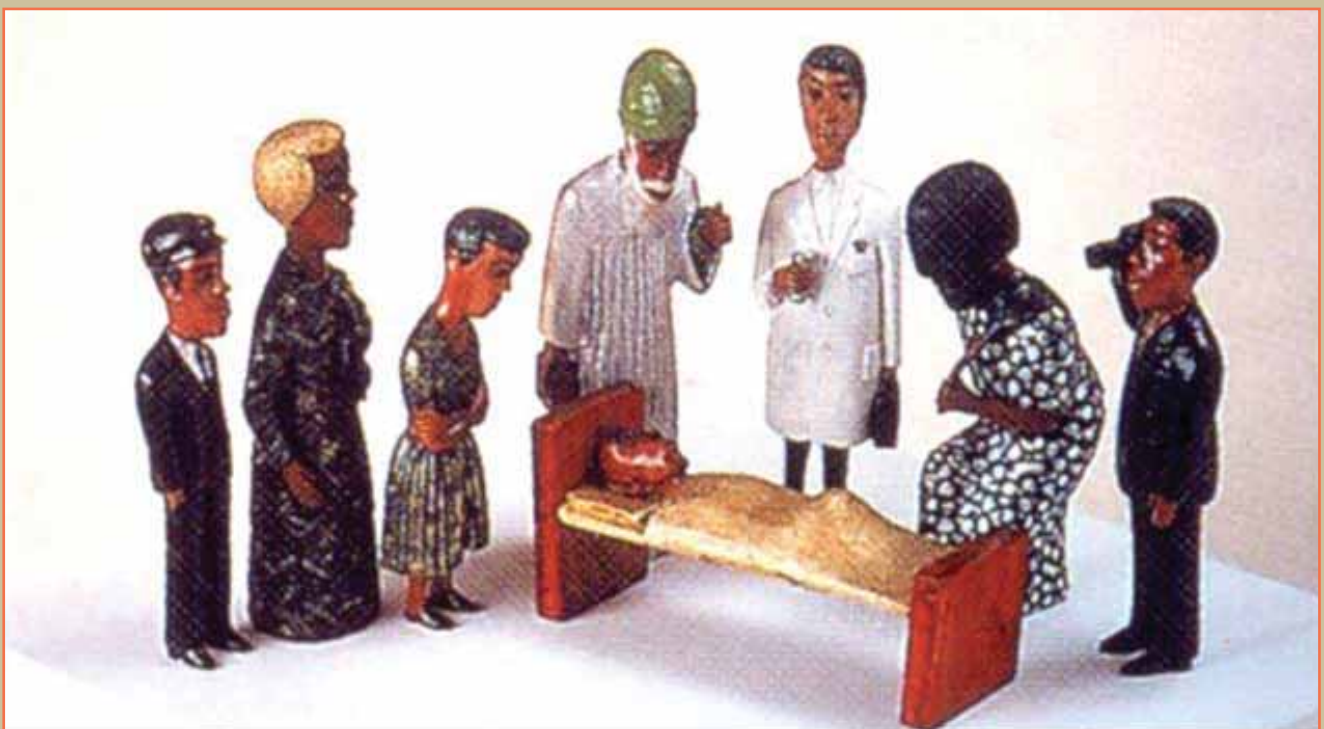


SECRETS AND LIES?

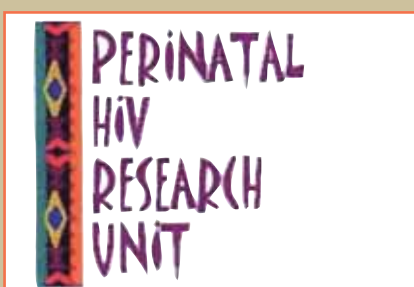
The ethics of HIV/AIDS reporting in South Africa

An HIV/AIDS Indaba hosted at the Nelson Mandela Foundation
in partnership with the HIV/AIDS and the Media Project



Johannes Mashego Sagogela

At the AIDS victim's bedside: patient in bed, his sangoma, priest, doctor, wife, son and daughter, and a TV cameraman



There is a good deal of criticism of HIV/AIDS coverage in South African newspapers. At the same time, journalists trying to provide better coverage are grappling with complex issues of how best to treat the issue. A discussion forum entitled "Secrets and lies? The ethics of HIV/AIDS reporting in South Africa", on the 1 February 2005, hosted at the Nelson Mandela Foundation in partnership with the HIV/AIDS and the Media Project, brought together these journalists with activists, scientists, doctors and others to debate how HIV/AIDS should be reported, and how the news media can best contribute to the battle against the pandemic. The forum was chaired by **JOHN PERLMAN**, journalist and host of AM Live on SAFM.

All photographs by **ELLEN ELMENDORP** ellen@mweb.co.za



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JOHANNA HANEFELD

"HIV/AIDS and the Media: a Global Perspective"



PANOS

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Johanna Hanefeld coordinates the Panos Global AIDS Programme from Panos Southern Africa in Zambia. The Panos Global AIDS Programme is a network of autonomous Panos offices in Europe, Asia, Africa and the Caribbean working with media and communication methodologies on participation, ownership and accountability in the fight against HIV/AIDS. Johanna's research interests include access to treatment and the role of media and communication in policy formulation. For the past three years she has been working with journalists in developing countries around the world.



PROFESSOR THOMAS COATES

"The United States Media and HIV/AIDS"



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Thomas J. Coates PhD joined the Division of Infectious Diseases at the UCLA David Geffen School of Medicine in 2003. Prior to that, he was at UCSF for 22 years where he directed the Centre for AIDS Prevention Studies and the UCSF AIDS Research Institute. His areas of emphasis and expertise are HIV prevention, the relationship of prevention and treatment for HIV, and HIV policies. His domestic work has focused on men who have sex with men, and he recently completed a nationwide clinical trial of an experimental HIV preventive intervention focused on this population. He is directing a community-randomised clinical trial in South Africa, Zimbabwe, Tanzania and Thailand to determine the impact of strategies for destigmatising HIV on HIV incidence community-wide. He was elected to the Institute of Medicine in 2000.



FRANZ KRÜGER

"Ethics in a time of AIDS"



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Franz Krüger is a journalist of over 20 years' experience. He has worked in print and broadcasting in South Africa, Namibia and the UK, at media groups ranging from the BBC and the London *Guardian* to East London's *Daily Dispatch* and the *Windhoek Advertiser*. He was founding group editor of East Cape News Agencies, a network of independent news agencies during the eighties which was subjected to considerable repression at the hands of the apartheid government. As national editor of radio news and current affairs at the SABC from 1994 to 1999, Krüger formed part of the first post-apartheid management team at the corporation and helped achieve a significant turnaround in the credibility and quality of radio journalism at the corporation.

PANEL DISCUSSION

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"HIV/AIDS AND THE MEDIA: A GLOBAL PERSPECTIVE"

BY JOHANNA HANEFELD

INTRODUCTION

I will focus on the media's role, its impact and potential in the fight against HIV/AIDS. After briefly looking at some of the changes that the media's undergone over the past years I'll take an in-depth look at trends in reporting and I'll focus particularly on the region of Southern Africa. Panos tends to work with developing countries so I'll feed some of the global perspectives into that. I'll show some of the challenges in working with media on HIV/AIDS and share some of the experiences of our network of offices around the world and how they've tried to meet these challenges.

WHY FOCUS ON THE MEDIA?

In over 20 year of responding to the epidemic there are frightfully few successes. However where significant efforts have been made there are some factors that appear throughout as success examples of fighting HIV/AIDS.

FIRSTLY, there's a central role for civil society – a very politicised community response (just like the Treatment Action Campaign) – which provides local expertise, knowledge and ownership.

SECONDLY, strong political leadership is required – Uganda may be the most famous example of that. Crucially there should be an environment where dialogue and debate can flourish and where communication can take place at every level of society. This is the key ingredient in changing the underlying inequalities that fuel the epidemic, such as gender inequality and poverty. This approach has been summarised under the umbrella or term of "communication for social change" by the Rockefeller Foundation, the Communication Initiative, Panos and UN agencies.

Finally, in facilitating all of these different viewpoints, an engaged and strong media play a crucial role.

SO WHAT IS THE ROLE OF THE MEDIA IN THE FIGHT AGAINST HIV/AIDS?

- ▶ Information provision: correct and accurate information about modes of transmission, prevention, treatment and care.
- ▶ A platform for public debate and for



communicating community responses and concerns: this is a very powerful aspect of the role of the media. If given the opportunity media can channel the concerns of the poorest and marginalised to national policy makers to international audiences. Examples are radio listening clubs, community radio stations and community programming on national broadcast channels.

