

Health Communication In Southern Africa: Social Representations Of HIV/AIDS In South Africa And Zambia: Lessons For Health Communication



Abstract

For people infected and affected by HIV/AIDS various linguistic representations have arisen, which create discourses as coping mechanisms and as systems of significations in order to make sense of HIV/AIDS. The AIDS epidemic has invited scientific efforts to revisit language and its role in the construction, positioning and repositioning of identities within cultural systems. This chapter highlights the relationships between language, culture and human experience. In studying the linguistic constructions of meaning vis-à-vis HIV/AIDS, this chapter heightens our understanding of the role of language and meanings in the creation of stigma. The chapter shows that language use with regard to HIV/AIDS is not neutral but has an ideological function. It plays on existing ideological conceptions as well as brings novel discourses into the sphere of interpersonal interaction. The acknowledgement of the power of language is critical for health communication, especially in multi-lingual ethnic groupings, who share similar linguistic forms. People engage with HIV/AIDS in their daily experiences by using familiar symbols, images, words and proverbs. It is argued in this chapter that this discourse of representation hinders the progress of public health interventions, especially with regard to HIV prevention and treatment with antiretroviral drugs. Public health communication and health promotion cannot merely rely on 'normative' linguistic labels to persuade, inform or negotiate health ideals, using the taken-for-granted myths/assumptions about the nature of HIV/AIDS and its effects. Listening to, and adapting the audience's appropriation of language, especially in contemporary times of HIV/AIDS, is important for audience-tailored messaging in order to achieve effective and meaningful

negotiation with individuals and communities, so that collective efficacy is strengthened.

Introduction

The HIV/AIDS pandemic has covered the world in a cloud of despair. The Panos Institute expresses it thus: “so much energy for so little hope” (Scalway, 2002). By the year 2001, 36 million people were living with HIV worldwide (Piot, Bartos, Ghys, Walker & Schwartlander, 2001), while sub-Saharan Africa shared the largest burden of the disease (DFID, 2003; Piot et al., 2001; The Henry J. Kaiser Family Foundation, 2004). By 2004, sub-Saharan Africa was home to 66 (25 million) of people living with HIV/AIDS (The Henry J. Kaiser Family Foundation, 2004). In 1999, this figure was representative of the entire population of Africa, 23.5 million out of an adult population of 268.9 million (Kelly, 2002). Contrary to the optimism of the Kelly-led report, the battle is far from being won (Kelly, 2002). Latest updates from UNAIDS give little hope of abating the epidemic, though stability is being recorded in some areas:

The global epidemic continues to grow and there is concerning evidence that some countries are seeing a resurgence in new HIV infection rates which were previously stable or declining. However, declines in infection rates are also being observed in some countries, as well as positive trends in young people’s sexual behaviours (UNAIDS, 2006).

What is particularly worrying is that in places where success was initially recorded, improvement is either slow or infection rates are increasing (UNAIDS, 2006; WHO, 2007). In most affected areas of sub-Saharan Africa, most of the infections occur through heterosexual intercourse. This is an important ingredient in understanding stigma, since sexuality is still shrouded in mystery and shame. The latest picture of the epidemic still shows a gloomy picture:

According to the latest figures published today in the UNAIDS/WHO 2006 AIDS Epidemic Update, an estimated 39.5 million people are living with HIV. There were 4.3 million new infections in 2006 with 2.8 million [65] of these occurring in sub-Saharan Africa and important increases in Eastern Europe and Central Asia, where there are some indications that infection rates have risen by more than 50 since 2004. In 2006, 2.9 million people died of AIDS-related illnesses (WHO, 2007).

The epidemiology of the disease in Africa locates the sub-Saharan region as the most affected.

Sub-Saharan Africa and the SADC region in particular carry the heaviest burden of HIV/AIDS in the world. It is estimated that by the end of 2005, the average adult prevalence of the SADC region was about 11 percent as opposed to the global figure of 1 percent. The SADC region with 4 percent of the global population is home to about 40 percent of people living with HIV/AIDS in the world. The SADC region continues to have a large share of new HIV infections, in 2005, 1.5 million new cases were estimated, representing about 37 percent of global infections (SADC, 2006, p. 2).

In South Africa alone, by 2005 the estimate for people living with HIV was 5.5 million (HSRC, 2005). By the end of 2003, 5.3 million people were HIV positive in South Africa (UNAIDS, 2005). The epidemic in South Africa is at a stage where there are more people dying of the disease. In Zambia, HIV prevalence stands at 16, making it one of the highest in the region despite recording some stability (WHO, 2006).

The role of language and metaphor in HIV/AIDS

Social construction of HIV/AIDS in public consciousness is dependent on already existing 'socially constructed reality' of the understanding of HIV/AIDS. These already existing constructions are frames within which knowledge, attitudes, and practices are experienced.

Sontag (1989) was amongst the first researchers to assess and record the role of metaphor in framing HIV/AIDS discourses. In particular, Sontag noted the use of military metaphors, like 'invasion', 'combat', 'villain' and 'victim' (Sontag, 1989) and she noted how this could enhance a particular view of the disease. At the heart of this metaphorical representation is the depiction of HIV/AIDS as an invasion that must be fought against. Those carrying the disease carry within them the enemy.

This was seen to have implications on the way people living with HIV/AIDS were treated in communities. The result was stigma and discrimination. The gist of the argument is in the use of language. And how language use is reflective of an attitude towards an issue, idea, or people, in this case individuals living with HIV/AIDS.

