
Media, Activism and HIV/AIDS



Loga Virahswamy, Media Watch Organisation, Mauritius, explains red ribbon. Credit: Gender Links



Debating HIV/AIDS Language: Talking about HIV/AIDS

By Mia Malan

Abstract

There has been much debate around the importance of language when covering HIV and AIDS in the media. Activists and people living with HIV have been largely successful in influencing the media's coverage of HIV. While many journalists continue to be unsure of what constitutes appropriate language, even more are aware of such issues, yet question the ability of the public to understand many of these terms.

Key words

HIV/AIDS, journalism, media

The language debate

It is a sultry summer evening in 2002 in Johannesburg, South Africa's sprawling metropolis. The South African Broadcasting Corporation's (SABC) 8 pm news bulletin is about to be broadcast. The service's health correspondent has filed a story on the exorbitant prices of anti-retrovirals in the country. The report's focus is on a woman with HIV who cannot afford the life prolonging medication.

The journalist has written a note in the corporation's news filing system that the subtitle to appear on the TV screen when the woman begins speaking should read, "Person living with HIV/AIDS (PLWHA)" and not "AIDS sufferer" or "victim." However, there are murmurs of dissatisfaction amongst the news team about the reporter's request.

Technical staff say it simply is not feasible; that the subtitle suggested by the health correspondent - which they'd be required to scroll across the screen during the live broadcast of the bulletin - is too lengthy. Some editors say the acronym "makes no sense." Pressure builds as the deadline rapidly approaches.

To add to the palpable tension in the studio, the medical journalist has chosen to be present during the news broadcast, in an effort to ensure that her request that the woman she has interviewed be labeled a PLWHA - or, at the very least, "Person with HIV" - is fulfilled. After all, if the woman is branded "victim" or "sufferer" by South Africa's national broadcaster, it is she, the reporter, who will be bombarded by calls from furious AIDS activists, not the editors or the technical staff members.

The journalist knows this from experience. This is not the first time she has found herself on this precipice, straddling this gossamer line between dedication to reportage and respect for human rights. She is constantly, and deeply, aware of the activists' argument, that HIV-positive people can live long and healthy lives, and that referring to them as "sufferers" or "victims" is disempowering and even discriminatory towards them, and creates the impression that everyone with HIV is decaying in bed, shells pathetically succumbing to death, with no control whatsoever over the situation.

I was the health correspondent described above. Scenarios like the one above took place more than a few times between the years of 1994 to 2002, when I was employed by South Africa's public broadcaster to report on health issues in the country.

As I grew into the job, I naturally formed close ties with members of South Africa's vocal - and sometimes downright militant - AIDS activist community. In the face of a president (Thabo Mbeki) who denied the very existence of the virus present in many of their bodies, and communities that often attacked, viciously assaulted and sometimes murdered those found to be HIV-positive, these advocacy groups exuded pure strength and bitter determination. They could not have survived otherwise. It was upon their instruction - and often their brutal insistence - that I learned to avoid the use of terms they considered stigmatising and insulting when I reported on AIDS.



Rose Thamae leads march, more positive images help to reduce stigma and discrimination. *Credit: Gender Links*

However, at the time, many of my editors argued that because they did not have access to the necessary drugs, most South Africans infected with HIV were indeed "suffering victims," and would eventually fall sick with AIDS-related illnesses and die. They pointed out that the media referred to people with other chronic illnesses, such as diabetes and cancer, as "sufferers" and "victims," and asked why AIDS should be treated "differently" and "specially."

The difference is, of course, that the HIV epidemic is the most politicised and stigmatised disease the world has ever seen. Moreover, the manifestation of this is especially prevalent in a country like South Africa. The mere fact that there are AIDS activists and not cancer or malaria activists is incontrovertible proof thereof. Language and politics are intertwined; language shapes beliefs and influences behaviour.

When AIDS interest groups put pressure on journalists to use certain terms surrounding HIV, and to avoid others, they exercise great and unprecedented influence over the media, and in so doing, influence the way that members of the public talk about the epidemic.

In the case of AIDS, insensitive language and inaccurate medical terms can foment stigma and discrimination.

Anton Harber, the head of the Journalism Programme that hosts the HIV/AIDS and the Media Program at the University of the Witwatersrand in South Africa, says, "Journalists have a fundamental responsibility to use language accurately and appropriately" and should strive to minimise any harm they may cause through usage of certain terms.

Nevertheless, the task of language usage when reporting on AIDS and the people it affects is sometimes more daunting than it sounds.

The latest list of the UNAIDS Terminology Guidelines contains 14 pages of terms that reporters are often expected to use - many of them politically correct non-governmental organisation (NGO) jargon, such as "orphans and vulnerable children", "opportunistic infections" and "client-initiated testing" that many newspaper readers, radio listeners and TV viewers are

unlikely to understand.

To the ears of seasoned media practitioners, many of these terms also sound boring and colourless. The list of "politically correct" AIDS terms continues to lengthen, with activists becoming increasingly prescriptive and pushy when attempting to compel journalists to use their preferred terminology.

Local Voices on HIV/AIDS

In 2002, Internews launched the Local Voices project in Nigeria and Kenya, with support from the US Agency for International Development and continuing support from the President's Emergency Plan for AIDS Relief (PEPFAR), to train and support local radio journalists, talk show hosts and DJs to improve their reporting and programming on issues related to HIV/AIDS. In 2005-06, the project expanded to Ethiopia and Cote d'Ivoire and included support for print journalists. Internews has also conducted support activities for improved HIV/AIDS coverage in Thailand, Cambodia, Vietnam, and Laos, in partnership with Internews Europe's project, Turnaround Time. Internews is also launching a Local Voices project in Tamil Nadu, India. Through practical training in technical radio production skills, script writing, research, as well as the science of HIV, participants learn how to create and improve reports on HIV/AIDS. Graduates have ongoing access to a media resource centre and technical support from an experienced journalism trainer.



Kenyan radio journalists on a site visit to the Kenya Medical Research Institute during an Internews HIV journalism training
Credit: Benjamin Kiplagat

"I've often bristled when told by public health colleagues that I can't or shouldn't use certain words because they 'carry a different meaning' in the context of HIV/AIDS,"

says John Pitman, a former Voice of America journalist now working as a blood safety technical advisor for a United States government HIV programme. Pitman believes that journalists should be aware of the "risks attached to certain words" like "sufferer" or "victim" but that "they should not be forced to use the dissembling jargon of global health, if it undermines their ability to tell a story truthfully and honestly."

Professor Harber echoes this, arguing that reporters should not allow anyone to prescribe to them. "We should use our judgment to select the appropriate words and phrases, but keep a keen ear for suggestions that the language we choose may be harmful or inaccurate. In other words, we should listen to activists - but not allow them to decide (what language reporters use). Activists, after all, may have special interests, or a narrow view - or they may be just plain wrong."

A study conducted by the University of the Northwest in South Africa in 2005 found that the country's print media regularly portrayed people with HIV as "victims," and that such language usage negatively influenced the way in which readers talked about the disease. However, the research also argued that the many terms that activists demand that people use when describing the epidemic, were sometimes unrealistic.

"What is HIV/AIDS other than a 'dreaded disease'?" the researchers asked. "It is to some extent necessary to tell people how ravaging AIDS is, to make sure they do not become unconcerned, without falling into the trap of sensationalism."

It is not only the South African media that sometimes uses words that AIDS activists and experts do not approve of. Many United States newspapers and broadcasters do the same. A search of the *Washington Post* and CNN archives from the past year shows that terms such as "fight" or "war" against AIDS, AIDS "victim", "patient" and "AIDS virus" – terms that AIDS activists disapprove of for various reasons – remain common.

However, many in the media say there are good reasons for this. Some media professionals argue that a blanket ban of certain terms is not constructive.

