

# IS STIGMA RECEDING? STORIES OF AIDS SUPPORT GROUP MEMBERS IN PIETERMARITZBURG, SOUTH AFRICA

**Philippe Denis**

School of Religion, Philosophy and Classics  
University of KwaZulu-Natal, Pietermaritzburg  
denis@ukzn.ac.za

**(with Molly Longwe and Ntokozo Zitha)**

## ABSTRACT

The paper describes the experience of people living with HIV in KwaZulu-Natal. It is based on oral history interviews with members of two support groups in the Pietermaritzburg area that were conducted in 2009 and 2011, respectively. The interviews show that, if stigma and discrimination remain a key component of the experience of people living with HIV in KwaZulu-Natal, certain evolutions are taking place. Nearly all the interviewees were on antiretroviral treatment and their health conditions had improved. They deeply appreciated the solidarity they found in their support groups. In most cases their families, friends and neighbours responded positively when they disclosed their status. Yes, obstacles remained. The interviewees, most of whom were women, saw gender stereotypes and men's resistance to testing, treatment and care as one of their biggest challenges.

## INTRODUCTION

The impressive, yet anonymous statistics of HIV prevalence in sub-Saharan Africa should not obscure the fact that HIV and AIDS are, first and foremost, a tragedy that touches individual people, day after day, in the restricted environment of their family, their neighbourhood and their work place. The stigma that is attached to the disease makes its disclosure difficult and many people live in denial.

Most AIDS-related studies are based on written sources such as seroprevalence surveys, medical research reports, policy papers, newspaper articles and political and religious comments. Equally important, however, are oral sources that reflect the experience of people affected or infected by HIV and AIDS, or caring for the victims

of the epidemic on a daily basis. Particularly lacking from existing records are the experiences, perceptions and attitudes of AIDS practitioners at the community level.

The purpose of this paper is to describe, through the methodology of oral history, the experience of people living with HIV in KwaZulu-Natal, a province heavily affected by the epidemic, and to see how this experience has evolved over time.<sup>1</sup> Special emphasis will be placed on denial and stigma. With Harriet Deacon we define stigma as an ideology that identifies and links the presence of a biological agent – in this case HIV – to negatively defined behaviours or groups in society (Deacon 2005: ix). Despite a ‘conceptual inflation’ (Miles 1989 quoted in Deacon 2005: ix) of stigma and the growing recognition, in the biomedical profession, that this phenomenon constitutes one of the biggest obstacles to treatment and care (Gewirtz and Gessart-Walker 2000; Parker and Aggleton: 13–24; Sowell and Phillips 2010) stigma is insufficiently understood, in the context of HIV and AIDS in particular. Researchers need to make more use of historical analysis for understanding the history and politics of stigmatising beliefs, and of participation observation for understanding the impact of stigma (Deacon 2005: xi).

The paper is based on two sets of interviews, conducted in isiZulu by University of KwaZulu-Natal postgraduate students Molly Longwe in 2009 and Ntokoto Zitha under the supervision of the author in 2011, respectively. The first interviews involved members of the Community Care Project (CCP), a faith-based AIDS support group in Pietermaritzburg; the others, members of Fountain of Life, an AIDS-support group with no link to churches but whose members often have religious convictions. These interviews are part of a research project of the Sinomlando Centre for Oral History and Memory Work in Africa, which aims to document, through oral history interviews, the experiences of non-governmental organisation (NGO) and community-based organisation (CBO) workers and pastoral agents confronted with the HIV and AIDS epidemic in the Umgungundlovu District Municipality (KwaZulu-Natal), from the late 1980s to the present.<sup>2</sup> This research project tries to establish how NGO and CBO workers and pastoral agents engaged with issues of power, faith, sexuality and stigma in the context of HIV and AIDS during the past three decades, how these engagements evolved over time, and what shifts and trajectories could be revealed in their analysis. The fieldworkers made use of a topic guide designed by the research project steering committee. They were asked to engage the research participants on a number of issues including power, sexuality, gender, disease stigma, religion, faith and community support. The interviewees signed a release agreement authorising the Sinomlando Centre to make use of the interview transcripts and audiotapes for research purposes.<sup>3</sup>