Moto (2004) carried out research in Malawi, in which he examines the type of language and linguistic expressions used in describing sex and sexual behaviour in a predominantly conservative and male dominated society. He worked from the premise that language is reflective of a people's culture and the inherent perceptions of social relations. In addition to linguistic investigation, he also assessed the language used to discuss HIV/AIDS (Moto, 2004). The study is undertaken with a view to present sexual issues in 'straight talk' form. For instance, calling a penis *chida*, i.e. weapon, may not be an explicit enough message (Moto, 2004). Having studied the lexicon of the language used, Moto concludes:

... that through the language studied, one gets the impression that despite the obvious awareness of the prevalence and the devastating socio-economic consequences of the pandemic, there is a sense of denial as well as acceptance of fate and determinism in some sections of the community (Moto, 2004, p. 344).

Moto noted that language use was indirect, euphemistic, and gendered and reflected a predominantly male society. For instance, the description of a man as beast (*chir ombo*, represents power, authority and dominance (Moto, 2004). HIV/AIDS is also called *magawagawa*, meaning to share. The connotation is that the disease is passed on from one to another, which literally symbolises a giving of the virus to someone.

When describing sex, words like *kugonama* (sleeping on each other) and *owongolera msana* (curing the waist) are used. The conclusion is that, it is important to be aware of what people say, if we are to understand their cultural frames of understanding the reality (Moto, 2004).

Metaphors and the nature of HIV/AIDS

Metaphors have also been used as representations of peoples' attitudes, perceptions and knowledge about disease. In the area of HIV/AIDS, analyses of talk has employed images that reflect people's collective understanding of a given phenomena. For instance, research carried out in Zimbabwe found that stigma is constituted and reproduced in language (Mawadza, 2004). Mawadza unveiled various linguistic constructions of HIV/AIDS discourses in Zimbabwe. For example HIV/AIDS is depicted as *makizi ya ku mochari* (keys to the mortuary) (Mawadza, 2004). This implies the inescapability of death and treats people living with HIV/AIDS as inevitably on the queue to the mortuary. In some cases it is

called Jemeza (sad times awaiting) (Mawadza, 2004), which depicts people living with HIV/AIDS as a sign of the advent of sorrowful times. Similar studies undertaken in Zambia, Tanzania and Ethiopia indicate related discursive construction of HIV/AIDS (Nyblade et al., 2003). In these studies, discourse analysis was used to unveil linguistic constructions of stigma.

Effective health communication interventions depend on understanding, the knowledge, attitudes, and practices of people from given cultural vistas. Hence the necessity of studying the use of metaphors in communities so that interventions fit into local frames of reference. People's experiences of stigma are constructed on the basis of connotations between AIDS and perceived promiscuity and sex. A sense of sexual shame usually accompanies AIDS in communities and acts as a barrier to accessing care and prevention services (UNAIDS, 2001). These connotations are then represented in metaphors to serve a social function by coding the subject in terms that may elude individuals or groups, who may not be intended recipients of the stigmatising messages (Campbell, Foulis, Maimane & Sibiya, 2005). Some of these metaphors may be based on incomplete or total lack of knowledge about HIV/AIDS transmission and prevention. Analysis of the language used to describe an individual's status may indicate a mal-adaptive form of behaviour arising out of fear of causal transmission through communal sharing of common utensil or mere social interaction. The language used may also indicate the perceived nonproductive nature of HIV positive individuals, who are seen as destined to the grave (Mbwambo, 2003). Through the analysis of language used in stigma, some researchers have concluded that there is widespread pessimism in HIV/AIDS discourse, in which the gloomy image of death and dying is invoked (Duffy, 2005; Jones, 1997). The conclusion is that the study of metaphor and the language people use gives insight into the internal states of the individuals within a culture and their shared worldviews.

Naming, perception and social discourse

The naming or labelling of a problem allows not only the identification of the problem, but also an inherent desire for a solution (Cameron, 2003). The naming of sex and HIV/AIDS also reveals people's hopes, fears, meanings, understanding, and attitudes towards this experiential fact. Due to lack of scientific names for HIV/AIDS in African languages, the disease is given names that reflect people's feelings and fears (Mawadza, 2004). More often than not, people with HIV/AIDS are named after their appearance (permed hair, way of

walking or body size). This comes handy as visual diagnosis is used to isolate individuals, who may be seen as infected. Other metaphors, which further stigmatise people living with HIV/AIDS, relate to death, the lethal nature of the disease, the advent of death, and a modern disease (Mawadza, 2004).

Some metaphors relate to HIV/AIDS as a self-inflicted disease. Studies indicate that stigma is more often attached to a disease whose source is perceived to be the bearers' responsibility. To the extent that an illness is perceived as having been contracted through voluntary and avoidable behaviours, especially if such behaviours evoke social disapproval, it is likely to be stigmatised and to evoke anger and moralism rather than pity or empathy (Herek, 1999). People living with HIV/AIDS are considered as having voluntarily and immorally engaged in practices, whose consequences are manifested in their state of sickness and are as such stigmatised (Herek, 1999). It is noteworthy that HIV/AIDS stigma does not arise out of the blue, nor is it something dreamed up in the minds of individuals. Instead, like responses to disease such as leprosy, cholera and polio in the past, it plays to deep-rooted social fears and anxieties. Understanding more about these issues, and the social norms they reinforce, is essential to adequately responding to HIV/AIDS related stigma and discrimination.