▶ The media play a key role in holding politicians accountable for the use of funds and the way in which response to the pandemic is designed.

▶ Media enforce good governance and they challenge governments to provide treatment, care and support for people living with HIV/AIDS. This is a function that really needs to be strengthened. There is a lot of potential but I would argue it is not fully realised.

▶ Media's reporting has an enormous effect in terms of how HIV/AIDS is viewed and as a consequence of that, an enormous effect in terms of stigma and discrimination. Initial reporting of HIV/AIDS in the Southern Africa Development Community (SADC) region portrayed HIV/AIDS as an alien, western disease associated with a "particular lifestyle". In the West, in the United States (US) particularly, it was portrayed as a "gay plague" within certain sectors of society. It took Magic Johnson to announce that he is HIV positive to change some of those attitudes. Thus, media are possibly the most powerful tool in humanising and normalising HIV/AIDS and taking it from a "disease"

status to a day-to-day reality of our lives.

All of the abovementioned points have now gained a particular urgency within the context of the treatment rollout. Provision of treatment literacy information, monitoring resource flows (as unprecedented levels of funding are disbursed) and providing a platform for social movements that deal with treatment access are some of the areas in which media should play a role.

SO WHAT HAS THE IMPACT OF THE MEDIA BEEN?

▶ Media have influenced individual behaviour. The World Service Trust Detective VJ series in India had an HIV-positive lead actor. A survey of 10 000 viewers was carried out where 30% said they changed their behaviour as a direct result of watching the series. This behaviour change included going for an HIV test or starting condom use.

▶ The media can effect societal change. For example, in Zambia radio listening clubs have highlighted rural women's concerns in remote communities. Here women discuss their concerns about HIV/AIDS on national channels, achieving national policy change and a national debate.

▶ The media is critical in challenging our norms and attitudes about sexuality. In Kenya men who have sex with men has been acknowledged as a mode of transmission following media reporting around the issue.

▶ The media have successfully influenced policy around HIV/AIDS. I'm sure South Africans are more familiar with this than I am.

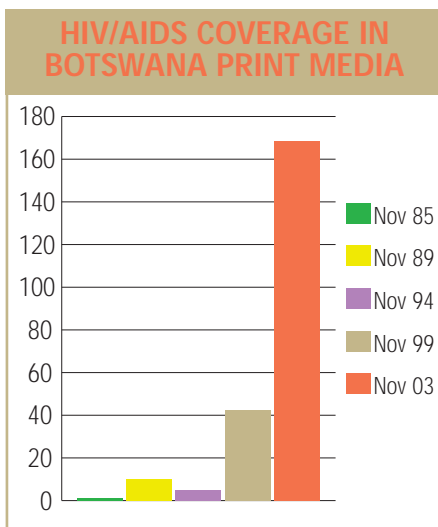
However, we have to acknowledge that the role of the media does change. Liberalisation, privatisation, new media formats and technologies shape the spaces of communication in which information emerges. These allow greater pluralism, access to information, democratisation and responsiveness of the media. Already networking and mushrooming of community radio stations is providing greater access and possibilities for bottom-up communication, enabling civil society to mobilise itself instead of being mobilised by top-down communication approaches.

But the media are becoming increasingly commercialised and these kinds of pressures can mean being more prone to sensationalism and chasing an easy story. Issues of drug resistance, supplies and equity of

access could lead to media sensationalism with profoundly negative consequences. The recent Nevirapine controversy in South Africa is a good example.

IF WE LOOK AT MEDIA COVERAGE IN DEVELOPING COUNTRIES OVER THE PAST 20 YEARS WHAT ARE THE TRENDS?

Panos Southern Africa has just published a study of reporting in eight SADC countries. Overall there's been a huge increase in reporting across the region and across the continent. The following graph illustrates this point:



Paper	Year	Number of stories
Times of Zambia	1985	11
	1992	30
	2000	75
	2003	124
Zambia Daily Mail	1989	28
	1995	43
	2003	71
Post Newspaper	1993	2
	2002	75
	2003	170

Source: Lessons for today and tomorrow: An analysis of HIV/AIDS reporting in Southern Africa. Panos, Zambia: 2004.

In terms of the quality of reporting, there has been a market change. Initially, there were stories of fear, portraying HIV as “killer disease” but this has changed to feature stories of hope and positive living. This is mirrored in the language of reporting. A tremendous impact has been made in terms of training and the way in which people living with HIV/AIDS are now portrayed. Terms such as “killer disease” and “AIDS victims” have virtually become unacceptable.

Despite the very many positive developments, many challenges remain. The full potential of the media in the fight against HIV/AIDS is yet untapped, especially in Sub-Saharan Africa. Many political and legal constraints are present. HIV/AIDS is very politicised and sensitive, especially given the level of donor funding coming into very poor countries. Government officials are very eager to be seen making the best use of funds.

Many of the editors we interviewed openly said that they were very reluctant to criticise the government too much: critical reporting is acceptable, but not for prolonged periods. There's still a great lack of resources and capacity on HIV/AIDS reporting in Southern Africa. Across the region and across the continent it is very hard to find a designated HIV/AIDS desk or even a health desk. This has consequences in terms of factual errors. Currently, the gun is pointed at the treatment rollout. Antiretroviral (ARV) treatment is a relatively technical issue. We found that microbicides were repeatedly being described as therapy instead of a preventative tool, which is a simple factual error.

There is still a lack of articles focusing on the perspectives of people living with HIV/AIDS. Overall coverage is on urban focused events and is personality driven. In a Kaizer Family Foundation study conducted at Princeton University it was found that coverage of HIV/AIDS in the US has increased in the South and decreased in the North. There is also a clear downward trend as HIV/AIDS competes with poverty reduction measures and the fight against terror (see chart 5).

WORKING WITH THE MEDIA: WHAT WORKS AND WHAT DOES NOT?

▶ Engage editors and journalists on a longer-term basis. Editors and journalists should be trained together. The editor should be sensitised so that the journalist is not frustrated by hearing “why should I print that?” after writing the story.

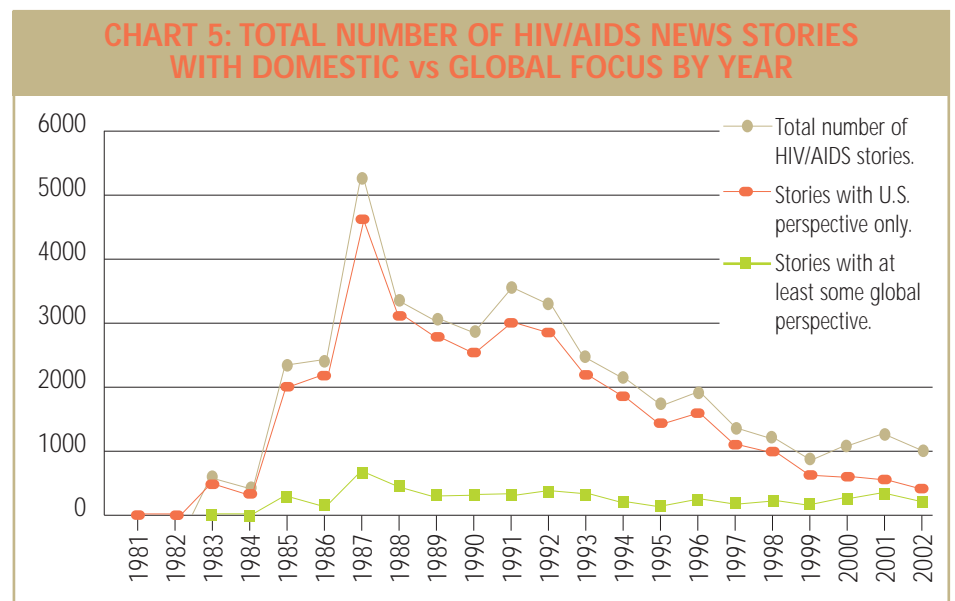
▶ Integrate thematic and technical training: move your workshop out of the office, take journalists on a field trip where they can interview and take along a technical trainer if you have one.

▶ Work through informal networks.

▶ Integrate and coordinate interventions across different organisations, so there is a longer training programme in place, instead of merely a series of once-off workshops. There are some steps being taken: the Communication Initiative, Panos and the Aids Media Centre are trying to do coordinate different media training activities so that there is less duplication.