The first cases of AIDS in the country were diagnosed in 1982 (Oppenheimer and Bayer 2007: 22). In 1987, blood screening suggested that HIV prevalence was already eight times higher among blacks than whites, through heterosexual contact, and was doubling every six months (Ilfie 2006: 44). In subsequent years, prevalence levels kept rising, reaching a plateau at the end of the 1990s. The epidemic peaked first in KwaZulu-Natal, but has reached high levels in all other South African provinces as well

as the neighbouring countries. Today an estimated 5.5 million people are HIV positive in South Africa. In KwaZulu-Natal close to 40 per cent of women attending antenatal clinics carry the virus. Since 2010 there are signs of a decrease in the rate of infection, particularly in the younger generation, but the level of infection remains unacceptably high. The good news is that AIDS causes fewer deaths than before. Thanks to a massive government-sponsored antiretroviral treatment (ART) roll-out programme the number of AIDS-related deaths has gone down considerably. On a national level life expectancy has risen from 54 years in 2005 to 60 years in 2012.

The history of AIDS in South Africa is a nascent field, first made apparent at the 2001 'AIDS in Context' conference at the University of the Witwatersrand, Johannesburg.<sup>4</sup> Authors such as Howard Phillips (2001), Didier Fassin and his colleagues (2004), John Iliffe (2006), Ruth Morgan (2009), Gerald Oppenheimer and Ronald Bayer (2007) have started to write the history of the epidemic and of the responses given to it in South Africa. In HIV and AIDS research, the boundary between history and anthropology is often blurred. References to history abound in the anthropological literature, although rarely in an articulate manner. Examples can be found in the work of Rob Garner (2000), Mark Hunter (2002), Catherine Campbell (2005), Adam Ashforth (2006) and Deborah Posel (2007).

The history of AIDS can be recounted in many ways and from many vantage points. Oral history is eminently suitable for documenting the day-to-day, subjectively apprehended and culturally appropriated reality of the epidemic. Authors who have written an oral history of the HIV and AIDS epidemic in countries other than South Africa include Gerald Oppenheimer and Ronald Bayer in the United States (2000), Wendy Rickards in the United Kingdom (2003) and Cesar Nkuku Khonde in the Democratic Republic of Congo (2006). In South Africa oral historians Gerald Oppenheimer and Ronald Bayer (2007) focused on doctors and nurses involved in the fight against HIV and AIDS, and Ruth Morgan on HIV-infected gays and lesbians (2009).

Documenting the history of AIDS as it unfolds under our eyes will help future generations to understand where they come from and in this way develop a sense of identity and strength in the face of massive adversity. HIV and AIDS, a bio-medical phenomenon with social, cultural, economic, political and spiritual dimensions, has become part of South Africa's cultural heritage and its history will have to be scrutinised for many years to come.

While focusing on the experience of people living with HIV, this paper also provides information on the history of HIV and AIDS support groups, one of the most remarkable civil society responses to the epidemic, some of them linked to clinics, hospitals or counselling and testing centres. Others, such as the Community Care Project, to which the first group of interviewees was linked, were founded by religious institutions. Quite a few, such as the Fountain of Life, the second support group studied here, are informal organisations. They develop in urban, semi-urban or rural areas and have a short or a long life. They play a crucial role in the lives of their members by providing them with

emotional support and by encouraging them to seek treatment and adhere to it.

The first group of interviewees belonged to the CCP. Discontinued in 2010 for financial reasons, the CCP was a project of the Pietermaritzburg Christian Fellowship, a local Pentecostal church, which aimed at providing psychosocial support and medical assistance to HIV positive people in the Pietermaritzburg area. It was founded in 1999, at a time when Pentecostalism started to mobilise human and financial resources to combat the HIV and AIDS epidemic in various parts of the world.<sup>5</sup> The majority of CCP support group members were men and women living in vulnerable conditions. Most had children and few were married. Many experienced disease and death in their families and communities primarily because of HIV and AIDS but also because of crime, sexual abuse and other diseases.