Language is an important vehicle used to constitute and construct meaning and attitudes in public discourse. Further research has indicated the role of language in constructing reality. Horne (2004) carried out research on some aspects of AIDS-related discourse in post-apartheid South African culture, in which she concluded that language does not just describe a condition, but constructs it (Horne, 2004). Language can never be separated from thoughts and feelings or from the context of its use. This is shown in how language has been used in South Africa to talk about and concomitantly shape attitudes towards HIV/AIDS. According to the findings, different metaphorical representations have revealed varying conceptions and attitudes towards the disease (Horne, 2004). It has been called the 'three words' (Leclerc-Mdlala, 2000), and the 'modern disease' (Posel, 2004). The indirectness employed in describing the cause of death in HIV/AIDS cases is reminiscent of fear associated with the disease (Horne, 2004). The mystery surrounding the disease is partly due to lack of medical explanation for its existence and cure (Posel, 2004). Some of the words used are *ilotto* and *iace*, referring to the risky nature of the sexual activity with regard to the disease, but also it reveals that people are not always in control of whether

they contract the virus or not (Horne, 2004). This metaphorical representation shows how deeply imbedded the use of metaphor, in the appropriation of meaning, is within the fabric of human interaction. The use of metaphors to describe sexuality and AIDS (Ross, 1988; Sontag, 1989; Watney, 1989) has demonstrated how human beings can tag disease in a particular way in order to negotiate meaning. Posel's metaphorical assertion carries weight: 'AIDS carries a heavy metaphoric burden' (Posel, 2004).

In South Africa, a study on stigma illustrates how language use is appropriated to represent illness and suffering within social contexts (Campbell et al., 2005). In Zambia, a study was conducted to assess the social representation of illness amongst young people (Joffe & Bettega, 2003). It was found that in representing new illnesses, individuals and communities tend to appropriate already existing images or taken-for-granted assumptions with new forms of representations. These are negotiated as an attempt to grasp the phenomena at hand (Joffe, 2002; Joffe & Bettega). As our study elaborates below, the representation of HIV/AIDS takes on contemporary images, like top-up drawn from a commercial discourse, appropriating airtime for cellular phones to ARV therapy. Religious discourse is also drawn from by, for instance, representing the onslaught of death as the eschatological second coming of Jesus, invoking a discourse of the inevitability of death. These forms of representations are not unique to Zambia, as the studies cited in the literature above indicate (Nyblade, 2003).

Recognising the role of language in the construction of reality, the United Nations Development Programme has developed a HIV/AIDS-related language policy, in an attempt to normalise the disease, and to reduce stigma and discrimination (Horne, 2004). It is recommended that a language of peace be used in describing HIV/AIDS over and against war metaphors. These war metaphors have depicted HIV/AIDS in militaristic language (Sherry, 1993), dividing the world into groups of the invader and the invaded. This is the reason as to why Sontag advocated for the retirement of the use of military metaphor due to its dramatic character and the resulting stigmatisation of illness (Sontag, 1989, p. 94). Several works show how contemporary forms of social representations reveal deep-seated attitudes and practices to HIV/AIDS as well as to individuals perceived to live with the disease (Campbell et al., 2005; Castro & Farmer, 2005; Joffe, 2002; Joffe & Bettega, 2003; Link & Phelan, 2006; MacPhail, Pettifor, Coates & Rees, 2008; Simbayi et al., 2006; Washer & Joffe, 2006).

Method

Participants in the study were selected from support groups of PLWHA in rural district of Durban, whilst others with whom in-depth interviews were held came from Zambia. Discussions and in-depth interviews were tape recorded. The recordings were then transcribed and translated from isiZulu/Bemba/Chichewa into English. Some key phrases and terms are, however, retained in vernacular languages in order to retain forcefulness of meaning. Data were manually analyzed according to the interview questions set out in the study. This paper does not reveal any names of participants. Ethics approval was given by the Ethics committee of the University of KwaZulu Natal in South Africa.

Some of the interviews were transcribed verbatim by the authors. The author's analysis was informed by the principles of Grounded Theory and in particular, the use of constant comparison of themes within the collected data (Charmaz, 2006; Mays & Pope, 2000; Strauss, 1987). Initially, we used open coding to explore the data throughout the process of data collection. This process generated many themes and we explored the varying dimensions of these themes. For instance, the use of labels such as 'walking-walking' (*kuyendayenda*) in reference to promiscuity, and how they were related to each other. Although we began with codes used by the participants ("AIDS" a sign of immorality), the final labels used in the text represent our own summary of respondent accounts (for example, *kanayaka*/light is on, as representing AIDS). Further analysis suggested groups of inter-related themes. Once these key themes had emerged, further development and refinement was informed by the literature on stigma, AIDS, social representation of diseases. A focus of the analysis was on 'deviant cases', where the accounts did not appear to fit with the emerging typology, i.e. what are the ways in which talk about HIV and AIDS deviates from 'normal' discourse. Close analysis of these negative cases assisted in further refining the conceptual categories as outlined in the conceptual frame, 'firstness', 'secondness' and 'thirdness'. We were aware that the observation setting, our role and interest as perceived by respondents and our individual disciplinary perspectives might bias both data collection and analysis. Despite this, the researchers found that the emphasis of respondent accounts was actually towards interpersonal aspects of representing HIV/AIDS in similar terms and images that served the purpose of socialising disease perceptions within the community. During analysis, we were careful not to merely allow a clinical bias or a philosophical abstraction on stigma to influence the coding structure. Once the typology was established, we

consulted with a reviewer who sought to identify the dominant version of the three levelled categories of 'AIDS representation in talk' in each observations, interviews and discussions. The researchers then read a sample of four transcriptions and independently identified the similar dominant versions for each. In addition to this validity check, we sought the opinion of anthropologist colleagues on the coherence and plausibility of the typologies.

Results

AIDS and moral culpabilities

When people talk about HIV, AIDS and sometimes sex, they are quick to position others, especially those living with HIV and AIDS in categories that label them as morally culpable for their 'diseased conditions'.

