even jump the gun and say that "here is the answer to the AIDS pandemic". It is best to work closely with researchers to avoid misreporting.

In fact, a journalist must seek clarifications at all times. There are sets of data which can be read in different ways and a reporter must be sure which is the right way. The debate over numbers of PLWHA in India is one such contentious issue. Also, a news story must be covered objectively; the journalist needs to remain emotionally detached from the event, and refrain from taking sides. The topic of AIDS "cures" and treatments, for example, demands particular scrutiny, and should be reported critically. When getting close or friendly with a source of information-either an individual or an institution-journalists need to pay particular attention to providing facts-based stories and objective portrayals.

- 4) Ensure that your source is authentic. Or else, more myths such as sharing of bathroom seats or kissing can cause HIV, will be created.
- 5) Identities should be disclosed only with permission. Even family members who are not infected must be asked if they want to come out. Journalists must respect an individual's right to privacy and human dignity.
- 6) When interviewing someone who is living with HIV/AIDS, it is crucial to be sensitive to his or her needs and perspectives. In fact, it may be helpful to prepare some questions for the interview and to ask someone from a local HIV/AIDS service organization to comment on their appropriateness. It is also helpful to go over the questions with the source before the interview, or before the person agrees to the interview. Questions must be asked with care and tact. Don't probe into painful details for the sake of sensational "soundbytes" or even weeping on camera. Don't thrust microphones into faces of bereaved people. It is important to treat them with compassion.
- 7) Conversations should only be taped if the source gives explicit permission and only when the source is fully aware of it. No hidden cameras should be used. Confidentiality must be maintained. Information that was shared in confidence must not be reported. Incidents of people with HIV/AIDS being ostracized, persecuted, and even murdered after their identities and HIV status were made public are widespread.

Careless reporting can cost lives

In Upper Assam, an HIV positive child was asked to leave school after a local television channel carried a report on the child and his family. The family was then hounded out of town. In another case of an HIV positive woman, this time in Lower Assam, local villagers attacked and almost killed her after they got to know her identity. Families of HIV positive people are often driven out of their homes, especially in rural areas. There are many cases, where PLWHA have to live near burial grounds and even burning ghats because they are society's new "untouchables". Violence against HIV positive people is on the rise. While there have been several reports of people being tied up in cattle sheds and forced to live with animals with little food and no care, now it's gone a step further. In an Andhra village, an HIV positive widow, whose husband had died of AIDS- related illnesses as well, was nearly buried alive. Villagers didn't want to wait till she breathed her last. Few want to touch the bodies of those who died of AIDS-related illnesses.

Even in big metros, the situation is no different. Despite the awareness and access to treatment, counselling and care, many people are choosing to kill themselves, unable to bear the discrimination. In two months alone, three HIV positive patients who were undergoing treatment for HIV in a leading hospital killed themselves, forcing authorities to post guards outside wards where HIV positive people were being treated. In such a barbaric climate, callously revealing the identity of HIV positive people can be dangerous.

- 8) All sources must be protected. Many times, a person speaks freely for the sake of some good. Say there's corruption in the disbursal of funds in an AIDS agency. But if his/her identity is revealed, then it puts the person in the dock, causing harm. This also means that information related to HIV/AIDS must be collected honestly and not illicitly. Say when a source shares information with the journalist with the understanding that it was simply part of a personal conversation, this information should remain private unless the source gives the journalist express permission to use it in a story. Often when TV stations demand authentication of any new data (sources say is usually not acceptable in TV), a journalist may be tempted to give out a name to guard their own end. But such a step would not only jeopardise the source but also kill a key avenue of information.

- 9) Take no favours from any agency, except data. Only the media organization for which the journalist works should compensate the journalist for covering stories. Accepting payment from interested parties creates a conflict of interest for the journalist and undermines the credibility of the news story.
- 10) Journalists should not expect, request, or accept payment for attending meetings, workshops, or conferences; the expectation of an allowance should not be the factor that motivates a journalist to attend such forums.

Look within

The media is playing a crucial and active role in raising the public's awareness about HIV/AIDS and health journalists stand on the front lines of this fight. As with anyone dealing with the issue, the first step is to examine one's own feelings, fears, vulnerabilities, and biases about the issue. This is imperative for journalists whose personal sentiments and beliefs may strongly influence how they approach and report a story. For instance, if a journalist has reservations about sex workers or the gay community, these biases will reflect in the story unless one steps back.

Journalists who understand the public policy implications and the medical facts of HIV/AIDS and who are aware of the myths surrounding the disease will produce better stories. These stories will hold governments and communities accountable for their programmes, educate the public about prevention, offer methods for coping with the disease, and discredit stereotypes surrounding HIV/AIDS.

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