



Published in final edited form as:

*Qual Health Res.* 2014 February ; 24(2): 209–216. doi:10.1177/1049732313519869.

## Terms Used for People Living With HIV in the Democratic Republic of the Congo

**Bavon Mupenda<sup>1</sup>, Sandra Duvall<sup>2</sup>, Suzanne Maman<sup>2</sup>, Audrey Pettifor<sup>2</sup>, Christina Holub<sup>3</sup>, Eboni Taylor<sup>2</sup>, Stuart Rennie<sup>2</sup>, Mujalambo Kashosi<sup>1</sup>, Mamie Lema<sup>1</sup>, and Frieda Behets<sup>2</sup>**

<sup>1</sup>Kinshasa School of Public Health, Kinshasa, Democratic Republic of the Congo

<sup>2</sup>University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

<sup>3</sup>San Diego State University, San Diego, California, USA

### Abstract

For this study we conducted in-depth interviews with 29 youth living with HIV (YLWH) and key informant interviews with 8 HIV care/support providers. We describe terms used to portray people living with HIV (PLWH) in Kinshasa, Democratic Republic of the Congo. Labels commonly used, mostly derogatory, described PLWH as walking corpses, dangers to others, or people deserving to die before others get infected. Blame and other accusations were directed at PLWH through anchoring or objectification. Being labeled sometimes made these youth suffer in silence, afraid to disclose their status, or avoid performing actions in public, preferring to let others do them. YLWH need psychosocial support to mitigate the harmful effects of these labels and strengthen their coping skills, whereas community, institutional, and national efforts are needed for stigma reduction.

### Keywords

adolescents/youth; Africa; Africa; sub-Saharan; HIV/AIDS; stigma; young adults

---

In Kinshasa, the capital of the Democratic Republic of the Congo (DRC), HIV prevalence is estimated to be 3.2% among people aged 15 to 49 years, according to the United Nations Development Program (UNDP). This amounts to roughly 95,000 people living with HIV, many of whom are youth below 25 years of age (Programme des Nations Unies pour le Développement, 2009). Meanwhile, stigma and discrimination are still common in the third decade of the HIV pandemic in many African countries (Amuri, Mitchell, Cockcroft, & Andersson, 2011; Kalichman & Simbayi, 2003, 2004; Ncama, McInerney, & Bhengu, 2008; Okoror et al., 2008; Petros, Airhihenbuwa, Simbayi, Ramlagan, & Brown, 2006; Rudolph et al., 2012; Simbayi et al., 2007; Visser, Makin, Vandormael, Sikkema, & Forsyth, 2009).

---

© The Author(s)

Reprints and permissions: [sagepub.com/journalsPermissions.nav](http://sagepub.com/journalsPermissions.nav)

Corresponding Author: Bavon Mupenda, Ecole de Santé Publique Université de Kinshasa, CIBAF, Kinshasa, Democratic Republic of the Congo. [bavonmupenda2@yahoo.com](mailto:bavonmupenda2@yahoo.com).

### Declaration of Conflict of Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

When people construct cognitive categories and link those categories to stereotyped beliefs (Link & Phelan, 2001), stigma can take the form of derogatory labels; that is, social stereotypes that distort the ways in which a person is perceived and treated by others (Victor, 2004). To date, few researchers have looked at terminologies used to describe HIV, AIDS, and people living with HIV (PLWH; Mutembei, Emmelin, Lugalla, & Dahlgren, 2002). In a study by Uys and colleagues (2005), the authors analyzed 290 descriptions that were classified into nine categories: (a) attributional, (b) neutral, (c) death-related, (d) physical-feature related, (e) factual statements, (f) lingering-illness related, (g) common-illness related, (h) wordplay, and (i) devaluing; showing negative labels and beliefs, but also the awareness of HIV's devastating effects on individuals.

Sontag (1990) described the usefulness of metaphors to think, interpret, and communicate, and the potential for harm that stigmatizing metaphors possess. Moscovici's (1984, 2000) theory about social representations identified two processes by which the unfamiliar is rendered familiar: the process of anchoring (to reduce strange ideas to ordinary categories and images in a familiar context) and the process of objectifying (to turn something abstract into something almost concrete, from the mind to the physical world). These two processes are so intertwined that it is sometimes difficult to differentiate them.