Jane: *Hey, you ... me ... I wouldn't allow someone who was jumping-jumping to come and live in this village...*

The choice of language of 'jumping-jumping' in association with HIV and AIDS is a label of moral blame. This is further expanded in saying *fyakuiletelela* (they brought it upon themselves). The implication of this is that whoever has HIV has brought it upon themselves and as such do not qualify for sympathy. In response to what some respondents thought of being tested, the following were the responses:

Interviewer: *What about you, have you been tested?*

Mercy: *No, I wouldn't dare, what if I find that I am sick, especially that I am married...*

Andrew: *What do you mean? What would my wife think of me?*

Firstly, there is fear of knowing one's status and secondly, this fear is justified by summoning marital status. And by implication marriage is then defined as the risk factor. Despite stigmatising individuals, who have come out in the open by disclosing their status, some individuals do acknowledge the possibility of risk, which is then immediately linked to marriage in order to mitigate the moral gravity of a possible HIV+ status. This is a common linguistic construction in which the othering of disease by displacing the respondent as an actor within the discourse tends to be common (Leap, 1991). There is tension between self-knowledge and knowledge of and about the other. It is easier to deal with the disease in others than to confront it in oneself. Hence, stigma is the process of

externalising our fears and labelling them on 'othered' individuals. It is a form of self-ostracisation, but in the other (Leap, 1991). Marriage becomes then, a way to abdicate personal urgency which does not emerge in the narratives on whether one would take an HIV test or not. The immediate reference in the narrative is to the 'other' partner, who may not approve or may become suspicious of a partner's sexual behaviour. This is in line with assumptions that HIV testing may in itself signify infidelity or lack of trust.

Mutale: *Let me ask, isn't it possible that when doctors find someone has tested positive can't they immediately give them a lethal injection?*

Fear of confronting HIV and AIDS is further manifested in extreme forms in which individuals wish for the extermination of individuals living with HIV. The suggestion of applying a lethal injection is a strong aversion to expel HIV and AIDS discourse from social interaction. The reason given for this suggestion is the perception that the absence of HIV positive individuals would eliminate the problem within the community:

Mutale: *It is better they are killed just there and then, so that they do not bring the disease to the community.*

There is fear that the disease may affect many people in the community, if people who are HIV positive are allowed back to live in the community. It is, however, ironical that one would rather not test but choose to live in ignorance. The problem seems to be that knowledge of HIV becomes synonymous with the existence of the disease. An unknown status becomes equivalent to non-existence of the disease. The need to eliminate an HIV threat from the community is revealed in this discourse of elimination, which is at the same time linked to individuals who are living with HIV. Individuals living with HIV/AIDS are seen as embodiments of the threat to the community. This notion of disease as a foreign invasion is not new (Nyblade et al., 2003).

Christians, moralities and AIDS

Christina: *No, for us we are Christians, we can't be sick of AIDS; we don't even talk about these condoms because our church doesn't allow!*

'For us we are Christians, we can't be sick of AIDS' describes the respondent primarily as a moral subject, more so of a Christian order. Whereas it

is known that HIV also affects Christians, this denial is still rampant as some people still fear to be labelled, 'unchristian' or 'immoral'. In some places, it would be another form of exclusion from the community of Christians, hence the choice for ignorance which is embraced as bliss. If one's status is not known, then there are no labels, no stigma. This comes into play only when visual clinical signs associated with HIV emerge.

While advocates of VCT may argue that VCT may lead to higher knowledge levels, and encouragement to lead a normal and healthy life, the reality is different when the meaning of life is itself intimately bounded up with how one fits within a social collectivity. The above discussion is embedded within a dominantly religious-Christian ideology which is drawn upon in representing HIV/AIDS.

Within the discourses of representation, a number of images arose that depict people living with HIV and AIDS. Most of these are associated with morality and sexual behaviour. In some cases, being HIV positive is described in terms which stand for moral recklessness. The following section dwells on representations of sexuality and HIV/AIDS.

Ubulalelale (sleeping sleeping)

This is an image that is used to signal 'casual sex'. When asked as to the cause of AIDS, *ubulalelale*, which is a synonym for promiscuity, equates the status of an HIV positive individual to 'immorality'. It is sometimes called *ubulwele bwa bucende* which means literally, 'disease of promiscuity'. The moral undertones are reinforced by a religious discourse in which promiscuity is defined per se as having casual sex outside the context of marriage. There is no room for committed relationships. Sex can only be lawfully had in a legally binding matrimonial bed. The choice of language equates HIV positive status to *ubulalelale* taking the symbolism of sex as a sleeping position and represented connotatively as a signifier of immorality. The symbol then takes on a common-sense (ideological position), which relates positive status to immorality.

Jesus is coming

Sometimes eschatological images are used. *Yesu Abwela* as in Jesus is coming. This symbolism is an invocation of the eschatological promise of the coming of the messiah. HIV and AIDS are, in popular religious discourse, related to eminent eschatological symbols, preceding the cataclysmic end of the world.

These eschatological signs include earthquakes, and incurable diseases, among others: HIV is incurable; therefore it is an eschatological sign. The agents of this end are the evil forces, which have not repented and have cooperated with the devil. Being HIV positive gives one a mark of the end times. He or she becomes the incarnation of the signs associated with the incurable diseases, which signify the 'end of the world'.

Whilst on a higher religious ideological level HIV and AIDS are talked about in terms of 'end of the world signs', individuals are seen as 'leaving us' (meaning *batisiya*). Others would simply describe people living with HIV and AIDS as being *paulendo* (on a journey) or *chakumanda* (to the grave). *Chakumanda* is a legitimate name in Eastern Province of Zambia, which is given to a child, who has survived after a series of infant deaths in a family. The name simply means someone has survived death. But, this symbolic name is taken up and appropriated to represent a person living with HIV/AIDS. The connotation is the necessary link between a positive HIV status and death. One is on his way to grave.

With these images circulating in communities, it is small wonder that individuals are too scared to take up HIV testing, which in the perception of the community makes one either a member of the *chakumanda* group or not. The risk is too much for perceived gain of longevity.