Summary of preferred terminology

Do not use this	Use this
HIV/AIDS	Use HIV unless specifically referring to AIDS. Examples include people living with HIV, the HIV epidemic, HIV prevalence, HIV prevention, HIV testing, HIV-related disease; AIDS diagnosis, children made vulnerable by AIDS, children orphaned by AIDS, the AIDS response. Both HIV epidemic and AIDS epidemic are acceptable.
AIDS virus	There is no "AIDS virus". The virus associated with AIDS is called the Human Immunodeficiency Virus, or HIV. Please note: the phrase HIV virus is redundant. Use HIV.
AIDS-infected	Avoid the term infected. Use person living with HIV or HIV-positive person. No one can be infected with AIDS, because it is not an infectious agent. AIDS is a surveillance definition meaning a syndrome of opportunistic infections and diseases that can develop as immunosuppression deepens along the continuum of HIV infection from primary infection to death.
AIDS test	There is no test for AIDS. Use HIV or HIV antibody test.
AIDS sufferer or victim	The word "victim" is disempowering. Use person living with HIV. Use the term AIDS only when referring to a person with a clinical AIDS diagnosis.
AIDS patient	Use the term patient only when referring to a clinical setting. Preferred: patient with HIV-related illness.
Risk of AIDS	Use risk of HIV infection; risk of exposure to HIV.
High(er) risk groups; vulnerable groups	Key populations at higher risk (both key to the epidemic's dynamics and key to the response)
Commercial sex work	Sex work or commercial sex or the sale of sexual services
Prostitute	Use only in respect to juvenile prostitution; otherwise use sex worker.
Intravenous drug user	Use injecting drug user. Drugs may be injected subcutaneously, intramuscularly or intravenously.
Sharing (needles, syringes)	Use non-sterile injecting equipment if referring to risk of HIV exposure; use contaminated injecting equipment if the equipment is known to contain HIV or if HIV transmission has occurred.
Fight against AIDS	Response to AIDS
Evidence-based	Evidence-informed
HIV prevalence rates	Use HIV prevalence. The word 'rates' connotes the passage of time and should not be used here.
Acronyms and abbreviations	Please spell out all terms in full. For example PMTCT should be prevention of mother-to-child transmission, etc.

Full guidelines available http://data.unaids.org/pub/Manual/2007/20070328_unaids_terminology_guide_en.pdf

"It's about using a term responsibly and sensitively," says one of South Africa's leading health journalists, Anso Thom. "I think when you use 'sufferer' within context, it says more than a million words could ever say. But then you have to understand that you need to communicate the context within which you are using it."

John Pitman agrees. He argues that many people still die because of HIV-related illnesses - despite the fact that ARV's are becoming increasingly accessible.

"(The term) 'living with' has its place to describe the courage and humanity of people struggling to survive - but 'suffering' remains a reality across the world. It

shouldn't be banished from stories about the pandemic," he emphasises.

The UNAIDS preferred terminology list also disapproves of referring to the "response" to AIDS as the "fight" or "war" against AIDS. The authors argue that these words are "combatant language" that can instill fear, and therefore instill negativity around HIV/AIDS in the public mind.



Images that use scare tactics, such as this poster in Tanzania, may further increase stigma. Credit: Trevor Davies

However, even the experts are extremely confused about the language they should use – or they simply disagree with the prescriptions forced upon them by AIDS advocacy organisations. In the March 9 edition of the *Washington Blade*, a weekly newspaper published in Washington D.C. with a predominantly gay readership, the United States Department of Health and Human Services and National Institutes of Health advertised for HIV-positive volunteers for a clinical trial using the catch phrase: "Help in the fight against HIV/AIDS."

Often, the activists themselves use language that they say they don't approve of. According to the UNAIDS list, it is scientifically incorrect to say that "AIDS has killed someone" or that "someone has died of AIDS." It should be "HIV-related" or "AIDS-related illness," because AIDS – a syndrome – can't lead to death. Yet, on 20 February this year, the South African Treatment Action Campaign's (TAC) Nathan Geffen, a leading AIDS activist in SA, published an

article that used the following sentence as its opener: "In 1997, Judge Edwin Cameron nearly died of AIDS."

Most people will, of course, understand what Geffen meant with his sentence; it is, after all, written in the way that most people generally talk about AIDS. Yet, according to many activists, it is scientifically incorrect and may even be discriminatory.

Journalists often ask: If the experts and activists themselves alternate terms about AIDS, how do they expect the media to constantly conform to their often brusque demands?

It is doubtful whether readers, listeners and viewers are able to understand many of these "preferred" terms. Orphans and vulnerable children (OVC's) is another politically correct term that many experts demand reporters to use. However, according to Thom, her readers cannot make sense of it.

"If I had to use 'vulnerable children', they would be really confused. Our job is to help readers understand the issues - not to make it more difficult. I think 'orphans' is a much more dignified term than OVC's. If we use such a term, we are in danger of turning children into acronyms, and that is really unfortunate."

National Public Radio science correspondent, Brenda Wilson - who has frequently reported on AIDS in Africa - is of similar inclination.

"My listeners would not understand what I'm talking about if I referred to children orphaned by AIDS as 'orphans and vulnerable children'. It's too NGO-ish. I just use the word 'orphan,' otherwise no one would know what I am talking about."

For Kenyan radio journalist, Anne Waithe, the UNAIDS definition of orphan – a child who has lost one or both parents to HIV/AIDS – is equally confusing.

"In Kenya, an orphan means someone who has lost both parents. A child with one parent would be referred to as 'a child from a single parent family' and those are very common in Kenya. The word orphan gives the idea that the child is totally alone.... which makes the 'orphan'

statistics that refer to all children that has lost one parent to AIDS-related illnesses open to misleading interpretations.”

Yet, NGOs refer to OVC’s in most of their press releases and interviews with journalists. It is one of the biggest challenges Pitman faces when training public health public relations officers in effective media relations.

“I try to emphasise that just because they know what an OVC, VCT or PLHIV means - that does not mean they’re the right words or acronyms to use when communicating with the public. On a couple of occasions I’ve asked PR people to read their releases aloud. Then I take the paper away and ask them to describe the event or issues in their own words, as if they were describing it to an uncle or cousin. It’s sometimes a struggle, but the verbal recounting usually resonates in a way the regurgitated lingo doesn’t.”

A recent case in point is that of a television journalist in Kenya. The reporter’s editors met with AIDS activists. After the meeting, the activists gave a list of preferred terminology to the editors. One of the activists’ recommendations was that people with HIV should never be referred to as “AIDS patients,” as, they stressed, many were able to live long and healthy lives and were therefore not “patients.” Shortly after the meeting, the journalist was sent to a hospital to cover a story about a person who was sick with HIV-related illnesses. Upon the reporter’s return, her editor refused to permit her to use the word “patient” in her script – even though the story was all about an emaciated man in a hospital bed who was – and this could very clearly be seen in the TV visuals – very ill.



Anne Waithera and Nasteha Mohammed interview a volunteer in an AIDS vaccine trial in Nairobi. *Credit: Benjamin Kiplagat*

“My editor says he’s been told to follow this list, or there’ll be big trouble,” says the journalist. “It’s now part of our broadcasting code and can’t be adjusted.” Thom disagrees with the kind of “stifling prescription” that sometimes happens in the AIDS sphere. That certain terms are accorded “usage status” to the “total and dictatorial exclusion” of all others rankles her.

“I think we have to acknowledge that there are journalists who have done a lot of damage by using terms in a derogatory manner, terms that feed AIDS-related stigma. But I think every story is different, every country is different and it is unfortunate if we expect to have one set of ‘rules’ for all AIDS-related stories.”

Thom believes the bottom line is: “As long as we do not harm people, we have to write the story in a way that makes the reader read it, and actually care about what has been written. We are not writing for the NGO community, we are writing for the man on the street. And it is often the man on the street that has the power to change the course of things.”

Writers Bio

Mia Malan is the Senior Health Journalism Advisor for Internews Network. Prior to this she was the Resident Journalism Advisor for Internews Network’s Local Voices project in Nairobi, Kenya. Before joining Internews Network, Malan was the national health correspondent of the South African Broadcasting Corporation (radio and television). She has won numerous awards for health reporting, including the Henry J. Kaiser Award for Excellence in Health Journalism (1998), the CNN African Radio Journalist of the Year (2000) and the South Africa – USA Leadership Reporting Award for Television in 2001.



**Everyone Knows Someone:
A Sunday Times Campaign**
By Susan Smuts



One day our editor, Mondli Makhanya, remarked that everyone knew someone with HIV or Aids. If we all knew someone, why were we not all talking about it?

We decided to start a campaign to remind ourselves and our readers that HIV was something that affected all of us. Since it affected all of us, we should acknowledge it openly and stop hiding behind the fear of stigma.

We launched the *Everyone Knows Someone* campaign in April 2006, with a number of public figures taking an HIV test. We invited our readers to share their stories. We hoped that we would get a few contributions from our readers to run before the campaign wrapped itself up. We had planned a number of stories to report on and didn't really expect a huge response from our readers.

We were in for a big surprise.

Our readers quickly took ownership of the campaign, sharing stories about losing loved ones to AIDS, recounting their own journeys of discovering their HIV-positive status, talking about deeply personal traumas and triumphs in the wake of taking the test that would change their lives forever.

Every single week for almost two years, we have published a story by one of our readers. No two stories have been alike. Some of the contributions have been by people who are living openly with HIV and who are comfortable with having their names published. Some are by people

who have not yet disclosed to anyone, or have disclosed only to a few people. We would like people to write under their own names because each person who discloses makes it easier for someone else to disclose. But stigma is still strong and each person needs to be ready to disclose before they take that step.

For some, the act of writing of their story is in itself therapeutic, because it articulates the feelings and experiences and somehow makes the situation more manageable. Some people have written in more than once, and we often get emails from people thanking us for running their stories. We have not had any negative feedback, nor has anyone expressed any regret about contributing.