▶ Research and understand the pressures and environment in which media operate. Our interventions need to engage with the pressures and realities of media institutions.

In conclusion, the media play a key role in fighting HIV/AIDS and ensuring a successful response, including a successful treatment rollout. There are some very positive signs in Southern Africa but there are enormous pressures and challenges remaining. We need to then actively change media environments to create the opportunity for them to fulfil their role in the fight against HIV/AIDS.



Source: AIDS at 21: Media Coverage of the HIV Epidemic 1981-2002. Kaiser Family Foundation, Princeton Survey Research Associates International; CRJ 03/04 2004: NY

"THE UNITED STATES MEDIA AND HIV/AIDS"

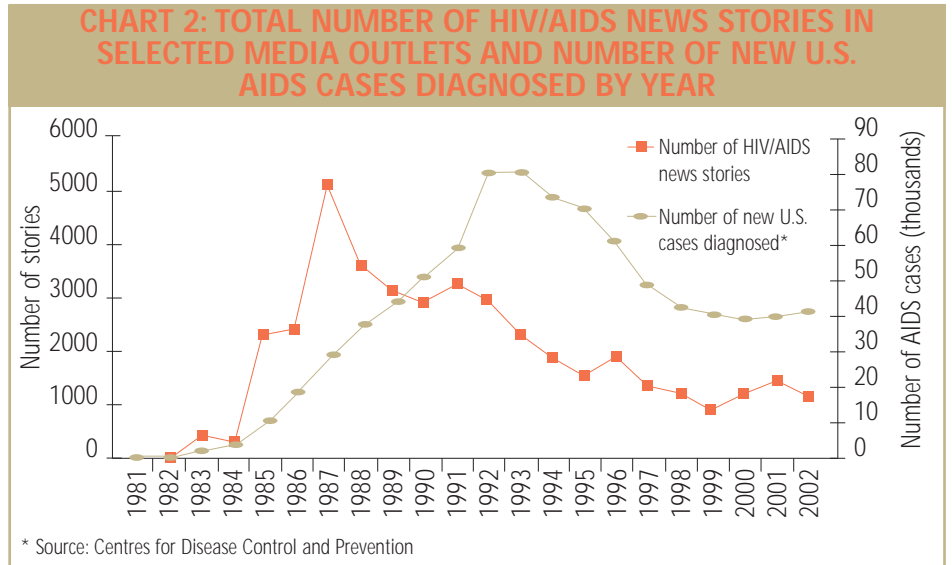


BY PROFESSOR THOMAS COATES

I don't want to pretend to be able to talk about, discuss, analyse or give advice about media and HIV/AIDS in South Africa, so I thought I what I would do is talk about our experience in the United States and the lessons we've learnt in dealing with media issues.

I WILL COVER THREE POINTS:

- ▶ How the media have covered HIV/AIDS and the changes that have occurred
- ▶ How the media might have been used



and currently are being used to highlight prevention and treatment.

▶ The difficult issue of media portrayal of people with HIV or people with AIDS and how the media have a difficult time with this.

It is important to remember that as we're discussing HIV/AIDS and the media, it is in a very deliberate context of the short-term sound bite and the pursuit of beauty, at least in the United States (US).

In the US, throughout the 80s and the 90s, the portrayal of HIV/AIDS was of a disease, a disabling disease and a disease that killed people. In a recent book about the history of the gay movement in San Francisco, 1980-1991 was referred to as the "plague years". Every year in San Francisco there is still a candle light memorial to commemorate people with HIV/AIDS. A sign of the times is that it is getting harder and harder to get people to turn out for this memorial. In a sense, and I

think this is going to be one of my main messages, at least in our part of the world, people have moved on to other issues. The difficult question is how and why we keep a focus on this issue.

Looking at some of the data from the Kaiser Family Foundation study that Johanna used, I think there are certain conclusions that we can draw in looking at the issue of HIV/AIDS in the US population.

FIRSTLY, it's not as important as it used to be (see chart 1). In 1987 68% of the respondents reported HIV/AIDS as the most urgent health problem facing the world. By January 2002 it was down to 17%. In the world it's much higher – 33% – but clearly the reduction is perhaps a natural human response. We can only sustain attention for so long, we do like novelty. HIV/AIDS has now become a chronic illness; it's certainly become part of the human condition. It may be a disease that's never eradicated from the world. It's another one of those terrible diseases that kill a lot of people.

SECONDLY, there is a decline of interest in HIV/AIDS stories in the media. In the US it does collerate with the reduction in AIDS cases. Chart 2 shows the peak of reporting and the peak of AIDS cases, the darker line being the number of HIV/AIDS news stories and the lighter line being the number of new HIV/AIDS cases diagnosed.

The big decline occurs in 1995/1996, with the introduction of combination therapy. But as you can see the stories of

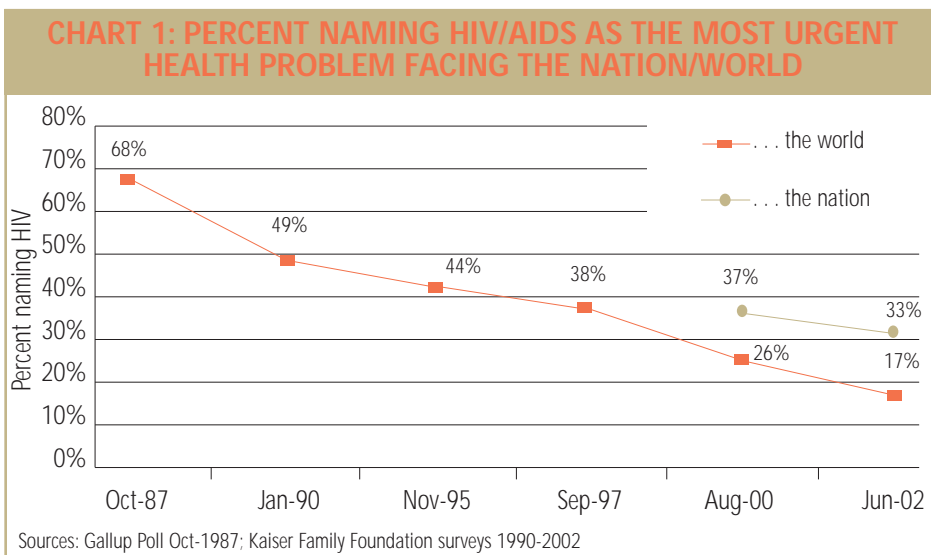
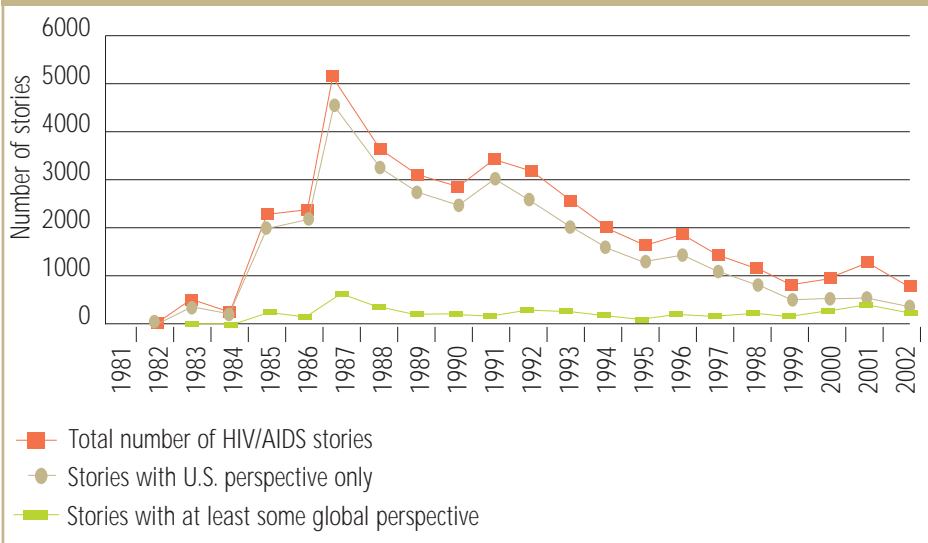


CHART 5: TOTAL NUMBER OF HIV/AIDS NEWS STORIES WITH DOMESTIC vs GLOBAL FOCUS BY YEAR



Source: Centre for Disease Control and Prevention

HIV/AIDS really have declined markedly. When I talk to reporters these days, they ask me “What’s new? What’s the angle? What’s the information?” They’re really looking for science. They’re really looking for new bits of information. Reporters really are trying to look at the new angle to which they should be paying attention.