The second group of interviewees belonged to Fountain of Life, a support group established in Pietermaritzburg in 2003. All members of this informal organisation are HIV positive. They meet once a month, usually on a Sunday in a shop rented by one of them in town for business. They share stories and encourage one another to take their antiretroviral medication. Some go to clinics and hospitals to engage in HIV awareness. With the help of several faith-based NGOs, the Pietermaritzburg Agency for Community Social Action (Pacsa) in particular, they distribute food parcels and money for transport to their members. Fountain of Life is not supported by or affiliated to any particular church but the majority of its members, including the founder, a Kenyan woman married to a South African former ANC cadre in the late 1980s, have strong Christian convictions.

## MULTIPLE TRAUMA

The life stories of the HIV-positive people interviewed for this project are stories of pain and resilience. All interviewees experienced some form of rejection from their families or their communities but also found support around them and this enabled them to move forward. A typical example is Ayanda. Like many South African women, she experienced a double form of trauma: sexual abuse and HIV infection. In 1999 when she discovered she was HIV positive, AIDS was still an unspeakable disease. It took her five years to disclose her status to her mother (A. M., Interview by Molly Longwe 10 June 2009).

Ayanda lives in the greater Pietermaritzburg area with her mother and other family members. She claims she was prepared for anything when she heard about her status. This apparent detachment, however, should not mislead us. What Ayanda experienced should rather be described as emotional numbness. Her HIV condition resulted from a rape. At the time she was working in a hotel in Durban. This is how she recounted her ordeal:

The time I was raped I was coming from work in the afternoon, going to my flat where I was staying. The other guy came. He said he wanted to talk to me and I said, "No, I am in a hurry."

And after that he took out a knife and said I must go, I must turn back. He took me to the park and there at the park I tried to fight with him. I had nothing in my hand. I tried to scream. It was a park and there was no one since it was night. And he pointed at me with the knife. After that he said I must take out my pants and my underwear, and he slept with me. After that he ran away. I went to my house and I told my friend and she took me to the police station. The police took me to the hospital. We did not find this guy. He was not arrested (A. M., Interview by Molly Longwe 10 June 2009).

She does not know why the rape happened. Up to this day this tragedy does not make sense to her:

I didn't know why he raped me. Maybe he raped me wanting to just give me some sickness, or for what because I didn't hate him. I did not say anything bad to him. He just came and raped me (A. M., Interview by Molly Longwe 10 June 2009).

It was, in fact, her second rape. The first one was committed by a white man in 1998 when she was staying with her mother in Pietermaritzburg. It was at night in the bush:

It was the second time. But during the first time I was stressed because that time I was a virgin, and it was a white man who raped me, and I was so stressed that time .... I was going to the shop, it was in the afternoon. Some other guy was visiting where my mum was staying. It was a white man and he raped me and that time I was so ... every time when I am doing ... the picture was coming back. The time how he caught me, how he raped me, and the time he raped me. I was even vomiting because I was so scared (A. M., Interview by Molly Longwe 10 June 2009).

Ayanda 'did not mind' about the test results, but she waited five years before disclosing her status to her mother. She did not want to speak to her before because she was scared of being 'thrown away'. She only disclosed her status when she fell sick of tuberculosis. Fortunately her mother reacted positively:

[In] 2004 I decided to tell my mum, but before that I asked her how she would manage if one of her children was positive. She said that she could not do anything because sometimes it is God who blesses her with a child who is positive. Then, the other day, I met my mum at tea and when she was having her tea, I said to her, "Ma, it's a long time now I was to make a decision that I am positive. How can you manage me?" She said, "You are still my child and I still love you, no matter how you are. No matter what you do, you are still my child" (A. M., Interview by Molly Longwe 10 June 2009).

She first disclosed her status to her mother, then to other family members:

I told my mum and my granny firstly. After that, I told them, all of them so that they know when I am sick, they must use some gloves to make themselves safe when they help me when I am sick. I told them (A. M., interview by Molly Longwe 10 June 2009).