To our knowledge, HIV-related labeling has not been researched among youth living with HIV (YLWH). In this article, we present the perspectives of YLWH and their health care providers on HIV-related stigma, especially via stereotyping, labeling, and other metaphorical terms. We analyzed the terms people in Kinshasa used to refer to HIV, AIDS, and PLWH. In a sub-Saharan African context like the DRC, labels sometimes accompany behaviors associated with both the speakers and those labeled; a behavior's label might convey a stigmatizing message that can be decrypted. By understanding the language that people use to describe PLWH and HIV/AIDS, one can learn how PLWH are treated in the community.

## Methods

### Population and Data Collection Procedures

Data for this article on HIV-related labeling were part of a study to inform psychosocial support interventions including positive prevention among YLWH. Participants included a total of 189 YLWH aged 14 to 24 years (mean = 21) receiving HIV care and support in Kinshasa, Democratic Republic of the Congo. They were recruited from four organizations that provided HIV care and/or support.

Using Excel random number selection formula, we randomly selected 29 young people (13 males and 16 females with a mean age of 19) from among the 151 YLWH who were aware of their HIV status, to participate in in-depth interviews. In addition, 8 HIV care/support providers (with an overall mean age of 41 years) participated in a key informant interview, 2 from each organization.

All in-depth interviews were conducted in the language most predominant in Kinshasa (Lingala) in private rooms by trained interviewers. The research was approved by the

University of North Carolina School of Public Health Institutional Review Board and the Ethics Committee of the University of Kinshasa School of Public Health. Selected participants provided informed consent if at least 18 years old. YLWH less than 18 years old provided informed assent only after a parent/guardian signed a parental permission form.

During in-depth interviews, we addressed one primary question: How are people living with HIV in Kinshasa treated in the community? Probing questions included the following themes: names/labels used to talk about HIV, AIDS, and PLWH; names the respondents had been called and how they felt when people used those names or labels; the most common names/labels used in their community/social group, including those used for HIV-positive youth; and the meaning of these different names/labels.

During key informant interviews with HIV care or support providers, we asked participants the same initial question and the same probing questions as in the in-depth interviews. However, unlike the in-depth interviews, probes were not intended to find out about key informants' perceptions of their own status.

### Data Analysis Procedure

We tape-recorded in-depth and key informant interviews in Lingala and transcribed them verbatim into French for analysis. We translated quotes selected for inclusion in this article from French to English. We imported all interviews into Atlas.ti 5.2 (2007) for coding and analysis. For data analysis, we searched for patterns in the data and conceptualized ideas that helped explain the presence of those patterns (Ryan & Bernard, 2000). Analysis of textual data consisted of five main steps: (a) reading for content: This step involved data reading and rereading of transcripts until content became intimately familiar, and emergent themes were noted; (b) coding: in this step, a list of codes found inductively from the transcripts and deductively from the research questions was created; to ensure intercoder reliability, a random sample of 25% of transcripts was double-coded by an independent coder; (c) displaying: major subthemes that reflected finer distinctions in the data were displayed; (d) data reduction: a table was created that categorized and displayed the data; and (e) interpretation: the final step included identification and explanation of the data's core meanings using the nine categories employed by Uys et al. (2005). We also used Moscovici's (2000) two processes that generate social representations: anchoring and objectifying. We coded data in multiple applicable categories.

### Results

Both samples (youth and caregivers) contained more women than men. Six YLWH (21%) reported not knowing any metaphorical terms used to label the PLWH (or YLWH), whereas all key informants reported one or more labels.

#### HIV-Related Labels

The 8 sampled key informants made 34 references to 18 HIV-related labels. In addition, 23 of the 29 YLWH made more than 499 references to 110 HIV-related labels or phrases. All 31 participants who reported HIV-related metaphorical terms and phrases reported that the terms were used regardless of the presence of a PLWH, including some direct insults and

other terms used to discuss the PLWH in their presence but without their knowledge (see Table 1).

In general, the YLWH were uncomfortable describing the terms and phrases used to describe PLWH or their condition. The 23 YLWH reported that HIV-related labeling prevented them from discussing their HIV status, as described by one of the youth:

When people label us, it is just as if they were insulting. When they say those things, I really feel hurt. Labeling people that way does hurt but there is nothing one can do about it. What do I normally do? When I hear those people insult us, I just go on and say nothing. (20-year-old [20] YLWH)

Our results revealed that fear of HIV/AIDS made people avoid and/or stigmatize PLWH, even in their presence. These labels were subjective distortions of HIV/AIDS, with which people seemed to make light of and soften the naming of the illness because it was about private, sensitive issues not usually named publicly, including sex and sexual behavior. These labels could be subtle, because some appeared neutral and nonstigmatizing on the surface.