But the thrust of the choice of metaphors, in this case, is not a coming for salvation, but the 'end of someone's life', a time when they have to account for their promiscuity. Being HIV positive is immediately linked to end of life. Whoever tests positive, therefore, has his or her end in sight. What was done in the dark is now revealed in the light of day. This disclosure is either by personal verbal disclosure or by ones physical clinical manifestations. Disclosure by physical clinical manifestations happens more often, because individuals often present themselves for treatment at very late stages of the disease, when, in some cases, very little can be done to help them. The result is a prevalent belief that HIV status equals death.

Pumping pills or top-up

Antiretroviral drugs are in some settings called pumping pills or top-up. The idea is that antiretroviral drugs make one to become artificially fat. One woman told us, "when they start taking *ifi miti* (medicines), they become fat and others even

look brownish (stereotype for beauty). Then suddenly they collapse and die". This process is likened the tube of a bicycle tyre, once pumped it goes flat again since it cannot be perfectly mended: *Mwelaŵe weka* (it is mere air being pumped for a short period of time to delay the inevitable). At a time, when antiretroviral drugs are noted for their treatment value, one would expect that they would be applauded as an advance in care and compassion within communities. But this happens not to be the case in some communities in Zambia and South Africa, where antiretroviral drugs are instead seen as artificially sustaining life before a sudden slump into death. In Zambia, the notion of topping up is the same as pumping pills, though top-up borrows from mobile phones, which means that in order for one to be able to make a call one must have enough 'air-time' (credit on the phone). But, when the account becomes low, then one is forced to top-up for continued use. Antiretroviral drugs are thus symbolised as top-up. This means that a person, who is on antiretroviral drugs is topping up his account to keep living. This symbol shows the truth of the value of antiretroviral drugs, but turns the symbol into mockery, which only serves to undermine individuals who are on treatment. The resulting connotation is one of stigma by interpreting the life of individuals on antiretroviral drugs as on artificial sustenance and dependant on artificial forms of credit for survival.

Kalaiti kanayaka (the light is on)

For fear of calling people, who are living with HIV by their status, community members tend to employ images that indirectly depict them as sick and moving

towards the grave. In social interaction, someone may simply say *kanayaka* and members of the community know by implication the meaning of the phrase. The images are drawn from normal social discourse. The above image of *kanayaka*, which is a short form of the warning light on the motor vehicle fuel gauge indicating the diminishing fuel. On the first level of meaning, this image relates to the actual meter reading, but is relationally connected to people living with HIV and AIDS by locating them within a general symbol in which they are like cars running out of fuel. The underlying cultural assumption is that death is eminent, since the light is on. Being HIV positive is a danger sign signifying an inevitable grounding of a vehicle due to lack of fuel.

Antiretroviral drugs making HIV positive people invisible Health promoters hold on to the assumption that hope will reignite for people on antiretroviral drugs and

that they will have a better life. Hence the promotion of the need to extensively rollout antiretroviral drugs. But little attention is paid to antiretroviral drugs being blamed as a danger to communities. This danger is immediately linked to the protection of the common good, i.e. the common health of the social web. HIV positive people or those suffering from AIDS must be made visible (i.e. actually seen) in order to act as a deterrent to reckless behaviour. Antiretroviral drugs tend to make symptoms disappear and as such make HIV infected individuals become invisible. In popular discourse this translates into a risky status, as individuals may not be able to make decisions to avoid 'these HIV+dangerous individuals'.

Linda: *These medicines are dangerous because HIV positive people are not visible. We can't know them, so how can we protect ourselves?*

For some people in communities, the fact that antiretroviral drugs diminish symptoms in people living with HIV and AIDS implies that they cannot physically be isolated and hence pose a risk to the community:

Bwalya: *Please do not give them ARVs, these people should just die. You see them sick and about to die and then suddenly, you find them walking up and about looking fat, and our young men, who find it very difficult to hold on, are on them; the next thing we are also sick.*

Individuals living with HIV and AIDS are generally secluded as "other" from the group through a process of visual diagnosis. Appearance becomes the characteristic trait that is used to single out individuals, as either likely HIV positive or negative. In instances, where symptoms usually associated with an HIV positive sero-status are invisible, it becomes almost impossible to know who might be a 'dangerous sexual partner'. "Our young men, who find it very difficult to hold on, are on them" represents the biological drive metaphor, in which men are seen as driven by this 'other' force: An uncontrollable sexual drive, which must be released. As such the blame is on invisibility: Our young men cannot diagnose HIV status, when ARVs are available. This then becomes the justification for their resistance to antiretroviral drugs in the community. One leader of the community suggested These medicines have made our people even more promiscuous. The state in being seen to be sick serves a 'positive' social function of deterrence in this community. The implication is that when people living with HIV and AIDS are left to be seen to be sick, there are higher chances of them

becoming a deterrent to casual sex, hence avoid transmission of the disease to those who are not infected.

Infwa yenda (death walking)

Others have chosen to use the term *infwa yenda*, which means 'death walking' to refer to people living with HIV and AIDS. It is equally a death metaphor, but depicts people as walking tombs. The tomb metaphor is a visual icon of the prevalence and inevitability of death resulting from AIDS related illnesses. This links HIV to death, not only as inevitable, but as well as deliberately caused. Such labels lead individuals further into denial, because of the fear of being categorised as 'death walking'. In general ethos, the grave is an isolated place, and no one communes with the tombs. That is a place of *abantu babene* (other people's people, who are not of this world). It is also called *kumalalo* (where they sleep). The graveyard is therefore a cold place where the 'dead sleep'. Linking this metaphor to daily life means that whoever embodies the 'tombness' cannot live with the 'living'. He or she belongs to the 'liminal space' embodying the transition between this world of the living and the world of 'living dead'.