THIRDLY, coverage of key events is not surprising. As you can see in Chart 3 the key event occurred early in 1987 when AZT was approved in the US. Another peak is when Magic Johnson announces he is HIV positive in 1991. Even though there’s a general decline, there are some peaks associated with various events:

President Mbeki questioning whether or not HIV causes AIDS and the creation of a Global Fund. But there is not as much coverage as one would have expected from the US media.

The trends are the same as described by Johanna. In the US language has changed from “disease” and “hopelessness” to “chronic” or “manageable disease”. There is also a decrease in stories with a consumer focus and an increase in human interest stories.

In Chart 5 we see that stories with a global perspective have increased somewhat but this is in a context of decreasing coverage

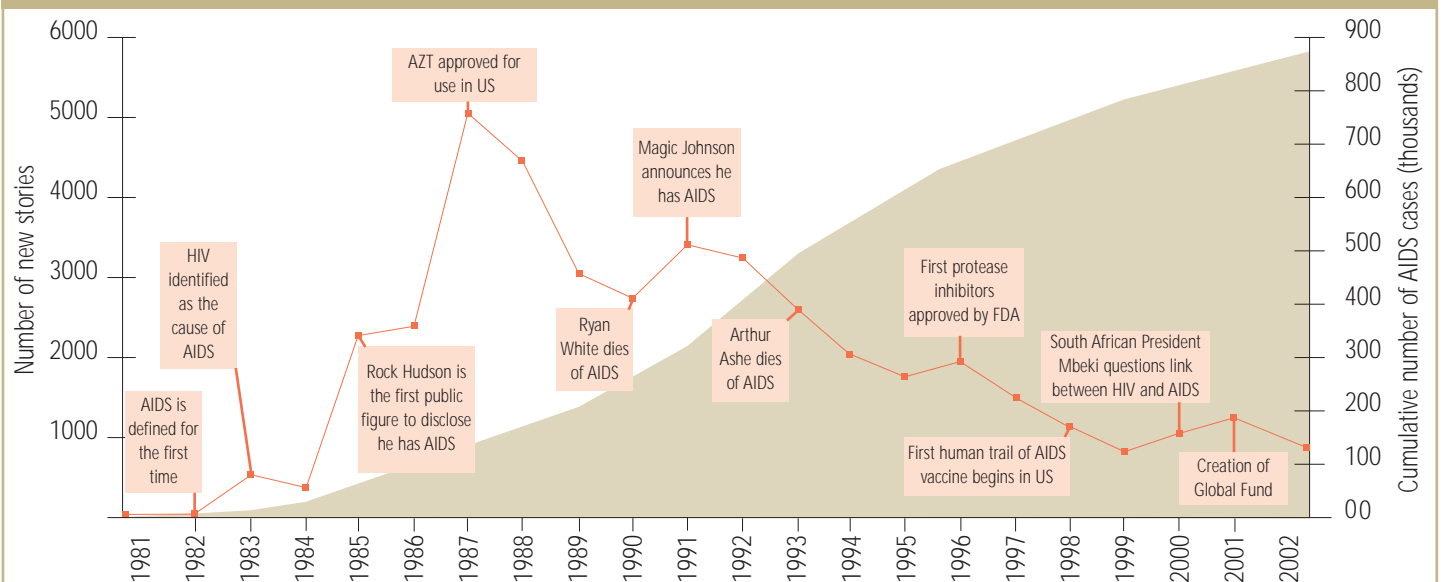
of HIV/AIDS in the US media. Interestingly, a global perspective is more likely in broadcast than in print media and more likely in nationally focused print media. For example, *The New York Times* and *USA Today* have very good coverage of the issue.

Chart 7 (opposite) shows that stories have become more pessimistic lately and this I find interesting. While there may be greater hope and optimism in South Africa, in the US we’re seeing more pessimism. In 2002 we see a decline in the optimism expressed in the stories and an increase in the pessimism expressed about the ability to deal with the enormity of the issue. Of course there’s been also an increase in interest in the relationship between economics and HIV/AIDS.

The most optimistic period of reporting was 1996 to 1999, with the introduction of highly active antiretroviral therapy (HAART), a dramatic decline in debt due to HIV/AIDS and an increase in HIV/AIDS as an economic issue. The Kaiser Family Foundation has analysed the nature HIV/AIDS stories over time. There is a decline in stories about social issues and HIV testing and increased stories about government funding and philanthropy.

The image of HIV/AIDS has been of “sufferers” – people left without families and caregivers. But there is also another side to the story in the US. There is the victim’s side and then there’s the victimiser’s side that is emerging. Now that HIV positive people are no longer victimised in the

CHART 3: TOTAL NUMBER OF HIV/AIDS NEWS STORIES IN SELECTED MEDIA OUTLETS WITH KEY EVENTS AND CUMULATIVE U.S. AIDS CASES OVER TIME



* Source: Centers for Disease Control and Prevention

■ Cumulative number of U.S. AIDS Cases*
 ■ Number of HIV/AIDS news stories

United States there's a portrayal of people with HIV/AIDS as victimisers.

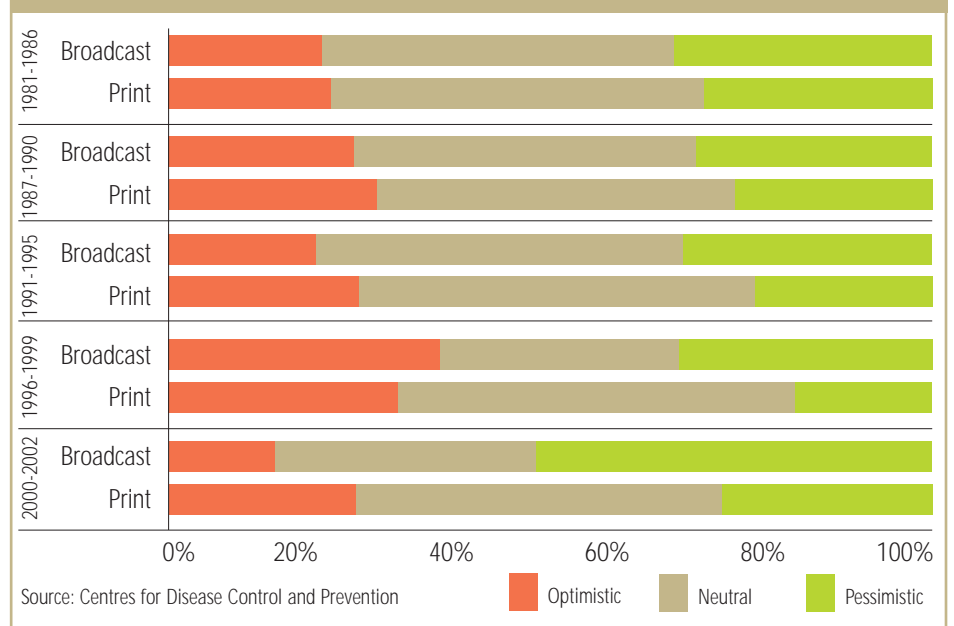
The other question then, is how can the media be used to prevent transmission? It has become more and more difficult to address this question, as HIV/AIDS is less of a frightening disease in the US.

The director of Sexually Transmitted Infections (STIs) services in San Francisco started running prevention posters around town when we started seeing an outbreak of syphilis among the gay community. We conducted focus group work and created an advert as a possible counterpoint to the "man on the mountain top" message, showing that HIV medications do have side effects. But one runs the risk of doing something like this. That is, one runs the risk of having people stay away from getting tested. The Staff Aids Foundation did in fact run a set of adverts to try and convince people that "HIV/AIDS is no picnic." There was another attempt to get people with HIV/AIDS to take control of the illness and it was called "HIV/AIDS stops with me". It was an attempt for HIV positive people to come out to be shown on television and say that they believe in themselves.

So what are we going to do in the US?



CHART 7: PERCENT OF OPTIMISTIC/PESSIMISTIC STORIES BY PERIOD AND MEDIA TYPE



One of the main problems is that we do have a schizophrenic relationship with regard to HIV/AIDS and the youth where HIV/AIDS is most likely to spread. We have incredibly sexually energised advertising focused on youth and yet are terribly criticised when using the same methods to focus on prevention. For example, an

advert was produced by the San Francisco Aids Foundation, called "Life, Liberty and the Pursuit of Happiness" (which is the beginning of our Bill of Rights) and was seen as too risky because of the portrayal of two gay young men draped in the American flag. But there is also some incredible advertising and media focus on the gay community. American Airlines ran the advert "Intolerance just doesn't fly" and Mercedes Benz ran "All cars are not created equal. All people are."