Many of the stories are heart-breaking. One of the first we received was from a man whose wife had been diagnosed HIV-positive. He felt that she was being punished for his indiscretions in his younger days. His love for his wife and his desperation to help her was immensely moving.

Another story was by a mother whose son had been deliberately infected by his HIV-positive lover. She recounted how she sat at his death bed wishing she could change places with him.

Many of the writers have spoken about how important it was to disclose their HIV-positive status to others. Once the burden of secrecy had been lifted, they were able

to deal with the psychological and medical aspects of HIV openly. Many of the people who disclosed their status found their courage rewarded with love and compassion. And their openness often made it possible for others to confide that they, too, were living with HIV.

Everyone Knows Someone Excerpts

"I was living with the fear that I was going to live for only six months, so I told one of my friends. She promised to support me. The week after I told her, we were invited to a party. I noticed that my friends were not as friendly as usual. We ran out of glasses for drinks and no one was prepared to share a glass with me. One of my friends called me to the ladies' room and told me that she had heard that I had the HI virus. I didn't enjoy the party after that."
- "I've learned to be strong in the face of rejection," Nomvula Shale.

"I attended a funeral one recent Saturday. It was in Khayelitsha, for a very pretty and clever 19-year-old girl known to me as Maxine.* She should not have died, but she was poor and the medical system really did not care."
- "A mother buries her pretty girl," Guy Ellis.

"One of the more significant moments of my life was when Dr Dave informed me of my HIV-positive status. He told me about the implications and gave me the best advice: "Go and live."
- "Positive mind-set keeps me healthy."

"I am not a secretive person to my family. I looked at my mom — I was so scared but I had to tell her. My mom is 73 years old. When I told her I thought she would die but she was so strong and supportive to me. We pray together and hold morning devotion every day. "
- "I was afraid to tell my mom, but she has been so strong."

"Being HIV-positive has taught me to be strong and to work even harder so that I can move up the corporate ladder so that when my time has come, I will leave something for my family to live on." Someday I will disclose, but for now, nobody knows...
- "Nobody needs to know my secret yet."

Read stories from the "Everyone Knows Someone Campaign" at <http://www.thetimes.co.za> Click on Special

A nanny had the courage to disclose to her employer, and the two of them set up a support group for nannies and domestic workers in their neighbourhood.

Some, however, have borne the brunt of callous rejection. One man spoke about being thrown out of his home and his church, and losing his job. He lived on the streets until a member of a church invited him to a support group, where he found companionship and understanding from those in a similar situation. Much later, his family welcomed him back and his church asked him to speak to the congregation about HIV. His capacity to embrace those who rejected him is truly humbling.

People have written about relationships gone wrong, about wanting to help people who are too afraid to test, about losing parents, children, siblings and friends to AIDS.

Some have written about being infected with HIV before antiretrovirals (ARVs) were available. They had to face their own certain death — but then came a medical reprieve. Others have written about people who refused to test until it was too late, even though ARVs were available.

Reading the stories is like hearing about the lives of your friends and family. Our readers have rescued us from thinking in terms of statistics and demographics. Important as they are, statistics and demographics can never reflect the human toll that HIV takes, in terms of both physical and mental health.

The contributions show us that there isn't a single "type" of person who has HIV. We have received contributions from black and white, men and women, heterosexual and homosexual, young and old, married and unmarried, an Appeal Court judge and a man who lived on the streets.

During the 16 Days of Activism Against Gender Violence, Gender Links has submitted contributions. Some of these have drawn a strong link between the abuse of women and HIV, some have highlighted the way HIV affects children. The voice of children has been rather scarce in the campaign, considering the extent to which they are affected by HIV, and we need to find ways to include them more frequently.



"I became HIV-positive as a result of a gang rape. I know, in the most painful way possible, the link between HIV and Aids and gender violence. I tell my story, over and over again, to get the government to provide

post-exposure prophylaxis to survivors of gender violence in the hope that others will avoid the fate that befell me."

- "A funeral every week, but also a life saved,"
Rose Thamae,



"I asked myself why I was worried about my mother, she was fine. I started to accept that my mother is not just HIV-positive: she is positive!"
- "My mother inspired me to help,"
Mpho Thamae



"My name is Kgomotso Thamae. I am 13 years old and I live with my grandmother in Orange Farm. After I discovered my grandmother's HIV-positive status, I felt very sorry for her. I kept asking myself, "Why is this

happening to my grandmother?"...I asked my friends about us starting a support group to help children who are in need."

- "I wish I could protect my grandmother,"
Kgomotso Thamae

The three stories of the Thamae women are part of the I Stories series produced by the Gender Links Opinion and Commentary Service for the "16 Days" campaign against gender-based violence and child abuse.

Our readers have sustained the campaign for two years. They have normalised AIDS in the sense that they have shown us that it is a disease that lives among us. Not one of the people who have contributed to the campaign deserved to be infected. No one does. Our readers have shown us that it could happen to anyone.

They have helped us face our fears by showing us how they deal with theirs. They have reached the human being in us by showing the human being in them.

I don't know whether this is activism or good journalism. Maybe it's a bit of both. The good journalism come from recognising the value of the contributions and committing editorial space to the campaign. The activism comes from understanding that HIV is an issue that we all face in one way or another, and from understanding that a mass-circulation newspaper has the power to take the message into millions of homes. And from letting our readers guide the discussion by sharing their stories about the challenges they face. They are the real heroes. They have taught us to see HIV/AIDS differently.



Writers Bio

Susan Smuts manages the Sunday Times HIV campaigns "Everyone Knows Someone" and "Each One Reach Five." "Everyone Knows Someone" is a campaign to encourage people to know their HIV status and reduce stigma. They publish the personal experiences (and, where the writer or subject feels comfortable, photos) of people in South Africa living with HIV or caring for loved ones with the virus. The stories appear in the newspaper or on the website. E-mail your story and photos to everyoneknows@sundaytimes.co.za or fax it to 011-280-5151.



Making Dreams Come True

By Karolina Pieters

Lying in my bed on the first night of our visit to Johannesburg last week I said to myself: is this true? Can we really be here? Is this a dream come true?

I am a teacher and the chair of the village council in Maltahohe in the dry Hardap region of Southern Namibia at the entrance to the Namib desert. Long before I became a councilor, I started a home for abandoned children. There is a high rate of alcoholism and gender violence where I came from. This is made worse by a high rate of HIV. There are currently 382 children in the home that I started, out of a village of 4000.

Six years ago my colleague Simon Anton and I started a culture group called Ama Buruxa, named for "Simply Amazing," for the children. Last year, I met the director of Gender Links, Colleen Lowe Morna, when she came to Maltahohe to conduct research on gender and local government. She asked me what I would most want for my children. I said, "I would like them to perform in Johannesburg!"

So here we are, and I can only say that this is a dream come true. While we have been here, the children have performed with several other groups from around Johannesburg, including at Museum Africa and at the Constitutional Court. We got a tour of the court and a history of South Africa from apartheid to the present. The children from South Africa and Namibia did an exercise on past, present and future. Then they wrote and performed a song together.

We got to go and see Umoja (the South African musical

that took London by storm). What an experience for the children of Ama Buruxa to watch those South African dancers who "dance like demons!" I believe in dance and song as a form of healing. What a healing experience this has been!

In the evenings, we sat in a circle and talked about our experiences, here and in Namibia. For the first time, I got to say "I am sorry" to Johannes* about something that has been painning me these few months. In October, we were performing at an old age home in Maltahohe. Suddenly I noticed tears flowing down Johannes' cheeks. His voice was quivering. Johannes' brother Peter is the drummer of Ama Bruxa. Later that day I learned that the boys' mother had just died of AIDS-related causes.

I could not forgive myself for having allowed them to perform that day. But they told me that they wanted to; that performing is what gives them strength. Their mother was a domestic worker whom both boys cared for lovingly before she died. They do not know their father. Peter is now doing the last two years of his secondary school in Rehoboth. He needs just over R2000 per year to finish his school. Where can I get bursaries from to help the children?

Then there is Rachel*, whose step mother died a year ago, also of AIDS-related causes, leaving behind a two month old baby. She has six brothers and sisters. Her father is disabled as a result of an accident while he was a construction worker. We are not sure if he and the baby are HIV positive

as they have not gone for tests. I had to tell Rachel that I could not take care of the baby; I just do not have the capacity to take care of the really small ones.

These things are so painful. But here in Johannesburg we have been able to talk. At one stage Rachel's father wanted me to adopt her. But I said that is not the right thing to do. She must never be disconnected from her family. My duty is to make sure that she gets an education, so that she can uplift the rest of the family.

Aletta* also lost her parents to HIV/AIDS. After caring for both of them, she wants to be a doctor. There is Ruth*, who narrowly escaped being raped twice. I had to send her to live with my older daughter in Windhoek to get away from it all.