Kalionde-onde (slimming)

Kaliondeonde is a term used to mean 'slimming'. It is an equivalent of the 'slim disease' as referred to in some African countries. This plays on the initial clinical manifestations of indications of a positive sero-status (Godrey-Faussett et al., 1994; Lucas et al., 1994).

Akashishi (infected with insects/germs)

The association of HIV with the visual image of *akashishi* or *kadoyo*, i.e. an insect or ant, gives the impression of an animal like creature, which has crept into someone's body. This may reinforce witchcraft notions of a living being, which selects its victims. The *akashishi* or *kadoyo* metaphor does not physically equal to an actual category of insects or germs. The closest association of the foreign entity in one's body is by visualising insects and how they infect fruits, for instance, and transposing this hegemonic image into understanding the process of HIV infection.

Sometimes proverbs, such as *chikome-kome cha mukuyu mukhati muli nyelele* (the beauty of external outlook, whilst the inside is rotten or full of insects) show how the *akashishi* or *kadoyo* metaphors entrench a discourse representing individuals living with HIV and AIDS as carriers of rottenness. Hence they must

be avoided.

Labelling HIV by association

In seeking to isolate individuals who may be testing to know their status, a discourse of association is employed by community members to identify various individuals, who may be HIV positive. Hence, sometimes individuals prefer to walk distances away from their villages in order to go and test for HIV in another village where they might not be known. This is done with a view not to be identified by familiar members of the community. In turn, it serves the purpose of evading labels that socially group these individuals into 'stigma classes'. In some villages, a clinic may have a counselling facility for people who have HIV and AIDS related concerns, but may be afraid to present themselves lest they gain the label of the 'room' or building. He/she is 'room 1' relates the room associated with HIV to individuals, who might have visited such a place. This association does not segregate the various reasons that may lead individuals to seek health services. Some of these people may actually be HIV negative. One lady, on rationalizing, why she did not go for HIV testing said:

Makhosazana: ... fear of HIV and the stigma. Fear of knowing and how the community will treat you once they know your status or they have seen you come to the clinic ... especially room 1.

Room 1 refers to a room reserved for voluntary counselling and testing. What is interesting to note is that she is able to name the problem: fear of HIV and stigma. She groups HIV and stigma as if they are synonymous, thus clearly highlighting the problem that HIV is intimately conceptualised in 'other' categories with value-laden moral judgements. The other feature that strengthens the negative impact of stigma is the fact that in these communities in rural Zambia and South Africa, communities live in a strong communitarian web of relationships. The identity of an individual is intimately connected to others in the community. One exists because others are.

Unlike the Cartesian *cogito ergo sum* or *je pense, donc je suis* ("I think, therefore I am"), these communities subject the individual to the 'We'. As such one's existence is seen in terms of "I am because we are and because we are, therefore I am" (Mbiti, 1969, pp. 108-109). The fear of being known as HIV positive is not linked to individual good, but is located within a community ethic in which either an individual fits in or does not fit in. This process of inclusion and exclusion

is prevalent in many facets of life experiences in these rural communities. Whoever deviates from the norm, for example, by becoming too rich, or by growing into old age, when many people die young, (for instance in Zambia with a life-expectancy of about 37 years), or by having successful children) is more likely to be associated with witchcraft. Deviance in these communities is defined, and consequently excluded by, identifying characteristics that are deemed threatening to the social order. Sexual immorality was another form of behaviour that in some communities called for moral sanctions and disapproval. In the era of HIV and AIDS, people can no longer hide their promiscuity. You get to know them through their sickness.

Sickness is therefore a signifier of immorality and is as such a visible social representation of a 'prostitute'. The word prostitute is used to translate *maule* or *amaule*, sometimes referred to as *amaswau*. These words express a moral judgment on sex workers, who are judged as sexually promiscuous. This term is then taken on in ordinary discourse to refer to people, who are deemed incapable of 'taming' their sexual appetites. The concomitant connotations are that *maule* are not only sexually permissive, but lack moral character which is judged from a lack of either marital stability or failure to get married. The unfortunate part of this labelling is that a woman, who does not marry earlier than her peers, is more likely to be labelled as such.

Labelling HIV by TB: a better label than HIV

TB is used as an option for labelling HIV. It seems a preferable condition to HIV as people seem to understand it and know that it is treatable. In other cases, TB has become a symbol used to mark individuals with HIV. *Balilwala TB ishipwa* (he or she is suffering from TB that does not finish) may mean two things. Firstly, the person may be suffering actually from actual tuberculosis and secondly, the person maybe HIV positive with the initial clinical manifestation of tuberculosis. Hence the preference of the TB label, which is deemed moderate in social stigmatising consequences compared to HIV and AIDS.

Labelling HIV by negative cultural symbols

Negative cultural symbols are also used to label HIV/AIDS. The negative cultural symbols associated with HIV and AIDS, as a means to the negotiation of meaning, vary from context to context. In Zambia, symbols used to label HIV/AIDS were taken from a moralistic cleansing discourse, especially in rural areas. Whereas in South Africa, sometimes traditional imagery is used in relation

to HIV/AIDS, like ipod, but cultural symbols and images to label HIV/AIDS were predominantly drawn from cosmopolitan images, like Channel O and BMW's Z3.

