

## **The Media and HIV/AIDS: A blessing and a curse**

AIDS IN CONTEXT CONFERENCE

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It took the death on 26 October 2000 of Presidential spokesperson Parks Mankahlana to awaken the South African media to the intricacies of reporting on HIV/AIDS. Until Mankahlana's death, there was no national debate in the media about ethical questions relating to HIV/AIDS.

When *City Press* newspaper reported on the death of Inkatha's Gauteng leader, Themba Khoza, in June 2000, the newspaper quoted "Gauteng IFP leaders, who spoke on condition of anonymity" as saying that Khoza had died of an AIDS-related illness. (*City Press*, 4 June 2000) The article did not generate much controversy, even though it recounted Khoza's affairs with a number of women and the fact that he had a number of children with different women in support of speculation that he had died of AIDS.

Not many people rose to the defence of Khoza's wife and family to argue for their right to privacy, as they did to the defence of Mankahlana's wife, Nthabiseng, and family.

Yet even President Thabo Mbeki appealed to the nation to stop speculating on the cause of Mankahlana's death. In a widely reported address to a memorial meeting in East London, Mbeki said: "When Nthabiseng says this is what my husband suffered from and this is what killed my husband I would hope, truly hope, that none of us will take it upon ourselves to come to a conclusion that we know better than she. Hopefully the matter will be allowed to rest. There's no political gain to be achieved by anybody to engage in something which is very deeply painful to many people very close to Parks." (*The Star*, 1 November 2000)

Different people, different political parties, different treatment – but by the same media. This is both an indication of how inconsistent journalists have been in reporting on HIV/AIDS and how the interests of the most powerful political party, the ANC, tend to dominate the media.

In past two years, there have been a number of media violations of the privacy of ordinary people living with HIV. Yet no one has stood up for them. No one has said: We must respect the right to privacy of all South Africans, especially those who are HIV positive. Let me give two examples.

In late 1999, a reporter with a US newspaper visited the Mthunzimpilo Project in Khutsong, Carletonville. Sex workers in this mining community play a pivotal role in AIDS prevention. They spoke happily to the journalist using their real names, secure in the knowledge that their relatives would never read the article, as it would be published in the US. Not so. A few weeks later, the women found themselves exposed in a local newspaper, named as prostitutes for all their relatives to see. The result? The sex workers felt they were exposed and violated and the project leadership decided to bar journalists from the programme for a while.

Last year, a photographer took pictures of a Durban-based HIV positive woman, telling her that the photographs would be published overseas. Again, this was not to be. They appeared in a Sunday newspaper, resulting in the woman's father expelling her from her home.

These were ordinary South Africans. They were exploited and humiliated. The Durban woman even lost her home as a result of trusting a journalist. Yet when complaints were made, the newspapers concerned did not think their plight was important. How can we live with these contradictions? I believe that journalists cannot continue to operate as though we live outside of society, untouched by this pandemic.

Thankfully, Mankahlana's death stirred a great deal of debate amongst journalists, and drove home the idea that reporting on HIV/AIDS is complicated and often controversial. Death and sex are most societies' deepest taboos. It is thus understandable that anyone trying to negotiate that terrain is going to encounter problems.

But the debate around Mankahlana's death centred on only one small aspect of HIV/AIDS reporting: his family's right to privacy. To briefly summarise events: no journalist had asked Mankahlana while he was alive whether he was HIV positive. However, after his death it was widely rumoured that the anaemia and subsequent heart attack that finally killed him were the result of AIDS. His wife denied that her husband had died of AIDS, yet in the days that followed his death, the rumour was widely reported in the press.

This caused tension in a number of newsrooms, sometimes along racial lines with some white journalists arguing for the rumours to be published in the public interest while some black journalists argued that this was disrespectful to the dead.

The Gauteng branch of the South African National Editors' Forum (SANEF) and the Freedom of Expression Institute hastily convened a meeting on ethical issues raised by Mankahlana's death held in Johannesburg on 9 November 2000. Two panellists, The Star's Lizeka Mda and Business Day's Jim Jones presented two opposing views.