It is difficult to say what do should do about all of this. The Institute of Medicine and other groups have said the HIV/AIDS crisis is not over but it's hard to get the public to pay attention. We still have 40 000 cases of HIV, probably more, occurring in the US annually and the incidence is increasing.

The main objective that the US media now need to focus on is increasing donations to the international effort. But you have to understand that this occurs in a context. And that context in the US is that the US accepts inequality. Inequality is at the cornerstone of our society and we have had study after study since the 1930s that have shown that African-American people die sooner from every disease and HIV/AIDS is no exception.

So the challenge is: how can we now use the media to portray the epidemic, particularly in developing countries where 95% of the cases occur, in a way that will motivate the American public to encourage their legislators to want to give more money to development? I suggest that coverage will have to be solution oriented.

“ETHICS IN A TIME OF AIDS”



BY FRANZ KRUGER

ASSUMPTIONS

A few years ago, there were quite strident calls in this country for journalists to change their ethics to bring them into line with African cultural realities and the new political order. In the wake of its controversial inquiry into racism in the media, the Human Rights Commission (SAHRC), for instance, recommended that “the current codes of conduct and various declarations that exist be reviewed . . . to ensure that they are consistent and in line with the current constitutional requirements and that they properly reflect the role of the media in a democratic society”.¹

In the wake of that call, the SA National Editors’ Forum (Sanef) and the SAHRC organised a conference, which ended inconclusively, and after that I embarked on a research project to find out what South African editors really thought were the principles that should guide their work. What emerged for me in around 30 in-depth interviews was that the new generation of editors didn’t feel that there was anything particularly inappropriate about the basic principles of independence, fairness, accuracy and the like. Interestingly, research done by Clifford Christians and Michael Traber, among others, has found the existence of what they call “proto-norms” - standards that all cultures value.²

CHANGING ETHICS IN CHANGING CIRCUMSTANCES

What did – and still does – need thought, though, is how those principles are applied in changing circumstances. The last ten years have seen some quite fundamental changes in South Africa. We usually think mainly about political change, but the first decade of democracy has also been marked by the eruption into our consciousness of the HIV/AIDS pandemic.

The South African experience seems to me to be an excellent case study about what happens to ethics in transitional soci-

eties, when the ground under them moves, so to speak. And the reporting of AIDS, specifically, has shown some particular shifts.

Two deaths, and the contrasting ways they were reported, provide a good illustration of this principle at work. First, there was the death in 2000 of presidential spokesperson Parks Mankahlana. Several news media reported speculation that the cause of death was AIDS, which caused a huge controversy that divided journalists along broadly racial lines. For some, reporting the speculation was justified because openness about AIDS is so important in fighting stigma, and because his previous statements on the issue aligned himself with a dissident view on HIV and AIDS. For others, it was racist, culturally insensitive, an invasion of privacy, and politically motivated.

ANC leader Peter Mokaba was among those who were sharply critical. At Mankahlana’s funeral, he said: “The media has disappointed us and I do not know how they are going to repair the damage. A comrade passes away, a comrade who served them well . . . and they want us to bury him with diminished status.”³

About 18 months later, Mokaba was also dead, under very similar circumstances. He had been a vocal proponent of the dissident view on HIV and AIDS – in his own right, not as spokesperson for anyone else, as Mankahlana had been. He was comparatively young, and the speculation was very strong that his death was also due to AIDS.

But the media handled this death in a different, and much more restrained way. There was no quoting of “informed sources” on the cause of death. *The Star* wrote merely that “The cabinet has refused to speculate on Peter Mokaba’s HIV status”.⁴

It is possible to identify two factors that made reporting of the second death so much more muted than the first. For one thing, the national debate around HIV and AIDS had shifted significantly – the dissident view had become much more marginal. Just before Mokaba’s death, the cabinet had accepted the value of antiretrovirals (ARVs), and the orthodox medical view of the disease. In addition, the fact that the reporting of Mankahlana’s death had caused such an outcry made journalists more cautious in handling the second. It wasn’t just a question of being intimidated.



Much of the criticism came from within, from black journalists who were senior figures in the newsrooms. Their views had to be taken seriously.

The handling of these two deaths illustrates the premise that basic principles are pretty fixed, but their application can shift. Journalistic ethics worldwide talk about respecting rights to privacy. They also talk about the public interest. These same principles were in contention in both cases. In Mankahlana’s case, the public interest was seen as weighing more heavily as his – and his family’s – right to privacy. In Mokaba’s case, privacy seemed to weigh more heavily than the public interest, and reporting was more restrained.

THE CHALLENGE OF HIV AND AIDS

If ethics have to respond to new situations from time to time, the question arises of what happens when those principles are read against the comparatively new reality of the HIV/AIDS pandemic. What kinds of specific challenges does HIV and AIDS pose to journalistic ethics?

A very useful and highly influential trio of principles was developed in the United States (US) in the early nineties by the Poynter Institute, on the basis of detailed interviews with hundreds of journalists and editors, and a close reading of many codes of conduct. These are⁵:

- ▶ Seek truth and report it as fully as possible, which seems to me to have two major legs: the need for accuracy, and the need for fairness.
- ▶ Act independently
- ▶ Minimise harm
- ▶ A fourth principle is sometimes added: accountability.

ACCOUNTABILITY

This simply means journalists should be prepared to defend their decisions. It is probably unnecessary to spend a great deal of time on this one.

MINIMISE HARM

This is slightly more complex. It needs to be thought about at the individual level, as well as the social level.

This is where the issue of **STIGMA** arises because it's the reason why journalists can do such serious harm to individuals. Why is it that a mere health problem has so much baggage? It is useful to be quite specific about this. Journalism, after all, should be about clarity, and the phrase "the stigma of AIDS" can itself become a euphemism, unless we remind ourselves exactly what that stigma is about.

A very useful booklet for journalists says: "Infected people are 'blamed', labelled as 'bad' people who in some way deserve Aids as a punishment."⁶ One can be even clearer: the stigma arises because in many minds, infection indicates an immoral lifestyle: promiscuity, homosexuality, drug use. That's why Peter Mokaba could say the reporting of his colleague's death was diminishing his status.

Stigma is very real. It hurts people, even kills, as the example of Gugu Dlamini shows. As journalists, we need to take it very seriously.

The right to privacy is enshrined in the constitution, it is a legal right and an ethical duty. The press code of conduct says: "In both news and comment, the press shall exercise exceptional care and consideration in matters involving the private lives and concerns of individuals."⁷ We all value the right to keep things about ourselves to ourselves.

In concrete terms, it means taking great care when it comes to reporting on people's status. Their story, the way their family deals with the situation, medical details – all of this belongs to their private sphere, over which they have control.

The issue has a particular slant where, as is so often the case, journalists are dealing with people who are poor and disadvantaged. They need to take particular care not to bulldoze people, pushing them into doing something they may not really want to do.

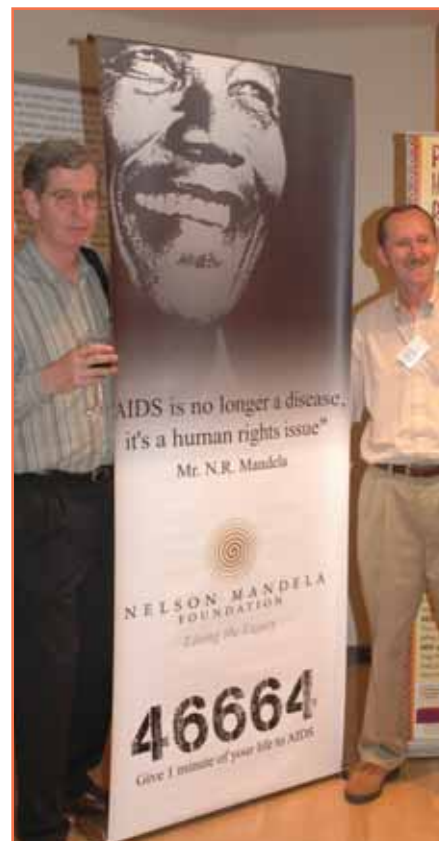
The very useful code of conduct⁸ developed by the *journ-aids* website talks about **INFORMED CONSENT**, which means making sure that people journalists want to report about know and have thought through the implications of putting their

lives on public display. This means journalists identifying themselves, explaining clearly and honestly what is intended, speaking in their language, avoiding promises that can't be kept and so on. The code also insists that people living with HIV and AIDS must have informed their family. That seems to give the journalist a little too much responsibility. Ultimately, it's not up to journalists to manage their lives.