Cleansing discourses are used by people in rural areas to describe the separation of the good from the bad, the infected from the uninfected, the moral from the immoral. In seeking to main hegemonic order in its 'pure' form, metaphors call upon images, like OMO, a brand name for washing powder that is common in the area. OMO (washing away) is used to show the removal of unwanted stains or dirt (infection) from clothes. 'Sieving' or 'winnowing', used in traditional preparation of food, is used to describe removal of chaff from grain or any other 'separatables' from essentials. This discourse positions individuals in the community into binary oppositions of the essential and the non-essential, the clean and the dirty. Thus the community is fragmented into either/or. The choice to be in one group or the other is a dilemma for members of such communities. Whoever tests positive is therefore placed in the 'other' category with all its negative associations. And since the sick are the chaff that is being disposed of from the community, or the dirt and infected that is being washed away by OMO, one has to choose to belong either to chaff or to the essentials. Going for an HIV test in itself places one on the borderline between the 'we' and 'them'; a choice that demands great courage to make. In contexts where one's existence is built by and within this community, the decision becomes a matter of being alive or dead. This uncompassionate community outlook may be surprising as it is cruel, but in linking HIV/AIDS metaphorically to OMO, which cleans the dirt and the infected from the community, it performs a 'positive' social function, and this is a critical factor that demands a conversion of ethos, not just the provision of knowledge.

Further to the ostracism of lepers from social communion is the use of *ipot* in South Africa. *Ipot* is formed by adding the Nguni prefix, 'i', to pot, which is a three legged, traditional Zulu cooking vessel used over an outdoor fire. The pot is used in collective cooking activities, and metaphorically connotes the discourse of commonness of the disease. It is unlikely that many speakers of Zulu for instance will fail to recognise *ipot*. It additionally indicates that something is 'boiling' or 'cooking' in someone's body, which will soon be eaten away. But this eating away is a taking away from the community. This discourse announces the inevitable dawn of death for the person living with AIDS. When the metaphorical food/sickness is brought to the boil, then the individual is ready for death. This metaphor reminds the infected that they should prepare for death rather than

preparing for positive living. Once you are diagnosed with HIV you are seating on fire with a three (HIV)-legged pot, ready for the inevitable conclusion.

In South Africa, cultural symbols and images to label HIV/AIDS were predominantly drawn from cosmopolitan images. The use of contemporary images, like 'Channel O', to represent HIV is testimony to the invocation of current prevalent images in order to appropriate meaning of a unique experience. But the choice for symbols is a choice for a form of silence that refuses to name but ends up paradoxically becoming louder than its initially sought to avoid. When an individual has malaria, people simply say he or she has malaria. But as for HIV, individuals in these communities simply spoke in symbols without directly naming the problem.

The use of channel is one such example. 'Channel O' is a risqué pop music station broadcast by the South African satellite television platform DStv. It is invoked as a visual metaphor to attach connotations of promiscuity to those known to be infected. Individuals, who are living with HIV/AIDS, are categorised as promiscuous, akin to the loose living depicted on pop music TV. Pop stars are depicted on Channel O as sexually appealing and charged sometimes with semi-exposed bodies (Channel O was banned in Zambia, as it was accused of promoting anti-Christian values by propelling semi-pornographic material into the airwaves). People going for voluntary testing and counselling are named as Channel Os. Semiotically, this naming identifies and others infected individuals in terms of the discourse of stigma.

Blame by association is the fourth discourse, which signified by an apparent excessive and conspicuous consumption, acquisition of material consumer goods and *embourgeoisification*. The sign, which connotes this fast living culture, is the BMW Z3 sports car model. This aspirational capitalist symbol mobilises the sign of promiscuity and links it to urban cosmopolitanism with its 'inevitable consequence of infection'. HIV infection is seen by rural people as a modern disease of the town. Those infected then return to the rural areas to die. The BMW Z3 thus connotes both positive upward class mobility and its negative opposite of the highlife aspired to being unsustainable and resulting in death. Hence, in Zambia the metaphors employed would include *kalaye ba noko*, "go and bid farewell to your mother (in the village)".

Conclusion

Language as a system for classifying meaning plays a central role in communicating health. It is the bedrock of any communication enterprise. Despite this understanding, health communication has not aggressively taken on the need to engage with language in itself i.e. deliberately targeting language that entrenches stigma and discrimination. This is important because people in any community conceptualise their problems within a particular signifying practice. This practice may offer insight into the way people conceptualise a problem confronting their daily lives. HIV/AIDS remains a stigmatising disease with dominantly 'othering attitudes', in which the disease is seen as affecting the other and not the person who is a subject of discussion or interviews. It is also understood within the prevailing religious ideologies which seem to offer categories for hopelessness, and a judgemental attitude that sees the other as deservingly oriented towards inevitable death. Stigma on HIV/AIDS seems to change in its expressions depending on the context and categories used for its descriptions.

This renders support to the enduring nature of stigma as a major obstacle to prevention and treatment (Whitehead, Mason, Carlisle & Watkins, 2001). As elusive and dynamic as the nature of stigma is, semiotic analyses may come to the aid of conventional social learning theories in capturing the prevailing cultural forms of representations. This is what we learn from the analysis of the role of language in fuelling stigma and discrimination. We learn that language is ever evolving; taking on new symbols and images. As such, the task for researchers and consequently public health experts is the appreciation of the discourses operating in communities in order to better engage them. This can only be done in empathic communication, which takes on local lenses so that preferential options for secluded individuals are advanced. In this time and age, we cannot afford not to intervene for people with 'leper bells' which are linguistically constructed variously. It is time for compassionate health communication that seeks for a complete metanoia (conversion of mind and attitude) of community attitudes to people living with HIV and AIDS, especially in language discourses.