Only one member of the family reacted negatively: her grandfather. He started to gossip

about her with his drinking mates:

It was only my grandfather. He was not accepting, but all of the other family members accepted me. My grandfather did not accept because he could even go out to the place where he drinks beer and he said about me that I am sick with HIV. Some people came and told us that ooh, your grandfather says that you are HIV positive and are sick with AIDS and that you are going to die of it (A. M., Interview by Molly Longwe 10 June 2009).

Strengthened by the support of the other family members, Ayanda ignored her grandfather's nasty words. She stood firm:

I was not interested in that because I know myself, I was not going to die and I will be better whenever am sick because I go to the clinic, where they help me (A. M., Interview by Molly Longwe 10 June 2009).

She also disclosed her status to her friends and told them to protect themselves. They remained her friends. In 2006 she joined the CCP AIDS support group. The twenty-plus members of the groups were meeting weekly. It helped them to deal with stress:

My support group is from the CCP, and when I came it was because sometimes I am stressed. I did not know how to deal with my stress, but when I started coming to the support group they taught us how to deal with the stress, how to deal with HIV, how to deal with AIDS, how to use some ARVs, what to do when you want to talk with someone about your status. They help me with everything (A. M., Interview by Molly Longwe 10 June 2009).

## GAINING THE TRUST OF THE COMMUNITY

Rumours and gossip are a fact of community life. They negatively affect people living with HIV by contributing to their stigmatisation and developing in them high levels of anxiety. The fear of stigma and the ensuing reluctance to disclose one's status are directly related to gossip. HIV-positive people are haunted by what people might say if they hear that they carry the virus. The following story dates from 2005, a time when ART was not easily available and when the confusion about the nature of the disease was still very high.

By the time of the interview Thobile was thirty-nine. She belonged to the long cohort of single mothers who had to face the consequences of an early pregnancy without the support of the child's father. The boyfriend left her for another woman when he heard that she was pregnant, but came back to her after the birth of the child, saying that he had found a job. He offered some money but declined to pay the *inhlawulo*, the customary fine for unplanned pregnancies. His mother refused to meet Thobile's family and he went away. When she died, he came closer to his child's mother, but he still did not go and live with her. At the time they were in Durban. One day he left and died some time later.<sup>6</sup>

Meanwhile Thobile moved to Johannesburg and found a new boyfriend. She spent two years with him. It was probably he who infected her. She did not ask him to use a condom despite the fact that she had fallen pregnant before, an attitude she now describes as careless. At the time she did know much about HIV. One day she had an argument with her boyfriend and went back to Pietermaritzburg.

When she tested positive in 2005, she had been sick for two years. 'My face changed to black, the body became shapeless and small and I lost weight,' she remembers. She was afraid of going to the clinic. But when she started to lose weight, a neighbour told her to go for a test.

During this period her main fear was stigma. The interview reveals a sharp contrast between the rejection of HIV in the community and the warm support Thobile received in the support group:

The community does not want me because they stigmatise me because I am HIV positive. Even to disclose my status I do not want because my neighbours do not want a person who is HIV positive. This is why I am here. I come to CCP. I tell the support group of CCP that I have a problem in my community about my status. The people at CCP advise me not to worry about them. Accept your status. You still go with HIV but you will not die because you know your status. Don't worry, don't worry, and now am not worrying anymore because I have no problem with my status. I tell anyone about my status, I have no problem and I feel better because CCP advises me (t. m., Interview by Molly Longwe 25 August 2009).

Three months elapsed between the test, conducted on 1 May 2005, and the first disclosure to her sister, on 2 August 2005. These dates are deeply inscribed in Thobile's memory. She resigned herself to the idea of disclosing her status because she was sick. As in Ayanda's case, she was surprised by the positive response of her entourage. She thought she would be rejected:

I felt very, very, very, very bad. I was not happy at all with my status because it was not right. I did not like it. So when I went home I cried, cried, cried, I cried a lot and I did not tell anyone, I kept it to myself, my secret until on the 2nd of August when I told my sister. I disclosed my status to my sister because I was sick. It was my first time to tell my sister about my status, on the 2nd August. I said to her, "My sister, I went to the clinic for testing and I am HIV positive." My sister gave me hope. She said to me, "Do not lose hope, you will still live and I am with you. If you have any problem, tell me. There is no problem. I will help you because there is no problem with your status. I still love you" (T. M., Interview by Molly Longwe, 25 August 2009).