The stress so far has been on the individual's rights to privacy, but the public right to information needs to be taken no less seriously. Journalists' first loyalty is to the audience. And it is critically important that the story of HIV and AIDS is told fully and well. The press code, in dealing with privacy, does include the rider that it may be overridden by a legitimate public interest.

On occasion, this may mean overriding an individual's rights to privacy. The *journ-aids* code says that instances of this kind include cases where a crime, anti-social conduct, threats to public health and safety or hypocrisy are being exposed.

I think journalists need to be very sure of themselves before they decide to go this route. Undoubtedly, openness is an important principle, but that doesn't mean people can be dragged into the trenches of this battle if they don't want to be there. After all, it's a matter that touches the most intimate spheres of their lives. Also, the stigma may affect their families – a partner, even children.



In a broader sense, journalists have a duty to minimise harm to society as a whole by reporting in a way that does not further irrational fears and myths, stereotypes and stigma. It means encouraging openness and it means being careful about **LANGUAGE**. Various documents provide lists of problem words and expressions, and there's no need to do so here. But it is interesting to note recent findings by the Panos Institute, which tracked the use of terminology in various countries. The institute's report says there has been "a marked improvement in terms of the quality and language used by journalists".⁹ A detailed, country-by-country analysis notes that there is unevenness between various countries. Swaziland, for instance, still lags behind.

INDEPENDENCE

This means keeping a distance from the various players, even those regarded as the good guys. The media have not had a problem with keeping a healthy distance from government, but it's just as important to maintain a healthy scepticism when it comes to the pharmaceutical industry and even Aids activist groups. A little while ago, the *Sunday Times* ran a prominent story about how the government was refusing free HIV tests. It turned out that the tests needed refrigeration, and there was a problem with tender rules. It seemed that the paper had been suckered by the public relations people of the pharmaceutical company involved.¹⁰

Journalists need to be wary of all the players, so as to be able to report honestly.

The requirement of independence also raises the issue of **PAYING FOR STORIES**. The expression "chequebook journalism" usually conjures up images of British tabloids paying vast sums for stories of minor royals behaving badly. But here we are dealing with people who really have almost nothing.

Sometimes, journalists will argue that it's not necessary to pay because reporting itself benefits people living with HIV and AIDS. In an article published in *the Star*, Kerry Cullinan of health-e news has dismissed that argument.¹¹ She writes: "Journalists cannot, in truth, say that anything concrete will come from our stories. Anyone who promises that their stories will lead to a flood of funds is lying. What is in it for journalists is crystal-clear: we are paid to write stories about HIV/AIDS, so we need those affected to open their hearts to us.

"To salve our consciences, some



journalists offer groceries or money in exchange for stories. While some may reject this ‘paying’ for stories as an odious tabloid-press habit, at least it offers benefits to both sides. The journalist gets the story and the family can eat for another month.” She does go on to argue that these arrangements remain unsatisfactory.

It is a difficult issue, but I do think the fact that audiences don’t, in general, trust stories that have been bought should be taken very seriously. And it’s instructive that the ethics social scientists use don’t allow for payment of interviewees either.

TRUTHTELLING

When considering this imperative, several points need to be made.

Journalists need to be accurate, that’s axiomatic. It means getting the **SCIENCE** right – knowing your ARV from your CD4 count, so to speak.

In a broader sense, it means **TELLING THE STORY FULLY**, describing the issue in all its complexity. It means reporting in a nuanced way about how the pandemic affects women differently to men, covering the rural areas as well as the urban, ensuring that it’s not represented as a “black disease.” The social, medical, personal, scientific, economic and the political aspects of this issue must all be covered. That kind of balance won’t be achieved in a single story, but it can be achieved over time.

It also means being careful about **WILD CLAIMS**. If somebody stands up and claims to have found a cure for HIV, there’s an ethical duty to at least find sceptical voices to counterbalance the claim.

In that context, the story of HIV and AIDS throws an interesting light on the principle of fairness. Ask any journalist, and you will be told that giving both sides of the story is absolutely fundamental. But journalists sometimes have to decide who the other side is. There was a time when Aids dissidents were taken a bit more seriously. But nowadays, nobody treats their views as having an equal claim to public attention as the orthodox views. When the government decides to roll out ARV treatment, newsrooms don’t say, “we’d better find out what David Rasnick thinks – it’s only fair.” The example of the Aids dissidents provides a fascinating example of the

way the application of ethics shift. It also illustrates a clash between the principle of **FAIRNESS** and the principle of truth-telling. Simply put, truth wins in this case.

A CHALLENGE TO FUNDAMENTAL VALUES

To conclude, I’d like to touch on how HIV and AIDS challenges our ethics at the most fundamental level.

Journalists are **LICENCED TRUTHTELLERS**. In this country, thankfully, that does not mean we are issued with a physical licence. But still, society allows us to do what we do because we perform a socially useful function. Our habit of asking embarrassing and sometimes stupid questions is tolerated, because society needs to know what is going on.

That basic function is mediated through all sorts of things. Almost all news media are also businesses. They develop particular audiences, generally those with disposable incomes. And so reporting is shaped by economic realities.

And journalists have developed news values to guide them. Stories are chosen on the basis that they will appeal to audiences. They need to be new, involve celebrities, conflict, surprise and much else.

But the story of HIV and AIDS doesn’t always fit neatly into these values. Journalists are great motion detectors: as soon as something moves or changes, we’re onto it. When it sits still, we can be very blind to it.

The story of HIV and AIDS did hit all the right buttons once: the conflict between Aids activists and the government made for great copy. But since that conflict has died down, it’s harder to write the story. Centre for AIDS, Research and Evaluation (Cadre), did a very interesting study on the media’s handling of the story.¹² One journalist told the researchers “HIV is boring”. Another said: “I mean how do you write about Aids orphans in a different way. How do you? ‘Aids orphans are all alone, they don’t have resources.’ What else can you say?”

“The story doesn’t change,” said an editor.

In addition, many audiences feel relatively unaffected. One editor is quoted in the same study as saying: “I don’t think Aids is going to kill our readers in the same proportion that it might kill other classes of people. The threat for our readership is an economic one, primarily.”

It seems to me that our news values, our normal practices, are actually in the way of our truth-telling duty, when it comes

to this particular story. Some have said we need to change our news values – I’m not sure that’s doable. Those values are very deeply ingrained.

But I think there are options. The normal news values are not as rigid as they are sometimes made out to be. Ours is a craft that values inventiveness, even though that may sometimes be hard to see in the grey expanse of everyday coverage. The classic hard news story may not easily lend itself to coverage of the pandemic. But there are other formats – it is often just a question of being inventive or original. *The Star* not so long ago invested considerable time and resources into the story of two women dying of AIDS. It ended up being a three-part series entitled “The fall of sparrows”. It was a great piece of journalism that deservedly won several prizes.

At bottom, the ethical challenge of HIV and AIDS is to tell the story properly despite ourselves. We need to find ways around our news values, and the sometimes myopic views of our audiences. We need to find ways to report on the pandemic in new and interesting ways.

All our ethics are built around the basic principle of truth-telling. If we want to be journalists worthy of the name, HIV and AIDS is the one story we need to tell well.

Footnotes:

¹ SA Human Rights Commission: *Faultlines: Inquiry into racism in the media* (SAHRC, Johannesburg, 2000), p83.

² Clifford Christians and Michael Traber (eds): *Communication ethics and universal values*, Thousand Oak: Sage, 1997

³ Agence France Presse report, 3 November 2000, posted at www.mg.co.za accessed on 22 September 2004.

⁴ *The Star*, 12 June 2002.

⁵ Jay Black, Bob Steele and Ralph Barney: *Doing Ethics in Journalism: A handbook with case studies* (Needham Heights, MA: Allyn and Bacon, 1995), p17.

⁶ *Health-e and Soul City: HIV/AIDS: A resource for journalists* (Soul City, Johannesburg, undated), p27.

⁷ *Press Ombudsman of South Africa: Press Code of Professional Practice* (Johannesburg, 2001)

⁸ Available at <http://www.journalism.co.za/modules.php?op=mod-load&name=News&file=article&sid=1774>.