Mda appealed for journalists to respect the dead, and chastised them for not asking Mankahlana his HIV status while alive. But Jones, pointing to the fact that Mankahlana had two child maintenance cases against him, said he believed the man died of AIDS-related causes. "He was no saint. He was not an icon, and he was promiscuous," said Jones. (The Star, 10 November 2000)

Participants at the SANEF-FXI meeting threw up a number of other interesting points, some of which I have summarised below:

- Attitudes towards death: Is the African approach to death different from that of other cultures? If so, do cultural concerns make it inappropriate to speculate in such cases?
- Public interest: Does the fact that Mankahlana spoke out in the HIV/AIDS controversy mean that his cause of death is relevant?
- Privacy: If a prominent person dies, since when do journalists wait for his widow to tell us why he has died? How far do we go with public figures? Should we ignore what we know because his family may not like it? Is the issue of privacy related to the dead person or to the dead man's wife and family? Where do we draw the line between public and private life? If a person chooses not to say that they are HIV positive, shouldn't we respect their choice?
- Racism in the media: Why haven't the deaths of prominent whites been treated in the same probing way? Do we polarise opinion along racial lines by writing too simplistically?
- Stigma: Are we taking a judgmental stance (i.e. he was promiscuous) to justify our stories about him? Has the media stigmatised Mankahlana? Is the media contributing to stigmatising HIV/AIDS or reflecting society's views?

(From SANEF)

While Mankahlana's death encouraged journalists to think and talk about HIV/AIDS in a way that they have never done in this country before, the Broadcasting Complaints Commission of SA (BCCSA) had the last say on the matter. After e-TV broadcast the rumour that Mankahlana had died of an AIDS-related illness, a member of the public (who is also a senior government official in the Department of Communication) lodged a complaint with the BCCSA.

However, the BCCSA dismissed the complaint, ruling that a dead person had no legal right to privacy or dignity and that the report did not intend to attack Mankahlana. The BCCSA said that while many might find the broadcast "in questionable taste", Mankahlana's involvement in the AIDS debate as a public official justified the report.

### **Politicisation of HIV/AIDS**

The BCCSA's reference was to a debate that had erupted earlier in the year, when President Mbeki appeared to be entertaining the idea that HIV was not the only cause of AIDS. As Mbeki's official spokesperson, Mankahlana was vocal in defending the president – and made a number of controversial statements while doing so.

The “does HIV cause AIDS” debate had the positive effect of encouraging journalists to study the science of HIV/AIDS – something that has been, and still is, sorely lacking in the national media.

However, the very unfortunate main effect of the debate was that the pandemic became highly politicised. Many of those critical of Mbeki’s flirtation with AIDS “dissidents” were labelled as being anti-government, even racist, by government officials.

For example, Health Minister Manto Tshabalala-Msimang claimed in a press conference at the AIDS 2000 conference in Durban in July that criticism of Mbeki’s handling of the debate was simply the media “bad-mouthing the black government”.

However, criticism of Mbeki was not confined to the South African press, but spilled over into the US and European media too. New York’s *Newsday* didn’t mince its words when it said: “A certain open-mindedness is fine. But a person can be so open-minded that his brains fall out. At worst Mbeki is a callous demagogue - skilfully diverting attention from a public health crisis he can’t control. Or maybe he’s a misguided fool. In any case he’s in deep trouble.” (June 2000)

In a similar vein, the British *Spectator* magazine carried a column by R.W. Johnson in which he said that “many now believe that Mbeki is no longer playing with a full pack – that he’s off his rocker”. (26 August 2000)

Such views served to widen the gulf between the South African government and the media, and lead to a breakdown in communication between journalists and the presidency.