Most of the metaphors used to describe HIV/AIDS or PLWH reported here show that people wanted to understand HIV, but it remained an unfamiliar abstract notion. To increase their understanding, they used anchoring by transforming it into concrete realities (e.g., disease of the lovers, of the four letters), and objectifying by naming it in comparison to already known things, including calling HIV an insect, poison, meeting the General of the enemy army, electric wire, nail, or thorn, or PLWH being considered dangerous. YLWH who are aware of such labels are likely to feel desperate and might hide their condition.

Our results illustrate some of the challenges the youth faced, including physical pain from their HIV infection, avoiding interactions with other people, eschewing public places, and contemplating suicide. Some YLWH used coping strategies to minimize the effects of stigma-related marginality, such as pretending to ignore the people who were talking to or about them. These results emphasize that no matter how obscure the derogatory labels were, people ultimately understood them. It might seem odd that the purpose of the labels was to understand strange things by making them familiar, and to think that they would be obscure to others. However, people made these things familiar for themselves, and at the same time they did not want the “victims” to see them openly. Some YLWH appeared to have internalized these labels, describing themselves as worthless and deserving to die.

Every category adopted from Uys and colleagues (2005) had at least one term or phrase used by YLWH or health care providers in our study. Labels used and a few representative quotes are given below.

### **Attributional Labels**

Attributional labels described the cause of the illness or the lifestyle associated with acquisition of the infection. Sometimes, PLWH were implicitly blamed for being careless and participating in socially criticized behavior that leads to HIV infection (Uys et al., 2005). This category had the most terms and phrases (22 labels in total used 96 times),

including labels that described the cause of being HIV positive, such as the disease of those who love (i.e., who have sex) and the disease of sexuality. These labels also referred to AIDS as the disease of socially judged lifestyles: I let my own money kill me, disease of greed for money, a punishment from God, a disease that one chooses to get, a tramp or a prostitute. These labels also described AIDS as the disease of people who were not careful enough: she or he stepped on a nail, she or he stepped on an electric wire, and she killed Lwambo, a famous musician of the DRC. A 24-year-old female YLWH described this attributional process as follows:

If they happen to know that you have HIV or if the signs of AIDS become visible, people will start talking to each other with disdain about you. Look at him/her; she or he is a person with an insect/virus. Be careful; whoever will make the mistake of being with her/him will be bitten. She or he has the insect/virus.

### Neutral Labels

Neutral statements refers to those that did not have either a positive or negative slant, and that said very little about the disease, the person having it, or the attitude of the person making the comment (Uys et al., 2005). The terms or phrases (10 in total used 14 times) of this category included the following: he or she was poisoned, he was involved in an accident, and she or he was bitten by a goat, which culturally means “bad luck” because a goat never bites. Additional labels included those that portrayed qualities of the PLWH or the disease: people with AIDS: the disease that comes with skin lesions; a symbolic description of transmission routes: a mosquito, comparable to malaria that is transmitted through a mosquito bite; a needle: referring to how HIV can be transmitted; and other neutral labels such as the person “is a member of a group” and she or he has “got it.”

Respondents said that people used these terms or phrases to avoid stating in public that their relative died of AIDS; therefore, they might prefer to say that their relatives were poisoned. In other circumstances, PLWH were simply called people with AIDS with no other underlying message. Although these terms are categorized as neutral, in some cases they might actually reflect that the speaker considered AIDS or PLWH derogatorily. It is possible that the neutral terms were used to hide what the speaker considered to be something negative.

### Death-Related Labels

Death-related labels suggested that PLWH had little or no future, or referred to the impact of the illness on a PLWH’s future. There were 82 references to the 12 terms of this label category, implying either a compromised future of the PLWH because of imminent death or that people caring for the PLWH were waiting for the person to die. Terms and phrases describing a compromised future for the PLWH included the following: she or he has entered the house for good; she or he has stepped on a land mine; is a walking/standing corpse; follow me to the grave; she or he is at the airport, ready to leave (i.e. to die), she or he is just an empty carcass, a person who died in advance; the disease that pushes me to go away (i.e., to pass away).

Death-related labels were also linked with the idea that relatives of PLWH were just waiting for death to come. Labels of this type included the following: just look, the person is no longer alive; only God has the final decision; and you think they are going to die tomorrow but they do not die. Other labels compared the behavior of the PLWH to that of a person who touched or was in contact with a deadly object. Labels of this type included she or he stepped on a nail, she or he stepped on an electric wire, she or he has swallowed a thorn, and she or he is an eternal coffin. Stepping on a land mine, for example, means that the person did not pay attention and stepped on a land mine that was ready to explode and would, therefore, die. Similarly, HIV or PLWH was compared to a dangerous thing that one should avoid. One label conceptualized PLWH as a poisoned gift: whoever had sex with him or her would think they had an attractive gift but they would end up getting poisoned (i.e., acquiring HIV).