Yes, my work can be very depressing, but it can also

be so rewarding. I have trained as a counselor, to help the children, and to help myself. I have learned that when children lose their parents, they become introverted and withdraw. Our role is to inspire them, fill them with hope, make them realise what they are capable of, make them know that they are, after all, "simply amazing."

I lie awake at night in Johannesburg, and the sounds of Umoja, the spirit of togetherness, run through my mind. I am thinking of new dance routines for Ama Buruxa. I am thinking of how to raise money for school fees so that every one of my children can finish their education. I am inspired. I am ready to soldier on.

**Names of the children have been changed to protect their identity.*

This article was originally published as part of the Sunday Times, "Everyone Knows Someone" series.

● **Writers Bio**

Karolina Pieters is a teacher and the chair of the village council in Maltahohe, Namibia and founder of Ama Buruxa.



Ama Buruxa perform at Museum African

Credit: Mariette van Dijk

Coração Aberto (Open Heart)

Published by IRIN PlusNews, this online and print publication is a collection of first-person stories from women living with HIV. The original idea behind the initiative was to portray women from Portuguese-speaking Africa who are managing to live with HIV, in spite of associated hardship and prejudice. Now, the collection has expanded to include men. What began as an online project has now also expanded to include a quarterly publication, with attractive design and photos.

However difficult their lives may be, the portraits are not of victims but of courageous people who face living with HIV and AIDS, who are not downtrodden and helpless, but active and hopeful. Their stories are strong and moving, and the photos are the face of HIV and AIDS portrayed with their children, in their homes, and frequently with smiles. The idea is to bring into the public perception that AIDS is not a death sentence, that it can happen to anyone, and that there is hope and life after a positive diagnosis. That society should help, not reject, people living with HIV.

Networks of people living with HIV and of AIDS service providers, United Nations agencies, ARV treatment providers, support groups and other AIDS actors in Lusophone Africa distribute the publication. For example, in Mozambique, the national umbrella of AIDS service organisations, Monaso, and of people living with HIV, Rensida, distribute the supplement with their magazines (combined circulation 4,800) ensuring it gets out into the provinces to the core constituency: people infected and affected, activists and caregivers.



Reactions to Coração Aberto

By Maya Sangawa

The waiting room of Hospital Esperança is full. After an interview with PlusNews, director Antonio Feijó leaves with PlusNews supplements in his hands. A nurse recognises the picture of Carolina Pinto on the cover: "She is our patient!". Nurses and patients gather around the director to see the material. Many people read the few issues together. Everybody notices the photos of a sick, then healthy Ana Maria Muhai. The director asks me to send him more issues.

The same scene repeats itself at the self-help group Paroquia Sagrado Coração de Jesus. Beth, who gave an interview to Coração Aberto, passes her copy along to other friends, who immediately

start reading the stories. Pombal Maria, coordinator of NGO Luta pela Vihda, also asks for more issues of Coração Aberto to send to the groups that his NGO is creating in Benguela, with Oxfam funds. Mwenho, a NGO that targets HIV+ women, also has interest in the material. The organisations executive secretary, Catarina Saldanha, suggest doing an Angolan issue with Mwenho members willing to talk about their condition. “We could publish a big photo of all of them on the cover.”

In an ANASO seminar about secondary prevention to HIV/AIDS, Carolina Pinto says that many people have already shown her the supplement: Roberto Campos, from UNAIDS, Antonio Coelho, from Anaso, and others. Many activists ask to take a

picture with her. She walks into the auditorium as a star.

When they see the supplement with Carolina Pinto on the cover, many activists ask for more issues. Associação Juvenil para o Desenvolvimento (Bengo), SOS Cedia (Zaire), Grupo Bíblico de Estudantes Cristãos de Angola (Namibe), Prazedor (Huíla), Associação Juvenil Etungafano (Kunene), Associação de Educadores Sociais (Malanje), Associação dos Amigos dos Seropositivos (Cabinda), Cruz Vermelha (Kwanza Sul) e Associação dos Naturais e Amigos de Calima (Benguela) are the NGOs that receive supplements.

Those who didn't get it complain. The PlusNews supplement will be read from Cabinda to Kunene provinces.



In “The power of love: I am HIV+ and my husband isn't” Carolina Pinto shared her story of being dignosed with HIV at 19, becoming an activist, and meeting and marrying her husband, who is HIV negative.

“Many people who live with HIV opt to have relationships only with others who are HIV+. They believe that the relationship stands a better chance to be successful. But this is not true. The fact that two people are infected with HIV does not mean that they share the same thoughts, have the same character, same feelings, that they will live together forever and that love will be more sincere. Love is variable, be it in a discordant relationship (where one partner is HIV+ and the other isn't) or not.”

Read Carolina Pinto's Story in Portuguese:
<http://www.plusnews.org/pt/HOVReport.aspx?ReportId=70579>



Tsha Tsha:
Entertainment-Education Series
Challenges Masculinity Among HIV-positive
Men in Soweto

By Frederick Oduor Ogenga

Abstract

This article is an excerpt from a study that aimed to examine the production of HIV/AIDS lessons on Tsha Tsha Entertainment-Education (E-E) and their reception by HIV-positive men in Soweto, and to find out whether this response affected their perception of their roles and responsibilities in HIV/AIDS. The rationale behind this study was that gender and HIV/AIDS has been critical in interventions aimed at combating the disease. The findings revealed that audiences (HIV-positive men) identified with lessons around HIV-testing, disclosure, support and those that challenge stigma and masculinity in HIV/AIDS. Disclosure emerged as a major theme compared with sub themes of testing, stigma, masculinity and social support to form categories that were presented as the findings.

Key words

HIV/AIDS, testing, disclosure, support, gender, masculinity, South Africa, entertainment-education

Masculinity

The study of gender and HIV/AIDS has been critical in interventions aimed at combating the disease. In South Africa, studies done under African sexuality in the area of HIV/AIDS have revealed that masculinity around sex and sexuality often depict women as more vulnerable to HIV/AIDS than men, and men as the drivers of the epidemic (Kometsi 2004). According to anthropologists, masculinity is a core set of activities or traits which are transculturally associated with men (Morell 1991, 5).

Masculinity is visible around issues such as having multiple partners, fear of testing, fear of disclosure, men's "macho" attitude that ensures they don't seek treatment, and rejection of their partners when they realise they are positive.

Culture partially constructs traditional gender roles, where notions of masculinity thrive, ensuring that men do not take responsibility in HIV/AIDS. These notions have disempowered men, leaving them vulnerable and making it difficult for them to cope with the epidemic.

The perceived vulnerability of women has led to several efforts to empower women with little efforts focusing on men's vulnerability (Kometsi 2004; Gupta 2000; Mane & Aggleton 2001). The empowerment of women in South Africa on gender equality has perhaps threatened and disempowered men. The "New Gender Order" amidst traditional masculinity has left men confused. They have lost their traditional roles dictated by power positions in the society. This is evident in the increase of domestic violence and sexual abuse of women and children including child rape (Morell 2001; Reid & Walker 2005)

However, as my research is now indicating, there are changing perceptions of masculinity, particularly related to HIV/AIDS, that are now penetrating the spaces of traditional masculinity, especially around men's roles and responsibilities in HIV/AIDS. (Reid & Walker 2001; Morell 2004; Garson 2004). Masculinity crumbles in the face of the epidemic, by the fact that men become weakened by the disease and they lose their dignity due to the association of the disease with 'bad sex' that leads to 'bad death' (Posel 2003). This forces men to forge a new masculinity especially around their roles and responsibilities, through taking certain actions at a post infection level. These decisions and roles follow the disclosure of their status to significant others to ensure their well-being and those of their partners. These are actions such as testing for HIV, living positively with HIV disclosure, coping with stigma and opening up for support for themselves and their partners at different levels (partner, family and community level).

Change seldom happens in a vacuum, there has to be social forces that drive the change. One of the possibilities of bringing about change is through the media. Entertainment-Education (E-E), has been used as one of the most effective vehicles for social change. This is evident through the evaluation of audience response to E-E programmes like *Soul City* and an evaluation of the first 26 episodes of *Tsha Tsha*, which showed the television programme contributed in the change of the audience member's perception to HIV/AIDS (Kelly *et al*, 2005). I conducted this research in Soweto and therefore looked at the production of HIV/AIDS lessons on the Entertainment-

Education television programme *Tsha Tsha* and their reception by HIV-positive men in Soweto.

The objectives of this research were two-fold: firstly, I wanted to assess the production of HIV/AIDS lessons on *Tsha Tsha* Entertainment-Education and their reception by HIV-positive men in Soweto and secondly, to find out whether this response impacts on HIV-positive men's perception of their roles and responsibilities in HIV/AIDS. The questions I was addressing in this research were; what lessons in HIV/AIDS did producers encode in *Tsha Tsha*? How did HIV-positive men respond to these lessons? And did these lessons help them change their perceptions of their roles and responsibilities in HIV/AIDS?