⁹ Panos Southern Africa 2004: *Lessons for today and tomorrow: an analysis of HIV/AIDS reporting in Southern Africa* (Panos: Lusaka, 2004) p11.

¹⁰ Cited by Kerry Cullinan: *The media and HIV/AIDS: A blessing and a curse, paper presented to the Aids in context conference, April 2001.*

¹¹ June/July 2000, copy from author.

¹² J Stein: *What’s news? Perspectives on HIV/AIDS in the SA media* (Centre for Aids Development, Research and Evaluation, Johannesburg, 2002)

Posted at <http://www.journaids.org/pdf/Whats%20news.pdf>, accessed on 1 March 2005

PANELDISCUSSION

Due to space constraints the following is an edited version of the panel discussion. For full transcripts please visit www.journalism.co.za or email ridgardn@journalism.wits.ac.za



FREDRICK OGENGA, WITS JOURNALISM PROGRAMME:

[Johanna] talked about communication for social change. My question is what is the role of the media, especially media research, in shifting audiences' frames of thought about particular sensitive issues like HIV/AIDS [...]?

JH: Communication as social change has emerged from practitioners in the field such as Panos. Basically I think you need to find the communication that works for your particular audience. Quite often the communication environment or media's environment is such that you don't allow the people to use communication to bring out their issues and the media there has a great role. Things like community radio are absolutely brilliant in allowing things to come out which haven't come out before. [...] I think the media have an incredibly powerful role here and I think we need more research particularly about development environments in the poorest countries. Often a lot of the staff is funded externally by people who know incredibly a lot about communication but nothing

about the communication environment in that part of the country.

TC: It's a very tricky issue. I was going to say that the discussion here is all focused on journalism, as we typically understand it. I was a participant in a forum at ABC studios sponsored by the CASA Family Foundation and the purpose of the forum was to help about 200 scriptwriters come up with ideas for a typical TV series. The idea was to educate them so that when they portray these stories, they will portray them with accuracy and sensitivity and with a lack of bias, lack of racism, lack of homophobia and so on and so forth. However, it would seem that their principal goal is to make money [and] increase their readership/viewership. In fact if they are not going to be able to do that then it's not going to work. So I think our goal of trying to convey a message is subordinate to the larger commercial goal.

DR LYNN MORRIS, NICD:

Given that there is a code of ethics, how do you enforce that, how do you regulate yourself and I'm thinking particularly about journalists who continue to publish false information about HIV. How does one control that?

FK: Well, a short answer is that there is a press ombud in South Africa, and a Broadcast Complaints Commission of South Africa (BCCSA) to whom one can complain. The press ombud's powers are very limited. He can order a retraction and apology and that's about it. The BCCSA can fine the media for getting things wrong and for other transgressions – I think the maximum amount is R40 000. Sometimes you can go to court if you are personally liable [...]

In a broader sense: of course it is very frustrating isn't it? I mean, we have these set of rules and people don't pay much attention to them. I have to say also, from my personal point of view, that I think the rules themselves are quite inadequate. I think both the BCCSA and the press ombuds' codes have huge holes in them. I'm always been particularly struck by the fact that the word "independence" doesn't occur. In other states and areas independence is a big and important issue, and rightly so. We don't seem to think it is and I

think some of the fights we've had in the past show just how far we still have to go until we understand that particular value. I do think though that the kind of instinct that people often have to say, "we must clamp down, we must stop people writing nonsense" is a problematic one because freedom of speech is an important right. And it does mean that unfortunately some people will right nonsense.

But to try and address [Tom's] point, you're quite right media are commercial entities. They're there to make money. Even in this country the SABC's reliance on advertising income is 85% - it's massive. So our media are commercial and of course this shapes the decisions around which stories are going to be covered. I think ethics give us a tool to fight against these tendencies [...]



PROFESSOR JAMES MCINTYRE, PHRU:

I'm interested by whose truth gets told sometimes and how journalists pick whom to ask for comment. We're quite aware of that [...] we're Johannesburg based, we are known as a "rent-a-quote" organisation – Glenda will give a sound bite on anything – and it backfires because it's easy for people who disagree with what we're saying to say, "But it's only that group". How do we scientists express to our media colleagues to take that further, to get more views, to expand away from the usual?

FK: Well, journalists are often very lazy. The person who's the easiest to get hold of is the person who gets quoted. From a journalist's point of view there is a real duty to try and spread the range of sources. We often think of that in terms of race and gender. You pick up a front page of a newspa-

per, you do and analysis of who's being quoted: they are white males. And clearly there's a duty to shift that. And I think the same applies in the context in which you're speaking. I think there's a great duty to go out there and find different voices [...]

JH: In the rest of the African countries there's not that much competition of experts who would give sound bites [...] You get very basic resource constraints which could also then lead to going to one source which you know you could reach easily. But I think generally from my experience with journalists is that if you put them in touch with someone then they tend to always go to them for information. But I do think that for journalists it's a matter of self-interest to vary their sources. I think with Aids activists what we've seen and what we are seeing now is a kind of fatigue with the number of names. In a lot of African countries there are one or two people who go out and tell their story and those guys are tired and the public is tired of their faces and of their stories.



JONATHAN BERGER, AIDS LAW PROJECT:

One point that struck a cord with me was the one that Franz Krüger made about media's independence from all stakeholders and perhaps he can expand on that. Because certainly from the work that we've done we've learnt that developing good strong working relationships with the media has been an absolutely essential part of the work that we do [...]

FK: As a journalist I want to have the freedom to report if things go wrong. I think there's a difference between scepticism and cynicism. I'm not calling for a cynical approach to everybody. I don't think we should go around assuming that everybody is a crook but I think we should be alive to the fact that people have agendas and interests. But I think as journalists we need to build that into our handling of stories. The thing that I'm reminded of is a couple of years ago there was quite a lot of conflict between the National Association of People living with Aids (NAPWA) and various other groups. I think it's important to capture those kinds of conflicts. If you're too close to a pharmaceutical company, a government, an Aids activist group you can't do that. You need to be in a position to say, "Look, my gaze is fixed on all the players and if there's something important and newsworthy to tell then we'll do that". That's what I mean.

TC: I think one of the comments that was made earlier was about the "Aids industry", if you will. Of course we had our own group of Aids dissidents in San Francisco. My understanding is that they were in email contact with the president of this country. They were HIV/AIDS denialists as well. But one of the things that they did point out in the midst of all their craziness was the fact that there are a lot of people feeding at the trough of HIV/AIDS. And the scientists were among them. Those who were outside screaming to get in are now easily at the table and easily supported by the very sources who they were screaming at: government, industry and so on. So I think the question is a very interesting one. How independent can the activists be because they are a part of the lobby?



IDA JOOSTE, JOURNALIST:

I'm interested in the relationship between news media about HIV/AIDS and other types of news media or even advertising media. I want to know when news should intervene [in] advertising media: an example is the Dr. Rath advert in the *Mail and Guardian* and the subsequent response – is that appropriate? [...]

TC: I think one of the issues that we face in the US is that we do have direct pharmaceutical company to consumer advertising. [Often] the objective of the advertising is so that the patient can go to their physician and say "I want this particular drug because I know it's the right drug". I think the difficulty of that is that [consumers] again have to discriminate: what is accurate scientific information? What is a campaign of a particular organisation, which perhaps has a commercial agenda? What is a campaign of a particular group of dissidents that may have a particular dissenting agenda? Or in the case of the US what is the agenda of a particular world organisation that has a morality agenda to pursue [...]



DR COSTA GAZI:

My question is on the role of journalists. What we have seen in Iraq, journalists can get embedded [...] and those that weren't embedded, that may have had the integrity or ethics, have been hampered in many different ways. My concern is that this habit may spread to journalists in general. They seem to be getting squeezed between government/propaganda on the one hand and large transnational corporations on the other, because our media are more and more centralised these days. [...] How do

you exercise integrity when the two interests may coincide, so that the government may expect something from the media and the media wouldn't want to upset government on this particular issue of HIV/AIDS, where we have a strongly denialist government which has reluctantly taken up the issue of providing ARVs. And where do spin doctors fit into this picture – are they part of media or are they just propagandists?