### Physical Feature-Related Labels

This category refers to nine labels used 69 times that were used to describe the appearance or actions of a PLWH. The references in the category were all negative, including the following: the person is now only skin on bones, with skin rashes, or she or he became a skeleton. Other labels in this category included just look at the person, she or he is no longer there; that one “has become a burn,” as if HIV was a fire that causes skin rashes; it is a sick hen; and a thin person who keeps on getting thinner and thinner. A health professional discussed physical-feature labels used among medical colleagues as follows:

I know for example in an NGO [nongovernmental organization] that I am not going to mention here, the nurses were discussing among themselves. One of them said, “Look, there is a visual determine for you. Watch out!” Visual determine means that, if you look at that person, you will see the signs ... of the disease. Determine is one of the rapid tests, you know. The phrase implies that you do not need to use determine rapid test to know that the person is HIV positive: you just use your eyes as the determine test.

### Factual Labels

This category refers to descriptions that used facts or medical terms to portray the illness and the people who have it. The 54 references to the six phrases of this category included she or he has got it, she or he has the disease of the blood (referring to the fact that HIV can be detected in the blood), she or he has the germ, or she or he has the insect, the animal (in Lingala, insect and animal are not sharply distinguished, and some people believe HIV is a parasite called *nyama* in Lingala). Other factual labels were as follows: AIDS people, she or he has the shingles, and she or he has the syndrome.

### Lingering Illness-Related Labels

This category includes metaphorical and idiomatic descriptions of the chronic nature of the illness. Participants referred 64 times to such types of descriptions, using the following six terms or phrases: she or he might die tomorrow (i.e., on any given day), she or he went into the house (maybe forever to hide himself/herself or because she or he is too sick to leave the house), the person is seated on the toilet for a long time because of diarrhea. Other labels

related to lingering illness included the following: she or he will never be cured, she or he has prolonged malaria, and she or he is sickly. Most of these labels can also be regarded as death-related.

### Common Illness-Related Labels

This category refers to how common (referring in some cases to prevalence) HIV was in the community. Participants used these phrases 16 times, including “lottery,” referring to the fact that HIV was common in the community but only a relatively few got AIDS, just like many people play the lottery but only a few win. PLWH were also referred to as a member of a group of people living with HIV. Some individuals were said to have called HIV the disease of the century, or the scourge of the century.

### Wordplay Labels

This category comprises descriptions using a play on words or sounds to label PLWH or the disease. People used the seven labels of this category 46 times. Terms included words such as *SIDA (Syndrome Imaginaire pour Décourager les Amoureux*; imaginary syndrome to discourage lovers); *aza’ na quatre lettres* (she or he has the four letters, referring to the four letters of AIDS); or they used *DASI* (the inverted acronym SIDA) or *sidonie*, which is a first name that resembles SIDA. They also used *SIDATE* to feminize SIDA, so people did not think it was about the virus or the disease, or to put SIDA in the negative form in Lingala, which if separated into two words, means “no AIDS.” Other wordplay labels included *LOPEMA*, a coined acronym for *Longue et Pénible Maladie* (lingering and painful disease), as well as *sinadawa* (Swahili; “disease with no medicine”), which in French also sounds like SIDA.

### Devaluing Labels

Many of the labels classified in other categories also belong to this category. Here only 24 labels are considered, and they were used 72 times. One phrase referred to murder: she or he “killed Luambo.” Luambo Franco was a famous musician in the DRC who is believed to have died of AIDS; therefore, this phrase emphasizes the potential for a PLWH to infect and kill others. Another term, *kakuba*, a slang word in Lingala meaning a pitiless prostitute, suggests that a PLWH is a cruel person, a harsh person who kills intentionally. Poison was a common theme as well: “a water source that killed a dog” means that a person with HIV is poisonous, just like an innocent-looking water source that can cause disease without a person realizing it until it is too late. Talk of a “bitter tree” suggests that despite appearing as a natural source of life and pleasure, a PLWH is inedible and deadly, and is not to be “eaten” (i.e., not someone to share life or have sex with). Other devaluing labels included describing PLWH as the devil, a mean person, *666* (the number in the Bible symbolizing the devil), *tigo* (the name of an inexpensive cell phone company that established a system of free calls and bonuses, like a PLWH who “gives a bonus” to sex partners), a sorcerer, a rotten and stray dog from which people should run away, a suspicious terrain, someone on whom to close the door (suggesting that people should close their door to avoid this “undesirable” person coming for visit), and a casualty of war.