While reviewing the background literature in the field of African sexuality studies, I realised that most scholars agree that there are different forms of masculinities. From a historical perspective, masculinity as a key concept in gender studies has affected HIV/AIDS in several ways. This is because masculinity has defined and shaped the nature of heterosexual relationships. Masculinity is seen as heterogeneous and there is nothing like a single version of masculinity practiced by all men. There are different masculinities and an increased awareness, by some men, of their identity as a gendered construction that is open to change (changing men).

The nature of relationships between men and women in South Africa and their general perception of their roles and responsibilities within those relationships should be contextualised. These roles are often patriarchal and limit men to exclude themselves in certain critical aspects of HIV prevention, testing, disclosure, care and support (Kometsi 2004, 31-32). Morrell argues that even though most men profit from hegemonic masculinity, not every man holds this kind of masculinity. Hegemonic masculinity therefore tends to exclude marginalised groups in the society. Women hardly benefit from this form of masculinity. Donaldson (in Zlotnik 2000, 12) notes, "a fundamental element of hegemonic masculinity is that women exist as potential sexual objects for men." Men gain sexual validation by not only pursuing women but also competing for them. This is where hegemonic masculinity is associated with sexual conquest and having many

sexual partners, partially accounting for the rising infection rates of HIV in South Africa.

Masculinity socialises men to be macho risk-takers and to crave social power. Campbell (in Kometsi 2004, 84) claims that "frequent and unprotected sex with multiple partners may often be one of the few ways in which men can act on their hegemonic masculinity." The active and conscious pursuit of real manhood or prescriptions of masculinity create anxiety precisely because of the shifting nature of the boundaries and its instability over time and place. The socialisation described earlier creates men and women as opponents. It creates the perception that masculine power and status are under threat from those who are not masculine (Hooks in Kometsi 2004, 85)

The effects of this hegemonic masculinity significantly concern relationships between partners, affecting their sexual health, especially when they are HIV positive. For example, one participant his partner will question his manhood. In other cases, this situation is often characterised by men's negligence in parental roles and their negligence of other roles and responsibilities such as HIV testing, disclosure, care and support. All participants found these issues problematic

Considering the fact that men are the ones that make many decisions in the family, it is imperative to ensure that they contribute wisely in decisions concerning their health and that of their partners. The burden that couples face due to HIV/AIDS is associated with the feeling of social rejection and stigma, feelings that are difficult to deal with. This is the moment when men and women are required to work jointly, to support each other psychologically, emotionally and financially. It is likely that the kind of relationship existing between partners can influence the choices they make regarding their health.

With sex being central to the self-imaging of men as real men - men with power, especially over women – women's insistence on practicing safer sex might be seen as a challenge to the power of men (Kometsi 2004, 83). Therefore, in looking at men's perception of their partners in their relationships and within the broader

aspect of HIV/AIDS, it is clear that some decisions regarding sex, for instance decisions about condom use, are problematic (Kometsi 2004, 12). Nevertheless, both men and women (the society) participate in ensuring certain masculinities are privileged and not others. Both men and women are active participants in the perpetuation of some forms of masculinity depending on whether they favour them or not.

Changing masculinity



Tsha Tsha character Andile cares for his mother who is dying of an AIDS-related illness.

However, masculinities are fluid and should not be considered as belonging in a fixed way to any group of men. They are socially and historically constructed in a process that involves contestation between rival understandings of what being a man should involve. Masculinities are constantly being protected and defended, are constantly breaking down and being recreated.

Deaux (in Zlotnik 2002, 9) observes that masculinity is socially constructed and changes as relationships between societies do, rather than being a natural attribute. Masculinity as a construct or set of attributes does not apply only to men. Rather, it is a construct that may constitute part of the identity of both men and women to some extent.

Unreal AIDS review research done by Kometsi at the University of Pretoria on masculinity and HIV/AIDS in South Africa, indicates that men's perceptions on masculinity influence their relations with others, especially their partners. There is a link between some of men's practices and the spread of HIV (Kometsi 2004, 81).

Power as an operational concept is essential in examining how some men relate to themselves, and more importantly to women. Traditional masculinity therefore becomes some men's practices in such relationships. These are practices that dominant images of manhood are associated with (Kometsi 2004, 81).

Connell (in Kometsi, 2004. p. 82) suggests the importance of looking at how men and women lead gendered lives as a lead-in to what the concept of masculinity means.

Masculinity represents not just an idea in the head, or a personality identity. It also extends into the world, merged into organised social relations.

What this means for entertainment-education

In the socio-economic and political context of HIV/AIDS in South Africa, testing, stigma, disclosure, support and how they relate to masculinity have contributed greatly in the shaping and reshaping of these masculinities. In the political context, there have been debates about the causal link between HIV and AIDS and the crossfire between the government, pharmaceutical companies, civil societies and people living with HIV/AIDS about treatment options, and safety and efficacy of the drugs used for treatment. Within such a complexity, *Tsha Tsha* as an entertainment-education is used as a case study. *Tsha Tsha* strives to highlight issues related to sexuality facing South Africans within a broader framework of addressing the problematic issue of HIV/AIDS.

Men are centrally implicated in the shifting sexual landscape in South Africa. There is a perception that the HIV/AIDS epidemic is driven by men, and men are blamed for the prevalence of domestic violence and child sexual abuse (Reid & Walker 2005, 9; Mane & Aggleton 2001). The concept that it is often men who spread the epidemic to women was ignored until the late 1990's. This is when it was recognised that since men have some power in sexual relationships they should shoulder the responsibility of preventing the transmission of HIV, protecting their own health as well as that of their female partners. *Tsha Tsha* presents new ways of targeting and addressing men that are not reinforcing traditional stereotypes of gender roles and masculine identities. Characters rather model new ideas of masculinity.

In the five interviews that I conducted with the producers of *Tsha Tsha*, there was an indication that they encode messages based on the assumption that human beings learn from their social environment through modelling (Bandura 1977). They use models that audiences can identify with and learn from. While the producers come up with TV messages in form of lessons through the programme, audiences (HIV-positive men) on the other side respond to such messages in a similar fashion.

After being exposed to 12 episodes of *Tsha Tsha* that had HIV/AIDS lessons purposely designed by programme producers about testing, disclosure and social support, the HIV-positive men indicated in the six focus group discussions that followed the viewing that they have learnt lessons about HIV-AIDS disclosure, testing social support through models in the programme. However, disclosure was the dominant theme as they explain in the following excerpts:

"There is no any other way, you just have to disclose to the person you are concerned with and see what's happening. Then you will get the support or you will get the negative response, it will depend. But it is better to stick to disclosure, you just have to disclose." - Wellington.

"Yah it's good to talk to avoid thinking too much."

This indicated that there is a level of success in changing audience perceptions if entertainment-education programmes purposely design strategies around HIV/AIDS themes. Other lessons that respondents indicated to have learnt through the programme were the need to discourage multiple partners, living positively with HIV/AIDS, disclosure and stigma, and having a better relationship.

Tsha Tsha therefore followed a theoretical approach that allows us to understand and partly explain production of lessons in *Tsha Tsha*, and largely explain the responses of HIV-positive men (audience) to the lessons presented. In this theoretical approach, encoding is done within the genre of E-E, determining the product that appears in the form of lessons. This genre (E-E) is defined by certain professional rules and regulations that define it.

Therefore, the intention of the producers was for the audiences to share their version of meaning to the lessons they present when decoding these lessons.

The encoding-decoding theoretical approach therefore helps us understand how *Tsha Tsha* programme producers design lessons that encourage shared “reading,” that is the messages that viewers took away with them. It also explains how HIV-positive men respond to these lessons depending on several other factors. These factors include, for instance, their HIV-positive condition. They identified with the lessons about HIV testing, disclosure and stigma out of the fact that they were already living with HIV (Morley 1980; Fiske 1978; and Ang (in Downing *et al* 1990)). *Tsha Tsha* audiences surveyed (HIV-positive men) had a preferred reading (shared reading, according to producers’ intentions) of lessons around HIV disclosure, testing and stigma, and opening up for support and supporting others (their partners) in HIV/AIDS.

Disclosure



Vive disclosing her HIV status

Disclosure is seen as challenging HIV/AIDS stigma and traditional masculinity, where men accept their condition, and take responsibility to continue occupying their space as men. This they do through actions that promote their health and well being as well as those of their partners. The line between gender roles thus becomes invisible when it comes to HIV/AIDS.

Disclosure was repeatedly shown in the episodes through different characters in different contexts. Disclosure of HIV/AIDS in the programme was presented across many episodes as a necessary step towards coping with HIV/AIDS for those infected. Most participants emphasised the need for HIV disclosure as a way of opening up for support and of helping infected people to cope with the physical and psychological stressors that come with the virus:

“Disclosure has helped us to be strong... in such a way that we are getting the support that we need in the support groups.”