Yet Thobile disclosed her status only to the women in the family, not the men. Male reaction to HIV is often irrational. When diagnosed HIV positive, men blame their girlfriends, sometimes against all evidence, or start gossiping in an effort to escape the reality of the disease. AIDS is an affront to their pride.<sup>7</sup>

Yes only my sisters, my mother and my daughter only. No boys, I didn't tell my brothers because they have a problem; they want to speak, speak too much (T. M., Interview by Molly Longwe

25 August 2009).

With Patricia, her daughter, the disclosure process took more time. She did not mention her condition to her at first, but when she did, Patricia responded positively: ‘Mama, I love you. There is no problem with your status.’

One day, Jane, one of Patricia’s friends, saw Thobile going to the HIV clinic and she pressed her friend to tell her why:

My daughter’s friend in her school talked to her about me. She asked my daughter, “Why does your mother go to the clinic every day? What does she go there for?” She used to ask my daughter this question every time. My daughter told her, “My mother goes to the clinic because she joined a support group.” My daughter told her that. She also told her that “My mother teaches there in the support group. That is why she goes there.” But my daughter’s friend was not satisfied with the answer and she continued to enquire, saying, “Any person who goes in that particular room at the clinic ...” Because there are different rooms at the clinic: one for VCT, the TB room, and one for those who are sick. That is how the clinic is: different rooms. But my daughter’s friend continued to probe, “You know the room at the back, the VCT, why does your mother go to that room, because that room is for those who are HIV positive?” My daughter asked her, “Why are you telling me that because I don’t know what happens there.” “I tell you that your mother is HIV positive,” she told my daughter. “How?” “Because I saw her going there.” My daughter said, “I don’t know and my mother never told me that.” This went on until my daughter and her friend had an argument at school concerning me (T. M., Interview by Molly Longwe 25 August 2009).

The matter was brought to the attention of the school principal who called the two mothers to resolve the case. Only Thobile came:

The principal wrote a note and gave it to Jane: “Go and give your mother this note.” The note just said, “Come to school, your child has a case here, come to solve it.” But she never came. I came alone and I talked with the principal. The principal said that I should go to court to open the case because that child spoke about your status, that you are HIV positive without testing. I went to court but I did not get anything from the court and so I just left it like that until today. But when I see that girl, I don’t like it but I do not have any problem with my status. I don’t worry. I am free with my status, because I know what happened (T. M., Interview by Molly Longwe 25 August 2009).

Patricia’s friend was not the only one to gossip about Thobile’s status. A neighbour also made offensive comments:

One day, there was a woman who drank alcohol. When I greeted her, she replied: “I don’t want to talk with you because you are HIV positive.” She shouted at me, shouted at me. I asked her: “Why are you telling me that? Why?” “Because you are HIV positive,” she snapped. “I don’t want to talk with you. Leave me.” But I did not take that seriously. I just left it like that, till now. But now she comes to me and greets me. She forgot what she said to me. I knew that she felt



sorry for what she had said (T. M., Interview by Molly Longwe 25 August 2009).

Such unpleasant episodes did not deter Thobile from adopting a positive attitude towards HIV and AIDS. Her strength came from the support group she had joined in 2006 at the local clinic. There she did not only find emotional support but work opportunities. The organisers noticed her social skills and she was offered a one-year contract. Her job consisted of going from home to home to counsel women:

I educate all mothers. But first of all I talk to them on one to one. After introducing myself – my name and where I live, then I ask the mother also “What is your name? Where do you stay? How old are you? Did you test for HIV?” And if she says yes, I ask her, “How do you feel about your status?” “Now I have no problems but at first it was a problem” (T. M., Interview by Molly Longwe 25 August 2009).