## Fear-Related Labels

Fear-related labels illustrate how people were afraid of the disease and its incurable nature. Most of the ten labels used also fit elsewhere. These labels were used 48 times and included the following terms and phrases: she or he had “swallowed a toad” (people believe that whoever has swallowed a toad will die; this label is also death-related), she or he has met the General of the enemy army, an insurmountable enemy; she or he was bitten by a “bad bee” (a bee with a fatal sting; also death-related); a bone has blocked his or her throat (i.e., choking to death); having no relatives or a disease with no relatives (i.e., one must depend on the mercy of relatives, all others are enemies); and a pitiless disease. A fear-related label that can also be classified as a lingering-condition label is “bad insect,” referring to the virus. A fear-related label that also functions as a factual label for HIV is “the one which people do not name,” because in local culture one also does not name powerful people, otherwise it is feared they will attack you. Similarly, the virus was referred to as a frightening authority: the one with the power to end everything, the one who pronounces the final sentence.

In the following quote, a 19-year-old YLWH used a number of labels and revealed his way of interpreting them:

Interviewer (I): According to you, what are names that are used to describe HIV?

Participant (P): Vulgar names or what?

I: Any type of name that people use to describe HIV.

P: Even nicknames?

I: Any type of name that you are aware of and that describes HIV.

P: They say that person has the insect. They can also say, “Look at that spoiled water source by a cadaver of a dog.” They also say, “Watch out. Do not step on that electric wire. You might get an electrical shock.” Others say, “Look at that person who is seated on a toilet pot!”

I: Any other names you can figure out?

P: That is all what I can remember for now. [pause] Oh yes! They also say, “That is a walking corpse.”

I: Any other name you can remember?

P: That is all I know.

I: Now let us look at each of the names you mentioned and have their meaning. You mentioned “the insect,” “spoiled water source by the cadaver of a dog,” “electric wire and electric shock,” “being seated on a toilet pot,” or a “walking corpse.” Could you explain these names one by one, please? What do people mean by “the insect”?

P: In my opinion, people think that HIV is a small insect that destroys the body.

I: What about the spoiled water source you mentioned?



P: People consider us not dignified to be with other people because, let us say you are told that a water source was spoiled by a cadaver of a dog. Will you drink from it again? That is the same with us. People do not want to socialize with us. They say that HIV has spoiled our body. People should not be with us.

I: In which way?

P: Socializing, talking to people. People are warned not to be with us in whatever way.

I: You also mentioned electric shock. What do you think people mean by that?

P: Just look at an electric wire and you will understand. Whoever touches it has a deadly shock. People living with HIV are considered exactly like that.

I: What about being seated on a toilet pot?

P: That is related to one of the symptoms of AIDS, that is diarrhea. HIV is described like diarrhea. A person living with HIV is described to be seated on a pot for long.

I: You also mentioned a walking corpse.

P: A person living with HIV is just about to be killed, with a shortened life; just like a walking corpse.

### Reactions of YLWH to Derogatory Labeling

The YLWH had varying reactions to metaphorical labeling. Their reactions included feeling hurt, no longer participating in public gatherings, contemplating suicide, or simply ignoring the labels. One 24-year-old YLWH described a disturbing experience in his church:

I am a Christian and I used to go to church, where I disclosed my serostatus to my pastor. I attended church services regularly until one day, as he was preaching from the pulpit about something else, the pastor invited people to pray. I also went there, not because of my HIV status but for something else regarding the message he gave that day. All of a sudden, the pastor changed the topic and publicly declared, "Look at that handsome boy over there. He has stepped on the nail." Imagine, that was in the church. From that day, I left that church and stopped going to church.

### Discussion

The results of this study reveal that fear of HIV/AIDS prompted people to avoid and/or stigmatize PLWH, including through the use of often creative labels, mainly to avoid a graphic discussion of sensitive subjects such as sex and sexual behavior. Sometimes labels were not easily recognized by the PLWH because they might have appeared to be neutral. Frequently, however, the language used in labeling expressed violence and war.

Some labels associated HIV with behavior that the speaker considered immoral. In these cases, AIDS-related stigma became a mechanism for sharpening the divide between "us" and "them" in what Ogden and Nyblade (2005) called the "innocence-to-guilty continuum" (p. 23).