“After knowing my status, I told myself I am like that and I will never change and I must give others the word...”

The focus group discussions with seven HIV-positive men indicated that they had a changed perception on various problematic issues in HIV/AIDS like testing, stigma, disclosure and social support. The HIV-positive men identified with the character Viwe (the modeling character) due to her courage to test and disclose openly to her family and community, as well as starting a support group to help others. They saw Viwe as their hero because she was strong and, therefore, gave them hope:

“Yah for me according to the role that they play I think Viwe is the hero because she is the one who talks about disclosure she is not afraid.”

Tsha Tsha encouraged HIV-positive men to talk about certain important issues in HIV/AIDS such as reduction of sexual partners, using safety measures, seeking treatment and the need to live positively with those infected. The HIV-positive men saw the programme as very encouraging because it teaches people and gives them information about HIV/AIDS:

“I see only one thing that this cassette is very good to show people [...people must] go and check their status, maybe this cassette can be

used to teach to change that disclosure is normal.”

In line with supporting their partners (their roles and responsibilities), most of them were abandoned and were no longer in a relationship because their partners had “run away” after they disclosed. Perhaps *Tsha Tsha* should have addressed the issue of partners being abandoned after they disclosed. However, after watching *Tsha Tsha* they indicated a changed perception of their roles in a relationship. Most importantly, the findings in this research indicated that masculinity is changing, with some men taking responsibility for themselves and “partners” (others) through disclosure after testing. It has also indicated *Tsha Tsha*’s contribution in providing lessons that bring about a change in perception in men’s roles and responsibilities in HIV/AIDS.

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Writers Bio

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Confronting HIV Stigma in African Communities in the United Kingdom Through Media

By Lucy Stackpool-Moore of Panos London (with guidance from Georgina Caswell and Rhon Reynolds from the African HIV Policy Network (AHPN), colleagues from Panos London, and Janet Boston and Anna Roberts from the Thomson Foundation.)

Abstract

African migrants account for the greatest number of new HIV diagnoses in Britain in recent years. In November 2007, Panos London and the African HIV Policy Network published *Start the Press: How African Communities in the UK Can Work with the Media to Confront HIV Stigma*. The publication challenges African communities to engage constructively with the media, and vice versa, to enhance coverage of HIV in the UK so that media coverage can confront – and not perpetuate – stigma related to HIV. The following paper is based on excerpts from the report.

Key words

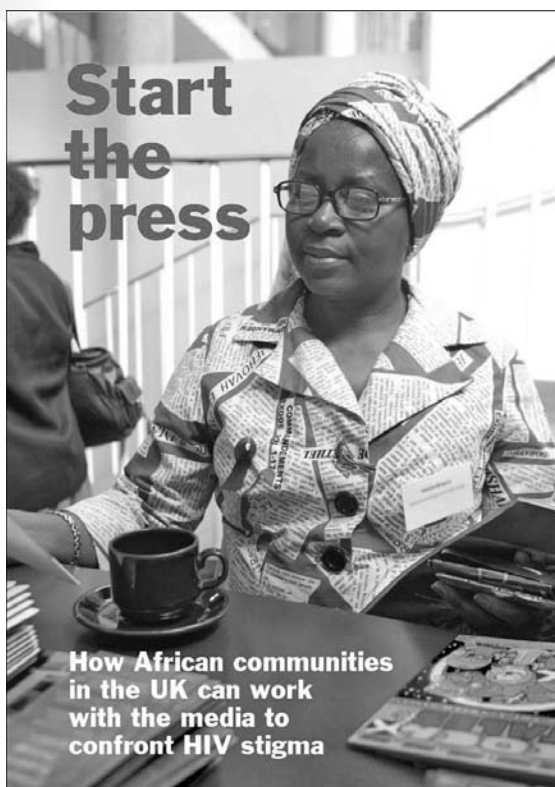
HIV/AIDS, migration

HIV Stigma among Migrants in the UK

In the United Kingdom, African migrants are among the social groups that are most vulnerable to HIV. They account for the greatest number of new diagnoses in recent years (Health Protection Agency 2006, 46). HIV has always thrived in the fractures of society, among groups who are marginalised because their sexuality, race, poverty or because their lifestyle choices (such as selling sex or injecting drug use) don't conform to social "norms." Once seen as being about individual attitudes and prejudice, stigma and discrimination are now recognised as broad social processes that sustain power inequalities (Parker et al 2002). An African person living with HIV in the UK may experience multiple levels of marginalisation,

apparent in inadequate living conditions, unequal income opportunities and limited visibility in policy decisions. These practical realities are exacerbated by current and historical constructions of racism, xenophobia, and stereotypes of African hyper-sexuality.

Stigma limits access to health services by silencing discussions about taboo issues that are integral to HIV vulnerability – such as race, poverty, gender relations, sexuality and drug use. Stigma reveals itself not only in issues that are scandalised or reported inaccurately, but also in what is left unsaid and in voices that are not heard (National AIDS Trust 2007). It is both what is talked about and how, as well as what is silenced and why, that fuel this vicious cycle linking stigma and marginalisation.



To read the full report:
http://www.panos.org.uk/PDF/reports/start_the_press.pdf

The media can play an important part in challenging stigma around HIV and AIDS (Kaiser Family Foundation and UNAIDS 2004). The African HIV Policy Network (AHPN), the Thomson Foundation and Panos London argue that by speaking out, people living with HIV and leaders among African communities can raise awareness about stigma and tackle the discrimination experienced by African communities and people living with HIV in the UK.¹

One way to achieve this is through better engagement with the media – by supporting responsible journalism that can challenge stigma, and equally by spotlighting inaccurate or misleading coverage that reinforces stigma.

Key findings

Start the Press draws on a content analysis of HIV coverage in selected UK newspapers (including national and ethnic

papers) between 30 November 2005 and 31 December 2006, and two community engagement meetings with people living with HIV and their advocates, leaders within the African communities, doctors, faith leaders and journalists from the national and ethnic press.

“ Stigma to me means to be regarded [as] an alien... in the community I live in. You are not treated the same as others... ”

As an African woman living with HIV I feel I am stigmatised more for where I come [from]. The media has informed and taught the world that HIV is from Africa and the poorest continent, which is equal to Zimbabwe, equals Mugabe, equals poverty, equals HIV. All these boxed in one make me feel so inferior... ”

After all, it is true that I am HIV positive and I am from Africa... ”

I appreciate the sympathy but I'll never tolerate the stigma surrounding my status.”

- African person living with HIV
 September 2007

The key findings of the research include the following:

- The UK press tends to present HIV as a disease in Africa, signifying a shift from framing HIV as a “gay disease.” More than half of all articles in the national and ethnic press focused on HIV in countries outside the UK – mainly Africa. In the national press, 31% (119 articles) included in the study looked at HIV as a domestic epidemic. Likewise in the ethnic papers, 19% (26 articles) focused on HIV in the UK.

- People who are most affected by HIV are rarely interviewed in articles: the main sources of information are government spokespeople (such as the Department of Health or NHS), doctors, or civil society organisations (such as the Terrence Higgins Trust, NAT or AHPN). In the ethnic papers, people identified as living with HIV were interviewed and quoted in 13.5% of the articles studied (12 articles); in the national press, they were quoted in 10% (40 articles). In both types of papers, the most commonly quoted sources were activists and NGOs, government or other political spokespeople, and doctors and scientists. The views and voices of African migrants living with HIV were largely absent.
- There is relatively little coverage of HIV and migration – approximately 6% of the total coverage we analysed (18 articles in the national press and 15 in the ethnic papers). Of this coverage, the tabloid newspapers (Sun and Daily Mail) contained the most stigmatising language, according to the National Union of Journalists (NUJ) guidelines. Articles that focused on HIV and migration in the UK were often framed around legal issues (such as the prosecution of HIV transmission). Only one article investigated the underlying inequalities that contribute to HIV vulnerability for African migrants in the UK; and that was a reprint of an AHPN press release – it was not written by a journalist.
- Coverage of HIV-related tuberculosis (TB) was low in both the ethnic and national press, with two articles in each, which accounted for 2.7% in the former and 0.5% in the latter. Even though HIV-TB co-infection is one of the most common AIDS-related illnesses among migrants in the UK, there was no coverage of the combined issues of TB, HIV and migration.
- Access to treatment and health services was the primary focus of HIV coverage in the ethnic press, rather than transmission or prevention. Articles focusing on treatment accounted for 55% (75 articles), which was almost double the attention given to any other single theme – for example, prevention was covered in 34% of articles, transmission in 28%. This suggests that the ethnic press perceived these issues as most relevant for their target audience – in this case, African communities in the UK.