The politicisation of the epidemic took a turn for the worse during the local government election campaign in late 2000, when HIV/AIDS became a major election issue. The opposition Democratic Alliance (DA) promised free anti-retroviral drugs to all HIV positive pregnant women and rape survivors living areas under DA-controlled councils.

The ANC’s spokesperson, Smuts Ngonyama, reacted to this promise by accusing the DA of “genocide”. He said by giving black people in Khayelitsha AZT, the DA was using them as guinea pigs, “[conning] them into using dangerous and toxic drugs that are detrimental to their own health”.

Ngonyama’s extreme view of demonising all that which the South African government – often legitimately – cannot afford in the fight against HIV/AIDS served to confuse matters, and heightened the political stakes involved in dealing with HIV/AIDS in an unhealthy and irresponsible manner.

Criticism in the media of Mbeki and his government’s handling of HIV/AIDS has not abated. This is despite the curious decision last year by the Independent Group to give government a number of free newspaper advertisements in which to explain Mbeki’s stance on HIV/AIDS.

As a result of the continuing criticism, the minister in the presidency, Essop Pahad, declared earlier this year that there was a media vendetta against Mbeki. “I don’t believe that in the history of this country we have had such a systematic, vile and vicious campaign against the head of state,” Pahad told a gathering at the Castle in Cape Town to mark the International Advisory Board meeting of Independent Newspapers. He also hit out at the “monstrously distasteful” suggestion that Mbeki was in denial about Aids. (*Cape Times*, 6 Feb 2001)

Thus, the terrain for reporting on HIV/AIDS has become seriously complicated by the politicisation of the epidemic and the growing hostility between the media and the government.

This is deeply problematic in a country where almost 25% of adults are HIV positive, yet most are in denial about the disease. It is also deeply problematic in a country undergoing transformation, where accusations of racism touch raw nerves and the emotions stirred up can obscure complex issues.

## **Ethical and practical questions**

As it is, there are many complicated ethical questions that journalists confront when trying to report on the epidemic. Ethical journalism does not have a strong tradition in this country, and there are few media forums that discuss the question of ethics. However, the political jostling around the disease has served to obscure some important issues that journalists should be discussing and debating.

Issues relating to race and class are paramount in reporting on HIV/AIDS. Journalists are all middle class (no matter what their origins may be) and many are white. The majority of those interviewed are black and poor. This is understandable, given South Africa's past, and given that 80% of South Africans are African and the majority are poor.

However, this dynamic has to be carefully negotiated. Under apartheid, the lives and experiences of poor black people were devalued. There is a danger that the HIV/AIDS pandemic will perpetuate this if reporters see themselves as "outsiders", and portray HIV/AIDS as a disease of those who are poor and black.

The virus is indiscriminate, but those with access to private health care – still mostly white South Africans – are more able to conceal its effects or delay the onset of AIDS by taking anti-retroviral drugs and having healthy lifestyles.

Reporters also need to unpack the social forces that drive the disease. The system of apartheid – particularly the migrant labour system and forced removals – destroyed the family lives and social networks of millions of black South Africans, rendering them vulnerable to HIV/AIDS in a way that those living at home with their families are not. The legacy of apartheid remains and continues to drive the pandemic.

Another key social force driving the pandemic is gender inequality, particularly men's attitudes towards masculinity and sex. This is not something that has received much attention in the media, yet it is key to understanding the spread of HIV/AIDS.

As US journalist Mark Schoofs, who won a Pulitzer Prize for reporting on AIDS in Africa, says: "Journalists must point out the larger forces that keep HIV spreading." (Address to AIDS 2000 Conference, 11 July 2000, Durban.)

One of the biggest challenges is to ensure that every person interviewed is treated with respect, and gives their "informed consent" to be interviewed and for their names and photographs to be used. People infected and affected by HIV need to understand that they have the right to refuse to be interviewed or photographed – even if their health workers or their home-based carers or other people in important positions of power in relation to their lives bring the journalists to them.