Most of the metaphors used to describe HIV/AIDS or the PLWH as reported here show that people used either anchoring, that is, transforming it into concrete realities (disease of the lovers, four letters, and so forth), or objectifying, by naming it in comparison to already known things (Moscovici, 2000), including calling HIV an insect, poison, meeting the General of the enemy army, an electric wire, a nail, or a thorn, or labeling the person living with HIV as a dangerous person.

One could also hypothesize that people used some labels to identify and yet avoid stigmatizing PLWH. Diseases are often feared in Kinshasa. Labels might have been used in some contexts such as clinics to keep a PLWH's serostatus confidential, which suggests that labeling can also be a supportive or protective activity and therefore convey a positive intention. Reactions by most of the YLWH showed that it was difficult for them to manage their disease if they felt the need to avoid public spheres and generally distance themselves from other people (EKOS Research Associates, 2006), or if they contemplated suicide (Préau, Bouhnik, Peretti-Watel, Obadia, & Spire, 2008). On the basis of the 6 youth who said they never heard of HIV, AIDS, or PLWH being labeled, one could say that the responses from these youth suggest that the targets of metaphorical terms about being HIV positive were not always aware of being labeled. Our findings also confirm reports in the literature that PLWH use coping strategies to minimize the effects of stigma-related marginality (Padilla et al., 2008), such as ignoring the people who are criticizing them or simply avoiding people.

## Conclusion

Participants reported that people avoid talking plainly about HIV/AIDS because they fear the disease, fear alerting PLWH to the gossip, or attribute blame to PLWH. Labeling in various categories (attributional, neutral, death-related, physical feature-related, factual statements, lingering illness-related, common illness-related, wordplay, and devaluing) were used through two mechanisms, anchoring and objectifying, and often reflected HIV/AIDS-related stigma and discrimination. Advocacy, public-awareness campaigns, community mobilization, and expansion of AIDS programs in the DRC to include HIV/AIDS education and stigma reduction efforts are needed.

## Acknowledgments

Special thanks to Torro Ntshukunyu, Michel Saleh, Maguy Makusudi and André Djoloko for translating documents, our partners from local organizations working with YLWH, and interviewers Elizabeth Asha, Angèle Mbuyi, Odette Daiku, Nicole Kutumbakana, and Cléo Tshimanga. The UNC Center For AIDS Research provided editorial assistance on this article.

### Funding

The authors disclosed receipt of the following financial support for the research, authorship, and or publication of this article: Support was received from NICHD (National Institute of Child Health and Human Development; contract number 5R24HD043551-05).

## References

Amuri M, Mitchell S, Cockcroft A, Andersson N. Socio-economic status and HIV/AIDS stigma in Tanzania. *AIDS Care*. 2011; 23:378–382.10.1080/09540121.2010.507739 [PubMed: 21347901]