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References

- Campbell, C., Foulis, C.A., Maimane, S., & Sibiyi, Z. (2005). 'I have an evil child at my house': Stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*, 95(5), 808-815.
- Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 95(1), 53-59.
- Charmaz, C. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.
- Department for International Development. (2003). *UK's Call on Action on HIV/AIDS*. London: Department for International Development.
- Duffy, L. (2005). Suffering, shame, and silence: the stigma of HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 16(1), 13-20.
- Godrey-Faussett, P., Mwinga, A., Hosp, M., Baggaley, R., Porter, J., & Msiska, R. (1994). Tuberculosis and slim disease in Africa. *British Medical Journal*, 309(6963), 1230b-1231.
- Horne, F. (2004). Some aspects of AIDS-related discourse in post-apartheid South Africa. *Alternation*, 11(2), 401-419.
- Human Science Research Council. (2005). *South African national HIV prevalence, HIV incidence, behaviour and communication survey, 2005*. Cape Town: Human Science Research Council.
- Joffe, H. (2002). Representations of health risks: What social psychology can offer health promotion. *Health Education Journal*, 61(2), 153-165.
- Joffe, H.L.N., & Bettega, N. (2003). Social Representation of AIDS among Zambian Adolescents. *Journal of Health Psychology*, 8(5), 616-631.
- Jones, R. (1997). Marketing the damaged self: The construction of identity in advertisements directed towards people with HIV/AIDS. *Journal of Sociolinguistics*, 1(3), 393-418.
- Kelly, M. J. (2002). *Challenging the challenger: Understanding and expanding the*

- response of Universities in Africa to HIV/AIDS*. Lusaka: University of Zambia.
- Leap, W. L. (1991). AIDS, linguistics, and the study of non-neutral discourse. *The Journal of Sex Research*, 28(2), 275-287.
- Leclerc-Mdlala, S. (2000). Silence, AIDS and sexual culture in Africa. *AIDS Bulletin*, 9(3), 27-30.
- Link, B.G., & Phelan, J.C. (2006). Stigma and its public health implications. *The Lancet*, 367(9509), 528-529.
- Lucas, S.B., De Cock, K.M., Hounnou, A., Peacock, C., Diomande, M., Honde, M., et al. (1994). Contribution of tuberculosis to slim disease in Africa. *British Medical Journal*, 308(6943), 1531-1533.
- MacPhail, C.L., Pettifor, A., Coates, T., & Rees, H. (2008). 'You must do the test to know your status': Attitudes to HIV voluntary counseling and testing for adolescents among South African youth and parents. *Health Education and Behavior*, 35(1), 87-104.
- Mawadza, A. (2004). Stigma and HIV/AIDS discourse in Zimbabwe. *Alternation*, 11(2), 420-439.
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320(7226), 50-52.
- Mbiti, J. S. (1969). *African religions and philosophy*. New York: Praeger.
- Mbwambo, J. (2003). *Understanding HIV-related stigma and resulting discrimination in sub-Saharan Africa Emerging themes early data collection in Ethiopia, Zambia and Tanzania*: Washington D.C.: International Center for Research on Women.
- Moto, F. (2004). Towards a study of the lexicon of sex and HIV/AIDS. *Nordic Journal of African Studies*, 13(3), 343-362.
- Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., Kidd, R., Banteyerga, H., et al. (2003). *Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia*. Washington DC: International Centre for Research on Women.
- Piot, P., Bartos, M., Ghys, P. D., Walker, N., & Schwartlander, B. (2001). The global impact of HIV/AIDS. *Nature*, 410(6931), 968-973.
- Posel, D. (2004). *Sex, death and embodiment: reflections of the stigma of AIDS in Agincourt, South Africa*. Johannesburg: University of Witwatersrand. WISER Symposium.
- Ross, J. (Ed.). (1988). *An ethics of compassion, a language of division: working out the AIDS metaphors*. New York: Hemisphere.
- SADC. (2006). *Expert think tank meeting on HIV prevention in high-prevalence countries in southern Africa*. Gaborone: SADC.

- Scalway, T. (2002). *Critical challenges in HIV communication*. London: Panos.
- Sherry, M. S. (Ed.). (1993). *The language of war in AIDS discourse*. New York: Columbia University Press.
- Simbayi, L., Strebel, A., Cloete, A., Henda, N., Mqeketo, A., & Kalichman, S. C. (2006). HIV status disclosure to sex partners and sexual risk behaviors among HIV positive men and women in Cape Town, South Africa. *Sexually Transmitted Infections*, 83(1), 29-34.
- Sontag, S. (1989). *AIDS and its metaphors*. London: Penguin Books.
- Strauss, A. (1987). *Qualitative analysis for social scientists*. New York: Cambridge University Press.
- The Henry J. Kaiser Family Foundation. (2004). *The Global HIV/AIDS Epidemic*. HIV/AIDS policy fact sheet Retrieved October 15, 2007, from <http://www.kff.org/hivAIDS/upload/3030-08.pdf>
- UNAIDS. (2005). *AIDS Epidemic Update*. Geneva: UNAIDS.
- UNAIDS. (2006). *Global AIDS epidemic continues to grow*. Press Release. Geneva: UNAIDS Retrieved October 15, 2007, from http://data.unAIDS.org/pub/PressRelease/2006/061121_2006_EPI_Update_en.pdf
- Washer, P., & Joffe, H. (2006). The 'hospital superbug': Social representations of MRSA. *Social Science & Medicine*, 63(8), 2141-2152.
- Watney, S. (Ed.). (1989). *Talking liberties: An introduction*. London: Serpent's Tail.
- Whitehead, E., Mason, T., Carlisle, C., & Watkins, C. (2001). The changing dynamic of stigma. In: T. Mason, C. Carlisle, C. Watkins & E. Whitehead (Eds.), *Stigma and social exclusion in healthcare*. London, New York: Routledge.
- WHO (2006). *AIDS Epidemic Update*: Geneva: World Health Organisation.
- WHO (2007). *Global AIDS epidemic continues to grow*. Geneva: World Health Organisation. Retrieved 15 October, 2007 from <http://www.who.int/hiv/mediacentre/news62/en/index.html>.