The content analysis found that HIV coverage in the national broadsheets and the ethnic press was generally factually accurate, clearly written and used non-stigmatising language. Some of the tabloids, however, tended to use words such as “victim”, “sex fiend” and “scandal” to frame stories about HIV transmission and often drew on unnamed sources and inaccurate information, as illustrated in the coverage of Everson Banda’s story, outlined below.

Coverage of HIV also remains highly medicalised, focusing mainly on treatment, with only a few articles investigating the wider social and cultural aspects underlying HIV or broader issues such as living positively with HIV, vulnerability to infection and access to appropriate health services.

A combination of what is covered in the UK press and what is left out contributes to perceptions that coverage is stigmatising. Coverage that specifically linked HIV and migration in the ethnic press usually framed the stories in terms of conflict and war (refugees and asylum seekers), the prosecution of HIV transmission, human rights and entitlement to services in the UK. The majority of articles in the national press were in the tabloids and predominantly focused on issues of undocumented migration. The framing of HIV and migration in terms of prosecution of HIV transmission and “illegal” migration in the tabloids – the most widely read papers in the UK² – risks conflating stigma around each of these issues.



From Start the Press: Masias Cowper of the African HIV Policy Network speaks out about African people living with HIV in the UK at the press launch for a new campaign. *Credit: Panos*

Case Study

Analysis of coverage of the case of Everson Banda in August and September 2006 highlights how the framing of migration and HIV in terms of scandal and illegality can conflate and stigmatise the issues and people most affected. It highlights a need and opportunity for people who are most affected by HIV to engage the media more effectively to promote accurate, informed and inclusive debate about HIV in the UK.

Everson Banda is a Zimbabwean man who allegedly had unprotected sex which led to the transmission of HIV to six women while working at a holiday camp in Essex. The coverage of his story highlights some of the key characteristics of overall coverage of HIV and migration in the period studied: the voice or perspective of central actors (in this case Everson Banda himself) was absent from the debate; coverage did not question links between HIV, migration and vulnerability; and the tabloid coverage tended to be inaccurate, framing the story as a scandal, with vague facts about the events. The press presented no evidence that Everson Banda had been tested, or that he was aware of his HIV status (whether positive or negative).

None of the articles named sources, simply referring to spokespeople from the holiday camp and immigration services – yet the Home Office has a policy not to comment on individual cases. *The Sun* in particular featured six stories about Everson Banda, with headlines such as “Lock up the HIV monster”, “Holiday camp sex monster has given me HIV”, and “HIV fiend put us on death row.” The stories address legal aspects of migration by repeatedly emphasising how Banda was sent home to Zimbabwe by the authorities when immigration officials found that he was in the UK illegally. The coverage framed HIV transmission in the context of illegality and scandal. In one story, Everson Banda was cited alongside a separate case of another migrant from Zimbabwe who was working at the Home Office: “the scandal is the second involving Zimbabwean illegals... Two months ago we were told how Joseph Dzumbira got a job at the Home Office after entering Britain as an asylum seeker” (*The Sun* 2006).

By scandalising and linking coverage of two completely unrelated individuals (Banda and Dzumbira), *The Sun* unnecessarily forces association between HIV, asylum and “illegal” migration and risks conflating stigma associated with each of these issues. The press coverage tended to hyper-sexualise Banda, reinforcing stereotypes that link African migrants and men in particular with sexually predatory behaviour. For example, Banda was described as a “burly African” who “seduced many of his conquests” (*Daily Mail* 2006), “woo[ing] girls...’c9 plying them with drink before walking them back to his berth” (*The Sun* 2006), and having sex with “literally scores” of women (*The Times* 2006). Such sensationalised stories can reinforce the stigma, discrimination and internalised stigma that people living with HIV and African migrants experience in the UK.

Readers’ responses to the *Daily Mail* article, posted online, illustrate how the framing of the article can influence the framing of public debate about an issue. Forty-six people commented online – mostly from the UK, with 10 from abroad, only one of whom was from Africa (Zambia). Many of the comments touched on morality, HIV prevention and the responsibility of women as well as men for safer sex. Of the responses, 13 directly responded to issues of migration or asylum (28%). One respondent did in fact question the link between asylum and HIV; however, the others referred to issues such as “border control,” medical checks for migrants and even “quarantine.” This indicates that even though there is no direct link between migration, asylum and HIV in Banda’s case, the framing of the story significantly influenced the public responses (in this case select ones posted on the website) and highlights the potential to evoke stigmatising, racist and/or xenophobic comments.

One story published in the *African Echo* was a direct follow-up to the coverage in *The Sun*, *Daily Mail* and *The Times*. The article, “Let’s support, not vilify people living with HIV,” discussed broader social and cultural issues such as discrimination, sexually transmitted diseases, HIV prevention, health services and testing. The headline and introduction to the story indicate that the paper is trying to encourage responsible reporting. The article highlights the importance of

different perspectives in the mass media, including different angles and coverage between the national and ethnic press. It also indicates that media coverage itself can encourage best practice across the sector – by printing an article that involves self-analysis, critique and suggestions for best practice on reporting on particular issues (HIV and migration in this case). However, the article was not written by a journalist – it was a reprint of an AHPN press release.

Media's role

By failing to do any investigative reporting into the underlying inequalities relating to the concentration of HIV among African migrants and other marginalised communities in the UK, all the papers are missing an opportunity to generate debate, confront stigma, and influence inclusive and evidence-based policy responses that reflect the priorities and needs of the most affected communities. By overlooking the voices of African migrants in these debates, UK press coverage risks perpetuating stigma and processes of marginalisation that entrench inequality and vulnerability to HIV.

Responsible media coverage can challenge stigma by:

- providing accurate information that facilitates access to appropriate health services;
- giving voice to people living with or affected by HIV;
- breaking the silence around issues that can be difficult to talk about – such as sex, sexuality and drug use;
- providing a platform for public debate that draws on a variety of perspectives; and
- influencing policy agendas and framing policy debates.

At the community engagement meetings, people living with HIV, their advocates and leaders among African communities in the UK all felt that press coverage of HIV and migration is stigmatising, highlighting key examples of such coverage. These findings generally support other studies that found stigmatising coverage of asylum and refugee issues in the UK press may exacerbate experiences of discrimination for Africans living with HIV even when the coverage does not explicitly link the issues with HIV.

These findings suggest that the framing and type of coverage of HIV and migration, and the broader history of constructed identities reinforcing inequalities (such as racism or stereotypes about African hyper-sexuality), rather than the amount of coverage per se, is responsible for magnifying perceptions that the coverage is stigmatising. Further research is needed to understand the differences between perceptions and experiences of stigma in the media in comparison with the content of the coverage itself.

Overall, the research indicates that UK press coverage could do more to promote debate about the underlying inequalities and stigma that make people vulnerable to HIV and hinder access to appropriate health services. People living with HIV, HIV advocates and the African community can engage the media to show the human stories behind living positively with HIV, and encourage journalists to challenge – rather than perpetuate – the stigma that exists around HIV and AIDS in the UK.

To confront HIV stigma in the UK effectively, media coverage must be factually accurate and balanced, and draw on the voices and perspectives of those who are most affected – including African communities. Journalists and editors should consider: the way they frame the issues; how they use language (for example, avoiding the use of words such as “sex predator” or “victim”); and the underlying causes of vulnerability embedded in the overlap between issues such as HIV and undocumented migration.

Tips from journalists for HIV advocates

People living with HIV and their advocates can engage the media better and build relationships to encourage responsive and responsible journalism. At the community engagement meetings, journalists offered the following suggestions for people living with HIV and their advocates, to help them work more effectively with journalists to enhance media coverage of HIV in the UK:

- Build relationships with journalists, to give them an added interest in checking the accuracy and language of their stories. By building trust, it is easier to ensure that the

issues and interviews are accurately represented.

- Complaints about a specific article should be directed in writing to the editor of the journalist concerned. Complaints about the accuracy of an article should be directed to the Press Complaints Commission.
- Journalists always want a human angle for their stories. Although it takes courage to speak out, journalists recognise that HIV advocates have quotes, case studies and the power to generate a story.

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Writers Bio

Lucy Stackpool-Moore is the HIV Officer for stigma and discrimination with the International Planned Parenthood Federation (IPPF). Formerly with Panos London and the Panos Global AIDS Programme, she has diverse research and practical experience with participatory communication. Lucy draws from experiences in youth work (Sydney), outdoor experiential education (USA) and research and project management on HIV communication (Southern Africa, Brazil, UK and international) to shape her work with HIV, community participation and stigma.

Notes

¹ Start the Press is part of the Changing Perspectives campaign, coordinated by AHPN, which aims to raise awareness of HIV-related stigma and tackle the discrimination experienced by African communities living in the UK by supporting better engagement between people living with HIV, immigrants affected by HIV, their advocates and the media.