- Atlas.ti. (Version 5.3) [computer software]. Berlin: Author; 2007.
- EKOS Research Associates. Distancing, risk, and treatment for HIV/AIDS. Ottawa, ON, Canada: Public Health Agency of Canada; 2006.
- Kalichman SC, Simbayi LC. HIV testing attitudes, AIDS stigma, and voluntary HIV counseling and testing in a Black township in Cape Town, South Africa. *Sexually Transmitted Infections*. 2003; 79:442–447. [PubMed: 14663117]
- Kalichman SC, Simbayi LC. Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS Care*. 2004; 16:572–580.10.1080/09540120410001716360 [PubMed: 15223526]
- Link BG, Phelan JC. Conceptualizing stigma. *Annual Review of Sociology*. 2001; 27:363–385.10.1146/annurev.soc.27.1.363
- Moscovici, S. The phenomenon of social representations. In: Farr, RM.; Moscovici, S., editors. *Social representations*. Cambridge: Cambridge University Press; 1984.
- Moscovici, S., editor. *Representations explorations in social psychology*. Oxford: Blackwell; 2000.
- Mutembei AK, Emmelin MAC, Lugalla JLP, Dahlgren LG. Communicating about AIDS. Changes in understanding and coping with help of language in urban Kagera, Tanzania. *Journal of Asian and African Studies*. 2002; 37:1–16.10.1177/002190960203700101
- Ncama BP, McInerney PA, Bhengu BR. Social support and medication adherence in HIV disease in KwaZulu-Natal, South Africa. *International Journal of Nursing Studies*. 2008; 45:1757–1763. Epub 2008 Jul 24. 10.1016/j.ijnurstu.2008.06.006 [PubMed: 18653188]
- Ogden, J.; Nyblade, L. *Common at its core: HIV-related stigma across contexts*. Washington, DC: International Center for Research on Women; 2005.
- Okoror TA, Airhihenbuwa CO, Zungu M, Makofani D, Brown D, Iwelunmor CJ. “My mother told me I must not cook anymore”: Food, culture, and the context of HIV- and AIDS-related stigma in three communities in South Africa. *International Quarterly of Community Health Education*. 2008; 28:201–213.10.2190/IQ.28.3.c [PubMed: 19095587]
- Padilla M, Castellanos D, Guilamo-Ramos V, Reyes AM, Sánchez Marte LE, Soriano MA. Stigma, social inequality, and HIV risk disclosure among Dominican male sex workers. *Social Science & Medicine*. 2008; 67:380–388.10.1016/j.socscimed.2008.03.014 [PubMed: 18410986]
- Petros G, Airhihenbuwa CO, Simbayi LC, Ramlagan S, Brown B. HIV/AIDS and “othering” in South Africa: The blame goes on. *Culture, Health & Sexuality*. 2006; 8:67–77.10.1080/13691050500391489
- Préau M, Bouhnik AD, Peretti-Watel Y, Obadia B, Spire B. Suicide attempts among people living with HIV in France. *AIDS Care*. 2008; 20:917–924. [PubMed: 18777220]
- Programme des Nations Unies pour le Développement. Province de Kinshasa: Profil résumé; Pauvreté et conditions de vie des ménages. Kinshasa: Programme des Nations Unies pour le Développement (United Nations Program for Development, Province of Kinshasa, Summary Profile; Poverty and household livelihood); 2009. Retrieved from [www.undp.org/content/rdc/fr/home/library/poverty/pauvrete-et-condition-de-vie-des-menages11111111/](http://www.undp.org/content/rdc/fr/home/library/poverty/pauvrete-et-condition-de-vie-des-menages11111111/)
- Rudolph AE, Davis WW, Quan VM, Ha TV, Minh NL, Gregowski A, Go V. Perceptions of community- and family-level injection drug user (IDU)- and HIV-related stigma, disclosure decisions and experiences with layered stigma among HIV-positive IDUs in Vietnam. *AIDS Care*. 2012; 24:239–244.10.1080/09540121.2011.596517 [PubMed: 21777075]
- Ryan, GW.; Bernard, HR. Data management and analysis methods. In: Denzin, NK.; Lincoln, YS., editors. *Handbook of qualitative research*. London: Sage; 2000. p. 769-802.
- Simbayi LC, Kalichman SC, Strebel A, Cloete N, Henda N, Mqeketo A. Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. *Social Science & Medicine*. 2007; 64:1823–1831.10.1016/j.socscimed.2007.01.006 [PubMed: 17337318]
- Sontag, S. *Aids and its metaphors*. London: Penguin Books; 1990.
- Uys L, Chirwa M, Dlamini P, Greeff M, Kohi T, Holzemer W, Phetihu R. “Eating plastic,” “Winning the Lotto,” “Joining the WWW” ... Descriptions of HIV/AIDS in Africa. *Journal of the Association of Nurses in AIDS Care*. 2005; 16:11–21. Retrieved from [www.ncbi.nlm.nih.gov/pubmed/16433113](http://www.ncbi.nlm.nih.gov/pubmed/16433113). [PubMed: 16433113]

Victor JS. Sluts and wiggers: A study of the effects of derogatory labeling. *Deviant Behavior*. 2004; 25:67–85.10.1080/01639620490248943

Visser MJ, Makin JD, Vandormael A, Sikkema KJ, Forsyth BWC. HIV/AIDS stigma in a South African community. *AIDS Care*. 2009; 21:197–206.10.1080/09540120801932157 [PubMed: 19229689]

## Biographies

**Bavon Mupenda**, MA, MPH, works with the the Interdisciplinary Center for Bioethics for Francophone countries, Kinshasa, Democratic Republic of the Congo.

**Mujalambo Kashosi**, MD, MPH, works with the Interdisciplinary Center for Bioethics for Francophone countries, Kinshasa, Democratic Republic of the Congo.

**Mamie Lema**, RN, works with the Interdisciplinary Center for Bioethics for Francophone countries, Kinshasa, Democratic Republic of the Congo.

**Sandra Duvall**, MD, works with the University of North Carolina at Chapel Hill, North Carolina, USA.

**Audrey Pettifor**, PhD, is an associate professor in the Department of Epidemiology at the University of North Carolina at Chapel Hill, North Carolina, USA.

