

Natalia A. Feduschak, a Kaiser International Fellow and a freelance journalist, wrote and delivered the following lectures about HIV/AIDS to journalism students at the Kyiv National Taras Shevchenko University and Kyiv International University between April 2005 and November 2006. The lectures are based on her own research and interviews conducted in Ukraine and Europe, through resources provided by the Kaiser Family Foundation, Transatlantic Partners Against AIDS, numerous Ukrainian non-profit groups and the experiences of people living with HIV/AIDS.

Lecture 5: Ethical Guidelines for Covering HIV/AIDS

Last week we discussed several aspects of how to report on HIV/AIDS and develop sources. This week we will look at ethical guidelines journalists should follow when covering the virus.

Ukrainians are full of preconceived notions about HIV/AIDS, one of the most prevalent being that it has nothing to do with them and does not merit their attention. Yet as we've seen from past lectures, HIV/AIDS long ago stopped being an issue that affects only a small group of people in Ukraine. HIV/AIDS concerns everyone. Journalists should not only tell the larger HIV/AIDS story, but also in ways that people see as being relevant to their lives.

Ukrainian journalists and editors have not yet developed ethical standards for covering HIV/AIDS issues. As the country's independent media develop and a core of journalists specializing in health issues is established, however, standards are likely to eventually be drafted.

Journalists from other countries, however, have established ethics guidelines for HIV/AIDS coverage. A number of those can be found at www.GlobalHealthReporting.org. One set of guidelines that merits mention was created by a group of South African journalists in 2004. Some aspects of the guidelines are specific to the situation in South Africa, but in general address many of the issues

Ukrainian journalists should be aware of when reporting on HIV/AIDS. Those guidelines can be found at www.GlobalHealthReporting.org under the “Reporting Tools Section” or through the link (<http://www.journalism.co.za/modules.php?op=modload&name=News&file=article&sid=1774>).

Another set of guidelines was developed for and endorsed by the Southern Africa Editors’ Forum. They can be found at www.journaids.org/ethics.php.

It is important to remember that the media do affect people’s lives and shape social thought. An inaccurate story can harm not only the people who have been the subject of a piece, but increase stigma and discrimination against people living with HIV/AIDS. The following are some of the guidelines taken from both South African groups that merit particular attention.

When reporting on HIV/AIDS:

1. Accuracy is critical, since important personal and policy decisions may be influenced by media reports. Journalists should be particularly careful to get scientific and statistical information right. Facts should be painstakingly checked, using credible sources to interpret information, verify facts and make statistics and science accessible and relevant to wide audiences. Sources should be named as often as possible. Stories should be written in context.
2. Misconceptions should be debunked, and any claims of cures or treatments should be reported with due care. Journalists should look at all stories critically.

3. Clarity means being prepared to discuss sex, cultural practices and other sensitive issues respectfully but openly.
4. Balance means giving due weight to the story, and covering all aspects, including medical, social, political, economic and other issues. Balance also means highlighting positive stories where appropriate, without underplaying the fact that HIV/ AIDS is a serious crisis.
5. Journalists should hold all decision makers to account in their handling of the pandemic, from government to the pharmaceutical industry and advocacy groups. They should be engaged with, but not captive to, any interest group.
6. Journalists should declare, and stay away from, conflicts of interests, or disclose if they received gifts or sponsorships from an organization when reporting a story.
7. When looking at privacy and confidentiality issues, reporters should note that:
 - The HIV status of an individual is private;
 - All individuals have the right to control personal information;
 - Children have a right to privacy (we will discuss this in more detail later)
 - The name or photograph of an individual with HIV should not be published without that individual's expressed informed consent. In obtaining informed consent, journalists, photographers and camerapersons should:
 - Clearly identify themselves when requesting to interview or photograph people living with HIV and AIDS;
 - State the purpose of the interview/photograph, the context in which these may be utilized and the potential ramifications for the individual, their children and other family members;
 - Consider whether the individual person living with HIV and AIDS is in a position to provide informed consent;
 - Remain sensitive to the dangers of implying, or placing a person in a situation that may imply, HIV status; and

- Avoid promises that cannot be upheld, such as the story will not be published in someone's hometown, or end up on the Internet;
- Media outlets need to decide if it is appropriate for individuals to sign consent forms as a means of protecting themselves in case of legal action later.

8. As we learned from earlier lectures, women have become the new face of HIV/AIDS.

Thus, the gender factor should not be overlooked in reporting stories. Journalists should be aware of and seek out the gender dimension of all aspects of the pandemic, from prevention to treatment and care, as this will add to the depth and context, as well as reveal new areas for reporting.

9. Be sensitive to the needs of people who have HIV/AIDS when interviewing them. For instance, if you have a cold or are not feeling well, it is best to postpone interviews. The immune systems of persons living with HIV/AIDS are often challenged and your illness may present a health risk to them.

Along with ethics guidelines, several other issues merit attention:

Children: This group is most vulnerable in society; particular care should be taken when dealing with the young. Many of the children in Ukraine who are HIV-positive are too young to know their status. For older children, it is not the journalist's place to reveal their HIV status to them. Be careful about questions asked, particularly those that are health-related. Do not comment on HIV/AIDS within earshot of children. As a rule, it is best to be accompanied by a worker from an orphanage or hospital when visiting either. Medical personnel tend to be very helpful while workers at orphanages feel they share a special bond with the children. Be sensitive to the needs of parents of HIV-positive children; their experiences are often quite different from those whose children are

considered “healthy”. These reports should also not be overlooked as potential stories. At the same time, remember that children have the right to participate in decisions that affect their lives. Thus, they also have the right to be heard, and their concerns should be reported, whether or not they know they are living with the virus. A supervising adult needs to provide explicit approval for a journalist to interview a child. In some cases, the journalist may want to have the adult sign a piece of paper authorizing the interview. For radio or television interviews, the journalist might want to have an audio record of the adult’s approval.