Particular sensitivity needs to be exercised when dealing with children. The AIDS orphans I have met have generally been unaware that they have rights, including the right to refuse to be interviewed or photographed.

In addition, sometimes a person may not fully understand the implications of being quoted or photographed. This needs to be explained, as the stigma attached to HIV/AIDS is still huge and those who "come out" with HIV may find that they face extreme prejudice.

I also believe that the name of a person living with HIV should not be published without their permission. There is a debate about whether to "out" government officials who take anti-retroviral drugs but argue against these drugs being provided by the health department system to others who do not have medical aids. However, outing needs to be carefully considered as it may do little more than sensationally perpetuate the stigma associated with HIV.

Sensationalism is a big problem. South African society is not used to open discussion about sex. As the epidemic deals with both sex and death, there is a temptation to sensationalise reports. Sensationalism relies on emotion, usually offering a shallow view of issues and presenting people as either "good" or "bad". Babies who get HIV, for example, are described as "innocent" whereas their mothers are often branded as promiscuous. Gay men are another target for sensation. No one "deserves" to get HIV.

Sensationalism tends to entrench the view that if you are HIV positive, your death is imminent. The constant association between HIV and death tends also to entrench stigma. There are, however, two TV shows aimed at people living with HIV.

Thus, sensationalism fails the media audience by failing to analyse issues and inform readers of complexities.

The way in which journalists handled the collapse earlier this year of Nkosi Johnson, the country's oldest known child survivor of HIV/AIDS, was generally sensational and insensitive. His imminent death was predicted in the press for weeks on end, and one senior journalist even wrote an article for a magazine pronouncing him dead – on the false assumption that, by the time the magazine hit the streets, he would be dead.

The very words we use to describe HIV/AIDS play an important role in shaping perceptions. Journalists need to ensure that our words do not carry value judgements (sex workers rather than prostitutes, for example) and are gender sensitive.

Language should be inclusive rather than creating a them/us mentality. Also, attention should be paid to how people themselves prefer to be described. Few HIV positive people like descriptions such as “infected person” or “AIDS carrier” as these stigmatise them and imply that they should be avoided. People living with HIV/AIDS has become the preferred term.

We also need to make sure that our facts are right. There are many confusing aspects to the epidemic, particularly when dealing with scientific aspects. We need to pay far more attention to educating ourselves (and our audiences) about a range of scientific facts, such as how the virus operates, what opportunistic infection are and how anti-retrovirals work.

In addition, there is much at stake in the HIV/AIDS field. Big money has been invested in drugs and research and there are many powerful forces at play. In the past few weeks, in the context of the 39 pharmaceutical companies' court challenge to our government, the media has been awash with public relations exercises from pharmaceutical companies.

I would argue that the journalist who published the sensational story about our government refusing to accept free AIDS tests (Sunday Times, 18 March) was manipulated by that pharmaceutical company's PR company. The tests turned out to need refrigeration and were in violation of existing tenders. Clearly, the intention was to make the South African government look as if it was not taking the epidemic seriously, and spurning “generous” offers from pharmaceutical companies'.

Finally, it is a challenge to keep HIV/AIDS newsworthy and topical. Sometimes it is really difficult as many media organisations feel that they've done their bit if they report on HIV/AIDS once in a while. As more and more people start falling sick and dying, we will have to find new and creative ways of covering what will soon be an everyday, common tragedy.

## **Conclusion**

There can be no question that the media has an important role to play in providing basic information about HIV/AIDS. Radio has a particularly important role to play. Radio stations have a massive audience, reaching many listeners who cannot or do not, read. In developed countries, some journalists argue that it is not their role to educate people about HIV/AIDS. But those are countries where citizens have access to a wide range of information and governments have the cash to run massive public media campaigns about issues. That is not the case in South Africa. And AIDS activists need to challenge the media institutions far more to provide basic information about HIV/AIDS.