**Stuart Rennie**, MA PhD, is an associate professor in the Department of Social Medicine at the University of North Carolina at Chapel Hill, North Carolina, USA.

**Eboni Taylor**, PhD, is a health scientist with the Center for Disease Control and Prevention.

**Christina Holub**, PhD, is a research assistant professor at SDSU Graduate School of Public Health, Institute for Behavioral and Community Health.

**Suzanne Maman**, PhD, is an associate professor in the Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, USA.

**Frieda Behets**, MPH, PhD, is a professor emeritus, Department of Epidemiology, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, North Carolina, USA.

Table 1

Metaphoric Labels Reported by Key Informants and YLWH in Kinshasa About HIV/AIDS and PLWH.

<b>Labels Used in the Anchoring Process: To Reduce Strange Ideas to Ordinary Categories and Familiar Images</b>	<b>Labels Used in the Objectifying Process: To Turn Something Abstract Into Something Almost Concrete; From the Mental to the Physical World</b>
<i>Attributional anchoring labels:</i> AIDS is the disease of those who love (i.e., those who have sex), a disease of sexuality, a disease that one chooses to get. PLWH is considered a tramp, a mean/bad person, a prostitute.	<i>Attributional objectifying labels:</i> AIDS is a punishment from God, a disease of greed for money, buying one's death with one's own money. A PLWH is seen to have stepped on a fatal nail or thorn or on an electric wire (power line or wire that conducts electricity to homes and businesses), or to kill celebrities.
<i>Commonness-related anchoring labels:</i> AIDS is the disease of the century.	<i>Commonness-related objectifying labels:</i> Getting AIDS is like winning a lottery. A PLWH is a member of a group of people living with HIV.
<i>Death-related anchoring labels:</i> A PLWH is expected to die the following day, a walking/standing corpse, an eternal coffin, just a carcass or the one for whom only God has the final decision, the one who is saying "follow me"	<i>Death-related objectifying labels:</i> A PLWH has stepped on a land mine; is at the airport, ready to leave, to die; a poisoned gift, the one who has swallowed a thorn or has stepped on a fatal nail or a thorn.
<i>Devaluing anchoring labels:</i> A PLWH is the devil, a mean person, a rotten person, a stray dog that should be run away from	<i>Devaluing objectifying labels:</i> A PLWH is a pitiless prostitute, like a water source where a dog was killed, innocent looking, like a bitter tree, the Biblical number to represent the devil, a suspicious terrain to be avoided
<i>Factual anchoring labels:</i> Talking about a PLWH, one says, She or he has got it, AIDS person, a person with shingles, with the syndrome. AIDS is the disease of the blood.	<i>Factual objectifying labels:</i> Talking about a PLWH, one says, She or he has got the insect, the small animal.
<i>Lingering illness-related anchoring labels:</i> Talking about a PLWH, one says, A sickly person (woman), the one who never gets cured because of a prolonged malaria (i.e., AIDS)	<i>Lingering illness-related objectifying labels:</i> A PLWH is said to have entered the house, to be sitting on the toilet because of diarrhea.
<i>Neutral anchoring labels:</i> A PLWH is said to have been given poison, to be a member of a fraternity group or to have been involved in an accident.	<i>Neutral objectifying labels:</i> A PLWH is a sentenced person, with body spots, given by a "mosquito." Sometimes, a PLWH is said to have been bitten by a goat (i.e., very unlucky), to suffer from the unnamed disease.
<i>Physical feature-related anchoring labels:</i> The PLWH is said to be now only skin on bones, a thin person, a skeleton, the one to just look at because she or he is no longer there.	<i>Physical feature-related objectifying labels:</i> The PLWH is said to be a visual determine (a rapid HIV test), identifiable as HIV positive simply by appearance, a burned person, a sick hen
<i>Wordplay anchoring labeling:</i> AIDS is an imaginary syndrome to discourage lovers, the disease of four letters (A-I-D-S), the <i>Lopema</i> (lingering and painful disease).	<i>Wordplay objectifying labeling:</i> AIDS is called <i>Sidonie</i> (a first name sounding like SIDA), <i>Sina dawa</i> (Swahili; a disease with no medicine; the name sounds like SIDA).
<i>Fear-related anchoring labels:</i> HIV is called a bad insect, that little thing, AIDS a disease with no relative, a pitiless disease.	<i>Fear-related objectifying labels:</i> A PLWH has swallowed a toad; has a bone blocked in his or her throat, has been fatally bitten by a bee. AIDS is called the Army general or the one who pronounces the final sentence