## A NEW WAY OF LOOKING AT HIV AND AIDS

The life stories collected by Molly Longwe show what HIV positive people said and how they felt in 2009 when the number of HIV positive people benefiting from antiretroviral treatment was still relatively limited. For most of them a positive HIV test was tantamount to a death sentence. Some patients discovered their status through a routine test, some after a rape, some when they became sick. Many delayed the decision to take a test for long periods of time, losing thereby the benefits of early ART. They rather lived in denial. Testing for HIV was an emotionally laden experience. Equally fraught with difficulties was the decision to disclose one’s status to friends or relatives. Disclosure was a lengthy process: people living with HIV and AIDS disclosed their status to one person at a time. Full disclosure could take months or years.<sup>8</sup>

There are indications that, since the time Molly Longwe conducted her interviews, the AIDS scene has changed, at least to a degree. The second set of interviews gives a different picture of HIV- and AIDS-related attitudes. There is better knowledge and HIV-positive people are more assertive. There is still stigma though perhaps less than before. Disclosing one’s status has become relatively easy for some people while remaining difficult, if not impossible, for others. Gender in this matter is a major factor. Generally speaking, women find it difficult to disclose their HIV status to men. They complain that their boyfriends or husbands are not prepared to talk about the disease. More than ever HIV and AIDS is a gendered disease.

The barrier of communication extends to in-laws. A married woman has as much to fear from her mother-in-law as from her husband. Beatrice, for instance, discovered that it was impossible for her to disclose her status to her mother-in-law. Zulu culture is, in her opinion, the biggest obstacle to disclosure.

For some it is easy because, as I speak, it is easy for me to tell somebody but for others with their cultural issues .... Let us say I am married. I give birth and I have a baby today .... At the

hospital they say that I should not breastfeed. Isn't it that the mother-in-law is there? Why are you not breastfeeding? I can't tell my mother-in-law that I am HIV positive. My mother-in-law will say, "You are the one who came with the virus." So cultural barriers as well ... It is really forcing people not to open up. And we go out and teach people and we see that a man has five wives. All of those people have not tested. And he is sleeping with all of them. You can see that this one is sick and this one is sick. But just because I paid *lobola* for you, so you cannot say no to me. You see? (B. P., Interview by Ntokozo Zitha 20 July 2011).

Beatrice knows that it is a good thing to disclose one's status. But she also knows that it can backfire.

There is fear because of the stigma. There is fear because people start discriminating against you as soon as they find that you are HIV positive. They start discriminating against you and that is painful. It brings a lot of stress. It brings a lot of pain to disclose. Sometimes I wish I did not tell that person .... I feel regret ... I want to be part of society and people are pushing me out. It is because of stigma (B. P., Interview by Ntokozo Zitha 20 July 2011).

Some relatives treated Beatrice badly. She challenged them and on one occasion she tried to explain her situation to them. She is adamant that men are less prone than women to disclose their status and to admit that they are on medication. Some people go for treatment far from home. When they meet a neighbour or a friend at some other clinic, they do not say a word even though they know that this person is also HIV positive.

What has changed perhaps, at least for some people, is the manner of relating to the disease. The widespread availability of antiretroviral medication, the dissemination of medical knowledge among HIV-positive people and a more proactive attitude on the part of the South African government contribute to a change of perceptions. Typical of this attitude is Nozipho, who tested positive in 2001 and joined Fountain of Life in 2005:

What helped me to accept my situation is the support group. I saw people of a higher rank than me, nice-looking, beautiful, educated and well established. I said to myself: why should I be left out if high profile people and even nurses have this disease. Why should I be left out? It is something that is there. People talk about it freely. So what should stop me from accepting it (N. D., Interview by Ntokozo Zitha 30 November 2011)?

She developed a philosophy or self-acceptance:

You can have a long life .... I thought about my family, I thought about my children, I thought that if I think that HIV will kill me it will definitely kill me. I have to love myself, love my family, and love my children. I have to accept myself so that other people can accept me. How can other people accept me if I do not accept myself and if I am discriminating against myself? I have to love myself and accept myself so that people can accept me. And it happened like that. I live the right life. I do not have any problem (N. D., Interview by Ntokozo Zitha 30 November 2011).