But from a reporter's point of view, it is not easy to report on HIV/AIDS. Fear, prejudice, ignorance, denial, political agendas and economics all play a part in shaping how South Africans see the epidemic. Other conflicts – such as those between what is in the public interest and what is in the interests of the individual -- are not easy to resolve, and need to be debated amongst journalists and by the public.

The SA National Editors Forum (SANEF), together with Soul City and my agency, Health-e News Service, are in the process of organising provincial workshops for journalists on reporting on HIV/AIDS. I hope that these will open the eyes of senior journalists both to the enormity of the problem posed by the pandemic, and to the importance of ongoing media attention. It may also result in a code of conduct being adopted which will at least guide reporters negotiating the epidemic.

South African journalists are far behind some African countries with lower HIV infection rates than our own in adopting innovative ways to campaign against HIV/AIDS. In Nigeria, for example, journalists have formed Journalists Against AIDS (JAAIDS) to educate communities and opinion makers about the human rights aspects of the epidemic. One of its methods involves getting HIV positive people to talk to journalism students. Another is maintaining a lively and active email discussion forum on HIV/AIDS, involving key stakeholders in Nigeria.

JAAIDS founder Omololu Falobi says his organisation is also involved in discussing a communications framework for HIV/AIDS in Nigeria. The aim of the framework, says Falodi, is to develop “a new direction for HIV/AIDS communication and examine ways of strengthening the capacity of Nigerian NGOs, governmental organisations and HIV/AIDS activists for communication of HIV/AIDS prevention, care and support”. (Personal correspondence.)

Even a small country such as Gambia launched an HIV/AIDS network for journalists on 13 February 2001. Co-ordinator Pascal Eze says he was inspired to start the network after attending an UNAIDS workshop for PANAPRESS correspondents in Dakar, Senegal, last December.

“Most of us are columnists and radio/TV presenters and producers and we use our columns and programmes to promote the campaign... which is that HIV/AIDS can and should be avoided and a friend with HIV/AIDS is still my friend,” says Eze, who is also Editor-in-chief of the *Daily Observer*.

“We also organise outreach programmes like football matches through which we capture the attention of football-loving Gambians. Training workshops, press conferences, radio discussion programmes are some of the things we do. At the moment, I am working on an AIDS song in English and local languages. I am also working with the current Miss Gambia, Astou Njie, on her foundation for children and orphans living with HIV/AIDS.” (Personal correspondence.)

South African journalists are just beginning to discuss HIV/AIDS, and so far there seems to be little prospect of the kind of unity of purpose shown by Nigerian and Gambian journalists.

One of the reasons for this, perhaps, is the fact that few journalists in the country are concentrating on HIV/AIDS reporting, and few newspapers or media groups (with the exception, perhaps, of the *Sowetan*) have committed themselves to sustained coverage of HIV/AIDS as a matter of policy.

Competition between the different media groups also militates against co-operation. However, as the Panos Institute's AIDS director, Martin Foreman, says: “Even those media whose primary goal is making money ... cannot afford to ignore an epidemic which reduces the number of people who will buy their products and restricts the buying power of those who survive. A society where a quarter or more of the population is preoccupied with sickness and death is not a society which will fatten the wallets of media owners.” (“An Ethical Guide to reporting HIV/AIDS” in *Media & HIV/AIDS in East and Southern Africa: A resource book*, UNESCO.)

But ensuring that there is sustained, interesting and ethical reporting on HIV/AIDS is no longer enough. Pressure also needs to be put on media organisations to “think big” about their involvement in fighting the disease.

Free prevention messages (through public service announcements and articles, for example) and fundraising drives for AIDS orphans and those rendered destitute by the epidemic are just two examples of how the media can be further drawn into the fight against HIV/AIDS.

The South African media needs to make a more significant contribution to fighting the HIV/AIDS pandemic – with sensitivity to people living with HIV/AIDS and a commitment to preventing the further spread of HIV as touchstones. In this way, the media could become more of a blessing it seldom is and less of a curse it often has been to those living with HIV/AIDS.