² The Sun has an average net circulation of almost 3 million readers per issue; the Daily Mail has almost 2.2 million, according to the Audits Bureau of Circulations UK (www.abc.org.uk). The Daily Mail alone has more readers than The Times, the Guardian, Financial Times and The Independent together (a total of almost 1.7 million for all four broadsheets combined)

In Practice: Phela Health and Development Communication

Phela is a Health and Development Communication organisation that uses the power of the mass media (radio, TV and print) to disseminate information in order to effect social and behaviour change. They aim to provide reliable, helpful and accurate information on HIV and AIDS, as well as other health and development related issues that is relevant for Lesotho. Phela's programmes are research-based and always go through pre-testing by both stakeholders and audiences before they are actually distributed and broadcast. Phela supports people to make choices, concerning their lives, which enable them to live longer, healthier lives. Programmes have included

Print

- HIV and AIDS Action Now! With print run of 850 000 (50: 50 Sesotho: English)
- Mother and Child Care with Print run of 7000 000 (70: 30 Sesotho: English)
- Help Stop Women Abuse with print run of 7000 000 (90: 10 Sesotho: English)

Radio Drama

- 'Musa Pelo- 60 episodes of 15 mins each
- Mafube a Bophelo- 45 episodes of 15 mins each

TV programmes

- 2x 13 episode series of 10 and 15 minutes. These were later repackaged into 1x 13 27 minutes episodes.

Process

Phela's multi media edutainment is research based and involves extensive formative research process that includes broad stakeholder consultations, literature review and empirical audience research. All materials produced (radio, TV and print) are pre-tested with the target audience to ensure resonance, clarity, effectiveness and to rectify unintended messages. Phela strives to work in partnership with stakeholders, and always calls upon them for input, support and feedback during research, development, production and implementation of multi media and advocacy programmes.

Next steps

Phela continues to disseminate well researched information on health and development issues using the power of various multi media and complementing the National Strategic Plan on HIV and AIDS.

- Developing new multimedia programs on Gender and HIV and AIDS and nutrition. These are already underway and will be distributed soon. We will also develop programs based on the ground breaking research we have done on Multiple Concurrent relationships and HIV and AIDS.
- Untold Stories: Phela is also developing a 1/2 hour film whose message is: ART improves the quality of life and prolongs life. Families and communities should support individuals on treatment.
- We plan to embark on an outreach programme that focuses on addressing the communities on Health and Development issues.
- Advocacy campaign by which we strive to influence the enactment of Domestic violence Act in Lesotho. This campaign is aimed at addressing domestic violence as the most common form of Gender based violence and a fuelling factor to HIV and AIDS.

Contact:

Phela

Save the Children building, Industrial Area Maseru.
Postal address: Private Bag A194 Maseru 100 Lesotho.
Tel: +266- 22327502, Fax: +266- 22327503,

HIV/AIDS and Media: Examples of Practice

Compiled by Cindy Dzanya

There are a wide range of media initiatives that address various aspects of HIV. The following are just a few examples.

African Broadcast Media Partnership Against HIV/AIDS (ABMP) - Africa



AFRICAN BROADCAST
MEDIA PARTNERSHIP
 AGAINST HIV/AIDS

ABMP is a pan-African coalition of broadcast companies that aim to reinvigorate and increase the effectiveness of broadcast media's contribution to the fight against HIV/AIDS. The ABMP aims to embrace all African countries and to include both public and commercial broadcasters. Inspired by UN Secretary General's call to action under the Global Media AIDS Initiative, the ABMP creates a structured framework for leveraging broadcast media resources with the goal of significantly expanding HIV/AIDS-related broadcast programming across Africa.

A central objective is to promote a new paradigm in the broadcast industry's approach to HIV/AIDS-content based on:

- promotion of a business-centred approach incorporating HIV/AIDS as part of broadcasters' core business and ensuring integration of HIV/AIDS-related messages and themes across all programme formats and schedules; and
- a consistent pan-African HIV/AIDS-related communications framework targeting key drivers of HIV such as gender inequity, stigma, coercion and peer pressure.

To meet its goals, the ABMP will facilitate two streams of content development within the pan-African strategic HIV/AIDS communication framework:

- Core content (generally public service announcements and short format programming) will be centrally developed with creative input from the signatory companies and distributed rights-free across all signatory companies.
- Company content will be developed by signatory companies integrating the key messages and themes of the HIV/AIDS communications framework across existing programme formats.

Source: <http://www.broadcasthivafrica.org/>

Southern Africa HIV and AIDS Information Dissemination Service (SAFAIDS) – Southern Africa

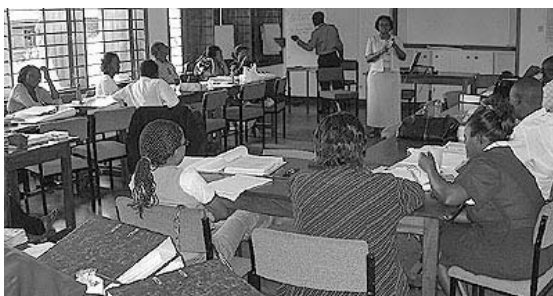


Established in 1994, SAfAIDS is a regional HIV/AIDS organisation based Harare, Zimbabwe. Its goal is to disseminate HIV/AIDS information to promote, inform and support appropriate responses to the epidemic. SAfAIDS provides:

- capacity- building to partner organisations and NGOs to enhance a multiplier effect in good practices;
- technical support and advice to NGOs, Governments, academic and other institutions;
- technical expertise to different sectors, through evaluations, strategic analysis and advisory work, policy development, advocacy and programming;
- assistance to other organisations in mainstreaming HIV/AIDS into their development and workplace activities;
- an interlink between research and programming through discussion fora on topical issues related to HIV/AIDS and sharing good practices; and
- gender analysis through the encouragement of the involvement of men in HIV/AIDS and development issues although women's issues remain a priority.

For more information, contact:

SAfAIDS
17 Beveridge Rd
Po Box A509,
Avondale, Harare, Zimbabwe
Tel: +263 4 336193/4 / Fax: +263 4 336195
Source: <http://www.safaims.org.zw/>



Participants at AfriComNet workshop.

African Network for Strategic Communication in Health and Development (AfriComNet) - Africa

AfriComNet is an association of HIV and AIDS, health and development communication practitioners who reside, work, or have a primary interest in Africa. Formerly known as the Regional HIV and AIDS Behaviour Change Communication Network (BCC Network), AfriComNet was established in October 2001 in recognition of the severity of the continent's HIV and AIDS pandemic and the need for high-quality strategic communication to respond to the crisis. The Network has three Strategic Objectives and these are:

- to promote effective Strategic Communication practices;
- to increase recognition of Strategic Communication as critical to the effectiveness of H&D programming; and
- to strengthen organisational capacity, credibility & visibility of AfriComNet.

Its approach to communication for social and behaviour change is grounded in the fundamentals of strategic communication, which include: social marketing, human rights-based approaches, entertainment-education, counselling and client education, and mass media.

For more information, contact:

The African Network for Strategic Communication in Health and Development (AfriComNet)
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HIV/AIDS and the Media Project (South Africa)

Based at the University of Witswatersrand in Johannesburg, 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. 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, editors, health professional and other key role players in this area;
- to provide high quality academic research, which ensures an informed and useful debate around this issue; and
- to monitor the role and the impact of the media

They engage in a number of activities to achieve this objective:

- Offer 4-6 month fellowships to working journalists to undertake longer term and in-depth research and writing outside of the newsroom. The writing that results from these fellowships is published in a wide range of media and peer-reviewed journals.
- Identify and research gaps in reporting. Previous and current fellowships have focused on media coverage and audience reception of HIV/AIDS news texts, the role of stigma and gender in Prevention of mother-to-child Transmission of HIV (PMTCT), the strengths and vulnerabilities of HIV-positive children and the role of traditional health practitioners in the mainstream treatment of their patients.
- Host an online resource for journalists on HIV/AIDS.
- Run wider discussion forums on HIV/AIDS and the Media to stimulate debate and discussion amongst journalists, editors, activists, doctors, scientists, academics, government and other stakeholders.
- Facilitate training of graduate and working journalists in HIV/AIDS reporting.
- Assist in the training of career-entry Honours students from the Wits Journalism Programme in HIV/AIDS reporting.
- Produce ongoing research, resources and publications.

For more information, contact:

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Journalists Against AIDS (JAAIDS) Nigeria

JAAIDS is a media-based non-governmental organisation in Nigeria working in the field of HIV/AIDS and development. Their mission is to contribute to the prevention, care and control of HIV/AIDS in Nigeria by providing innovative communication interventions that will facilitate positive behaviour change to reduce the spread of HIV/AIDS. Their vision is a Nigerian society where all persons are able to freely access information, facilities and services on health/HIV and are empowered to utilise these for their personal protection and national development. They do this through policy advocacy; programme support; research and communication; and training and institution building.

For more information, contact:

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