Use of names: Some people are willing to provide their names for publication, or be used on the air. Most, however, will not for fear of repercussion, whether from family, friends, employers or society at large. Don’t try to convince people to change their minds. HIV-positive individuals face a great deal of stigma and non-acceptance in Ukrainian society. Offer instead to use a pseudonym and then in the story make clear this is not the person’s real name. Couch information in such a way that it is difficult to identify a person, i.e. a drug dealer in Donetsk, a twenty-something sex worker in Odessa. Television reporters should shoot someone in shadow if necessary to shield the person’s identity while radio reporters should distort the individual’s voice. To be sure, some people believe these steps further stigmatize those living with HIV/AIDS. Thus, the reporter, editor and subject of an interview should decide ahead of time how best to protect a person’s identity. The decision may be that it is more important for the story to run than to withhold it.

Showing sources stories before publication: This is a difficult issue for many Ukrainian journalists, given today's media environment. As a rule, Western journalists don't show stories before they are published or aired because that opens the door for sources to censor information. If the question arises of showing a source a story before it is published or aired, however, the reporter should discuss this with their editor. A compromise might be to offer to show the source full or partial quotes, or the graphs where they have been mentioned, to ensure their words have not been taken out of context. Uncertainly over stories often arise because sources believe the journalist has not done a good reporting job. To that end, do not be afraid to call sources back several times to ensure you have understood them and the ideas they are trying to convey. The important thing is to be accurate. While it is important that journalists protect their sources, particularly when reporting on corruption, as a general rule, it is best to tape interviews, unless they are off-the-record or on background. Keep recordings, notes and any email exchanges you have with sources in a safe place should you need to protect yourself against legal action in the future.

Approvals: Make sure you have the necessary approvals to visit orphanages, hospitals, HIV/AIDS-related clinics or prisons. In cases where you are talking to HIV-positive individuals in a hospital, make sure that medical personnel know patients have given their approval to be interviewed. This is a backup in case there are any misunderstandings later. Be sensitive when speaking to people in a hospital environment. Not everyone who is in a hospital wants to be listening to an interview given by the person lying in the next bed, particularly if you are dealing with sensitive issues. When interviewing persons

in prisons, make sure you do not put yourself in a compromising position; follow the rules of prison officials. This is for your safety and that of the institution.

Breaking the law: Should a reporter break the law when covering HIV/AIDS issues in order to tell a more complete story? (I.e. one issue that has arisen in Ukraine is the ease with which adolescents are able to buy prescription drugs from pharmacies to get high. Should a reporter experiment and buy drugs to see how easy they are to purchase?) This is an issue that should be discussed with an editor to determine if the interview should take place.

Asking how someone acquired HIV/AIDS: There has been some debate between journalists and individuals in the HIV/AIDS community whether it is appropriate to ask someone who is HIV-positive how they acquired the virus. As a rule, journalists should ask themselves if knowing the route of transmission is really necessary to their story and what context it will be used in. If journalists are honest with themselves, they will often find that it is for their own interest rather than the story. Much, however, also will depend on the individuals themselves. Sometimes people who are being interviewed will offer the information, while others will want to do feel uncomfortable because they fear the journalist and public will pass moral judgment on life choices that they made, (i.e. why they started using drugs or going into the sex business). The reporter can too easily pass that judgment on in a story.

Kalpana Jain, a journalist and consultant with the Kaiser Family Foundation, shared her views on the subject in the version of the Kaiser reporting manual that was published in India:

“During interviews with (HIV) positive people, it almost became an unspoken condition that the route of transmission was not to be discussed. In fact, I felt that just asking this one question would seem judgmental on my part. It seemed to be so sensitive an issue with people living with the virus that I feared breaking a bond of trust that was building with those who were allowing me access into their very private spaces. Gradually I realized that people living with HIV are extremely sensitive to these moral judgments.”

Use of Language: The kinds of words journalists use in their reports can go a long way in lowering stigma and discrimination toward people living with HIV/AIDS. The Kaiser Reporting Manual lists many of the terms that should not be used in stories and provides suggested alternatives. It also provides an explanation of why certain words should not be used. Also guard against sensationalism, whether in the tone of a story or language used in a headline.

Paying for Interviews: Sooner or later, the question will arise should an interview be paid for. It is generally best to stay away from this practice. Once such a transaction occurs, the question will always remain if the information was reliable or “spruced up” in some way to fit a story. Sometimes, however, the person being interviewed is so poor that they aren’t able to even feed themselves. In that case, if appropriate, the journalist

may consider conducting the interview over a meal, for which they will pay. Again, these decisions should be made with the editor before reporting a story begins.

Emotional issues for journalists when reporting on HIV/AIDS: Reporting on HIV/AIDS can be emotionally difficult. Although reporters will try to remain objective, it is sometimes hard not to get emotionally involved in the lives and problems of the people they are interviewing. Hard as well is dealing with the death of an HIV-positive source, particularly if the individual was special to the reporter. There are no magic answers. Outreach workers, who interact with people who are living with HIV/AIDS on a daily basis, however, have said it is important to maintain a balance. Reporters need to understand they won't change all the problems related to HIV/AIDS. But if they are doing the best job they can in accurately reporting the situation with HIV/AIDS, then that is a good first step in dealing with the emotional issues.

Reading:
From Kaiser Reporting Handbook, Recommended Phrases

Exercises:

- 1) Have students read the Recommended Phrases section out loud in class and discuss why certain phrases sound better than others.
- 2) If students have been assigned to write a story on HIV/AIDS, have students critique each other's pieces, looking for word usage and tone of an article (i.e. is it judgmental) in particular.