FK: I think part of the reason why I feel so strongly about why we need to assert independence, although its difficult to see occur in practice, is because we have all these pressures and it actually takes the shape of what you are describing. Government will lay on a trip to Smithsdrift to show journalists how former San trackers are being accommodated and a pharmaceutical company will lay on a fancy lunch to launch their product. A lot of this goes on and I think that there is far little discussion of it and of where the boundaries are. I think that in the real world we can't say we will not have a relationship with any of these people with an agenda. [...] I think there is a problem and the way to deal with it is being alive to the pressures, by being prepared to discuss them, and by saying, "this we can live with, with this we can't". I think very often the thing that makes a difference is if we declare our interests. If we say, "Okay, we went off to rural KZN to do a story about whatever and this trip is being sponsored by whoever". At least then the readers/audiences know where the money came from. I think it helps.

NOKUTHULA SKHOSANA, PHRU:

We are so many years into democracy. And with the HIV/AIDS epidemic as we have it here in South Africa we're still not seeing the people most affected talking for themselves. And I was hoping that people would start reflecting on the fact that people can talk for themselves. Why is it that we have experts, we have people who are spoken about, we have people who are being surveyed? I suppose my concerns are very basic in that we seem to be again writing the history of this country from a one-sided point of view and we seem not to be looking at ourselves. How is it that we remain experts, how is it that other people cannot talk for themselves about themselves and be part of writing this history [...].

JH: Basically from my institutional/organisational viewpoint, the ethics that guide the organisation I work for is very much for

having people living with HIV portrayed or speaking for themselves. But I think it's also quite tricky because you can't force people into the media limelight – that is the worst think to do. If you think of the media as more than just the big newspapers and national broadcaster then there's a lot of ways in which media has been used and people do speak out. I do think there's this problem in many countries across the SADC region that you have one or two spokespeople who have become incredibly vocal, who've got a certain set of media skills. But it does wear a little thin after a while. We're now reaching a stage where we need more different and diverse voices to come out. [...]

FK: The first point that I think we shouldn't lose sight of is that we are all affected by HIV/AIDS in various ways and so in that sense we need to hear voices of everybody whether they are living with the disease itself or not. Secondly, I think journalists have a duty to bring those kinds of voices into the public domain, to let audiences hear the stories from the remote rural areas. It is important to do that. I can't disagree with you at all.



KAITIRA KHANDJII, MISA:

I'm interested in media fatigue in reporting HIV/AIDS – that "HIV is boring" which is talk I always hear. Franz mentioned this, where do we locate this media fatigue? Who is tired? Is it the journalists or audiences? Because if I go around in all the countries speaking to people, I find that people seem to be interested in knowing about HIV/AIDS [...] If the fatigue is within media itself then how can we overcome this media fatigue?

JH: I think in terms of editors – they tend to not want to come to workshops. From our experience with working with editors we find they are more aware of the pressures and the pressure might be more fatigue of the audience. [Editors] say "let's run a different story that's sexier". And I think that's the important point that you made there that yes, AIDS has a cross-cutting aspect. If you sensitise editors they will say for example, "we'll do more work [on HIV/AIDS] with business reporters".



MARK VAN DER VELDEN, SAPA:

I'd like to direct my question to Franz [...] referring to the insensitivity around the death of Parks Makhahlana, the insensitivity if it can be called, around the death of Peter Mokaba. Nelson Mandela's son died recently and he opened a very significant doorway in reporting HIV/AIDS by saying "yes, my son died of AIDS" and "lets talk about it more". Some media then took that maybe literally and proceeded beyond that to dig up a story about the son having had an extra marital affair knowing he was HIV positive and passing it on. Now, the Mandela family from what I could see closed ranks around that one saying it's disrespectful and an invasion of privacy. My question is those media that did try to pursue that story, were they crossing the boundary that you talked about or were the rest of the media that ignored that story sensitive, particularly sensitive of the name attached to that story?

FK: I think it's a good question and it is something I would like to think about a little bit. Very cautiously and carefully, I suspected it was a legitimate story actually because I think this had become such a

public death and such a public life in this context. Like I said I'm saying this cautiously and carefully, I stand to be persuaded otherwise. But I think these kinds of things are best discussed and considered.



PORTIA KOBUE, KAYA FM:

Franz, you spoke about the fact that the media's role in HIV/AIDS was interesting when there was a lot of haggling

between government and other role players. Does that not take away from the journalists' responsibility if reporting on issues around the epidemic so that people have information? Are we not taking away our responsibility of informing and educating about the pandemic when focusing on the haggling? And not to say that this is not important, because I think that especially in South Africa it is at the root of the problem of HIV/AIDS.

**NICK ISHMAEL PERKINS,
AMARC AFRICA:**

[...] The quotation here by Nelson Mandela says, "HIV/AIDS is a human rights issue". One of the things we've been trained to do is actually approach HIV/AIDS less as an epidemiological issue and more as a socio-economic issue [...] And I think this may respond to some of the questions about "who are the experts?", "who gets to speak and when and how?" because I think that opens up a different perspective on the arena of HIV/AIDS in which everyone is a player and you can also report on your stories slightly differently. This may counter a lot of the fatigue because a lot of journalists in newsrooms



in urban centres think of the HIV/AIDS story as following a very particular kind of line. I think there are a lot of other perspectives on this which are informed by a whole range of anthropological concerns which actually inform the science of it. I was at a workshop recently where the Director of the International Programme for AIDS in Africa said that a lot of the problem is that we are creating meanings around HIV/AIDS at a community level and think that is an extremely important thing to come to grips with [...]



John Perlman and the panel

WHAT IS THE HIV/AIDS AND THE MEDIA PROJECT?

The HIV/AIDS and the Media Project investigates the role and the impact of the news media on the HIV/AIDS pandemic in South Africa. The focus of the project for 2004/5 has been on media coverage of the Prevention of Mother-to-Child Transmission of HIV (PMTCT).

SPECIFIC OBJECTIVES OF THE PROJECT ARE:

- ▶ To encourage and enable journalists to play an informed role in combating HIV/AIDS
- ▶ To promote discussion and debate among journalists and other key role-players in this area
- ▶ To monitor the role of the impact of the media and to provide research which ensures an informed and useful debate around this issue

WE UNDERTAKE THE FOLLOWING ACTIVITIES:

- ▶ We offer 4-6 month fellowships to working journalists to conduct longer term and in-depth research and writing outside of the newsroom. We partner with the Media Monitoring Project on some aspects of the research. The writing that results from these fellowships is published in various forms of media and peer-reviewed journals
- ▶ We identify and research gaps in reporting. For instance, this year we are looking at the role of men in PMTCT, uptake in rural areas and infant feeding
- ▶ We are in the process of developing the website journalism.wits.ac.za, in partnership with Cadre, which will be a resource on HIV/AIDS and PMTCT for journalists
- ▶ We run wider discussion forums on HIV/AIDS and the Media to stimulate debate and discussion amongst journalists, activists, doctors, scientists, academics, government and other stakeholders
- ▶ We run smaller discussion forums specifically for journalists on various aspects of the HIV/AIDS pandemic and

the role of the media. The South African National Editors' Forum (Sanef) partners with us in these forums

- ▶ Each year we are involved in the training of career-entry Honours students from the Wits Journalism Programme in HIV/AIDS reporting

If you would like any more information on the project, please do not hesitate to contact the Research Coordinator, Natalie Ridgard, at:

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The project is jointly managed by the Perinatal HIV Research Unit and the Journalism and Media Studies Programme at the University of the Witwatersrand, and supported by the Health Communication Partnership based at the Johns Hopkins Bloomberg School of Public Health Centre for Communication Programmes



and the President's Emergency Plan for AIDS relief through the United States Agency for International Development, under terms of Award No. SAF-HCP-16. The opinions expressed herein are those of the authors and do not necessarily reflect the views of the U.S. Agency for International Development.

THANKS TO THE FOLLOWING PEOPLE FOR THEIR ASSISTANCE:

- ▶ Elaine McKay, Nelson Mandela Foundation
- ▶ Bate Felix Tabi Tabe, Saaleha Bamjee and Philile Masango, Wits Journalism Programme
- ▶ Anna Veileroglou, Wits Functions and Events
- ▶ Jane Green and Frontline Bar Services for catering
- ▶ Leanne Flint for layout and design

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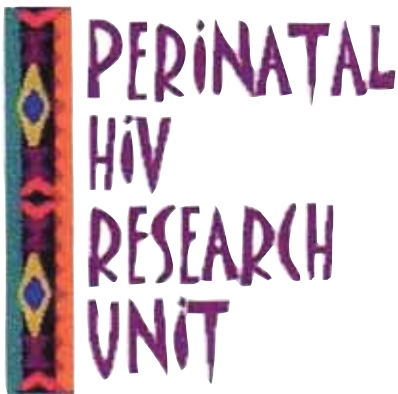
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