Nozipho thinks that ‘God hears our prayers even though he does not answer them quickly’. He answered her prayers and permitted her to come back from the hospital in good health. She does not think HIV changes the Zulu culture. It is not because people learn that sharing a razor is dangerous that culture changes. She is positive about the public health system, which provides free treatment. For her there is knowledge but people do what they like anyway.

For Nozipho disclosing is easy when you are educated. If you are not, it is difficult. But it is definitely a good thing. Like Beatrice she considers that disclosing is easier with women.

You cannot see the men. A man does not tell his partner that he is on treatment. He will not tell you. You will find out when you have the problem and then you will be surprised that it has happened (N. D., Interview by Ntokozo Zitha 30 November 2011).

## CONCLUSION

This paper only uncovers a fraction of what the members of Community Care Project and Fountain of Life said in the interviews, not to mention the other community workers and pastoral agents involved in the Memories of AIDS Project. It is impossible to condense in a few pages the richness of these testimonies. The support group members’ willingness to share their stories was remarkable. That in itself is an important finding. The four interviewees we quote here confirm what public health professionals and social scientists have observed for some time: stigma and discrimination are a key component of the experience of a HIV-positive person. And it is there to stay. Yet, certain things are changing. All interviewees spoke positively of their support groups. They found a place where disclosure is no longer a problem. They also found that their immediate environment – family members, friends, neighbours sometimes – responded positively when they disclosed their status. These are exceptions, however. Many interviewees saw Zulu culture with its strong bias against women as an obstacle to free communication and acceptance. They recognised that attitudes were changing but felt that, generally speaking, men were lagging behind.

More research is needed to assess the changes that are taking place with regard to HIV and AIDS in South African society. In particular one should better understand men’s response to the epidemic. This could be the topic of another research paper.

## ENDNOTES

- 1 On the growing use of oral history in post-apartheid South Africa to deal with the memories of the past and create a new sense of identity while contributing to a new body of knowledge on contemporary social practices, see Denis in Denis and Ntsimane (2008: 9–16). See also Field (2010).
- 2 School of Religion, Philosophy and Classics, University of KwaZulu-Natal, ‘Sinomlando Centre’, n.d. Online: [www.sinomlando.org.za](http://www.sinomlando.org.za) (accessed on 10 June 2013). The research project from

which this paper is drawn received financial assistance from the National Research Foundation of South Africa and the South Africa Netherlands Research Programme on Alternatives in Development. I express my gratitude to these institutions for their support.

- 3 The Sinomlando Centre follows the code of conduct proposed to its members by the OHASA, see “Oral History Association of South Africa”, n.d. Online: [www.ohasa.org.za](http://www.ohasa.org.za) (accessed on 10 June 2013). To respect the confidentiality of the informants, all names of persons have been changed and any information that might help to identify them has been removed. The University of KwaZulu-Natal’s Humanities and Social Science Research Ethics Committee granted ethical clearance for the project.
- 4 For an overview of the history of HIV and AIDS in South Africa, see the webpage compiled by the international AIDS charity AVERT, “History of HIV and AIDS in South Africa”, n.d. See also Denis (2009).
- 5 On religious responses to the HIV and AIDS epidemic in sub-Saharan Africa, see Denis (2011). On HIV and AIDS and Pentecostalism in Africa, see Prince, Denis and Van Dijk (2009).
- 6 The lack of attachment of teenage fathers is a common occurrence in South Africa. As in Thobile’s boyfriend’s case, the reason is often a difficult relationship between the two families. See Swartz and Bhana (2009).
- 7 On changing masculinities in the context of HIV and AIDS in South Africa, see Hunter (2010). For examples of ‘gendered patterns of blame’ in East Africa, see Sikiwele, Shonga and Baylies (2000: 69–72).
- 8 On the difficulty of disclosing one’s HIV status in South Africa, see Ntsimane (2006).

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## CORRESPONDING AUTHOR

### **Philippe Denis**

School of Religion, Philosophy and Classics

University of KwaZulu-Natal

Pietermaritzburg

E-mail: [denis@ukzn.ac.za](mailto:denis@ukzn.ac.za)